

**RENEWING THE CONVERSATION: RESPECTING
PATIENTS' WISHES AND ADVANCE CARE
PLANNING**

HEARING
BEFORE THE
SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE
ONE HUNDRED THIRTEENTH CONGRESS

FIRST SESSION

WASHINGTON, DC

WEDNESDAY, JUNE 26, 2013

Serial No. 113-7

Printed for the use of the Special Committee on Aging



Available via the World Wide Web: <http://www.fdsys.gov>

U.S. GOVERNMENT PUBLISHING OFFICE

93-290 PDF

WASHINGTON : 2016

For sale by the Superintendent of Documents, U.S. Government Publishing Office
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RENEWING THE CONVERSATION: RESPECTING PATIENTS' WISHES AND ADVANCE CARE PLANNING

WEDNESDAY, JUNE 26, 2013

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

The Committee met, pursuant to notice, at 2:04 p.m., in Room SD-124, Dirksen Senate Office Building, Hon. Bill Nelson, Chairman of the Committee, presiding.

Present: Senators Nelson, Wyden, Whitehouse, Blumenthal, Donnelly, Warren, Collins, and Ayotte.

Also present: Senator Warner.

OPENING STATEMENT OF SENATOR BILL NELSON, CHAIRMAN

The CHAIRMAN. Good afternoon. We have established a new kind of procedure here. Sometimes, we give opening statements. Sometimes, we do not. Sometimes, I turn to the most junior members of the committee.

[Laughter.]

And I am going to have Senator Collins start out and then I will make some comments.

OPENING STATEMENT OF SENATOR COLLINS

Senator COLLINS. First of all, thank you, Mr. Chairman. This is typical of how gracious you are and the bipartisan manner in which we jointly run this committee, even though you are the Chairman and I always recognize that fact.

I want to thank you for calling this hearing to discuss the importance of advanced care planning and to examine ways to improve how we care for people at the end of their lives. These are critical issues that at some point will confront each and every one of us and I commend the Chairman for focusing the committee's attention on them today. These issues also have long been of personal interest to me. One of the first bills that I introduced as a new Senator was called the Compassionate Care and Planning Act, and I introduced it with Senator Jay Rockefeller way back, I think, in the late 1990s.

Noted health economist Uwe Reinhardt once observed that Americans are the only people on earth who believe that death is negotiable. Advances in medicine, public health, and technology have enabled more and more of us to live longer and healthier lives. When medical treatment can no longer promise a continuation of

life, however, patients and their families should not have to fear that the process of dying will be marked by preventable pain, avoidable distress, or care that is simply inconsistent with their values and their needs.

Unfortunately, most patients and their physicians do not currently discuss death or routinely make advance plans for their end-of-life care. As a consequence, about one-quarter of Medicare funds are spent on care at the end of life that is geared toward expensive high-tech interventions and rescue care. While most Americans say that they would prefer to die at home, studies show that the vast majority still die in institutions, where they may be in pain and where they may be subjected to high-tech treatments that merely prolong their suffering.

We are making some progress in meeting the wishes of those at the end of their lives. More people over age 65 are dying at home and in hospice care and fewer are dying in hospitals, and I want to make clear that for some people, dying in the hospital is the right choice and the right option. But we should be respecting individuals' wishes.

At the same time, a recent study published by the Journal of the American Medical Association found that end-of-life care continues to be characterized by aggressive interventions. Increasing numbers of patients are receiving care in an intensive care unit in their last month of life, and a growing number are shifted back and forth between different care sites in their final three months.

Moreover, while the study found that hospice use has increased, more than 28 percent of hospice patients were enrolled for three days or less. I was astonished by that statistic, because I always thought hospice was supposed to be for the last six months, not the last three days.

Clearly, there is more that we can do in this country to improve the way that we care for people at the end of their lives. Advance care planning has been shown to increase satisfaction not only for the person who is dying, but for the family members, as well, and it improves health outcomes because people with advance directives are more likely to get the care that they want in the setting they prefer and avoid the care that they do not want.

Still, while 93 percent of Americans say that advance care planning should be a priority, only about a third of us have completed an Advance Directive.

I mentioned the bill that I introduced in 1997 with Senator Rockefeller. It was intended to facilitate the discussions about end-of-life issues with physicians and other health care providers and encourage advance care planning. It required that every Medicare beneficiary receiving care in a hospital, nursing home, or other health care facility be given the opportunity to discuss end-of-life care and the preparation of an Advance Directive with an appropriately trained professional. It also required that if the patient had an Advance Directive, it must be displayed in a prominent place in the medical record so that everyone caring for the person could clearly see it. And last but certainly not least, it provided Medicare coverage for advance planning consultations between patients and their physicians.

Mr. Chairman, patients and their families should be able to trust that the care that they receive in their final days is not only of high quality, but also consistent with their values, their wishes, and desire for autonomy and dignity. This issue, I know, has been a high priority for you, Mr. Chairman, for many years, as well. And again, thank you for calling this important hearing.

[The prepared statement of Senator Collins follows:]

**STATEMENT OF SENATOR SUSAN COLLINS
SPECIAL COMMITTEE ON AGING HEARING
“RENEWING THE CONVERSATION: RESPECTING PATIENTS’ WISHES AND
ADVANCE CARE PLANNING”
JUNE 26, 2013**

Mr. Chairman, thank you for calling this hearing to discuss the importance of advance care planning and examine ways to improve how we care for people at the end of their lives. These are critical issues that, at some point, will confront each and every one of us, and I commend the Chairman for focusing the Committee’s attention on them today.

Noted health economist Uwe Reinhardt once observed that “Americans are the only people on earth who believe that death is negotiable.” Advancements in medicine, public health, and technology have enabled more and more of us to live longer and healthier lives. When medical treatment can no longer promise a continuation of life, however, patients and their families should not have to fear that the process of dying will be marked by preventable pain, avoidable distress, or care that is inconsistent with their values and needs.

Unfortunately, most patients and their physicians do not currently discuss death or routinely make advance plans for their end-of-life care. As a consequence, about one-fourth of Medicare funds are spent on care at the end of life that is geared toward expensive, high-tech interventions, and “rescue” care.

While most Americans say that they would prefer to die at home, studies show that the vast majority still die in institutions where they may be in pain, and where they may be subjected to high-tech treatments that merely prolong suffering.

We are making some progress in meeting the wishes of those at the end of their lives. More people over 65 are dying at home and in hospice care, and fewer are dying in hospitals. At the same time, however, a recent study published in the *Journal of the American Medical Association* found that end-of-life care continues to be characterized by aggressive interventions. Increasing numbers of patients are receiving care in an intensive care unit in their last month of life and a growing number are shifted back and forth between different care sites in their final three months. Moreover, while the study found that hospice use has increased, more than 28 percent of hospice patients were enrolled for three days or less.

Clearly there is more that we can do in this country to improve the way that we care for people at the end of their lives. Advance care planning has been shown to increase satisfaction and improve health outcomes because people with advance directives are more likely to get the care that they want, in the setting they prefer, and avoid the care that they don't want. Still, while 93 percent of Americans say that advance care planning should be a priority, only about a third of the adult population has completed an advance directive.

One of the first bills that I worked on when I came to the Senate in 1997 was the Advanced Planning and Compassionate Care Act, which I introduced with my friend and colleague from West Virginia, Senator Rockefeller.

Our bill, which we went on to introduce in subsequent Congresses, was intended to facilitate appropriate discussions about end-of-life issues and encourage advance care planning.

It required that every Medicare beneficiary receiving care in a hospital, nursing home, or other health care facility be given the opportunity to discuss end-of-life care and the preparation of an advance directive with an appropriately trained professional within the health institution. It also required that, if the patient had an advance directive, it must be displayed in a prominent place in the medical record, so that all of the doctors and nurses could clearly see it.

The legislation also established a telephone hotline and information clearinghouse to provide consumer information and advice about advance directives, end-of-life issues, and medical decision-making. And, last but certainly not least, it provided Medicare coverage for advance planning consultations between patients and their doctors.

Mr. Chairman, patients and their families should be able to trust that the care they receive in their final days is not only of high quality, but also respects their values and desire for dignity and autonomy. This issue has also been a high priority for our Chairman for many years, and I look forward to learning more about how we can encourage these important discussions.

The CHAIRMAN. Senator Wyden.

OPENING STATEMENT OF SENATOR WYDEN

Senator WYDEN. Thank you very much, Mr. Chairman. Like colleagues, I am under the gun, but Senator Warner was here before me.

Senator WARNER. Please go ahead.

Senator WYDEN. Are you sure?

Senator WARNER. I am not even on the committee. He is letting me come.

Senator WYDEN. Oh, my goodness. Well, first of all, let me thank you, Mr. Chairman and Senator Collins, for your good work on this issue. This is about making sure that our people have all the choices they want, that they can get the services they need when they need them. And I think it is important to set out right at the outset that the good and bipartisan work that Chairman Nelson and Senator Collins are doing is the opposite of rationing. This is the opposite of rationing. They are expanding services to vulnerable people and I commend them for it.

Mr. Chairman, if I could, I just would like to introduce briefly—we have got an Oregonian here who is part of a pioneering effort. She is the leader in Oregon but also the national leader of a very important program called POLST, and it stands for Physician Orders for Life-Sustaining Treatment. Ms. Vandenbroucke is here to tell the committee about POLST, which is an approach to make sure that we can again emphasize the wishes of the patient, that the patient is in the driver's seat in order to get the kind of care that they deserve.

It is a holistic method of planning for end-of-life care and also incorporates a specific set of medical orders that ensure that the wishes of the patients are being honored. And as we will hear from Ms. Vandenbroucke, it also helps to expand conversations with family members and patients and others so that everybody is trying to think through what kinds of options and the extent of care they would like in various kinds of situations.

And as a result of those conversations, patients can elect to create a POLST form, which translates their wishes into actionable medical orders. The form assures that professionals are going to provide only the treatments that patients themselves wish to receive and are in keeping with the goals of their program.

Ms. Vandenbroucke has a J.D. from DePaul, her undergraduate degree from Bucknell. We are very glad you are here.

I will only close by way of saying, Mr. Chairman, I think it is particularly timely that you are looking now as we think through what the next steps are in health reform. I was very pleased that as part of the Affordable Care Act, we were able to get something included that, for the first time, people who sought hospice care would not have to give up the option of curative care. Again, the opposite of rationing.

So I just commend you, Mr. Chairman, and appreciate your letting me sort of parachute in here for a few minutes to make an opening statement, and Ms. Vandenbroucke, we are very proud that you and the POLST program are being featured today and we thank you, Mr. Chairman.

The CHAIRMAN. And, Ms. Vandenbroucke, you realize that your Senator from Oregon is the next Chairman of the Senate Finance Committee.

Ms. VANDENBROUCKE. I did not. Thank you.

The CHAIRMAN. Senator Warner.

OPENING STATEMENT OF SENATOR WARNER

Senator WARNER. Well, thank you, Mr. Chairman and Ranking Member Collins. I also appreciate the courtesy.

I am not a regular member of the Aging Committee, but feel this is one of the most important issues we have got to address. I have tried to address it as a Governor and as a Senator, but also as a son in a family where my mom had Alzheimer's for ten years. The last nine years, she did not speak. And our family did not grapple and do it right and we know the anguish that particularly my father and my sister, who were there 24-7 as caregivers, went through as we went through her final days.

I want to pick up where Senator Collins' comments were, because we are very much dovetailing that 93 percent of Americans who say advance planning ought to be part of our health care system. And what I also emphasize with Senator Wyden is this is not about rationing. This is about expanding options and honoring people's choices.

And picking up again where Senator Collins is, during the last two Congresses, I have had legislation, the Senior Navigation and Planning Act, which helped to try to grapple with a lot of the very same issues. How do you get that consultation? How do you make sure directives are honored across State lines? How do you rationalize something that is still a patchwork?

This year, I have been working with my colleague and good friend Senator Johnny Isakson from Georgia, where we are reworking and revising the language, and we are not quite ready yet, but we do hope in the next couple of weeks to introduce the Care Planning Act, changing the name, as well. And echoing what everybody has said, it is to align the care people receive with the care they want, no more and no less. The Care Planning Act is not going to try to fix all the challenges of advanced illness care but has targeted an effort that people, I think, will most benefit from, which is a planning process for people with advanced illnesses.

These are the people who have the greatest need to, one, just understand their disease and what the potential outcomes and timelines are; think about their goals, values, and preferences, not only with medical professionals, but oftentimes with their faith leaders; three, choose in that setting with that consultation the care options that reflect their goals, values, faith, traditions, and preferences. And then, when they have made that choice, to find a way to document that plan, and that, again, we have an enormous quilt work of even the term "advance directive" is only a partially used term in terms of different States do not even have that terminology.

This legislation will also shore up the Patient Self-Determination Act by requiring providers to provide qualified assistance to individuals who want help and by requiring discharge planners to assure that that care plan travels. Too often, we have somebody who

may have had some advance directive in one State, but family members or others, they end up in a hospital in another State and their wishes are not respected. Some of the most fascinating conversations I have had at some time have been with hospital system operators, and you get them in a closed room and they will acknowledge that this is not handled in an appropriate way.

I remember, as well, before I close here, that I had a series of meetings with faith leaders, and I remember one minister at one point saying, acknowledging that they were pretty good about the business of taking people through life and they were pretty good about people in the afterlife, but they did not really have a very good job of taking people through the transition. So we do think—at least I believe—that faith leaders have an important role to play.

So I want to again thank the Chairman and the Ranking Member for holding this important hearing and I look forward to hopefully having the opportunity to participate.

The CHAIRMAN. Senator Donnelly.

OPENING STATEMENT OF SENATOR DONNELLY

Senator DONNELLY. I am happy to participate in this and ready to listen to our witnesses.

The CHAIRMAN. Okay. And I, too, and without objection, my opening statement will be entered into the record.

[The prepared statement of Chairman Nelson follows:]

Opening Statement of Chairman Bill Nelson

Senate Special Committee on Aging: Renewing the Conversation: Respecting Patients' Wishes and Advance Care Planning
June 26, 2013

Good afternoon everyone and thank you for being here. Over the next few months, this committee will be looking at many important issues facing Americans as they confront their long-term needs. Today, we are going to discuss end-of-life care.

What kind of medical care would you want if you were too ill to express your wishes? And, who would you want to make important decisions about your health if you could no longer do so yourself?

These are difficult questions to ponder and even harder conversations to have with your loved ones. Polling shows that most Americans want to have a conversation about their advanced care needs, but like many other aspects of long-term care, they don't know how or with whom to have these conversations.

Consequently, most Americans haven't taken steps to fill out a living will or designate a health care proxy. In fact, one recent survey found that only 29 percent report having a living will that states their wishes on end-of life medical care.

So what can we do to get people talking and informed about this issue? One option would be for the Centers for Medicare and Medicaid Services (CMS) to revisit its decision to remove advance care planning as something that could be reimbursed as part of the Medicare's new annual wellness. Another would be for the Department of Health and Human Services to update research on advance directives last done under the Bush Administration.

I am happy to have a wonderful panel before us today that can shed some light on what's preventing most Americans from making their health care wishes known and how best to educate the public about exercising their options.

I look forward to our discussion.

The CHAIRMAN. I think it is worth noting that only 29 percent report having a living will that states what their wishes are in end-of-life care, and that was one of the reasons I had a little bit to do with when Ron Wyden and I were doing, in the Finance Committee, the health care bill, of getting in there where there would be a consultation on advance directives. And what we got in the bill was that that was going to occur on the first consultation with regard to Medicare, when a person became eligible for Medicare. But since then, we have tried to get CMS to put the advance care planning as a part of an annual consultation and CMS removed it. We also want to get the Department of HHS to update its research on advance directives.

So, we have a star-spangled board here of witnesses to talk to us, and first, we are going to hear from Jim Towey. He served in official positions. He has been on the staff of Senator Bob Graham. He served as the Director of the White House Office of Faith-Based and Community Initiatives. He has been the president of a small Catholic college in Pennsylvania. He is now the President of Ave Maria University, which is near Naples, Florida. He is a Floridian and, in the fairness of disclosure, he is one of my dear personal friends who uniquely brings to this discussion today the creation of an advance directive called Five Wishes, which is distributed around the country.

We also have Harriet Warshaw. She is the Executive Director of The Conversation Project. It is dedicated to helping people talk about their wishes for end-of-life care.

And then we have, as Senator Wyden has already introduced, Amy Vandenbroucke, Executive Director of the National Physician Orders for Life-Sustaining Treatment Paradigm Task Force. And so you bring another unique perspective.

And then we have Gloria Ramsey, a Registered Nurse, an attorney. Dr. Ramsey is recognized nationally for her leadership in the areas of end-of-life care, health disparities, working with vulnerable populations, particularly African Americans and disabilities. Dr. Ramsey, instead of reading a prepared statement, I would appreciate it, after you listen to the other three testimonies, which will all be of about five minutes in length, if you would comment on what you have heard and provide your expertise as a nurse and a medical researcher.

And we have been joined by the very happy and smiling senior Senator from Massachusetts.

[Laughter.]

Senator WARREN. Yes.

The CHAIRMAN. Senator Warren, would you like to make a statement, and we are ready to start with our witnesses.

OPENING STATEMENT OF SENATOR WARREN

Senator WARREN. Thank you very much. I appreciate it, and I apologize for being late. We have activities, and I am going to have to excuse myself before we are all through. This is also Senator Cowan's last day and he will be making his remarks from the floor—

The CHAIRMAN. Yes.

Senator WARREN [continuing]. So I will be joining him.

But I do want to thank you and I want to thank Ranking Member Collins for scheduling this hearing and for reopening the conversation about advanced planning for medical treatment.

Too often in today's health care system, medical care is focused on treating a disease, not on helping an individual patient. It used to be that a family or town doctor would treat a person for most of their lives for any medical issue. People and their doctors built up strong bonds over time and physicians knew their patients as unique individuals.

Advancement in science and medicine gradually caused more and more doctors to begin specializing and only treating certain diseases or certain parts of the body, and now, according to the CDC, only 56 percent of office visits are to a primary care doctor. Patients, especially seniors, see several specialty doctors each year that focus on different aspects of the individual's clinical needs.

So, we are slowly gaining evidence that coordination among doctors giving specialized care can improve a patient's quality of life and keep people healthy longer. I am proud that Medicare demonstrations like the Care Management Program at Massachusetts General Hospital are contributing to this evidence and improving our outcomes for seniors. Through the Affordable Care Act, we are encouraging even more coordinated care through medical homes and Accountable Care Organizations.

But in all of the talk about improving coordination and quality in health care, I think we have missed something vitally important, something we used to know way back when we had only one town doctor. Patients need to be treated like whole people, people with loved ones and families, people with dignity and values, not like a collection of parts and problems. Somehow, we need to make sure that people are still being heard in medicine.

So I am looking forward to the testimony of our witnesses today, hearing about the tools that we have available to help patients participate in medical decision making along with their physicians and their loved ones, and about what stands in our way so we can begin to work through the barriers and ensure that our seniors' voices are being heard.

I want to thank you all, and again, thank you, Mr. Chairman. The CHAIRMAN. Thank you, Senator Warren.

Senator Ayotte, we are already teed up, ready to go, but we want to hear any comments that you have prior to their testimony.

Senator AYOTTE. I will just wait for the questions. Thank you very much for this hearing.

The CHAIRMAN. Yes, ma'am.

Okay. Mr. Towey.

STATEMENT OF H. JAMES TOWEY, FOUNDER, AGING WITH DIGNITY, AND PRESIDENT, AVE MARIA UNIVERSITY, AVE MARIA, FL

Mr. TOWEY. Thank you, Mr. Chairman and members of the committee. It is an honor to be here before you. I am happy to be the warm-up act for this distinguished panel, and it is also good to be back working here in the Senate after working for Senator Hatfield seven years. I was here when the Hart Office Building opened, so

for me to be here before the Aging Committee is also appropriate. It is holding up better than I am.

