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

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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 first-hand 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.