[Laughter.]

But getting old or becoming ill is not a curse. It is part of life, with its own unique blessings and demands, and people should not dread old age. But why do so many? In part, I think it is because our health care system has turned dying into a medical moment and has many who are ill feel powerless, as though they are objects on some health care conveyor belt. So dying in America is too often characterized by poor pain management, loneliness, and spiritual starvation.

From the beginning, Aging with Dignity was an advocate for consumers and individuals, particularly the disabled and the poor, who had the most at stake, arguably, when it comes to preserving their fragile human dignity. From the day in October 1998 when the late Eunice Kennedy Shriver and I launched Five Wishes, I have witnessed firsthand the need for people to have advance directives and also their reluctance to engage in discussions with family members and medical personnel about their wishes during times of serious illness.

So I would like to turn to the topic of advance care planning first by citing some of my thoughts on how it came historically. Of course, when it started with Living Wills, very few used them and they were written in language that was beyond their reach, often by lawyers and individuals with graduate educations. And so you saw that this led to the Patient Self-Determination Act, which was a very important act of Congress in 1990 and placed the primary role of decision making with the patient and his or her designees.

Over the past 15 years or so, advance care planning policies generally improved in ways strengthening patient rights, and I think Five Wishes has been part of that nationally. When I began this project with Five Wishes, there were 17 States that required you to use a mandatory form, and now there are only eight States, and Charlie Sabatino here from the American Bar Association has been a real leader in that movement. But what has often happened seems to fly in the face of the Patient Self-Determination Act and what happens with the protection of patient wishes.

So I think that while we have seen progress with advance care planning, we are also seeing novel improvements and novel challenges. Certainly, POLST has a lot of promise, and I commend the work of my colleague here in advancing POLST, because unlike advance care directives, POLST does not require interpretation. It is an actionable medical order. And I think that that is great. I think for you to have a physician order in place during times of serious illness is important. And I think that we also have to be very mindful that if you have POLST used in situations other than when individuals might be in their last year of life, you could run into differing opinions on its usefulness, especially whether a patient's family members were consulted or not, because I think there is a lack of consensus on how far upstream POLST can be used and should be used and whether there are other concerns that would be of importance to Congress.

So I am going to raise, simply, five points really quickly on POLST. I think that the order should clearly note it is intended for

people diagnosed with a life-threatening illness that could lead to their death within the next year. That is how POLST began. I think it is important to keep it moored to that.

I think the order should include space to describe qualifying conditions and diagnosis, so if the patient is seen also by another physician in the future, it is easier to determine the qualifying conditions and the wishes of the patient.

I think that the order should note who discussed this with the patient.

I think, also, POLST should not deny the rights of health care surrogates and the individual's right to designate an individual to speak for them when they cannot speak for themselves.

And, of course, it should not be effective indefinitely.

Finally, I would like to simply say to this committee that I applaud your leadership, Mr. Chairman. Back in 2005, when you first sponsored legislation to add advance care planning as one of the items discussed in the "Welcome to Medicare" visit, and I urge your continued efforts and success. We know that this can become a real flash point in the public square. It happened with the Affordable Care Act. It could happen again if there is not a thoughtful discussion like we are seeing today by this committee.

Finally, I would just like to simply say in the way of recommendations that I hope that you consider national legislation to affirm the Patient Self-Determination Act, that you make advance care planning consultations reimbursable, that you members lead by example and have yourselves and your family members and staff members availed the opportunity to do advance care planning. I am happy to provide Five Wishes. You will not have to disclose it on a gift form. We give them away free when needed. And, also, I am hoping that as POLST is developed and further integrated in our health care systems, that it is done in a way that stays true to why it was introduced in the first place, which I think was a necessary improvement on helping families get the kind of end-of-life care they want in a care setting.

So with that and my time up, I want to simply thank you for this opportunity to come before this committee and to participate in this discussion.

[The prepared statement of Mr. Towey follows:]

Testimony of Mr. H. James Towey

Founder of Aging with Dignity, a Florida not-for-profit corporation founded in 1996, and current president of Ave Maria University, Ave Maria, Florida

June 26, 2013

Mr. Chairman, Senator Collins, and members of the Committee: I am honored to appear before you at this hearing to discuss the importance of advance care planning and the challenges that attend these discussions.

I founded the non-profit organization Aging with Dignity in 1996 to affirm and safeguard the God-given right of individuals to maintain their human dignity as they age. A former chairman of this Special Committee, the late Senator Lawton Chiles, as well as former Governor of Florida Jeb Bush, joined you, Mr. Chairman, at the time you served as Florida's Insurance Commissioner at the time, as founding members of this national organization.

When I think of how one can age with dignity, I think of your late father-in-law, Mr. Chairman, and also Senator Collins' mom, who is still with us. Their refinement, wisdom and beauty are the very same characteristics I saw in Mother Teresa of Calcutta, whom I was privileged to befriend the last twelve years of her life. Getting old or becoming ill isn't a curse. It is a part of life with its own unique blessings and demands. People should not dread old age. But why do so many? In part, I believe, because our health care system has turned dying into a medical moment, and has made many who are ill feel powerless, as though they are objects on some health care conveyor belt. Dying in America is too often characterized by poor pain management, loneliness, and spiritual starvation.

From the beginning, Aging with Dignity has been an advocate for consumers - for individuals and their families, particularly the disabled, the poor and others who arguably have the most at stake when it comes to preserving their fragile human dignity. Mr. Paul Malley, the president of Aging with Dignity since 2002, has established the organization as perhaps the single largest provider of advance directives in the world. To date there are almost 20 million copies of Five Wishes in circulation throughout the world, and it is now available in 27 different languages. Aging with Dignity has never advertised and yet 35,000 partner organizations, including places of worship, hospitals, health systems, hospices, attorneys, and other groups, have used Five Wishes to help individuals navigate the difficult personal, family, and spiritual terrain of end-of-life decision-making.

From the day in October 1998 when the late Eunice Kennedy Shriver and I launched the Five Wishes advance directive at a press event only a few miles away at the National Press Club, until this day, I have witnessed firsthand the need people have for advance directives, and the accompanying reluctance they have to engage in discussions with family members and medical personnel about their wishes in times of serious illness.

It is a distinct privilege to appear before this Senate Special Committee and I am happy to share with you my thoughts on advance care planning, on emerging trends and developments, including the expansion of the medical directive, POLST, and also some recommendations for Committee consideration.

But before I turn to advance care planning, I want to place my testimony within the context of what many consider the single largest domestic challenge facing America, and of course, I am talking about the "age wave" that is bearing down upon our country, Europe, Asia and elsewhere.

Mr. Chairman, you represent a state that is at the epicenter of the aging of America phenomenon, and so your leadership is critical. While the U.S. percentage of Americans 65 and older is 13.6%, Florida's is 17.6%. By the time an infant born in Florida today reaches college age – and enrolls at Ave Maria University – the state's percentage of 65 and over will be a staggering 26%. Each day in America 10,000 Baby Boomers reach the age of 65.

And while Baby Boomers have pioneered everything from rock and roll to cosmetic surgery, they also have been trendsetters in a less flattering way: they are fatter and sicker than their predecessors. Of 14 health indicators, Baby Boomers trail their predecessors in eleven, including hypertension, drinking, diabetes, high cholesterol, and immobility issues.

In a nutshell, Mr. Chairman, Florida today is what the rest of the United States will look like in 20 years, and Florida in 20 years will look like no other people of any age in human history. This has taken place because of the enhanced longevity – the average life expectancy for people turning 65 is about 85 for women and 83 for men. As my 95-year-old mother who is one of your constituents might say, this means we will have a lot of "tough cookies" around to take care of.

I will not delve into the pressures this age wave places on Social Security, Medicare, and Medicaid, and other health and social service programs. About a fourth of Floridians will spend a week or more in the intensive care unit during the last six months of life, and this Committee is well aware of the cost implications of such pilgrimages.

My focus this afternoon is on human dignity, and what happens when society begins to see old, sick people, particularly individuals who are disabled and very vulnerable, as burdens to society instead of gifts to us all.

I founded Aging with Dignity when I saw how Jack Kevorkian's solution to terrible end-of-life care, was assisted suicide. I felt strongly then and now that America deserves better than the choice between pain and poison. I am not surprised that the assisted suicide movement is gaining traction because Baby Boomers cherish autonomy, hate conformity, and often have an undeveloped understanding of human suffering. In states across the country, including New Jersey, Connecticut, Massachusetts, and Vermont, aging Baby Boomers are lobbying in their state houses to allow doctors to prescribe life-ending drugs for the terminally ill. This isn't just a "left coast" phenomenon. Kansas has this debate underway, and more states will surely follow.

And beyond the political debate on assisted suicide are some troubling statistics about the suicide rate itself. In May the Centers for Disease Control and Prevention reported a spike in suicides among middle-aged people, particularly white, Native American and Alaskan men, of 50 percent and 30 percent for men and women, respectively. These tragic endings, too, provide momentum for the so-called "right to die" movement.

Mr. Chairman, I have a grave concern that the right to die is a right the poor and disabled will get unless steps are taken immediately to increase the rights of patients and their advocates to make informed choices and decisions about the kind of care they want – or don't want – during times of serious illness. Many minority citizens do not fear too much medicine – they fear the systematic denial of health care and the encroachment of a "duty to die" expectation when incapacity appears. In a country riven with class divides and cultural differences, care at the end-of-life is certain to become a national flashpoint. The "death panel" spectacle of a few years ago is proof of my point.

So I would like to turn to the topic of advance care planning, first by citing how the advances in medical technology have pushed human life to its natural limits and made decision-making more complicated, and then by discussing current trends, the growing interest in granting final authority to so-called physician orders, and some recommendations for the Committee to consider. And then I would be happy to answer any questions you have.

Advance care planning in perspective

Americans living today have witnessed the most rapid advancement of medical technology in all of human history. The advent of trauma medicine, even to the extent of restarting a stopped heart, has extended countless lives. It was in the 1970's and early 1980's that Americans began to see this advancement in technology impact their families. While there was great excitement and wonder at the quickening pace of medical innovation and the life-saving miracles that were now becoming commonplace, there was also growing confusion and discontent.

As life expectancy grew, so did the length of time that people were now able to live with chronic illness. As new technologies and medical protocols were unveiled, patients and families began to face new and unprecedented questions, such as whether or not these new treatments were always the best option in every instance. They experienced the often long and isolating deaths of loved ones, most often in a hospital or nursing home, hooked up to tubes and machines they may not have wanted.

Many individuals and families felt unequipped and un-empowered to make treatment decisions. The balance of power was heavily tilted toward doctors, with patients and families often made to feel that it was not their place to even question the treatment decisions, let alone make the decisions for themselves.

The first response in the form of advocacy came from the Euthanasia Society of America. They created the first living will and set in motion a structure of end-of-life decision making that revolved around legal documents. The fact that living wills trace their genesis to the assisted suicide movement causes concern to this day. The vestiges of these groups like the Hemlock Society -- now called Compassion & Choices -- still use living wills to advance their cause.

A new challenge arose as living wills became more common and states codified them in law. The advance care planning process was developed by doctors, lawyers and legislators with little involvement from patients and families. The state statutes were written mainly for the purpose of guaranteeing protection and immunity for providers who followed living wills. The actual living will documents themselves were most often the products of legislative negotiation. While we can all be proud of our democratic traditions, documents created in this process may not be the most appropriate way to start a family conversation about care at the end of life.

By 1990, only a handful of people had completed any sort of advance directive. Patients and families found themselves being bystanders in the most critical moments of their lives. They were at a disadvantage in a system where the power of decision-making rested with the medical team. This was the impetus for the landmark Patient Self-Determination Act (PSDA) in 1990, which placed the primary role of decision making with the patient and his or her designees. In true American tradition, Congress acted to safeguard the rights of its citizens at a time when those rights were most vulnerable. It is not a coincidence that it was in this same environment, in the same year, that the Americans with Disabilities Act was signed into law. In both instances, Congress took decisive action to protect the rights that were being threatened.

Throughout the 1990s, advance care planning became more commonplace in American health care. Hospitals, in compliance with PSDA, began asking every patient upon admission if they had an advance directive. If the patient did not have an advance directive, one would be offered. This was a positive step, but often resulted in actions that were “too little too late.” The time of crisis is not the best time to make informed decisions. So even these efforts of health care providers to encourage advance care planning were often rebuffed, or simply ignored, by patients and families.

Put simply, the average person could not pick up an advance directive and quickly see the benefit. Most documents were written in legal jargon, at graduate school reading levels.

Fifteen years ago – in October 1998 – Aging with Dignity proposed a different solution. Rather than having a system of advance care planning dictated by the terms of doctor and lawyers, it created a planning tool focused on those things that are meaningful for patients and families. The result was Five Wishes.

Five Wishes brought advance care planning out of the emergency room and into family living rooms, places of worship, and the workplaces. It allowed people to make important medical decisions on their own terms and based on things that are meaningful to them. By including matters of the heart and soul, and addressing comfort and dignity, it conveyed the important message that what matters to patients and families really does – and should – matter to everyone involved in their care.

We are not all doctors, lawyers, or legislators. But we are all sons or daughters – and spouses, siblings, and friends – who want to care well for those we love. This is the common bond that connects us. We are motivated by the common desire to give the absolute best care to the people who are close to us. When done well, this is the heart – and the outcome – of advance care planning.

The reality is that caregiving is hard. We can have the desire to offer the best possible care, but more often than not, there is no clear definition of what that entails. There is a common refrain heard by family caregivers: “I want to be the best son or daughter to my parent – or the best spouse to my husband or wife – or the best friend to my neighbor... but I don’t know what to do. I don’t know where to start.” When done well, advance care planning becomes a customized instruction guide to the caregiver about what dignified care means to their loved one. It offers tangible ways that they can fulfill their desire to care well for someone, and gives them confidence that they are following that person’s wishes.

Current trends

Over the past 15 years, advance care planning policy has generally improved in ways that strengthen patient rights. One clear measurement is found in what are identified as the “Do It My Way” states. When Five Wishes was introduced nationally, in 1998, there were 17 states with mandatory form requirements. These states required residents to use only the advance directive forms written in state statute. Today the number of states with such a requirement is down to eight, which is an improvement, but still eight too many.

Here is what this means practically: Residents of Alabama, Indiana, Kansas, New Hampshire, Ohio, Oregon, Texas, Utah, are required to use a state-written form to express their personal end-of-life decisions. The current statutes in these states mandate that advance directives must be in the form contained in the statute. Such a position seems to fly in the face of the PSDA, which establishes the federal right of patients to have their end-of-life wishes

honored. The PSDA does not say this is a right granted only to those who complete the mandatory state form; it affirms the rights of all.

Ironically, most of these eight states have sections in their statutes that protect the rights of residents of OTHER states to make their wishes known in the form of their choosing. New Hampshire, for example, recently considered relaxing the mandatory form requirement, thereby allowing residents to use the advance directive that is best for themselves and their family. The bill was defeated based on objection from medical providers. In its place, the state legislature strengthened the reciprocity clause of the statute, guaranteeing that residents of other states could use any form and their wishes would be honored in New Hampshire. The end result is that a hospital in Manchester would honor any advance directive if the patient is a resident of Vermont or Massachusetts, but if the patient is a New Hampshire resident, then only the state-approved form is considered valid.

Beware the trend to re-medicalize advance care planning

Following years of progress in the effort to bring advance care planning into the mainstream, a new challenge has arisen. Patients and families were talking about their preferences, and more – though still not a majority – were completing advance directives. But these conversations and the resulting directives often do not translate directly to clinical decisions. No document, no matter how substantial, can envision every possible scenario near the end of life. There are gray areas that require judgment on the part of health care providers, designated agents, and caregivers.

The truth is that advance care planning does not answer every possible question or take away all uncertainty. This can pose a challenge to clinical decision making in emergency situations.

As a remedy, there is growing interest in medical order models that take the ambiguity out of clinical decision making. The most popular form is called the Physician Order for Life Sustaining Treatment (POLST). Others are known by other acronyms such as MOST, POST, MOLST, LA-POST, etc.

Unlike an advance directive, POLST does not require interpretation. It is an actionable medical order that transfers with a patient across health care settings, and determines if the patient will or will not receive aggressive treatment or comfort care only, antibiotics, or CPR. It can also determine if the patient would be transported to a hospital in the event of a health crisis – or if the patient should not be transported.

POLST aims to offer a solution to a real challenge. In a segmented health system where patients are often unknown personally to their treating physician, it is difficult to begin each encounter from scratch. This is especially challenging in emergent situations when a patient is transferred to a hospital and unable to make his or her own decisions. Even if the patient has an advance directive, it will require interpretation. If the patient has appointed a health care surrogate, that person will need to be consulted. It can be a time-consuming process when time is critical.

It may be entirely appropriate for a physician to write a medical order for treatment based on the patient's wishes in cases when a patient is near the end of life, when his or her diagnosis and prognosis are understood and discussed, and when it would not be a surprise if this condition led to the patient's death within one year. This is the rationale of POLST, but it is not the reality of its implementation.

Intended as a way to translate patient wishes into actionable medical orders, POLST sounds like a laudable concept. The problem is that POLST usage is not limited to those patients for whom it was created. Most definitions of POLST match the description above. However, most state policies (either in statute or regulation) do NOT define what types of patients are appropriate for POLST. The most critical aspect of this paradigm is left undefined. This is not unintentional. In fact, when the issue is discussed, the lack of consensus is clear. Some physicians believe all adults should have a POLST, others see it as the quick and easy advance directive that does not even require a patient signature.

There are real and legitimate concerns that this medical order model will override the wishes of patients and families. Uncontrolled misuse could serve to revert the Patient Self-Determination Act to the Physician-Determination Act.

These orders have become high-stakes forms that control patient care with a few strokes of a pen. One side of one piece of paper determines critical treatment decisions. Once the order is written, it is effective until changed by the physician. In case of a health emergency, providers would follow the POLST first, without any expectation of including the patient's designated health care agent in the process. In such cases, family members or trusted friends are sidelined or simply not consulted on the care decisions.

This may be convenient for health care providers because it removes ambiguity, but it raises serious concerns about the diminished role of the patient and his or her designated health care agent.

The accuracy of POLST – if it matches patient preferences – depends largely on the communication skills of the physician. It involves the completion of a high-stakes form where the checkboxes will determine the course of treatment in case of an emergency. Did the doctor have a relationship with the patient? Did the doctor talk about POLST with the patient for one minute or ten minutes? Did the patient have family members present during the discussion? So many variables can influence the final product of this form.

Some of these concerns could be mitigated by a few changes to the typical POLST structure:

- 1) The order should clearly note that it is intended for people diagnosed with a life-threatening illness that could lead to their death within the next year. Some may suggest that such wording will discourage completion. However, if POLST is intended for a certain population, then it should be so. The current strategy of leaving it to chance or interpretation is not working.
- 2) The order should include space to describe the Qualifying Condition or Diagnosis. In this space the physician can write the condition(s) that necessitate the order. This establishes a baseline; if the patient is seen by another physician in the future, it becomes easier to determine if the qualifying condition that necessitated the POLST remains constant or changed. If it is seen as too cumbersome or discouraging for the physician to note the qualifying condition, then perhaps the level of communication is not yet sufficient to complete the high-stakes form.
- 3) The order should note if the patient has an advance directive that should be considered when making treatment decisions.
- 4) The order should note who discussed the order with the patient (it is often NOT the signing physician) and the length of the discussion.

- 5) The signature of the patient, or his/her surrogate, should be required. Physicians may point out that patient signatures are never required on physician orders, which is true. However, this is a different type of order with life or death implications. It seems reasonable to require patient consent, at a minimum. In fact, to allow otherwise would seem to contradict the spirit of the PSDA.
- 6) The order should not be effective indefinitely. Since the order is intended for people whose death would not be a surprise within the next year, it seems reasonable to set an expiration date for the order. If the order has not been updated or affirmed within the past 12 months it should cease to be effective. The alternative is that emergency medical treatment decisions could be made for patients based on orders written years earlier by a doctor the patient visited once.

The criteria listed above do not address all the concerns related to POLST. However, these modifications to the POLST structure would make significant progress toward safeguarding the proper role and rights of patient and families to make their own health care decisions.

Reimbursing for advance care planning consultations

Mr. Chairman, I want to applaud your leadership in the area of advance care planning. As you know we supported your efforts in 2005 when you sponsored legislation to add advance care planning as one of the items discussed in the "Welcome to Medicare" visit. This was a common-sense approach that, like the PSDA, made it more likely that patients would be aware of their rights to make end-of-life decisions. The beauty of this legislation was its simplicity. It did not tell physicians what they were to discuss, how they were to discuss it, or how they must describe the benefits. It simply said that the physician should ask if the patient has an advance directive and offer the appropriate resources and information.

The same cannot be said for the original section of the Affordable Care Act that dealt with reimbursements for advance care planning. This was, of course, a topic of great controversy and widely misunderstood. That the ACA encouraged discussion of advance care planning and physician conversations was not concerning; what was troubling was that the proposed legislation was being used to tell doctors exactly what they were to discuss in order to be paid. For example, in order to be in compliance with the standards for payment, the doctor would have to tell the Medicare patient about "the benefits of POLST" (without mentioning that POLST is intended for those with a serious illness, not just for those over the age of 65). It is also common to see language that requires the physicians to describe the "full range" of options available. That sounds benign, but not if you are a physician who, as a matter of conscience, is not able to participate in assisted-suicide. Such a physician practicing in a state that has legalized assisted-suicide would be faced with the option of offering it against his conscience and good judgment to all seriously ill patients, or not being paid for the consultation. It is clear why advocates of assisted-suicide support such provisions.

Recommendations

Mr. Chairman, I want to conclude my testimony by offering five recommendations for action. These are not meant to be comprehensive in scope but certainly a starting point for the U.S. Senate as it considers how to promote advance care planning.

- Consider national legislation that affirms the PSDA and the primary role of patients, family members, and caregivers as end-of-life care decision makers. Clarify that an individual's end-of-life decisions when made in writing, signed, dated, and witnessed by two people carries the full force of law and should be considered by health care providers as a valid expression of patient wishes.
- Make advance care planning consultations a reimbursable expense. In doing so, Congress should not adopt any agenda apart from affirming patient rights. Any attempt to dictate the terms of this consultation, what should be discussed, or what should be distributed, would disrupt the doctor-patient relationship. It creates the perception that Congress is using this discussion as an opportunity to influence how Americans make end-of-life care decisions, which would reasonably engender fear and distrust.
- Lead by example - what you do matters and people pay attention. Consider offering advance care planning resources to your Senate staff. Aging with Dignity is happy to provide resources to you and offer presentations to your staff as a benefit to them and their families. Challenge the business, community and faith leaders in your state to do the same.
- Call on the US Department of Health and CMS to offer guidelines to states using POLST medical order models to ensure the rights of patients and their designated agents are respected. The current approach lacks consistency and definition. There is disagreement about critical elements, principally which patients are appropriate for POLST, and the lack of definition is resulting in a wide range of implementation schemes.
- Recognize that the primary role of Congress, as related to end-of-life care, is to safeguard the rights of Americans to make their own health care decisions. It should remove any barriers or threats to patient and family rights. It should not drive the discussion or dictate the terms of advance care planning. That may require Congress to resist the urgings of those who would define how, when, where, and with whom these discussions occur. It is not correct to say that Congress has no role in advance care planning, but it should not have a defining or determinative role in the process in such a way that tramples the rights of patients and the dynamics of trusted doctor-patient relationships.

Mr. Chairman, I conclude my testimony by again thanking you for your leadership and interest in this important issue that will only grow in importance over time. I would be happy to answer any questions that you, Senator Collins or your colleagues have.

The CHAIRMAN. Thank you, Mr. Towey.
Ms. Warshaw.

**STATEMENT OF HARRIET WARSHAW, EXECUTIVE DIRECTOR,
THE CONVERSATION PROJECT**

Ms. WARSHAW. Thank you. And on behalf of Ellen Goodman, who unfortunately cannot be here because she is in Barcelona today at an international health care conference, and our Board of Directors, I would like to extend our appreciation to the committee for inviting us here today.

The Conversation Project is a national public engagement campaign dedicated to helping people talk about their wishes for end-of-life care. We have a simple but audacious goal, to assure that everyone's end-of-life wishes are expressed and honored.

The Conversation Project grew out of Ellen's personal experience with her mother's journey through the health care system. It was a journey that Ellen was not prepared for, filled with many decisions about what kind of care her mother would need since her mother was no longer able to make these decisions for herself. Ellen was very close with her mom. They talked about everything. But the one conversation they never had was how her mother wanted to live at the end of her life.

After her mother had experienced what Ellen would call a "hard death," leaving Ellen filled with uncertainty about what her mom might have wanted, Ellen began telling her story to her friends. To her surprise, she learned that others had similar experiences with their loved ones. Ellen, being Ellen, she looked for a path to see how she could improve the way others experienced the death of a loved one.

Ellen reached out to a group of colleagues and concerned media, clergy, medical professionals, to share stories of good deaths and hard deaths within their own circle of friends. They realized that the difference between the two experiences often hinges on whether or not they had had the conversation. The consensus from this group was that although some progress had been made in the field of end-of-life care over the past 30 years, major change would not occur until there was pressure from the outside pushing the health care system, respectively, to be receptive to and solicitous of people's wishes for their end-of-life care.

From this discussion, The Conversation Project emerged as a grassroots engagement campaign to change the cultural norm from not having the conversation to having the conversation around the kitchen table with our loved ones long before there is a medical crisis. To do this, we have embarked on a three-part strategy using traditional and new media, collecting stories of good deaths and hard deaths to share with others, and to make The Conversation Starter Kit tool accessible to people where they live, where they work, and where they pray.

Our hope is that our work will give people the confidence and courage to have the conversation about their end-of-life wishes, first with their families and then with their health care providers, long before there is a health care crisis.

We have been overwhelmed by the public's response to The Conversation Project. Since our official launch in August of 2012, our

story has been covered by 200 news outlets, including the New York Times, the Wall Street Journal, ABC News and World Report. Our innovative Web site has been visited by over 100,000 people in the first six months, and strikingly, almost 50 percent of those who have visited the site have downloaded the starter kit and other tools. We have been asked to speak in front of national, State, and local organizations, businesses, and health care communities.

What we have learned during the past ten months is that we have touched a tender nerve within the American public. There is a deep desire to have end-of-life conversations with our loved ones, but people do not know how to begin. This disconnect is consistent with the findings of the California Health Care Foundation, which found that 60 percent of people say that making sure that their family is not burdened by the tough decisions is extremely important. Yet, 56 percent have not communicated their end-of-life wishes to their loved ones.

We know that in Massachusetts, 17 percent of people have had end-of-life conversations with their physician. And in California, only seven percent. As a result, while 70 percent of people say they prefer to die at home, surrounded by their loved ones, the reality is that 70 percent are spending their last days in hospitals and other health care facilities.

We have learned that our goal that people expressing end-of-life wishes resonates with communities across the country. We have been welcomed into California, into Contra Costa County, to work with medical societies, businesses, faith-based communities, to make the county conversation ready. We have been asked to convene and speak at educational forums in Boulder, Colorado, that was started by residents and in a forum that had over 300 residents in attendance. We have spoken at day-long forums at Wake Forest University sponsored by the Medical School, the Divinity School, and the Center for Bioethics. And there is now a pipeline of communities from the State of Rhode Island, to Kennebunkport, Maine, to Akron, Ohio, to Chicago, Reno, Tucson, Portland, Oregon, and the State of Hawaii, all who want to initiate The Conversation Project.

One thing is for sure. No matter where we live, no matter what side of the political aisle one sits on, we have, each of us, experienced, or will experience, the death of a loved one as well as our own mortality. The question for each of us is what we want for our care towards the end of our life and how we are going to assure that the wishes of our loved ones and ourselves will be expressed and honored. We believe that the best place to start is around the kitchen table, having an honest and open conversation with those we love. Our simple transformative goal is that we will be asking, have you had the conversation, and hear in response a resounding, "Yes."

And so, our question to each of you here today, respectfully, is have you had the conversation? Thank you.

[The prepared statement of Ms. Warshaw follows:]

the conversation project

Have You Had the Conversation?

The Conversation Project is a national public engagement campaign to ensure that all people's wishes for end of life care are both expressed and respected. The campaign has its roots in the growing understanding that too many people are dying in ways that they would not choose and that too many loved ones are left guilty, depressed and uncertain about whether they did the right thing.

Dying is the one universal experience. Nearly everyone has a story about a good death or a hard death among those they love. The difference between these experiences may well rest on whether we have shared our wishes for how we want to live at the end.

The Conversation Project's goal is ambitious: to change the cultural norm from **not having** these conversations to **having** them. To change that norm, we have to change when people have end of life conversations. We need to move the conversation from a time of medical crisis in the ICU or emergency room back to the kitchen table. We can best change how the health care system responds to the end of life from the outside in.

To reach our goal, we have developed a three-part strategy for cultural change.

One: Raise public awareness of the need for conversations about how we want to live at the end of our lives.

The Conversation Project (TCP) has already launched a successful national media campaign through our own website and outreach to both traditional and social media. The project has been featured in *The New York Times*, *O Magazine*, NPR, *The Wall Street Journal* and in dozens of other publications and broadcasts, including an ABC World News feature with Diane Sawyer. TCP has also established an active presence on Facebook and Twitter, and we are linked to numerous other social media platforms.

Our innovative website was visited more than 100,000 times in its first eight months. We welcome people to tell us how they want to live at the end and to share their stories with us, and many have already done so. We offer families a user-friendly Conversation Starter Kit that has been downloaded almost 50,000 times and has been reproduced and circulated thousands of times thereafter by interested organizations and individuals. We have also developed a kit on how to talk to your doctor or care provider.

Two: Everyone has a Story

At the heart of our strategy is story telling. Social change begins when people from all walks of life share their stories and discover how deeply their words resonate with others. We are most influenced to change our beliefs and behavior by hearing such powerful stories. Stories can be shared on-line in a dedicated bank of true narratives from a vast array of people from all cultural and demographic groups. Stories can also be shared through social media, amplifying their impact each time they are passed on in a posting, tweet or blog.

The Conversation Project looks to greatly increase story telling and sharing on every available platform and in every community. With a designated story manager working on social media platforms from Twitter to YouTube, and by reaching out to media partners, we hope motivate people to talk with their loved ones before it is too late. By audio and videotaping them, we expect to make their conversations echo across the country.

Storytelling also takes place in movies, television, and webisodes. We hope to work with the entertainment industry to include the conversation in shows appealing to a broad demographic audience around the country. We also plan to create an engaging video for community presentations that links Hollywood moments of moving, familiar, absurd, unrealistic, and telling scenes of dying—*How Hollywood Does Death*—to real life and the message that we need to start talking right now.

Three: Bringing the Conversation Project to people where they live, work and pray

As we enhance our media presence, we are keenly aware that that we must also bring The Conversation Project directly to people where they are everyday: in their town halls, congregations, and companies. The Project lives and thrives both in the air and at the grass roots.

The genuine sense that we are at a tipping point has come from the remarkable number of unsolicited invitations TCP has received from communities stretching from Providence to Honolulu to bring them into the conversation. In the last six months, we have been invited to and featured at 22 events and workshops. We will also be starting to work shortly with Corporate America-- in particular with two major companies which have invited us to share our resources and coach up their own professionals to be prepared to speak to the importance of The Conversation with their own employees and retirees upon request.

The Conversation Project now plans to create a pioneer group of ***Conversation Ready Communities***. We see these communities like an archipelago, points of cultural change spanning the country and serving to influence those around them. In these communities, the Project will work to engage everyone from faith leaders to local officials, from human resource and employee assistance professionals in businesses to medical educators and professionals, from book groups to other civic and community groups, from leaders in hospice to volunteers

who can coach others to have the conversation. We have both the understanding and —through our work to date—the experience, to launch this as a national model resulting in true local change.

Multiple ways to achieve a single ambitious goal

The intricate braiding of these three strategies—a national media campaign, an agenda to promote individual storytelling and sharing across multiple platforms, and a grassroots strategy to reach out to communities across the country—can and will fuel the most significant change in the end of life experience in decades. We are not looking for small changes. We expect nothing less than wholesale cultural shift.

Our simple transformative goal is that we will be able to ask, "*Have You Had the Conversation?*" and hear, in response, a resounding "*Yes.*"

Brief Background and History

The Conversation Project grew out of the experience of Ellen Goodman with her mother's journey through the healthcare system. It was a journey that Ellen was not prepared for, filled with many decisions about the kind of care her mother should receive once she was no longer able to make those decisions for herself. Ellen was very close with her mother; they talked about everything. But the one conversation they never had was how her mother wanted to live at the end of her life.

After Ellen experienced her mother's "hard death," she was filled with uncertainty about what her mom might have wanted. Ellen began telling her story to her friends and to her surprise learned that others had similar experiences with their loved ones. Ellen looked for a way to take her learning and improve the way others experienced the death of their loved ones.

Ellen reached out to a group of colleagues, media, clergy and medical professionals and invited them to gather and to share stories of "good deaths" and "hard deaths" within their own circle of loved ones. The consensus of this diverse group was that although some progress had been made over the past thirty years in terms of end-of-life care, major changes would not occur until there was pressure from the outside pushing the healthcare system to solicit and honor peoples' wishes. What was necessary, in short, was a grassroots national public engagement

campaign to change the cultural norm from not having timely end-of-life conversations to having conversations starting around the kitchen table.

In the Fall of 2011, The Conversation Project was invited by the Institute for Healthcare Improvement (IHI) to co-locate in its Cambridge, Massachusetts offices and to collaborate with its professionals in developing the campaign. IHI is a highly respected not-for-profit organization that helps lead improvement of health care throughout the world. Several months thereafter, The Conversation Project incorporated itself as a not-for-profit organization and filed its application for federal tax-exempt status. While its application is pending, IHI also serves as TCP's fiscal sponsor.

The collaboration with IHI has been instrumental in the launch and rapid expansion of TCP's campaign. So has the generosity of a number of other funders around the country led by the Cambia Health Foundation of Portland, Oregon which is a founding funder of TCP and which has shared its own vision, resources and wisdom to help propel the campaign forward and expand its reach. Also essential to TCP's development has been an outstanding Board of Advisers composed of highly accomplished professionals from a variety of disciplines whose experience and insights have been helpful in shaping TCP's direction and strategy.

To learn more about the work of The Conversation Project, please visit our website at www.theconversationproject.org

The CHAIRMAN. I have had part of the conversation.

[Laughter.]

Ms. WARSHAW. We will help you with the other part.

The CHAIRMAN. And, having gone through the loss of a couple of family members recently, I cannot say enough good things about hospice and especially when you try to create the environment that you are speaking about—

Ms. WARSHAW. Absolutely.

The CHAIRMAN [continuing]. At home, surrounded by the family and the loved ones, and that, in what is otherwise a painful experience, is a positive experience.

Ms. Vandenbroucke.

STATEMENT OF AMY VANDENBROUCKE, EXECUTIVE DIRECTOR, NATIONAL PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT PARADIGM PROGRAM

Ms. VANDENBROUCKE. Thank you. Even though he is gone, I want to thank Senator Wyden for his kind introduction.

Chairman Nelson, Ranking Member Collins, and other distinguished members of the committee, thank you so much for having me here today. My charge is to describe the POLST Program to you.

As you have heard, POLST stands for Physician Orders for Life-Sustaining Treatment and is a specific set of medical orders that document the treatments that a patient does or does not want in the time of a medical crisis. As detailed in my written testimony, it provides orders to health care professionals, including emergency personnel, on resuscitation, other medical interventions, antibiotics, and artificially administered nutrition.

The POLST Program is not just a specific set of orders on a form. It is also an approach to end-of-life care planning based on conversations between patients, health care providers, and loved ones. It was created over 20 years ago by a multi-professional task force convened by the Center for Ethics at Oregon Health and Science University in Portland, Oregon. POLST was subsequently adopted by Oregon's medical profession, ensuring that health care professionals could honor the treatment preferences of patients diagnosed with serious advanced illness, regardless of where the patient is during an emergency.

The POLST Paradigm Program has developed through grassroots approach in some States, like Oregon, and through State legislation and regulation in others. In 2004, the National POLST Paradigm Task Force was created to develop a set of standards for POLST Programs. The Task Force is charged with endorsing programs when they have proven that their program falls within those standards. Currently, we have 16 States that have endorsed programs and we have 25 States that are working towards this endorsement.

The Task Force also mentors States developing POLST Programs, States like Maine, Senator Collins. Thanks to the Retirement Research Foundation, Maine's coalition received a three-year grant to develop their POLST Program in accordance with the national standards, and my predecessor, now me, has received funding to formally mentor Maine. And through this, they have been

able to develop their program, and this year, I will be helping them submit their application for endorsement. There are several other States that also receive funding, such as Florida, Pennsylvania, Rhode Island, New York, West Virginia, Connecticut, Tennessee, Illinois, New Hampshire, and others.

In Mr. Towey's testimony, you did hear about advance directives, and in my written testimony, I describe the detail between—the differences between POLST and advance directives, but I want to highlight two here.

First is the target patient population. While all competent adults should be encouraged to have advance directives, the POLST form is not appropriate for everybody. It is only when a patient is diagnosed with a serious advanced illness that a POLST form would be appropriate. For those patients, they are able to consider their specific diagnosis and prognosis and their goals of care and then complete a POLST form so that they have standing orders for emergent or future medical care reflecting those goals.

The second is that this is a medical order signed by a health care professional giving orders. POLST forms turn the wishes expressed in an advance directive into action as a medical order.

Max's story, which I included in the written testimony, is a great example of when an advance directive is not enough. He had clearly documented his decisions on the treatments he did not want to receive when he was diagnosed with progressive heart condition in an advance directive, but when he collapsed as a result of that condition, the EMTs responding were unable to honor his wishes because they did not have a medical order. And for EMTs, when they are responding in a medical emergency in Oregon, they need to have medical orders. Otherwise, they have to do everything possible to attempt to save a person's life. And the POLST form can convey those orders. Max's death would have been very different if the responding EMTs had had the POLST orders to direct his care. He would have been allowed to have the natural, peaceful death that he so greatly desired, and his family would have had the comfort of knowing that his wishes were honored and respected.

There is still work to be done. As you likely know, electronic medical record systems can be complicated, and even though a record can be in the system, it may not be easily located. Although POLST is primarily a State effort, we invite the committee's endorsement of a uniform standard for electronic medical record systems to ensure that documents that are needed at the time of an emergency to honor a patient's autonomy are easily found, ideally with a single click.

Four final observations about POLST. First, comfort measures are always provided. In fact, research now shows that a patient with a DNR and a POLST form is likely to receive more palliative care than those with just a DNR.

Second, POLST is voluntary. The POLST—the National Task Force does not endorse or encourage programs where the completion of the POLST form is mandatory.

Third, POLST can be easily modified or revoked. The Oregon registry shows that about 15 percent of all POLST forms submitted each month is a modification of a previous form. So as a patient's disease progresses, their care goals can change and their treatment

preferences can change, so it is fundamental to the POLST Program that we allow for that.

And, finally, this is the patient's voice. Either the patient is the one having the conversation with the health care professional filling out the form or their surrogate is. So if the patient's voice is not heard, the surrogate is the person to look to. By encouraging the advance care planning conversation between health care professionals and patients and by completing a POLST form when it is appropriate and desired, we are respecting patient autonomy.

I appreciate the opportunity to be with you today. Thank you.

[The prepared statement of Ms. Vandenbroucke follows:]

“Renewing the Conversation: Respecting Patients Wishes and Advance Care Planning”
Senate Special Committee on Aging
June 26, 2013 Hearing
Written Testimony by Amy Vandenbroucke, Executive Director
National POLST Paradigm Program

Chairman Nelson, Ranking Member Collins, Senator Wyden and other distinguished members of the Committee, thank you so much for having me here to speak today. I am Amy Vandenbroucke, Executive Director of the National POLST Paradigm Program. My charge today is to describe this program for you.

1. What is POLST?

The Physician Orders for Life-Sustaining Treatment (POLST)¹ is a tool for translating patient’s goals of care into medical orders so that they are easily located and portable across care settings. POLST is not just a specific set of medical orders documented on a form; it is also an approach to end-of-life planning based on conversations between patients, loved ones, and medical professionals. The POLST Paradigm is designed to ensure that seriously ill patients can choose the treatments they want and that their wishes are honored by medical providers.

A key component of the system is thoughtful, facilitated advance care planning conversations between health care professionals and patients and those close to them. Completion of a POLST form requires shared decision making between the health care professional signing the form and the patient, or his/her legally authorized health care representative identified pursuant to state law. In order to complete the POLST form, there must be a discussion of the patient’s diagnosis and prognosis; the available treatment options given the current circumstances, including the benefits and burdens of those treatments; and the patient’s goals of care and preferences of treatment. Together they reach an informed decision about desired treatment, based on the person’s values, beliefs and goals for care. Then, if they wish, their health care professional completes and signs a POLST form based on the patient’s expressed treatment references.

POLST is not for everyone; only patients with serious advanced illnesses should have a POLST form. For patients where a POLST is appropriate, their current health status indicates the need for standing medical orders for emergent or future medical care. For healthy patients, an advance directive is an appropriate tool for making future end-of-life care wishes known to loved ones. The general guidance is that the POLST form is for seriously ill patients for whom their physicians would not be surprised if they died in the next year. It would be inappropriate to provide a POLST to all patients.

¹ POLST is known by different names in different states, including MOLST (Medical Orders for Life-Sustaining Treatment), MOST (Medical Orders for Scope of Treatment), POST (Physician Orders for Scope of Treatment), LaPOST (Louisiana Physician Order for Scope of Treatment), COLST (Clinician Orders for Life-Sustaining Treatment), IPOST (Iowa Physicians Orders for Scope of Treatment), SMOST (Summary of Physician Orders for Scope of Treatment), TPOPP (Transportable Physician Order for Patient Preference), and SAPO (State Authorized Portable Orders). For simplicity, the term POLST is used when referring to POLST Paradigm forms or programs in general.

Two key tenets of POLST are:

- (1) POLST is voluntary because everyone has the right to make his or her own health care decisions; the National POLST Paradigm Task Force (NPPTF) does not endorse programs where completion of a POLST form is mandatory.
- (2) POLST must be easily modified or revoked. Oregon's POLST Registry shows about 15% of POLST forms submitted to the registry each month are modifications of a previous POLST form. As the disease progression continues, patient desires for certain treatments may change so it is fundamental to the POLST Paradigm Program that POLST forms be easily modified.

2. The POLST Form

The POLST form varies among states but states endorsed by the National POLST Paradigm Task Force have all met the same standards.

a. What Does a POLST Form Order?

POLST forms are divided into a couple of key sections; the order may vary by state. For illustration, I will use the Oregon POLST Form (Attachment 1) as an example.

Section A: Cardiopulmonary Resuscitation (CPR). These orders apply only when the patient has no pulse and is not breathing; this section does not apply to any other medical circumstance. If the patient wants CPR, the box should be checked and full CPR measures should be carried out and 9-1-1 called. If the patient does not want CPR, the box should be checked and CPR should not be performed.

Section B: Medical Interventions. This section is designed to guide care in an acute situation when the patient is not in cardiopulmonary arrest. There are three levels of medical interventions generally found on POLST forms:

- i. **Comfort Measures Only/Allow Natural Death.** The treatment plan is to maximize comfort through symptom management. Antibiotics may be used as a comfort measure. This should be ordered if a patient's goal is to maximize comfort and avoid hospitalizations unless necessary to ensure comfort needs are met.
- ii. **Limited Additional Interventions.** The treatment plan is to hospitalize if needed but to void mechanical ventilation and generally avoid ICU care. This should be ordered if a patient's goal is to obtain treatments for reversible conditions or exacerbations of his/her underlying disease with the goal of restoring the patient to his/her current state of health. Examples include hospitalization for dehydration or for pneumonia.
- iii. **Full Treatment.** The treatment plan should include all life-sustaining treatments possible, including intubation, advanced airway intervention, mechanical ventilation, cardiobypass, transfer to hospital and use of intensive care as indicated with no limitation of treatment.

While it is possible to order Do-Not-Resuscitate (DNR) in Section A but Full Treatment in Section B; in this circumstance, a patient would want all measures provided but would not want to be resuscitated if those attempts fail and their heart stops. It is not possible to order CPR in Section A and Comfort Measures Only in Section B because, in providing CPR, the next step is for intubation and ventilation, which is not consistent with the Comfort Measures Only option.

Section C: Artificially Administered Nutrition. These orders indicate the patient's instructions regarding the use of artificially administered nutrition for a patient who cannot take fluids by mouth. Statutes vary among the states as to the standard for evidence required to limit tube feedings. For endorsement, the NPPTF requires POLST forms to clearly state that "food and fluids must be offered as tolerated."²

It is also a requirement that comfort measures always be provided to patients and that information be clear on the POLST form.

b. How Does It Work?

Since POLSTs are medical orders they can be made to be easily located in an emergency since they are part of the patient's medical record. There is no requirement for electronic medical record (EMR) systems to provide such easy access to a POLST, or an advance directive, but it should be so that health care professionals are confident they can locate patient wishes in an instant during an emergency (see Section 7 below). Additionally, the original POLST form is given to the patient to keep (copies are put in medical records); states use brightly color forms for easy identification by emergency personnel.

Several states, including Oregon, West Virginia, Idaho, Utah and New York, have registries for POLST forms, ensuring emergency personnel and health care professionals know the treatment wishes of their patients during an emergency. This provides a third avenue in which a form can be located in an instance, because health care professionals can call the 24/7 registry line and get information about a patient's POLST form.

So, for example, in an emergency in Oregon, when EMTs are called to a scene they will arrive and are trained to look at/in the refrigerator for a bright pink form; patients and families are told that this is where the form should be kept. Additionally, EMTs are trained to call the Oregon POLST Registry anytime: (1) they suspect a patient has a POLST; (2) they are told a patient has a POLST but are unable to located it; (3) the patient has a chronic, progressive illness; (4) the patient is a frail or elderly patient; and (5) if a POLST form is produced on the scene but there is a problem or question as to the orders selected, or validity of the form.

The value in having a single form for medical orders allows emergency services personnel to: (1) follow medical orders in the field because they are trained to find information in an instant and (2) incorporate such a procedure in their scope of practice.

² POLST Request for Endorsement Program Status Form; Item 9 under "Form Information".

c. Revisions/Voiding a POLST

As a patient's disease progresses his/her goals of care may change and so it is important that the POLST be easily amended or voided; both are easy procedures in endorsed states.

Revising a POLST Form.

The health care professional responsible for the patient's care should review and update the POLST form, with the patient or his/her surrogate, as needed based on the patient's medical condition and treatment preferences. At a minimum, the POLST should be reviewed in the following circumstances:

- (a) When the patient is transferred from one care setting or care level to another;
- (b) When there is a substantial change in the patient's health status; and
- (c) When the patient's primary care professional changes.

A patient with capacity, or his/her valid surrogate when the patient lacks capacity, may also initiate a revision of a POLST form at any time.

Revisions of POLST forms generally require voiding the current POLST form and writing/signing a new form, as well as giving the patient the updated form with instructions to destroy all older versions and putting the most current form in the patient's medical record (and archiving the old POLST form).

Voiding a POLST Form.

A patient with capacity, or his/her valid surrogate when the patient lacks capacity, can void the form and request alternative treatment at any time. A form is generally voided when "VOID" is written in large letters across the form, but the process varies by state, particularly if there is a state registry to be notified.

d. Signatures

The POLST Paradigm Program requires health care professionals be trained to conduct shared decision-making discussions with patients and families so that POLST forms are completed properly. State law authorizes certain health care professionals to sign medical orders; the POLST form is signed by those health care professionals, who are accountable for the medical orders.

The POLST form may be signed by the patient with capacity or his/her valid surrogate when the patient lacks capacity, but such a signature is not required in all states. In Oregon, the patient or surrogate's signature is only recommended; in New York, the patient or surrogate only attests that the conversation has taken place.

The NPPTF encourages all states seeking endorsement to require a patient or surrogate's signature on the POLST form, but is it not a required form element for endorsement. Since traditional medical orders are not signed by patients or surrogates, NPPTF's focus is on encouraging programs to design systems to ensure the conversation about patient's treatment options and goals has taken place.

3. POLST and Advance Directives

The POLST form is not intended to replace an advance directive document or other medical orders. The two documents differ, as will be discussed below, but they ideally work together. In short, the POLST turns the patient's wishes expressed in an advance directive into action as a medical order.

a. Key Differences

While all competent adults- regardless of health status- should have an advance directive, not everyone should have a POLST. As discussed in Section (1) above, POLST is for a very specific patient population. The POLST form is a set of medical orders, similar to the do-not resuscitate (allow natural death) order. POLST is not an advance directive. POLST does not substitute for naming a health care agent or durable power of attorney for health care. The differences are best presented in a chart:

POLST Form	Advance Directive
Medical Order	Legal Document
Immediately takes effect	Needs interpretation and discussion to be effective
Communicates medical treatments specific to patient's current state of health	Communicates general wishes about medical treatments in future states of health
Does <u>not</u> appoint a health care surrogate or representative	Appoints a health care surrogate or representative
Easy to locate (as medical order is in medical record). May also be in a registry. Most current version can be made easily available in medical record.	Generally not available when needed (patients have onus to ensure a copy is in the medical record and/or given to family to provide at time it is needed). Patients also have the onus to provide new copies when updating the document.
For those with advance illness or frailty- at any age	All competent adults over 18 should have (or whatever age of majority is in specific state)
Signed by health care professional (state law dictates which professionals may sign medical orders)	Signed by individual, his/her health care surrogate or representative, possibly by witnesses and possibly requires notarization (depends on state law)

For healthy patients, an advance directive is an appropriate tool for identifying a surrogate decision-maker and making future end-of-life care wishes known. Advance directives are generally completed when an individual is unaware of what disease or medical issue they may have in the future so it only provides general guidance. Further it is a legal document requiring interpretation and, because of that, it does not give directions in the field during an emergency.

Conversely, the POLST is a medical order. POLST takes effect as soon as it is signed by the health care professional and gives orders to other professionals, including emergency service personnel, which can be acted on. It is only when a patient is diagnosed with a serious advance illness that a POLST form would be appropriate. For these patients, their current health status indicates the need for standing medical orders for emergent or future medical care and they are able to make decisions about their care knowing their specific diagnosis and prognosis.

POLST orders are more easily located in an emergency. Further, having a single form for medical orders provides consistency that allows emergency service personnel to follow the medical orders in the field because they know where to look for specific information in an instant (this is also helped by the NPPTF encouraging all states to have all medical orders on the front page of the POLST form); this consistency then allows emergency service personnel to incorporate a procedure for using POLST in their scope of practice. Additionally, several states, including Oregon, West Virginia, Idaho, Utah and New York, have registries for POLST forms, ensuring emergency personnel and health care professionals know the treatment wishes of their patients during an emergency.

b. Max's Story

While the POLST Paradigm Program supports the completion of advance directives, clinical experience and research demonstrate that these advance directives are not sufficient alone to assure that those who suffer from serious advanced illnesses will have their preferences for treatment honored unless a POLST form is also completed. Max's wife, Suzanne, shared his story with POLST this year; his story exemplifies the differences between advance directives and POLST and explains why POLST is necessary. You may wish to watch the video [here](#).

Max was born and raised in rural Oregon; he was a devoted father and doting grandfather, as well as a gifted athlete. He was a champion squash player, who loved to play golf, hunt and fish. His active lifestyle was dealt a life-changing blow around the time of his 75th birthday when he received the sobering diagnosis of aortic stenosis. Open heart surgery was his only treatment option, and the alternative was an increasingly frail state of health as the valve slowly closed. He thought deeply about his choices, especially given his other health problems. And the conclusion he reached was crystal clear: he did not want the surgery.

Although he loved technology, and had embraced it in his life's work, he was, according to his wife Suzanne, "a man of nature." He was adamant that he wanted his life, and death, to unfold naturally—without tubes or machines. So, with great care, he completed an Advance Directive to document his end-of-life wishes, which he then shared with his family. He took comfort in the fact that his wish for a peaceful, natural death was clearly documented in an Advance Directive.

Suzanne and his family knew what he wanted and were comfortable with his decision. They knew he believed in the quality of life and had thought about it carefully based on who he was and how he wanted to live out his days.

Sadly, this careful planning was not enough. Five years later, when Max collapsed from heart failure while playing golf on Mother's Day, his strongly-held wishes could not be honored. His

Advance Directive, completed with such care and intention, did not serve as the medical orders needed to direct his care in this emergency situation. Max had just hit a good drive off the first fairway when his heart gave out. An ambulance was called to the scene and, when Suzanne arrived about 15 minutes later, she was deeply disturbed by what awaited her.

Emergency medical personnel were clustered around her lifeless husband, doggedly performing CPR in an attempt to revive him. And she realized with horror that this was exactly what Max had most wanted to avoid. She begged them to stop, telling them that she had his Advance Directive in her purse. But they kept going. And she looked around, seeing all these people coming to see what was going on. And she felt even worse, knowing that Max—who was a very private man—would not have wanted this at all. He would have hated it.

In a medical emergency, EMTs have no choice but to do everything possible to save a life unless they have *medical orders* to the contrary. The POLST form provides the medical orders necessary to turn patients' wishes about the treatment they do and do not want into action. The advance directive is not even reviewed until Max is at the hospital.

Max's death would have been very different if the EMTs responding to his collapse had had a POLST form to direct the course of his care. He would have been allowed the dignified natural death he deeply desired. And his family, in their grief, would have had the comfort of knowing that his wishes had been both honored and respected.

c. How POLST and Advance Directives Work Together

Patients with decision-making capacity can modify their POLST at any time to reflect changing circumstances—for example, when treatment has been initiated and more medical information becomes available regarding diagnosis, prognosis, or potential outcomes, the patient's goals and preferences may change. If the patient becomes incapacitated, the advance directive plays an important role in developing goals for care consistent with the patient in his/her new state of health. The surrogate identified by the patient in his/her advance directive would participate in either initiating a POLST or updating POLST orders in a manner consistent with the patient's preferences as the patient's health status changes.

4. What is the National POLST Paradigm Program?

The National POLST Paradigm Program's headquarters are at Oregon Health & Science University in Portland, Oregon. While it has a small staff, including its Executive Director, the National POLST Paradigm Task Force (NPPTF) is responsible for governing the strategic decisions for the National POLST Paradigm Program.

a. Key POLST Paradigm Public Policy Principles

There are five key principles of the National POLST Paradigm Program.

- (1) Health care professionals should encourage and offer assistance to all adults to designate a decision-maker and document their care goals and preferences.
- (2) Health care professionals should have a process to convert treatment goals and preferences of persons with life-limiting illness into medical orders (e.g. the POLST

Paradigm Initiative) to ensure that the information is transferable and applicable across all care settings.

- (3) In the absence of a validly executed advance directive, any authentic expression of an individual's goals, values, or wishes with respect to health care shall be honored.
- (4) Universal implementation of electronic medical records and internet based personal health records shall prominently include and integrate timely information about patient proxy designations, care goals and preferences, and medical orders for life-sustaining treatment.
- (5) The federal government should support research, education, and development of best practices relating to the quality and continuity of care planning and care implementation for persons with life-limiting illnesses across care settings.

b. The National POLST Paradigm Task Force (NPPTF)

The NPPTF was convened in September 2004 to establish quality standards for POLST forms and programs and to assist states to develop such programs. The NPPTF includes one representative chosen by each state endorsed by the NPPTF.

c. The Goals of the NPPTF

In the early 1990s the POLST Paradigm Program was developed to improve patient care and reduce medical errors by creating a system that identifies patients' wishes regarding medical treatment and communicates and respects them by creating portable medical orders. The system focuses on a growing segment of the United States population, those seriously ill patients with advanced, chronic progressive illness. While the NPPTF supports the completion of advance directives, clinical experience and research demonstrate that these advance directives are not sufficient alone to assure that those who suffer from serious, advanced, progressive chronic illnesses will have their preferences for treatment honored unless a POLST form is also completed.

A key component of the system is thoughtful, facilitated advance care planning conversations between health care professionals and patients and those close to them to determine what treatments patients do and do not want based on their personal beliefs and current state of health. In these conversations patients are informed of their treatment options and, if they wish, their health care professional completes a POLST form based on the patient's expressed treatment preferences.

A number of states have implemented the POLST Paradigm, and most others have expressed interest in doing so. POLST research shows that POLST use results in treatment consistent with patients' wishes more than 90% of the time, significantly reduces unwanted hospitalizations, and decreases medical errors.

The NPPTF is continuing to conduct research and develop quality measures to further assess the impact of the POLST Paradigm Program on patient outcomes. The goal of the NPPTF is to assure that the wishes of those with advanced illness and frailty are elicited, recorded and honored.

d. Activities of the NPPTF

Overall, the NPPTF is dedicated to overseeing the success of the POLST Paradigm in every state and to establish clear tenets of the POLST Paradigm Program. Through its various committees, the NPPTF mentors developing states, reviews and approves (or denies) endorsement and mature status applications, and advises on communication, research and registry efforts.

5. State POLST Programs

a. How Does POLST Develop?

POLST has developed in states primarily through a grassroots approach, such as in Oregon, or through legislation or regulation. Current legislation in the states can be located in the legislative guide created by the ABA Commission on Law & Aging (Attachment 2). Development of the first twelve states adopting can be found in the attached AARP Public Policy Institute Research Report entitled "Improving Advanced Illness Care: The Evolution of State POLST Programs" (Attachment 3).

b. Current Status of the POLST Paradigm Program

The NPPTF categorizes states based on their development status; the National POLST Map (Attachment 4) shows the current status of each state.

- (1) States With Contacts.** When states are exploring the development of a regional or statewide POLST Paradigm program they can formally connect with the NPPTF. This level is for states not yet ready to complete the Developing POLST Paradigm documentation but who would like to participate in the National POLST Paradigm Program (e.g., receive emails from the national office, attend various education sessions put on by the National Office or the NPPTF, etc). Oklahoma and Arkansas are currently in this category.
- (2) Developing States.** Programs are recognized by the NPPTF as "developing" when they have both: (1) submitted the Developing State Status Application form and (2) presented the state's POLST form and progress to the NPPTF's Developing State Assistance Committee. Developing POLST Paradigm Programs may be at various stages of development, ranging from the initial design of a POLST form to active usage of POLST forms, but are working towards the goal of implementing the POLST program statewide. In general, programs at this step are starting to contemplate addressing all Seven Core Elements of Sustainability (Attachment 5). There are currently 22 Developing States: Arizona, Connecticut, Florida, Illinois, Indiana, Iowa, Kansas, Kentucky, Maine, Michigan, Missouri, Nevada, New Hampshire, New Jersey, New Mexico, North Dakota, Ohio, Rhode Island, South Carolina, Virginia, Vermont and Wyoming).
- (3) Endorsed States.** The NPPTF will endorse state POLST programs when they have developed and implemented a POLST program and form meeting the NPPTF standards (See Request for Endorsement Status Form, Attachment 6). Endorsed programs are statewide or regional POLST programs that have become standard components of

advance care planning in their location. These programs have addressed legal and regulatory issues associated with POLST, and have developed strategies for ongoing implementation and quality assurance. There are currently 14 endorsed states: California, Colorado, Georgia, Hawaii, Idaho, Louisiana, Montana, New York, North Carolina, Pennsylvania, Tennessee, Texas, Utah, Washington, and Wisconsin, however, Wisconsin is only regionally endorsed.

- (4) **Mature States.** Mature status is the highest level of endorsement by the NPPTF and is reserved solely for states with statewide POLST programs that, among other requirements (see Request for Mature Program Status Form, Attachment 7) are the standard preferred method of advance care planning for persons with advanced illness or frailty. Mature POLST programs are used by 50% or more of hospitals, nursing homes, and hospices in each region (as defined by established criteria such as EMS, Department of Health, or the Dartmouth Atlas) of the state. These programs are actively gathering data for quality assurance programs and have considered centralized POLST databases. There are two states with Mature Program status: Oregon and West Virginia.
- (5) **States with Programs that do not conform to POLST Requirements.** There are some states that have developed POLST-like programs that, either from how the program was implemented, the development of the form, or for legislative reasons, will not be endorsed by NPPTF in their current form. There are four currently identified:
- a. Minnesota: Currently their form expressly states 911 should not be called when a patient's POLST orders are for "Comfort Measures Only". This violates the tenet of the POLST Paradigm Program that comfort measures are always provided to the patient; Minnesota's form overlooks instances where a patient cannot be provided comfort care in his/her current location. For example, if the patient falls and breaks a bone at home, it is unlikely their comfort can be adequately addressed in that location and it is likely the patient must go to the hospital for treatment to control their pain.
 - b. Maryland: Legislation going into effect this year requires POLST forms be completed for all patients except those in three limited categories. Their program violates the POLST Paradigm's tenant that a POLST is always voluntary.
 - c. Delaware: This program requires a patient be diagnosed as terminal before a POLST can be completed. Focus groups have shown that patients find the term "terminal" offensive. This program is too narrow in limiting the patient population that can access POLST; the target POLST population includes those patients where his/her health care professional would not be surprised if the patient died within the next year.
 - d. Massachusetts: The current form does not include the Section B discussed in Section 2(a) above but, instead, has a variety of questions. This lack of structure in the form causes confusion and lacks clarity.

Since this is a relatively new distinction, the NPPTF is working to evaluate other states currently in the "Developing State" category in light of recent legislation or form development. It is important for the NPPTF to clarify this category as the principles are important to the program; only mature and endorsed states should be used as examples of the POLST Paradigm Program.

We currently do not have contact with five states: Alabama, Alaska, Mississippi, Nebraska, and South Dakota.

6. What Are the Benefits of POLST?

POLST improves the quality of patient care and reduces medical errors by creating a system that identifies patients' wishes regarding medical treatment and communicates and respects them by creating portable medical orders.

A 2010 study by Susan Hickman in the *Journal of American Geriatric Society* showed that there was a reduction by 67% of medical interventions unwanted by the patients (mainly emergency room visits and hospitalizations) for patients with POLST forms with orders for Comfort Measures Only by compared with POLST orders for Full Treatment and 59% less than traditional Do-Not-Resuscitate orders. In short, POLST orders for Comfort Measures Only reduces hospitalization, readmissions and emergency room visits, as well as reducing care patients do not want to receive.³

7. What Is Needed for POLST to Be Successful?

Although it is a state effort, a uniform standard for electronic medical records should be a requirement that all EMR systems be designed in ways that POLST orders, as well as advance directives, be found quickly so they are easily accessible during an emergency. EMR systems are complicated and while a document may be "in the record" it may not be easily located. For documents that may be urgently needed- in order to ensure a patient's autonomy is respected- the NPPTF strongly recommends POLST forms be in a unique field/tab that can be accessed instantly – ideally in a single click. An example of how to find POLST in an EMR is attached as Attachment 8.

8. Other Considerations

POLST orders honor patients following their religious values. For example, the POLST form allows Catholics to make decisions consistent with the United States Conference of Catholic Bishops Ethical and Religious Directives for Catholic Health Care Services, 5th ed. (2009) and ensures that those decisions will be honored in an emergency and across care transitions.

In general, the POLST form enables physicians to order treatments patients want and to direct that treatment that patients would not want, including those a patient and his/her health care professional would consider "extraordinary" and excessively burdensome. Further, the POLST form requires that "ordinary" measures to improve the patient's comfort and food and fluid by mouth, as tolerated, are always provided. The POLST form is actionable and prevents initiation of care the patient does not want and that the patient considers disproportionately burdensome extraordinary treatment.

³ Hickman, Susan E. et al, (2010). " A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program." *Journal of the American Geriatric Society* 58:1241–1248.

POLST orders record patient wishes to have or limit treatment but it is never the intent for the orders to be written with the goal of hastening death; POLST recognizes that allowing natural death to occur is not the same as intentionally shortening life. Some patients near the end of their lives wish to stop treatments they find burdensome and have the primary focus of the care on their comfort. For these patients, POLST orders for Comfort Measures Only document their wish to step aside from medical treatments and allow nature to take its course; Comfort Measures Only is sometimes referred to as "Allow Natural Death".

In Oregon all of the hospitals including the Catholic health systems participate in the POLST program and use POLST orders to record the wishes of some of those with advanced serious illness under their care. For those patients desiring Comfort Measures Only, the POLST form documents orders to refuse treatments the patient finds overly burdensome in the advanced stage of their illness.

This is in stark contrast to physician assisted suicide. Not a single Catholic hospital participates in the Oregon Death with Dignity Act, which is the deliberate hastening of death. Though this Act and POLST both came to fruition first in Oregon, there is no relationship between them. The POLST Program is completely separate from "death with dignity" and POLST forms do not allow orders to be written for medication with the goal of hastening death.

9. Other Resources

The National POLST Paradigm website (www.polst.org) has additional information, including a variety of videos, POLST forms and educational materials, FAQs and resources. It has citations of the research done about or related to POLST and provides materials for states participating in the POLST Paradigm Program, such as the POLST Quality and Research Toolkit (PQRsT). This toolkit was designed to facilitate the study and improvement of POLST programs through data collection and analysis. The PQRsT consists of 30 instruments that have been created to study POLST for research or quality improvement projects, along with related research materials. POLST programs and researchers who have studied POLST programs have generously shared the instruments in the PQRsT in order to benefit POLST programs nationwide. Each instrument is paired with a summary, which provides more information on utilizing the instrument in data collection.

The CHAIRMAN. Thank you, Ms. Vandenbroucke.

All right, Professor. You have heard the testimony of the previous witnesses. What do you think? How would you advise us?

STATEMENT OF GLORIA RAMSEY, R.N., ASSOCIATE PROFESSOR, UNIFORMED SERVICES UNIVERSITY OF THE HEALTH SCIENCES

Ms. RAMSEY. Great. Thank you. Thank you, Mr. Chairman, Ranking Member Collins, and distinguished members of the committee. I am really pleased to have the opportunity to speak with you this afternoon and to comment on the testimony that we have heard thus far, and also to have an opportunity to share with you some of the research that I have been engaged.

I would like to begin with the comments or the testimony from Mr. Towey. At the onset, we heard about individuals who are poor, who are disabled, and who are powerless. It is the vulnerable populations that I would like to underscore that have not been a part of the discourse over the years. Although the PSDA was passed in 1992, as Mr. Towey said, not all communities have been a part of the conversation.

I would also like to comment with Ms. Warshaw and The Conversation Project and the idea that this is a grassroots effort, and believe me, change comes from the grassroots community, that the cultural norm needs to change, that these conversations need to happen where we work, where we live, and absolutely where we pray. My research largely embraces the faith community, and I will share that in a bit.

Also, I would like to underscore that there is a deep desire to have the conversation, but individuals, even health care professionals, need assistance. They need help in how to begin the conversation, and that is equally important. And having it at kitchen tables sounds like a really great place, before the crisis, before the medical event when everyone then is uncertain about what is afoot.

And, lastly, Ms. Vandenbroucke's comments about the POLST and really introducing yet another opportunity to engage the patient and the patient's voice.

And it is all of these efforts that, I submit, are important for us as we renew the conversations that we have been charged with today, and we thank you for the opportunity to revisit some of what has occurred.

And to that end, I would like to say that the views expressed are personal and do not reflect those of the Uniformed Services University of the Health Sciences or the Department of Defense.

As I think about my own work, certainly starting in 1992 with the U.S. Supreme Court's decision in *Cruzan v. Director, Missouri Department of Health*, and the Congress' passage of the PSDA, this was a wonderful opportunity, if you will, to begin to inform patients of their rights to accept and refuse medical and surgical interventions.

Today, we have heard statistics about the number of persons who are completing those, and I will certainly say to you, those who come from racial and ethnic diverse backgrounds as well as persons with disabilities, those numbers are far less.

And since passage of these laws and in recent years, recent studies report on the differences in decision making among racial and ethnic populations and patients with disabilities, and generally speaking, patients facing end-of-life care have the need to feel a sense of control, to have their pain appropriately assessed and managed, and as Senator Collins said, to be treated with respect and as a whole person.

Barriers to quality end-of-life care for African Americans stem from mistrust of the health care system, inability to access health care, inability to identify with providers, and the lack of financial resources, especially as death approaches. In my own research, we found significant differences between whites', non-Hispanic whites', and blacks' completion of advance directives and even their willingness to engage in health care planning conversations. Many feel that if they complete directives, that would be tantamount to an abandonment of care.

So there is much to be done as we think about the health disparities that we see across our country, and yet the opportunity for us to really begin to elicit the patients' perceptions, beliefs, and values.

In conclusion, African Americans and other racially and ethnically diverse populations' shared experiences, beliefs, and values influence their willingness to participate in advance care planning discussions, and advance care planning is an urgent public health concern and I thank you for renewing the conversation.

[The prepared statement of Ms. Ramsey follows:]

The CHAIRMAN. Excellent discussion.

Senator Collins.

Senator COLLINS. Thank you, Mr. Chairman.

Mr. Towey, I think that most people believe that advance directives are used solely to give direction on the kind of care that a patient does not want to receive. But, in fact, they also, as your Five Wishes document shows, can be used to direct the kind of care that they do want to receive. How do we make sure that as health care providers discuss these issues with their patients, that they do so in a neutral way and not bias the decision one way or the other?

I heard part of an NPR story this week that talked about how the way the question is asked can greatly influence the choice that is made, such as if you ask, do you want us to perform CPR if it means cracking open your ribs as we do so, you get a different response than if you put it in a different way.

Mr. TOWEY. Well, Senator, I think you have identified one of the real defects with how Living Wills were promoted up until very recently. They were biased in favor of only communicating declination. I do not want this treatment. I do not want that treatment. Well, this has been remedied. As you said, Five Wishes now has let people choose to say, I do want in this circumstance of if I am seriously ill.

I think beyond that, though, you get to the heart of the question, which is trust. There is such a mismatch. Many individuals have a crisis going on in their health before they even have these discussions. Then they are dealing with health care professionals that are speaking a language they do not understand. They are facing a health care system that has become increasingly more complicated.

As a result, a lot of distrust exists. People feel mismatched and inadequate to the conversation.

I think the nice thing about The Conversation Project and what we have been doing in Five Wishes since 1996 is pushing it away from the emergency room and into the living room, the kitchen, and so forth. But there is this trust element, which is why a health care surrogate's role is very important. And so often, if you do not have the conversation, then your surrogate is in as much of the dark as the health care provider.

So I think that a good place to start, I think, would be for Congress to communicate to States in some way that they should not require individuals to fill out a form which says, I do not want care in—in other words, a form biased the way you describe. Currently, there are eight States that require you to fill out a State form. It is usually long. It is usually impossible to decipher by all but the most educated. And it is often of little or no use to health care providers.

So a good start would say for the States to understand that these old vestiges of the past, where you have these antiquated Living Will statutes, give way to the more modern approach that lets people put their wishes in their own words. Let them have conversations, reduce it in writing, and communicate it to a health care surrogate, their health care professionals. That is the preferred route to go.

Senator COLLINS. Thank you.

Ms. Vandenbroucke, I was fascinated and touched by the story of Max that is in your testimony because it is so disturbing because he ended up getting care that was completely inconsistent with his wishes, and yet he had done everything possible to prevent that. You say in your testimony that EMTs have no choice but to do everything possible to save a life unless they have medical orders to the contrary, and I gather an advance directive is not considered to be a medical order, because you mentioned that his wife shows up with the advance directive and it does not do any good.

I guess what I do not understand is how would the POLST system solve that? I mean, you are not going to be carrying the orders with you.

Ms. VANDENBROUCKE. Well, you could.

Senator COLLINS. But that is pretty unlikely——

Ms. VANDENBROUCKE. It is unlikely, I absolutely agree. So, you are right. To reiterate, the POLST is a medical order. It is not an advance directive, so advance directives are signed by individuals. A health care provider may never see it until there is a time of crisis and someone happens to be able to locate it at the time. But a POLST is a medical order signed by a health care professional.

So in Max's situation, if his wife had shown up, and this is our bright pink form, with it, then they would have said, okay, yes. We have got these medical orders. It is signed by a professional, a health care professional, and we are able to do what this form says to do or not to do.

In Oregon, we do have a registry, so there are also certain situations where emergency personnel show up, and in this situation, if Max had completed a form but no one had it with them, which would be reasonable, they could say, he has got a POLST form, and

the emergency service people would call the registry and the registry would say, yes, this is the individual. Okay, he did not want CPR. He did not want this. Or, yes, he wants CPR. He wants that. And they would be able to act on those orders in the field at that time.

Senator COLLINS. Thank you.

The CHAIRMAN. Senator Warner.

Senator WARNER. Thank you, Mr. Chairman.

I want to follow up with Senator Collins. I think, is this not again one of the reasons why, though, we need some incentives so that that POLST order can translate across the State line? Could you speak to that, Ms. Vandenbroucke.

Ms. VANDENBROUCKE. Yes. So, we do have some States that have put reciprocity for POLST orders into action, or into their State legislation. Some States just do it from a grassroots perspective. I know recently in Oregon, there was an Oregonian that had been vacationing in Wyoming and they happened to have their POLST form with them and they had an emergency, and the Wyoming folks ended up calling the Oregon registry, confirming that this was, in fact, a medical order, and they were able to treat the individual based on their POLST form at that moment.

But it is certainly something that we are looking to, especially with the endorsed States. If you are a State that is endorsed by POLST, you know that the form has certain elements and certain things are not included on it, and so there is some standardization across those. So it is pretty easy from a reciprocity standpoint between those States, but as we are building in other States, it is something that we are working on.

Senator WARNER. I would like to ask all of the witnesses, perhaps starting with Professor Ramsey, but just one of the things that we have been looking at in terms of—I think it is great, you have got to start the conversation, maybe in one setting, but then you have to then have that conversation with medical professionals that then gets translated into this medical order.

The thing that we have kind of drilled down on, and starting with Professor Ramsey, but anybody could comment on, is that we found even within the kind of reimbursement that Medicare does right now, there is an availability to actually have a consultative team so that it is not just simply—it may be a nurse, it may be a social worker, it may be a doctor, so that there is some ability to help this kind of translation issue. Do you want to talk about that notion?

Ms. RAMSEY. Yes, sir. That is important, because one of the things we found in our work is that individuals from the community would like to see individuals from the community, individuals who they perceive understand their preferences, their values, their social-economic status, their spiritual beliefs, and the like.

African Americans do complete advance directives. We use the Five Wishes document in our research, and more than 80 percent of our persons have completed those. So to get a health care team who absolutely understands and appreciates the diversity and the inclusivity and also the cultural nuances and language considerations, as well, is important to really fully engage, and the Five Wishes document, again, was certainly one of those that was very

successful in our community and that we encourage our individuals to go to our local health care facilities with the document and the team is educated to know that it is a legally binding document and it is respected.

Senator WARNER. I might just want to add, too, that one of the things we are looking at adding in our team is that ability to have that faith leader as part of that team, as well.

Does anybody else want to comment on that?

Mr. TOWEY. Yes, if I could just add to that, because I think it is not only just an issue of trust, where individuals want to believe that their wishes are going to be followed. There is a concern if the conversation is being held with individuals who have a financial stake in their decision. So if an individual is saying, I want the works until the very last breath, there is a financial dimension to that communication versus one that says, no, I do not want my sternum cracked. Please do not do this.

And so as you move upstream, and you have, I think, very correctly said, Senator Warner, that you have got to go beyond just filling out a document and having a remote conversation. You actually have to have actionable plans, which is what I think POLST came into existence to remedy and has done effectively.

Beyond that, you have got to have parties involved that are disinterested, that do not have a stake, that have no skin in that game financially. Otherwise, there is a feeling that people have that if they do not give the right answer, they may have trouble in their health care setting if they are feeling pressured to say, I do not want care. So that has been our experience. I am not sure how to remedy it, but again, I think the more communication is in place with the health care knowing exactly what that individual wants, I think it helps them further upstream when there is a crisis.

Senator WARNER. But it is kind—and I want to hear from Ms. Warshaw—but it is a little bit of you have both examples. You have the example of someone feeling pressured maybe to kind of check too many boxes, but I will tell you, you also hear lots and lots from hospital systems where they will acknowledge where the absent relative who has not seen Grandma for months comes in feeling guilty and says, do it all. Disregard the wish of the patient. And trying to get that right is a real balance.

Ms. Warshaw.

Ms. WARSHAW. Thank you. I just wanted to comment, also, about the need to help our health professional staff feel comfortable having these conversations. What we have seen is they are humans, just like us, and find it challenging to have these conversations. And so we have been working with care managers, physicians, asking them to take off their professional hat, go through the starter kit, and experience what it is like and how challenging it is to have these conversations so that they then can lend that empathetic understanding and be ready to receive this discussion with their patients, because so few doctors feel comfortable starting the conversation, so—

Senator WARNER. Thank you, Mr. Chairman.

The CHAIRMAN. Senator Warren.

Senator WARREN. Thank you, Mr. Chairman.

So, Ms. Warshaw, I appreciate your question, and you asked, have we had the conversation. We should lead by example. I just want to take this chance to say publicly, yes, I have had the conversation. I had it twice.

My Aunt Bea started in about 40 years before she died—she died at 98—having the conversation. She was a shy, self-effacing woman, but she was determined that I would know what she wanted when the time came. And when we lost my mother very suddenly, my father after that insisted on having the conversation. Both of them said, “Betsy, we will be depending on you.”

And I just want to say about the conversation, I had the confidence that I was doing what Aunt Bea wanted, what my Daddy wanted. It was their final gift to me, and that is what really mattered about the conversation.

Ms. WARSHAW. I have had it with my two adult children, young adult, but adult children, and it was a hard conversation to have because nobody wants to have this. No one wants to think of their parents’ mortality. But, to me, it is a gift to them. It is unburdening making such difficult decisions. I never want them to have any regrets, and I had wonderful role models with my parents. Both of them have passed away, but I knew exactly what they wanted, and the last period, their end of their life, was a joy to be with both of them.

Senator WARREN. Yes. So thank you. Thank you, and I encourage everyone to have the conversation.

But what this discussion shows are the many benefits that we have from treating the whole patient, and the quality of life both for the patient and for the loved ones, and how we should strengthen our ways for getting more information here. And we have heard some great tools today. But the question I want to ask is how we can improve our Medicare program to make certain that seniors are being treated with dignity and respect, receiving the quality health care that is consistent with their individual values. You know, there is a lot of power in Medicare and I just want to start there, if we can.

Dr. Ramsey, could you comment on that, please.

Ms. RAMSEY. Great. Thank you. Again, in terms of my personal opinion, in terms of what the Federal Government has done, looking back in 1992 with the PSDA in terms of what were some of the opportunities that this particular legislation has provided, we have heard today that there is—Senator Warner is working on proposed legislation. And so I think that each of these that will have teeth, if you will, that actually expresses some guidance, would be enormously helpful for us. I think there was a lot of good that has come out of the PSDA. Was it—did we complete our total objectives? Not so much, but certainly, we are long on our way. So I think that in terms of using prior laws, examples such as that particular Federal law, will help us as you look forward with the current legislation.

Senator WARREN. Thank you.

Mr. Towey, would you like to add anything on that.

Mr. TOWEY. Yes, Senator. It is the reimbursement system. So you have got to incent good practices, and so there should be review of how hospitals and care facilities and care providers are doing with urging individuals to do advance care planning and have discus-

sions. Certainly, funding hospice in ways that gets them an earlier encounter, an earlier discussion with patients. They often are only brought in at the very end. There is a bias—it has been documented by the Dartmouth research that there is a bias toward hospitalization and curative care to the point where individuals, had they known what they were going to face the next 90 days, would not have tried radiation a third time. But, often, this is not communicated. It is simply a physician saying, we are going to try this.

So these conversations are best, I think, also incented in medical schools, where you start training the next generation of care providers to understand that if you are really going to be in the caring professions, you cannot simply treat them as an object for your health care practice, that you have to help them understand, here is what is ahead if you choose this option versus this option. Often, the patient has no access to a physician, and so then the discussion is held by a social worker who has no idea who the individual is and it is broken down from the very beginning because their case-loads are too great and they are not funded any more by Medicare.

So I think that a good way for Medicare to leverage its money is to incent good practices and also for us to be doing more with the medical schools to inform them about good pain management and earlier referral to hospice and better information for families and patients.

Senator WARREN. Good. Well, I see my time is up, but I just want to say, thank you all. Thank you for the work that you do every day. And thank you again, Mr. Chairman, for reopening this conversation for all of us.

The CHAIRMAN. Thank you, Senator.

Senator Whitehouse.

Senator WHITEHOUSE. Thank you, Chairman. Let me join the rest of the panel in thanking you and in thanking the Ranking Member for having yet another hearing on this issue and continuing to persist for results. This is so important.

Ms. Vandenbroucke has Max. I had Martha, and it was the exact same situation. She was a very, very proud lady. She was determined that she was going to go out on her own terms, and she had her advance directives and everything else laid out, but she passed away in Virginia. And at the time, if you did not have a bracelet around your wrist that showed that you had signed up for this very specific program, the exact same thing happened. The EMTs came. She could have had her doctor, her lawyer, her priest, her family, her advance directive all right there saying no and the EMT would have said, well, tough bounce to all of you. We are doing what we are doing and we do not care. And they were legally obligated to do so. It is not because they are cold-hearted people. So fixing that, I think, is very important.

And we are working on MOLST in Rhode Island. Maureen Glynn, who used to work for me in the Attorney General's office, is leading that charge and is doing a terrific job and we are trying to get it through the Health Department right now. I want to thank particularly our Catholic Diocese, which has been extremely productive and helpful in the MOLST. Ms. Vandenbroucke says POLST for Physician. We call it MOLST for Medical, but it is the same idea. The Catholic Church has been very, very productive in

this discussion, has been very, very helpful, and in a State as Catholic as mine, it makes a big, big difference.

And so keep doing what you are doing. If there is more that we can do to push this forward, give us advice, I am directly involved in that process in Rhode Island and I would love to be helpful in any way that your organization can give us advice.

And thank you for reminding us, Ms. Warshaw, about the conversation. It is important to have. And I will reassure people that I have had it on both ends and I do not think it is that bad of a conversation. Kind of screwing up your guts to raise the subject is the hard part. Once you start talking about it, it tends to bring a cone of trust and of affection and of family reciprocal loyalty out in people.

And so I do not think it is a conversation that we should be the least bit scared of or dread. In fact, every time I have talked to somebody about the conversation, when they are done with it, they feel way better than beforehand. It is not something where you walk away from it thinking, oh, that was a real ordeal. It is the exact opposite of that. It is a good thing for families to have that conversation.

We are in an environment here where we can observe that most people who die are old people. Most old people are on Medicare. Medicare will have a lot to do with how these decisions get made at the end of life. And we are also in a political environment in which something as vile and pernicious as the death panel notion was able to actually get traction and frighten people that there might actually be such a thing.

So what do each of you think would be the simplest, clearest, and most hobgoblin-proof improvements that we could make to Medicare, either by changing the law or by pushing the administration to make administrative changes, that would be a step forward in this direction, maybe not the final step forward, but a doable, clear, simple, non-controversial step forward? And quickly, because my time is running out.

Ms. WARSHAW. So, since we are at the beginning of the food chain on this discussion and we are really interested in a whole cultural change, not just some—

Senator WHITEHOUSE. We cannot do cultural change that quickly, with a simple change. What can we do that is simple and clear? What can we push for? What is the first step?

Ms. WARSHAW. Well, then I would suggest working with health systems to put the starter kit in every primary care physician's office.

Senator WHITEHOUSE. Okay. Ms. Vandenbroucke.

Ms. VANDENBROUCKE. I would say—I know it is not necessarily non-controversial, but promoting that conversation. As Mr. Towey said earlier, the advance directives in some States, you need a Ph.D. to understand what they are saying and what they are asking for, and really, unless you have the conversation with a health care provider about what your options are, you are going to be believing that if you have CPR, or if you need CPR, it is going to be a couple of presses on your chest, you are going to be fine, because TV shows 75 percent of people that have CPR on TV walk away,

when the reality is it is more like eight percent. And so people just do not even understand simple concepts, much less——

Senator WHITEHOUSE. We rewrote ours in Rhode Island because they are usually done when people are drafting their wills.

Ms. VANDENBROUCKE. Yes.

Senator WHITEHOUSE. So they are written by lawyers and for lawyers. Well, lawyers are not going to read them. Doctors are going to read them, and doctors speak a different language than lawyers, so——

Ms. VANDENBROUCKE. Exactly.

Senator WHITEHOUSE [continuing]. We changed it from lawyerese to doctorese, and that helped at least a little bit.

My time is expired, so let me just ask if you could reflect on my question as to what simple, clear steps would be that would be a good step forward, that are achievable in an environment in which the notion of a death panel might actually take footing, and just get back to us, because I do think that——

Senator WARNER. Share it with all of us.

Senator WHITEHOUSE [continuing]. We very much want to work together on this issue. This is a truly bipartisan issue and a truly human and humane issue, and I appreciate the wonderful work that you are all doing to advance the cause.

The CHAIRMAN. I always learn something from Senator Whitehouse, and today, I learned this beautiful turn of a phrase. Cone of trust.

Senator WHITEHOUSE. Modeled on Maxwell Smart's cone of silence.

[Laughter.]

The CHAIRMAN. Senator Ayotte.

Senator AYOTTE. Thank you, Mr. Chairman.

I appreciate all of the witnesses being here on such an important topic, and I know that there was a question asked to some extent when I was out of the room on this, but what I have heard from some of my concerns from constituents is that they have a situation where they either have two homes or they are traveling to visit a family member. Where they have an advance directive, they are worried that if—I have heard some, frankly, really bad stories about people who had advance directives, but one State did not respect the advance directive of another. And I know that some States do have some reciprocity, but what is it, in your view, that we could help make sure, not even—that States would respect the decisions and making sure that it is—the advance directive is drafted in such a way that there is some universal recognition?

If you could help me—I know you may have already answered this, but this is an important issue that I think if we are going to respect people's wishes in this regard, you know, we are a mobile society and there are too many of these stories and we never know when something is going to strike someone.

Mr. TOWEY. Well, Senator, I think you have raised a very important issue, which is being able to carry your—nobody travels with their advance directive unless they are really on top of things. So Five Wishes is a national document used in 42 States. Eight States, of course, have language that requires you—and their statutes require you to use their form. But you still have the Patient

Self-Determination Act, which provides individuals this right as a Federal right. It has not been tested in court. Who wants to be a test case?

But it is our view, as an advocate from the consumer standpoint, without any stake in the health care financing system, it is our view that they should be able to write it on a paper bag, their wishes, if they wanted to. It is not an effective way. It is not a good way. But it brings out the rights of individuals to communicate their wishes the way they would like.

So I think what the Federal Government could do is renew its point that the Patient Self-Determination right supercedes State statutes that are limiting an individual's exercise of their Patient Self-Determination right, at least as it applies to Medicare and Medicaid. You are paying for it. Why could we not see these States that have these mandatory forms recognize if they do not get with the better practices, they will lose their Federal funding? But until you do that, you will have this fractured system in place.

Now, people with Five Wishes, fortunately, can travel to most States. But a lot of places, you run into horror stories, where individuals did not have their advance directive and a State will say, well, we do not honor what you have. You did not fill out the State form.

Senator AYOTTE. No, I appreciate that. I do not know if anyone else has anything to add on that.

One of the issues is we have talked a lot about, certainly, this issue with regard to end-of-life decisions when it comes to the elderly, which is, I think, very important to all of us. I am blessed to have a 97-year-old Grandfather and a 96-year-old Memay [phonetic] that are still with us, and, frankly, the sharpest people in the family when it comes to what is happening in the nation's capital.

But I think that one of the issues, when we think about it, this is not just an issue of impacting the elderly—we are here in the Aging Committee—but how do we start this conversation with people throughout their life, even younger people? You do not want to think about, obviously, when you are young, anything happening to you, but tragedies can happen at any moment in life and so this is sort of part of the life continuum.

And so I just wanted to get your thoughts on—it is kind of like we are getting to the point where you are older and we are going to have this conversation, and it almost becomes a harder conversation because we are not incorporating that for some younger people in younger situations that can find themselves, obviously—none of us wants to think about this, but all of us want to make sure that our wishes are respected.

Ms. WARSHAW. So, one of the ways that The Conversation Project is addressing this is recognizing that we need to start the discussion with people where they work, where they live, and where they pray. And so we have been working with employers to have this conversation with their employees, no matter what age they are. We have brought together in Boston 20 faith-based leaders, actually, two weeks after the Marathon bombing, and had an extraordinary working session with them. Together, we are beginning to develop a faith-based strategy for Boston that encompasses every

faith being represented and universally, not by age, bringing it to the faith-based communities.

So, I think that you are right. As we learned in Boston, you get up in the morning and you do not know what is going to happen. And so we are trying to bring this concept, and that is why I say it is a cultural change, and we are hoping that we promote the day after Thanksgiving as “Talk Turkey” day with your family, when everybody is around, to have the conversation.

So, if the government with Medicare would like to be a partner in this media campaign with us, we would love to have you as our partner.

Senator AYOTTE. Thank you. I appreciate you all being here.

The CHAIRMAN. Having been whipsawed on death panels and having gone through the experience of a Floridian, Terri Schiavo, I would think that younger people would want to go ahead and complete an advance directive. But, of course, we see the opposite in the statistics that you have given us.

What do you think, is it human just “put off until a later day” kind of attitudes that is preventing us from having these discussions, and also of actually executing advance directives? Tell us what you think.

Ms. VANDENBROUCKE. I heard about a book recently, and it was written by a young woman, and it was something like *The Things That I Didn't Know I Needed to Know as an Adult*. And I think with advance directives, at least in my experience, being somewhat still young, people just do not know and they do not know the laws.

I was in-house counsel at Oregon Health and Science University and one of the things that surprised a number of people is that the Oregon law, once you hit 18, there is no one that is legally designated to speak on your behalf. They expect you to fill out an advance directive to say, this is the person that can speak for you if you are incapacitated, and people just do not know that and they are not thinking about it.

So, trying to get people aware of truly what can happen to them is, I think, something that can be an eye-opener, having a good story and just kind of communicating it that way.

Mr. TOWEY. Senator, not only taking it to the workplace, and also, when you talk to young people—I am at Ave Maria University—the last thing they are thinking about is their mortality. So, one of the things that we have done with young people that has been helpful is to say, if you want to be a good son or daughter, have you talked to your parents about what they want so you can be there for them when they need you the most? And that has been effective to a point, because they do not mind getting in the face of their parents.

And the real problem, when you look at the numbers in the Medicare and the Baby Boomer population, that group is going to live forever. Mick Jagger is going to be holding rock concerts until he has to have both hips replaced, and so they are, thankfully, joyfully forever young. And so trying to get the Baby Boomers engaged, I think, is even a greater, more important challenge for Congress, because they are the ones that are the consumers and so many of them do not have this.

And they have also—I put in my testimony, their profile health-wise is terrible. They are failing relative to previous generations on their health. So they are going to be needing more expensive care, more frequent care, and yet they have not even communicated their wishes. So we find that getting the kids to go to their parents now has been an effective strategy.

But I think, lastly, is the faith community. They do not have any skin in the game, so they are able to speak with a voice that is unbiased, that is not tainted. There is no perception of a conflict of interest. Certainly, getting the leadership of our faith communities engaged in this discussion would be very helpful.

The CHAIRMAN. And how do you take the information from a form such as Five Wishes and get this transferred over to Ms. Vandenbroucke's form that actually has the doctor executing?

Mr. TOWEY. Well, in States that have POLST, you certainly want to communicate to individuals, particularly if they are sick when they are filling this out, that they should know about POLST. We, of course, talk about DNR, but that is not enough. POLST is much more comprehensive.

So what you would like to have, Senator, happen, is first, the advance care document filled out. That is your legal right. The discussion with your health care surrogate who knows exactly what you want, including issues related to POLST. And then, third, in your medical discussion with the physician, it is the physician, too, who should be bringing up the POLST discussion. Do you have an advance care directive? And have you had any discussion about POLST? So, hopefully, that is how the sequence would work.

Ms. VANDENBROUCKE. And I would just add that the next step is then putting it into the medical record in a way that it is easily found at the time of an emergency, because if you have the forms and we cannot find them, then they do not have much value.

The CHAIRMAN. And, of course, if we can get HHS to require this in the annual Medicare visit, that is just going to all the more add to the conversation.

Does anybody know why HHS would not put that in? Is it money?

Mr. TOWEY. I can speculate that I think they are fighting about getting anywhere near the death panel issue again.

The CHAIRMAN. Ah.

Mr. TOWEY. And so I think until—if ObamaCare is fully implemented, I think there is a fear that it will get derailed. The discussion will get diverted. So I think there may have been a reluctance on them to engage. That is just my speculation. Gloria or others may have a different point of view.

Ms. VANDENBROUCKE. No, I agree with that. That is one of the grassroots efforts, I think, of most States that are trying to develop or enact the POLST Program, is reaching out to health care professional facilities who have EMRs, like Epic, and get them to modify it in such a way that you have a header like the one that is on the last page of my written testimony, where you can easily click on it. But they are having to do that more on a case-by-case basis.

The CHAIRMAN. Ms. Warshaw.

Ms. WARSHAW. Yes. I would just add that if we require our physicians to do this, we also need to educate them, because otherwise,

it will just be a checklist. There will be a check-off and there will not be a really robust conversation. And it is the subtleties of that robust conversation that influences whether your real wishes are implemented.

Ms. RAMSEY. And I would add, in addition to the physicians, to the Advance Practice Nurses, the Doctors of Nursing Practice, the other health care professionals.

I did want to comment in terms of the earlier comment about engagement of younger persons. One of the things that we are really seeing is that when you think about health disparities, the burden and incidence of disease among minority populations, whether it is cancer, cardiovascular disease, and the like, the burden of disease is taking its toll. And so the idea about why these conversations are particularly important is one that really has helped to upstream the conversation.

So albeit the Karen Ann Quinlans and the Nancy Cruzans of the world were much younger, what we are finding with our work, because of the burden of disease and the lack of access to health care and the like, that we are seeing individuals who are living with chronic diseases and that we are forced—or at least it allows an opportunity to have a conversation, which is really providing access in a way that we have not seen in the past.

The CHAIRMAN. Senator Collins.

Senator COLLINS. Thank you, Mr. Chairman.

As I have been listening about the debate on the discussion today, I thought of the fact that filling out a POLST order, for example, is very different at age 18, which was the point that Mr. Towey was making, than it is at my age or my parents' age. And I do not know that we should be encouraging college students to fill out advance directives and POLST orders. I mean, I could easily fill this out now, but when I was at age 20, my answers would probably be totally different than they are now, and Mr. Towey, I think, was trying to get at that point when he talked about when this should be used. And, Ms. Vandenbroucke, you did say it was in most cases when someone would have less than a year to live or something like that.

But talk to me about this issue and when we start, Mr. Towey, and go down. I mean, should this conversation that Ms. Warshaw has talked about, Professor Ramsey has talked about—is not this conversation a different outcome depending on how old you are?

Mr. TOWEY. Yes, Senator. I do think that individuals that are older, it is a more immediate question and they have a different perspective, different values. And so one of the things that we see in advance care planning is individuals change their Living Wills all the time, or they go to their health care agent and they say, "I have changed my mind."

I just saw a friend that had a bad experience. I do not want that to happen to me. And so you will see changes, which is why I believe POLST has great promise, provided that it is used and kind of limited to the situations for which it was created, which is in the face of imminent health difficulty, serious illness, so that it is not seven years later that something you said after a car accident is being applied to you now that you have had a minor stroke.

So we urge there to be time limits on POLST for when it is written, and also the physician who is having that discussion with the patient, that there be documentation so you know who did it, so that there is a verification that this was done with the free, voluntary assent of the individual, because as Gloria has mentioned, many groups feel pressured, coerced, and inadequate to those conversations with a physician.

Senator COLLINS. Thank you.

Ms. Warshaw.

Ms. WARSHAW. So, as I said, we are at the beginning of this discussion, and so what we encourage people to do is to speak with their loved ones about what their values are and what they want their end-of-life to feel like or look like, not specifically what tests or what type of health care they want.

So it will change over time, and I think if you had asked Ellen what the perfect name for our organization would have been, she would have said "The Conversations Project," but it is too difficult to say. So we recognize that this is just the beginning and it is a lifelong conversation.

Senator COLLINS. Ms. Vandenbroucke.

Ms. VANDENBROUCKE. Yes, so you are correct that the POLST form really is for the end-of-life and the focus is, earlier on in life, I think, completing that advance directive. And I think it is worth having the conversation early on because you just do not know what is going to happen. And as long as you have the conversation, even if the form is never filled out, you have a general sense of what your family member would have wanted.

With respect to the POLST form, it is almost—I know that some States view it as a medical error if you fill it out too soon. So, one, this is a form that is initiated by a health care provider, not the individual.

And, two, if a health care provider gave me a POLST form and said, "Fill it out," or said, "I want to fill out this form for you," that is completely inappropriate because this is putting a medical order into place that—well, one, if they are mandating it, that is a problem, but it is setting up for medical orders that would not be appropriate, because I am young, I am healthy, and I would want full treatments regardless, and that is what the law already provides for. So this is—it is something that would be reported to a board for a serious infraction if people are misusing this form.

Senator COLLINS. Ms. Ramsey.

Ms. RAMSEY. And I would only add that for the younger individuals, advance care planning is a process. It is not a one-shot deal. And so the idea about lots of your values, your attitudes, and your preference about other things are actually also addressed as we are having the advance care planning conversation. As my community member said, "If I were to step outside and get struck by a car, who would that person be that I would want to be there at my side to be the advocate for me, to be the navigator for me while I am hospitalized and receiving care?"

So I think that, certainly, the end of life is along that continuum, but I think there are lots of advantages for engaging early, and that is what we have seen.

Senator COLLINS. Ms. Ramsey, just one final question, because you have just touched on an issue I wanted to raise, and that is I have heard so many stories and have seen friends where family members cannot agree and have very different views on what should be done and the patient is too ill to give direction and that conversation never took place. So you have made the very good point about making sure that there is someone who can make the decisions for you, but should that always be a family member necessarily?

Ms. RAMSEY. Not necessarily, and I think that when I use the Five Wishes document in our work, one of the things that is expressly stated in the form, that it need not be a family member, because sometimes family members are not the best person. And so that is an important conversation, that it need not be your spouse or your oldest child, but rather it should be someone who is going to be able to articulate your preferences, is comfortable with that, and really is available to you, among some other criteria that would be helpful to consider. But, no, not necessarily that it has to be a family member.

Senator COLLINS. Thank you, Mr. Chairman. Thank you.

The CHAIRMAN. Senator Whitehouse, you have a request.

Senator WHITEHOUSE. Mr. Chairman, I just wanted to ask unanimous consent that the opening statement I had intended to give if I had been here on time be included in the record as if I were.

[The prepared statement of Senator Whitehouse follows:]

**Opening Statement for Senator Sheldon Whitehouse
Senate Special Committee on Aging
“Renewing the Conversation: Respecting Patients’ Wishes and Advance Care
Planning”
June 26, 2013**

Mr. Chairman, Ranking Member Collins: Thank you for holding a hearing on the important topic of advanced care planning. Issues of dignity and choice in end-of-life care affect every family. I appreciate having a few minutes to talk about my interest in and work on this topic.

As Rhode Island Attorney General, I worked for years with medical professionals, faith leaders, and advocates for seniors focused on care for the terminally ill. We worked on the assessment and management of pain, the socio-economic factors that underpin decisions about care, and the legal protections available to patients to ensure their care wishes are heard.

On this committee, I chaired two hearings on advanced illness and end-of-life care issues: one in 2008, the other last June. I’ve met several times over the past year with Senators Warner, Isakson, and Johnson who share my interest in a range of end-of-life care issues, to discuss ways to build bipartisan consensus on areas ripe for improvement. Our work has been supported and encouraged by a terrific new alliance of advocates, providers, and payers that has emerged to focus on advanced care issues, the Coalition to Transform Advanced Care. I encourage Members interested in digging into this issue to give C-TAC a call.

Finally, I come to this hearing with the personal experience of witnessing the sickness and death of loved ones, as do, I expect, many in this room. I know just how important and powerful that experience can be, not only for those who are ill, but for the family members and caregivers invested in their care.

Today’s hearing is offered as an opportunity to “renew the conversation.” I greatly appreciate the Chairman’s and the Ranking Member’s effort to raise the profile of this issue. It is far past time to review how our health care system is and isn’t working for those diagnosed with serious or advanced illness, such as Alzheimer’s disease, dementia, or late-stage cancer.

Indeed, the price of *not* having this conversation is dear, as long as there are patients who fall through the cracks, families who don’t know where to get help, or providers who struggle to fulfill a patient’s wishes within an unwieldy health care system.

Many of these challenges were highlighted by the witnesses at the hearing I chaired last year. Four specific issues deserve further exploration by this committee:

- (1) failures of advanced directives, either because they don’t exist, they aren’t clear, or they aren’t being honored;
- (2) handoff failures at transitions of care, characterized by one witness as being “lost in transition”;

- (3) controlling and treating pain and the availability of palliative care; and
- (4) lack of attention to family and caregiver supports.

I hope we can touch on some of these issues today. I thank our witnesses for joining us today and for adding your voices to this discussion. I look forward to continuing the conversation about improving our health care system in a manner that puts patients first, honors their wishes, and provides them the best care available.

Thank you, Mr. Chairman.

The CHAIRMAN. Indeed, without objection.
Are you in your cone of silence?

[Laughter.]

Senator WHITEHOUSE. No, I am prepared to yield to Senator Blumenthal.

The CHAIRMAN. Senator Blumenthal.

Senator BLUMENTHAL. Thank you, Senator Whitehouse, and thank you, Mr. Chairman.

I wonder—for the panel, I appreciate all of you being here on this very profoundly important topic. Connecticut, as you know, has taken a number of steps in this direction, and while I was Attorney General of the State, I supported those efforts, options for patients to provide instructions or to appoint someone to provide instructions to physicians, family members, and others about care choices. We thought this was especially important, and Connecticut helped to lead, when patients are unable to express themselves on these issues, and planning and preparation, and the term “conversation” was not quite as much in vogue as it has become today, so we thought there ought to be talks and discussions and family meetings and as much frank, good talk about this as possible.

But there are also a lot of legal complexities surrounding these issues, and I have looked over some of the examples provided for options for end-of-life planning and advance directive and the Five Wishes form and so forth. I wonder, what options are available to enable people to better understand the governing law of their States, whether that is something that needs addressing. Obviously, people are not going to want to pay a lawyer, understandably, to do this for them, and most cannot afford a lawyer. So what options are there for furthering public understanding in the face of what they may think are legal complexities?

Mr. TOWEY. Senator, it certainly has been the province of law firms often to provide a Living Will as part of their estate planning practice, and that has been somewhat effective, although they typically use the State form, so there is not really a useful document in play to begin with.

But worse than that is the fact that most individuals who are poor, disabled, have no access to an attorney in the first place, and so we have been out there promoting the use of Five Wishes, make it—I think it is a dollar each for 25 or more—for faith communities, for financial planners, but also, you know, parish nurses, other individuals that are in the community itself, the aging centers, to be able to go upstream, reach individuals.

And then our document is meant to be educative. It is meant to kind of help them understand what their rights are. You have passed, or Congress has passed the Patient Self-Determination Act. No one knows what is in it. It has been over 20 years. So that is why one of my recommendations was a renewed voice by Congress on the importance of advance care planning.

I think when you deal with elderly in nursing homes, Senator, typically, when I go to a nursing home, I always ask at the front desk, how many people here have no visitors ever, and you get over half is the answer. So when you start talking about advance care planning for that population, you run into a whole different set of

circumstances. Then you layer on depression, which is not uncommon for individuals as they approach death.

So as we educate families about their rights, one of the most important rights is to identify individuals who can be health care surrogates, maybe someone from their church, maybe the local community, that comes into a care setting like that and says, I am going to be helpful and befriend and visit those individuals. That would help them exercise their right.

Senator BLUMENTHAL. Thank you.

Any other responses?

Ms. RAMSEY. One professional organization, the National Hospice and Palliative Care Organization, has a myriad of resources that are consumer-friendly in their initiative called Caring Conversations, and that has been one of the places that I have been able to, certainly, advise patients and families to also consult with. Not only is the directives from each of the States, whatever type of directive that State recognizes, whether it is a Living Will or a Durable Power of Attorney for Health Care, but they are both there, as well as instructions.

And what they have also developed is a series of documents, pamphlets, that are really developed for consumers that is helpful for individuals to begin the conversation as well as to help them understand, well, what is life-sustaining treatment, you know, what does that look like, and the like. So that would be one of the examples that I would offer.

Senator BLUMENTHAL. And I note that a number of the experts in this area have said that physicians are sometimes reluctant to address these issues, for whatever reason. Are you satisfied that physicians are, in effect, accepting the need to raise the issue proactively with their patients and persuade them to make some of these decisions and enlist others to do so?

Ms. RAMSEY. I think in terms of medical schools across the country, nursing schools across the country, it is certainly something that we are getting better at. I think, as Ms. Warshaw said earlier, physicians and providers are waiting for patients and patients are waiting for providers, and that disconnect there really does give rise to a delay in time that is important to really begin the conversation. So in terms from an academic perspective, medical schools and nursing schools are really eliciting this content in terms of—into the content of the curriculum—excuse me—so that we can begin to help individuals role play in how to begin the conversation, how do you break bad news so that it is not as difficult as it is.

And, lastly, it is another opportunity why the consumers, the lay individuals, need to be informed, so that they can be supportive in bringing the conversation up, as well.

Ms. WARSHAW. I think we are experiencing a conspiracy of silence about discussing end-of-life issues, both from the medical community and from the public at large. And just like a generation ago when my parents would not use the word “cancer,” or we would not talk about gay rights, or there was no such term as “designated driver,” there has to be a cultural shift recognizing that this is a necessary adult responsibility of all of us to talk about what kind

of care we want at our end of our life, because death is not natural anymore with the enhanced technologies that we have.

I would like to also add that the Institute for Health Care Improvement, where The Conversation is housed—which we are very appreciative of—is in the process of developing a curriculum in their open school program, which means it is online and free, all about The Conversation Project and how to begin having this conversation, and that is geared for interdisciplinary health care teams.

Senator BLUMENTHAL. Well, I thank you very much. My time has expired, but I think the term “conspiracy of silence” is a very strong one, and I do not dispute it because I have no factual basis to dispute it. But I would have hoped that we would move beyond that, but I gather this panel feels that we have not and that is a very important call to action for all of us who are involved, which really means all of us, because we are all going to be there and all of us will have relatives, loved ones, friends, neighbors, who will be there, as well.

So, I thank you very, very much, and thank you, Senator Nelson and Senator Collins, for having this hearing.

The CHAIRMAN. Thank you, Senator. You are a very valuable member of this committee and you bring a great perspective as a former Attorney General.

Ms. Ramsey, minorities—it was stated here that there are disparities in the minority communities about advance directives. Expand on that a little bit.

Ms. RAMSEY. One of the things that we have found is that—I think it was stated at the onset that most times, we think of completion of advance directives as to refuse intervention. And for some, refusal is not what they are interested in. The idea is that, for many, there have not been access to health care, access to services, and that, finally, we do have access and now you want us to limit it or refuse it. Completing advance directives sometimes is perceived as being that you are going to be abandoned, that the care that you are getting, you are no longer going to get any of the care. And so that is part of the notion or the background about minorities and completion of advance directives.

Similarly, about eight percent of minorities utilize hospice services. That is a very small number as compared to the majority at 82 percent. That eight percent has been pretty static over—too long. And so the idea about individuals having access and knowledge about these services and to know that you can accept or you can refuse them, but at no time will you be abandoned and that your pain will be appropriately assessed and managed.

The CHAIRMAN. You have been involved, Professor, in the Veterans Advisory Council on End-of-Life Care, and you know about the concerns about how advance care planning has been handled with our veterans. In your experience, tell us about your work with the Advisory Council and how these issues are raised with veterans.

Ms. RAMSEY. Yes, sir. In terms of that particular Advisory Council, and recently, I completed an end-of-life nursing education consortium training for veterans, the idea is that many individuals who have served our country are not necessarily dying in places

like the VA or where individuals are trained in caring for veterans. And so the idea was that if individuals who served our country are in other acute care settings across the country, in hospices, that what are some of the things that would be important for providers to know as they transition, as they prepare for dying.

And so it has been important for us to recognize that there are some particular considerations, if you will, for persons who have served and what we can do to make their dying experience meaningful and valuable, as we have done for others, but also appreciating that they have served our country.

The CHAIRMAN. Thank you.

Ms. Vandenbroucke, explain for the record the difference between the DNR form and the POLST form.

Ms. VANDENBROUCKE. Thank you. The DNR form focuses just on resuscitation and the POLST form goes further and most States, it is a Section B, by saying, if you do not have an issue with resuscitation, what are the other things that you want at the end of life?

So there are generally three options. You want comfort measures only, meaning that you want to allow natural death. You do not want to do anything to prolong your life. Limited additional interventions, which means that you would like things done. You might be in the ICU for a little bit, but you will get antibiotics and other treatments. Or full treatment, which is you want everything.

And so this form goes a little bit further in asking those types of questions, whereas a DNR is generally just the one.

The CHAIRMAN. Well, we have heard that sometimes patients with the traditional DNR, they get less treatment geared to the patient's comfort, palliative care, but studies have shown that patients with a DNR order on a POLST form get more palliative care. Is that true?

Ms. VANDENBROUCKE. Yes. There was a study that was done by Susan Hickman that was published in 2010 in the Journal of the American Geriatric Society that spoke to this, and she was essentially saying that POLST forms were highly associated with people making decisions about what they wanted at the end of life. And so when you had more orders that had greater specificity, you had a greater sense that this is what the patient wanted, whereas with DNR, generally, when people are seeing it, that that was just kind of treated as a way of just not providing as much care. They were interpreting it that the patient wanted less aggressive treatment done, when that may not have, in fact, been the case. And with a POLST, that was additional information about the level of care that the patient wanted in addition to the DNR.

The CHAIRMAN. In the case where some physicians fill out the POLST form without involving the patient in the discussion of their goals and wishes, is there any evidence that any of you all know that this, in fact, has happened? It is not supposed to.

Ms. VANDENBROUCKE. It is not supposed to, and I do not have any evidence of it. Most of the States do require signatures of the patient or the surrogate. Oregon happens to be one of the unique ones where we are just recommending that the signature occur. But the expectation from the program is that this conversation is occurring. The POLST, as I said at the beginning, is not just a

form, it is a conversation, and the form is only as good as that conversation.

The CHAIRMAN. Thank you very much.

Professor Ramsey, I want to go back to the previous question. There was the suggestion in the VA that they were creating death panels. What do you know about that?

Ms. RAMSEY. I do not, sir.

The CHAIRMAN. Okay. I want you to ask about that the next time you are in the Council.

Mr. Towey.

Mr. TOWEY. Mr. Chairman, as you know, back in 2009, when the VA floated a document called "My Life, My Choices," there was controversy around it. The concern for the poor and the handicapped and others that feel mismatched to begin with is when a huge provider of services is also very anxiously trying to discuss it, it can be—to discuss the issue, advance care planning, they could have a serious conflict of interest, because they also are under tremendous budgetary pressure to save money.

That does not mean we should be funding every last bit of care every individual wants, and, in fact, most people do not even want that care at the end of life. They do not. If you ask people, do they want their last three days spent that way, they would say no. And so part of advance care planning is for them to say, I want it in this situation, but I do not want it in this situation, the same as POLST would allow.

The problem when the health care community directly, such as VA, or secondary, such as a reimbursement scheme of Medicare or Medicaid, when they are leading the discussion, people are suspicious. They are frightened that what you are really trying to do is cut costs, and they are saying what is really better for you is to go straight to palliative care when, in fact, your treatment plan in front of you, curative care, could lead to a recovery. So that is why I think the VA has to proceed very cautiously when it seeks to promote end-of-life discussions.

The CHAIRMAN. And, of course, the subject of this entire discussion, advance directives, could alleviate any of these questions about whether or not there are going to be death panels. And, of course, if it is appropriately authenticated and signed with an order, with, as you said, Ms. Vandenbroucke, the patient's signature on there, as well, then I think it starts to alleviate a lot of the concern.

Senator Collins.

Senator COLLINS. Thank you, Mr. Chairman.

I do not have any more questions for this panel, but I want to thank each member for your very informed, insightful, and intelligent discussion of this issue. Both the Chairman and I are truly committed on this issue, and I think it is really sad when this important discussion degenerates into slogans and demagoguery, such as death panels, when it is so important to each and every one of us. And I commend all of you for the work that you have done, your research, the Five Wishes Program, the other initiatives to elevate the discussion, which it deserves.

So, thank you very much, and Mr. Chairman, thank you for your longstanding interest and work in this issue.

The CHAIRMAN. And with those very kind words, we both extend
a hearty thank you to all of you for an excellent discussion.
The meeting is adjourned.
[Whereupon, at 3:53 p.m., the committee was adjourned.]

APPENDIX

**Respecting Patients' Wishes and Advance Care Planning
Question for the Record from Senator Richard Blumenthal
JUNE 26, 2013**

*Amy Vandenbroucke, Executive Director, National Physician Orders
for Life-Sustaining Treatment (POLST) Paradigm Task Force*

QUESTIONS FOR AMY VANDENBROUCKE: Your testimony expressed support for including POLST in electronic health record (EHR) systems, but “meaningful use” requirements only address advance directives in the second phase of the program. POLST are not mentioned at all. While there is currently no federal mandate for inclusion of POLST, to what extent have EHR systems incorporated POLST and has there been variation in the market so far? How should POLST most effectively be integrated into EHRs to establish consistency in EHRs across health systems and across the country and how would that inclusion interact with existing Department of Health and Human Services requirements to include an option for advance directives?

Amy Vandenbroucke Response:

Thank you, Senator Blumenthal, for your questions. There is no single version of an EHR, even by a single vendor, to my knowledge; each vendor of EHRs permit the health care facilities to modify the features (what is visible and what is not) and change locations of different elements. A couple of health care systems have created toolbars or patient headers on patient pages so any health care professional logging in and looking at the patient record will immediately be able to see whether or not the patient has a POLST and, if the patient does, click once to access the POLST orders. Attachment 8 of my written testimony shows what that bar looks like in an Epic system. I am also including here a second example (Attachment 1). I am also attaching the guidance the National POLST Paradigm Task Force has created for including POLST in EHR systems (Attachment 2).

The most effective integration of POLST into EHRs would be a requirement that all systems be able to show whether the patient has a POLST at the top of the patient toolbar or header and, if the patient does, to make those orders accessible in a single click. The POLST is needed immediately in an emergency and, therefore, must be easily located. While advance directive documents are also needed in an emergency situation if the patient lacks capacity, it is important to keep these documents separate from POLST orders since each has a different role. The Epic example I provided (see Attachment 8 of my written testimony) shows a good example: a health care professional can easily see whether the patient has an advance directive and a POLST when

looking at a patient's EHR (there is no "advance care planning" link that needs to be clicked on before the health care professional can see what documents the patient does, or does not, have).

With respect to the Meaningful Use Standards established, the National POLST Paradigm Task Force submitted the attached comments on January 11, 2013 in which we identified three serious shortcomings of the meaningful use criteria with respect to advance care planning documents. Our recommendation was that Stage 3 criteria for Meaningful Use include a "records advance care planning" objective met by the following measure: more than 50 percent of all patients who die in an eligible hospital or CAH inpatient department during the reporting period have at least one of the following in the patient's medical record: a copy of the patient's advance directive, advance care planning notes, or a copy of a POLST form.

**Respecting Patients' Wishes and Advance Care Planning
Question for the Record from Senator Tammy Baldwin**

JUNE 26, 2013

*Amy Vandenbroucke, Executive Director, National Physician Orders
for Life-Sustaining Treatment (POLST) Paradigm Task Force*

The recently published *Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life* identifies Wisconsin's Respecting Choices as an evidence based, replicable program that results in high levels of participation in advance care planning and ensures that such plans are included in the individual's medical record. (*Hastings Center Report*, page 40).

- 1) Do you agree with this assessment of the Respecting Choices program?
- 2) Might this program be the model to help make a significant improvement in advance care planning nationally?

Amy Vandenbroucke Response:

Thank you for your questions Senator Baldwin.

- (1) I have not participated in the Respecting Choices program; however, many of the state coalitions participating in the National POLST Paradigm Program have and recommend it when mentoring other state coalitions. My understanding is that this program offers excellent, intensive education. It is housed at the Gunderson Medical Foundation in La Crosse, WI and they can offer additional information about the program (also found [here](#)).
- (2) This program is expensive and, therefore, it poses challenges to scalability.

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MRN: Bed: DOB: HR: Allergies: **Sulfa** Code Prior: POLST: Yes Eye Care

COE: Language: Age/Sex: Last Vt: Allergy Prior: **None** Isolation: **None** **FM**

Snapshot Snapshot VSQ4 I/O Lab Micro Rad Med MedHx Ord Ordx Report Snapshot ?

Demographics **Allergies**

SULFA (SULFONAMIDE ANTIBIOTICS) Other (Specify with Comments)

Problem List **Chronic** **Medications** **Long-Term**

National POLST Paradigm Task Force

Recommendations for Electronic Health Records and Physicians Orders for Life Sustaining Treatment (POLST) Paradigm Forms Adopted 1/26/2012

Preamble: The National POLST Paradigm Task Force has developed the following recommendations to foster the conversion from paper based state POLST Paradigm Forms to electronic POLST forms stored in a variety of Electronic Health/Medical (EMR) Systems. State specific e-POLST electronic templates are usually developed, approved and updated by state coalitions and/or state agencies. For more information on the POLST programs, go to www.POLST.org.

These recommendations specifically address recommendations for integrating the POLST Paradigm form into the EMR and do not address the important separate issues of storage or retrieval of advance directives and other types of advanced care planning records.

Recommendations:

1. The EMR system offers access to an external POLST form database and/or system via a secure, authenticated portal, interoperable data exchange standard or link— so that a state specific POLST Paradigm e-POLST document could be accessed while the health care professional is still working within the EMR system. We prefer no additional log on.
2. The EMR system has the ability to rapidly receive and accurately store and display the external document within that patients' EMR.
3. The POLST Paradigm forms will be in a unique POLST field/tab and can be accessed instantly preferably within one click. The tab can be marked with a yes or no box, so that the provider can see if a form exists before opening the tab.
4. State specific e-POLST electronic templates developed, approved and updated by state coalitions and/or state agencies and standards for

wording and printing would be set and changed only by POLST coalitions and/or state agencies.

5. As POLST Paradigm updates occur, the EMR system accepts and stores the updated forms, form definitions [electronic templates].
6. The unique POLST Filed within the inpatient and outpatient EMR contain only POLST medical orders.
7. As allowed by state law or regulation, the EMR system should allow export of POLST paradigm forms to a regional or statewide database/system/register for storage and authorized access of forms; using accepted interoperability standards; when such a statewide or regional system exists.



Date: January 10, 2013
To: Office of the National Coordinator for Health Information Technology.
From: Margaret Murphy Carley
RE: **Comments Regarding the Stage 3 Definition of Meaningful Use of Electronic Health Records (EHRs)**

The National POLST Paradigm Task Force (NPPTF) submits these comments in response to the request for comments on its draft recommendations for meaningful use Stage 3, published on November 26, 2012, at 77 Federal Register 70444. We have adapted with permission the comments by the ABA Commission on Law and Aging.

The Stage 2 meaningful use criteria establish the objective “Record advance directives” in the menu set, not the core set, and only for eligible hospitals and critical access hospitals (CAHs). It is not applicable to eligible providers (EPs). The criteria are deemed to be met if more than 50 percent of all unique patients 65 years old or older admitted to the eligible hospital or CAH inpatient department during the reporting period have an indication of an advance directive status recorded as structured data.

The criteria and measure provide little in the way of useful data, and may even do harm in light of research that shows that a significant proportion of providers make erroneous assumptions about the wishes of patients when told of the existence of a directive without details of its contents.¹ We recommend that in Stage 3 this criteria and measure be replaced by a much more robust and relevant criteria as further explained below.

The most salient shortcoming of the Stage 2 criteria is the irrelevance of documenting that an advance directive exists without any documentation of its contents or of the identity of a legally authorized representative for health decisions. The justification for not including the directive in

¹ Ferdinando L. [Mirarchi](#), et al., “TRIAD III: nationwide assessment of living wills and do not resuscitate orders,” [J Emerg Med](#) 2012 May;42(5):511-20; Ferdinando L. [Mirarchi](#), et al., “TRIAD I: The Realistic Interpretation of Advanced Directives,” [J Patient Safety](#) 2008 December; 4(4): 1-6.

the record in the Stage 2 final rule merely noted:

“As we stated in our Stage 1 final rule (75 FR 44345), we have continuing concerns that there are potential conflicts between storing advance directives and existing state laws.” 77 FR 53968-01

No further explanation of this cryptic comment was given. We have tracked and reviewed state advance directive legislation for over two decades and know of no legal barrier for hospitals or other health facilities to store advance directives in the medical record. Without documentation of the patient’s wishes or identity of their duly appointed surrogate, the goal of patient-centered care medical care, which is one of the statutory goals of the Office of the National Coordinator for Health Information Technology, is substantially undermined.² All patients should be requested to provide a copy of their advance directive and it should be included in the record if provided by the patient.

The second serious shortcoming is the failure to capture the key components of advance care planning. Advance directives are just one component of documentation for advance care planning. Advance care planning notes written or dictated by the physician that reflect a discussion with the patient regarding goals of care, treatment preferences, or related decisions are a second key component of advance care planning.³

Additionally, neither Stage 2 nor proposed Stage 3 measures contemplate patients who exercise their right to refuse to participate in advance care planning. It should be possible for CAHs to meet the required benchmarks if they are permitted to include patients who have deliberately decided not to complete any advance care planning document, upon documentation of one or more meaningful discussions with the patient about advance planning.

A third component, now in use or in development in a majority of states is Physician Orders for Life Sustaining Treatment (POLST) which is a vital care planning tool for patients with advanced medical conditions. The POLST Paradigm Program, known by a variety of names,⁴ is a clinical process designed to facilitate communication between health care professionals and patients with advanced illness (or their authorized representatives) that facilitates shared, informed medical decision-making. The result is a set of portable medical orders that is applicable in all settings and across care transitions, is reviewable, and respects the patient’s goals for care in regard to the use of CPR, breathing machines, and other interventions. More

² “The National Coordinator shall perform the duties under subsection (c) in a manner consistent with the development of a nationwide health information technology infrastructure that allows for the electronic use and exchange of information and that-- *** (2) improves health care quality, reduces medical errors, reduces health disparities, and advances the delivery of patient-centered medical care;” 42 U.S.C.A. § 300jj-11

³ P. Kernerman, D.J. Cook & L.E. Griffith, “Documenting Life-Support Preferences in Hospitalized Patients,” *J Crit Care*, 1997 Dec;12(4):155-60.

⁴ POLST originated in Oregon, but examples of the program using differing names include West Virginia’s Physicians Orders for Scope of Treatment or “POST” and New York’s Medical Orders for Life-Sustaining Treatment or “MOLST.”

information about the POLST programs and the states that are using it can be found at www.polst.org. Research on the POLST program confirms that it improves documentation of a range of treatment preferences and is associated with low rates of unwanted hospitalizations.⁵

For the objective to be meaningful, we are recommending that the required documentation in the record include a copy of the patient's advance directive, advance care planning notes, or a copy of a POLST Paradigm form.

The third serious shortcoming of the Stage 2 criteria is the inadequacy of the target group as the denominator of the measure, which currently consists of all patients admitted to an eligible hospital or CAH who are age 65 or older at admission. While age is globally correlated to death and disability, it is a poor proxy of the need for advance care planning. Advance care planning documentation is most essential for adults facing advanced and eventually fatal illnesses. Many people in this group are younger than age 65, and many people age 65 or older are not in this group. The most accurate denominator to capture those in this target group are those who die.

The National POLST Paradigm Task Force recommends that the meaningful use measure specify that a minimum percentage of adult patients who have died in the eligible hospital or CAH have an advance directive, or an advance care plan, or POLST in the medical record of the treating institution at the time of death. For Stage III, we recommend that this percentage be set at 50 percent.

In summary, we recommend that Stage 3 include an "Record advance care planning" objective which is met by the following measure: more than 50 percent of all patients who die in an eligible hospital or CAH inpatient department during the reporting period have at least one of the following in the patient's medical record: a copy of the patient's advance directive, advance care planning notes, or a copy of a POLST form.

Submitted By Margaret Murphy Carley
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⁵ Susan E. Hickman, et al., "A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program," *J Amer. Geriatrics Soc.* 2010 Jul ;58(7):1241-8

Senate Special Committee on Aging

Senator Bill Nelson (D-FL), Chairman

Hearing Title: "Renewing the Conversation: Respecting Patients' Wishes and Advance Care Planning"

Hearing Date and Time: June 26, 2013, 2:00 PM EDT

Name and Address of Submitting Organization:

Robert L. Fine, MD, FACP, FAAHPM
Clinical Director, Office of Clinical Ethics and Palliative Care
Baylor Health Care System
3600 Gaston Avenue, Barnett Tower #605
Dallas, Texas 75246

Chairman Nelson and distinguished Committee Members,

I applaud you for holding a hearing to engage thought leaders on this important topic and am pleased to have the opportunity to submit this statement for inclusion in the record of the hearing on “Renewing the Conversation: Respecting Patients’ Wishes and Advance Care Planning.”

Baylor Health Care System, where I serve as the Clinical Director, Office of Clinical Ethics and Palliative Care, is one of the largest health care systems in the United States – we served more than 1.4 million patients in 2011. Baylor University Medical Center (BUMC), our major teaching, research, and referral center, is a USNWR highly ranked hospital, a Level 1 trauma, major solid organ and bone marrow transplant, cancer, heart, and rehabilitation center. We have been actively involved in advance care planning and advance directive efforts for decades: Baylor was one of the first hospitals in the nation to develop and distribute patient education handouts on advance care planning and advance directives in 1988ⁱ; we were major contributors to the drafting of the Texas Advance Directives Act in 1999^{ii iii}; and Baylor was the site of the first Joint Commission certified palliative care program in Texas or the South, as well as one of the first 10 certified programs in the United States.

Advance care planning has always been important to us and has helped us achieve major improvements in end-of-life care, including treatment more consistent with patient wishes, better symptom control, and more appropriate resource utilization during the last chapter of life. For example, according to the 2010 Dartmouth Atlas for Health Care, the percentage of Medicare patients treated at BUMC enrolled in hospice during the last 6 months of life was 59.5%, and hospice days per decedent were 23.9, both well above the national average of 47.9 % and 18.5 days, respectively! Compared to other tertiary care centers (which typically have lower hospice utilization) across the country, BUMC end-of-life metrics are even more notable.

Despite our successes, we have faced many advance care planning challenges where I know we could have done even better. Had we done so, more patients would have received treatments consistent with personal preferences; more families would have felt better about their loved ones’ experience at our hospitals, and more of our doctors and nurses would have felt more satisfied in their work serving the most seriously ill among us. And yes, money, much more patient/family money and much more taxpayer money, could have and should have been saved, rather than spending it on ineffective, *unwanted* medical interventions at the end of life.

At Baylor Health Care System, we never rest on past success, and we always seek to learn from past failures. Our Board of Trustees has made advance care planning a major system priority. We are in the process of making advance care planning a performance improvement metric (much like flu vaccines or other scheduled preventive services). As leader of Clinical Ethics and Palliative Care, I have overall responsibility for improving advance care planning, and I have sought new ways of promoting, creating and storing advance care plans. In so doing, I have come to the conclusion that the digital creation and storage of advance directives is far more effective than any paper-based process.

I was the major physician author of the Texas Living Will embedded in the Texas Advance Directives Act of 1999. I believe it is one of the best paper-based living wills in the country, one

of only a few that allows a patient to request or refuse aggressive treatment in the setting of either terminal or irreversible illness. But the Texas Living Will I lead the effort to write pales in comparison to what can be achieved with a digital living will, such as that developed by MyDirectives (www.mydirectives.com). I and my team have worked closely with MyDirectives for several years (without any financial arrangement between us) to enable our patients to create advance directives that best fit each patient's unique needs while ensuring that health care professionals are aware of the existence of and have real time access to our patients' future treatment wishes.

I am aware that my respected colleague, Amy Vandenbrouke, JD, of the National POLST Paradigm Task Force is testifying about the benefits of POLST forms. I believe POLST documents are quite useful, so much so that my health care system has its own version (because the Texas legislature has not yet adopted the POLST concept). As good as POLST is, however, even a great POLST form can't do all that a digital directive can do, and relying on paper transmission of POLST forms is fraught with potential clerical error. Not only can patients create highly nuanced advance directives on the MyDirectives site, patients can upload and store POLST/MOST forms on the web site, forms that can then be digitally retrieved at any time.

A major advantage of a service like MyDirectives is that when a patient creates, changes, or even entirely revokes an advance directive, it immediately shows that in the online MyDirectives site. If a patient changes his or her surrogate or changes treatment preferences, the site immediately shows that. The patient has the option to electronically notify his or her health care providers, caregivers and loved ones about the directives and to have any updates automatically be transmitted to them. These built-in tools take conversations about critical/emergency treatment and end-of-life medical treatment wishes to an entirely new, vastly superior level.

Although I currently primarily practice Palliative Medicine, my background is in Internal Medicine and Geriatrics, and I am quite aware I am submitting testimony to the Senate Special Committee on Aging. However, advance care planning is not only a concern for the aged. Over half the seriously ill patients served by our Supportive and Palliative Care teams across Baylor Health Care System are between 18 and 65 years old. Furthermore, one need only look at the history of clinical ethics cases in our country, including cases such as Cruzan and Schiavo, to realize that advance care planning is important at all ages. One never knows when tragedy may strike! Accordingly, I believe that advance care planning should not be reserved only for persons who are older, frail, or chronically or terminally ill. Rather, I urge this Committee to do the legislative work to encourage persons of all ages not only to "start the conversation," but also to actually "complete the conversation" by creating a document that will have value to all stakeholders and that can be found in an emergency. I feel certain that each of your witnesses can tell stories of patients who either never had a living will because the paper documents available could not adequately capture the patient's thoughts, or who had living wills that no one knew about or looked at until the patient had been in the ICU for weeks or even more, receiving unwanted, highly burdensome and very costly interventions at the end of life.

I believe that in the age of "digital everything", moving toward digital advance care planning with creation, storage, and retrieval of digital advance directives is of paramount importance. I believe no health care system can truly claim to provide patient and family centered care without

doing so! Baylor Health Care System is moving in this direction already, and if we become Baylor Scott and White, I can assure you I will be pushing for that new “mega-system” to do the same. This would all be so much easier with the right enabling legislation.

In summary, our Government’s noble, long-stated goal of scalable widespread use of advance directives is possible, but only with bold legislative leadership, thinking outside the old paradigms and supporting what we at Baylor Health Care System refer to as safe, timely, effective, efficient, equitable, and patient centered (STEEEP) communication about and care for each unique patient! I applaud this Committee for seeking solutions, and I stand ready to help with future testimony and advice should you wish further input from me.

Thank you.

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- i Fine, RL. Personal Choices: Communication Between Physicians and Patients When Confronting Critical Illness. *The Journal of Clinical Ethics*, Volume II, Number 1, 1991.
 - ii New Texas Law Simplifies End-Of-Life Care Planning. *The Texas Internist*. Winter 2000.
 - iii Fine, RL. The Texas Advance Directives Act of 1999: Politics and Reality. *Healthcare Ethics Committee Forum*, 2001. 13(1): 59-81.



**Hearing of the
U.S. Senate Special Committee on Aging**

**RENEWING THE CONVERSATION: RESPECTING PATIENTS' WISHES AND
ADVANCE CARE PLANNING
June 26, 2013**

**Written Testimony of Ashley Carson Cottingham
Director of Policy and Advocacy, Compassion & Choices**

Compassion & Choices is a national nonprofit consumer organization dedicated to improving care and expanding choice at the end of life. We appreciate the opportunity to address the committee today on the important topic of respecting patients' wishes and advance care planning. These are issues that we've worked on since our founding.

Compassion & Choices works diligently to ensure that all Americans are able to direct their own health care decisions and that they are free to make the best personal choices when they have advanced or terminal illnesses. We advocate on their behalf to ensure they are able to achieve a peaceful death. These private, personal decisions belong to all Americans and have been upheld by the United States Supreme Court.

Today, I want to discuss two things: first, the issue of unwanted medical treatment and second, the tools that Compassion & Choices has available for patients to ensure that their wishes are honored.

Patients have the right and the responsibility to guide their own health care throughout their lives, with their trusted health care professionals and families. Many Americans give thoughtful consideration to medical decisions that may need to be made if they are injured, debilitated, or have a life threatening advanced illnesses. They often articulate their decisions in advance directives.

Congress passed the Patient Self-Determination Act (PSDA) in 1990 to reinforce an individual's right to determine the course of her/his health care. This Act amended Medicare and Medicaid law to require providers to follow policies and establish procedures with regard to advance directives. The PSDA established that if these policies are not followed, the Secretary of Health and Human Services (HHS) may decide that the provider is ineligible for payment through Medicare and Medicaid. Unfortunately,

providers do not always honor the expressed wishes of patients. The time is now to put teeth in the PSDA and empower HHS to act when patient wishes aren't honored.

President Obama reasserted the importance of respecting patients' rights in a 2010 memorandum to HHS asking the agency to, "ensure that all hospitals participating in Medicare and Medicaid are in full compliance with [these regulations]...[t]hat all patients' advance directives...are respected, and that patients' representatives otherwise have the right to make informed decisions regarding patients' care."ⁱ Nevertheless, many patients' decisions are overridden or ignored in the weeks and months before their deaths. This can lead to invasive and fruitless testing, needless suffering, unrelenting pain and a prolonging of the period before death. Patients are often tethered to monitors and machines despite their determination to reject unwanted treatment and desire to die at home in the embrace of loved ones.

A new study published in JAMA found that between 2000 and 2009, treatment in intensive care units in the last month of life increased from 24% to 29%.ⁱⁱ The accompanying editorial concluded, "The focus appears to be on providing curative care in the acute hospital regardless of likelihood of benefit or preferences of patients. If programs aimed at reducing unnecessary care are to be successful, patients' goals of care must be elicited and treatment options such as palliative and hospice care offered earlier in the process than is the current norm."ⁱⁱⁱ Compassion & Choices could not agree more.

Policymakers can and should use both the carrot and the stick with providers to ensure that patients' wishes are honored: financial incentives for educating about and honoring advance directives and financial disincentives for disregarding patients' expressed wishes.

The Centers for Medicare and Medicaid Services (CMS) should deny payment to providers where there is clear evidence that specific treatments were unwanted — similar to policies where unnecessary treatment (not covered in practice guidelines for example) is provided.

The Justice Department is investigating and taking legal action against hospitals and doctors groups when instances of unnecessary treatment are exposed. The same due diligence should be trained on unwanted medical treatment. It is always unnecessary and should be considered a never event.

The explosion of the aging population coupled with the nation's financial and moral commitment to providing health care to an ever-increasing number of Americans reveals that the scourge of unwanted treatment should be a high priority for this committee.

Among the next steps Compassion & Choices recommends are:

Initiate and improve the quality of conversations among health care professionals, patients and families about advanced illness and end-of-life decisions, including:

- 1) Reimbursing medical providers for participation in advanced care planning with patients and their families well in advance of illness or before facing end of life;
- 2) Providing financial incentives and training to encourage medical providers to offer all the information and counseling necessary for decision making when securing informed consent;
- 3) Ensuring that the full range of medical care and treatment decisions, including curative care, palliative care, and medical assistance in dying, are freely available to patients without institutional or reimbursement barriers.

Further, CMS should:

- 1) Exclude from covered services and reimbursement any treatment that contravenes an adult patient's informed health care decision;
- 2) Track complaints where patient wishes were ignored and ensure that the survey and certification processes for providers require attention to patient's advance directives;
- 3) Revise billing forms to have providers indicate that care was rendered in conformance with patient's advance directive and informed consent.

Finally, we would like to draw your attention to the tools that Compassion & Choices has available to consumers. We have an End of Life Consultation (EOLC) program designed to provide support and information to terminally ill patients and their families. We always have trained counselors ready and willing to help when the phone rings. We also have a full range of excellent advance care planning tools, specific to the laws of each particular state, available on our website for download.

Compassion & Choices offers several unique documents for advance care planning. For example, our "dementia provision" can be easily added to any advance directive and advises physicians and family of the wishes of a patient with Alzheimer's disease or other forms of dementia. We also have a values worksheet and a hospital visitation form. Each of these documents is designed to help patients and families avoid unfortunate and unwanted situations at the end of life.

We thank you for the opportunity to provide testimony today, and are happy to answer questions or provide written follow-up at your convenience. Thank you.

ⁱ Memorandum, Respecting the Rights of Hospital Patients to Receive Visitors and to Designate Surrogate Decision Makers for Medical Emergencies, 75 FR 20511 (April 15, 2010).

ⁱⁱ Teno JM, Gozalo PL, Bynum JW, et al. Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009. *JAMA*. 2013;309(5):470-477.

ⁱⁱⁱ Jenq G and Tinetti ME, Editorial: Changes in End-of-Life Care Over the Past Decade More Not Better. *JAMA*. 2013;309(5): 489.