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**May 21, 2014**

**US Senate Special Committee on Aging**
Members Roundtable: *"Continuing the Conversation:*
*The Role of Health Care Providers in Advance Care Planning"*

Mr. Chairman, Senator Collins, and members of the Committee, I am grateful for your continued attention to this important topic and honored to participate in this roundtable discussion. We are, after all, talking about an issue that will touch every life, every family and every home in America at some point. At the core, we are talking about how we care for people – our family, friends, neighbors and fellow citizens – when they are seriously ill.

I spent the majority of my childhood by my grandparents' side, in assisted living facilities, nursing homes and hospitals. The challenges they faced were real, and affected not only my parents, but our entire family. In fact, it was this personal experience that led to my desire to help families navigate similar challenges. Almost 16 years ago, I was drawn to the mission of the Florida non-profit organization Aging with Dignity. It was an organization which had recently been founded by Jim Towey, inspired by his experience working with Mother Teresa of Calcutta. We were guided by an outstanding founding advisory board that included Senator Nelson.

Aging with Dignity offered an interesting solution to the growing challenges related to advance care planning. Medical technology had expanded with such rapid speed over the preceding few decades that individuals and families were faced with difficult medical decisions that often required on-the-spot answers. Like my own family, most felt ill-prepared and lacked the necessary information they needed to make these decisions. Medical and legal experts created living wills that were intended to answer the questions that mattered most to doctors and lawyers.

Aging with Dignity created a new approach, a living will called "Five Wishes," that offered an easy way for all adults to express what mattered most to them. Originally dubbed, "the living will with a heart and soul," Five Wishes struck a chord with the American public. Not only did it include the important legal and medical elements of an advance directive – the designation of a healthcare agent and instructions regarding life support treatment – it also touched on areas that meant the most to people with regard to personal, emotional and spiritual matters. It allowed people to express their desire to remain at home, to be surrounded by friends and family, to receive spiritual care, and to express love and forgiveness.

How do we know Five Wishes is making a difference? More than 20 million copies of Five Wishes are in circulation, and the document is distributed by more than 35,000 partner organizations across America and a growing number abroad. For the past 16 years, we have been hearing stories from families who cared for a loved one who used Five Wishes. They tell us that Five Wishes became a personalized instruction book on how to care well for the person they love.

When it comes to advance care planning, health care professionals and patients often have different perspectives. Most doctors and lawyers, concerned with providing immediate and quality care, want to know the name of the health care agent and the code status of the patient. On the other hand, most individuals are primarily concerned with wanting to be comfortable, to be with their family, to be cared for with dignity, and to be at peace with their loved ones and their God.

As we discuss advance care planning, we do well to remember what is most important to the people we desire to serve. When all is said and done, we all want to care well for our loved ones. We want to take good care of our parents, grandparents and spouses.

**Haste and Caution: Do not "re-medicalize" advance care planning**
Going forward, especially during this current time of rapid change in our nation's healthcare delivery system, we must proceed with both haste and caution. We must act with haste because American families and healthcare providers need help navigating, and working together, to care well for people at the end of life. We must act cautiously because there seems to be a growing trend to re-medicalize advance care planning.

There are some who believe that the answer to good end-of-life care in America will be found in creating the best process or system to document every individual's absolute choices. Then good end-of-life care could become focused exclusively on looking up the right answer to determine patient care. They believe that we can create the perfect Electronic Medical Record (EMR) that will have just the right check-boxes, or ask just the right questions, to take away all ambiguity related to end-of-life decisions. Or perhaps they believe that we can create medical order models that tell providers exactly what to do for every seriously ill patient. Some suggest that state and federal government agencies should regulate or standardize the formats for advance care planning that are deemed most effective. There may be important value in some of these things. However, there is no replacement for the role of family and loved ones in both caregiving and decision-making at the end-of-life.

Today I would like to share with you what we have seen on the frontlines, particularly related to healthcare providers and their desire to provide the best possible care at the end of life.

In general, **healthcare providers:**

- Want to honor the decisions of patients at the end of life, and to know that they have served their patients well
- Do not want to referee family disagreements
- Have knowledge and medical understanding that is important to individuals and families when the time comes to make end-of-life decisions

- Feel awkward raising the topic of advance care planning with patients and families, and wish that someone else had raised the topic sooner
- Face organizational pressures related to cost containment and the desire to limit hospital readmissions, and try to balance this with the needs of patients and families
- Face growing skepticism and distrust among the public

In general, **federal and state governments and agencies**:

- Want people to exercise their right to make their own healthcare decisions, and to have those decisions respected
- Do not want to legislate, or create agency guidelines, based on heartbreaking cases
- Have the mechanisms in place to incentivize advance care planning and to standardize the process (although, that may not be advisable)
- Face growing pressures to reduce healthcare costs and limit hospital readmissions
- Face growing skepticism and distrust among the public

In general, **individuals and families**:

- Want to take good care of their loved ones
- Face limitations – financial, physical and emotional – when providing care
- Lack detailed medical understanding and may need guidance when making decisions for loved ones based on a diagnosis or prognosis
- Maintain an absolute commitment and loyalty to their loved one, with any bias being toward what is best for the individual
- Become the best advocates for one another

Although there may be disagreements when it comes to different approaches, it is widely agreed and accepted that it is far better to make important end-of-life decisions **<u>before</u>** a health crisis (i.e advance care planning). However, it is important to understand our roles, and our respective biases. Aging with Dignity believes that decisions related to advance care planning are best made by individuals and families.

Healthcare providers find themselves at an interesting crossroads. They see the value in advance care planning. It is not just good medicine, it is good personal care. Many are wary of creating their own advance care planning process, because they know they have a financial stake in the decisions people make. They want to provide professional medical guidance, but they want patients and families to drive the conversations and decision-making.

This is precisely the reason that thousands of healthcare providers – including some of America's largest health systems and health plans, teaching hospitals and community hospitals, medical schools, physician networks, hospices, home care providers, long-term care and assisted living facilities – have partnered with Aging with Dignity.

**Healthcare providers partnering with Aging with Dignity:**

- Provide Five Wishes to staff: encourage staff to use it for themselves and their family
- Use the Five Wishes DVD for staff training and patient educations (via closed-circuit television or provider website)
- Provide Five Wishes to every patient
- Provide Five Wishes to the extended community: public education workshops and distribution through the provider network
- Use the "Sharing the Gift" Presenter's Guide as a template community presentation that requires little preparation
- Offer Five Wishes in 26 different languages to serve families from diverse traditions
- Use these resources to partner with places of worship, civic organizations and employers – increasing the likelihood that decisions will be made long before a health crisis

**Providers tell us they partner with Aging with Dignity because:**

- They want to promote advance care planning without driving the conversation based on their organizational and personal biases
- They want to facilitate advance care planning without assigning or hiring new staff for this purpose – they don't have the desire or the budget to have a legion of social workers leading advance care planning consultations
- They want simple resources that are easy for staff and patients to understand
- They want an advance care planning format that does not rely on repeated, time-consuming and expensive staff training

Clearly, there are differences in how advance care planning is perceived by providers and families. Aging with Dignity has proven that these gaps can be bridged. We help providers broach the awkward topic of advance care planning in terms that are meaningful and understandable to the average person. We help individuals and families communicate their wishes to one another, and to their healthcare providers. We support the desire of our nation's elected leaders to protect and provide for the most vulnerable among us by helping individuals to exercise their right to make their own decisions and for their voice to be heard.

Most families would agree with this sentiment: When our grandparents, parents, spouses, and friends are near the end of life – we do not want doctors to consult forms or electronic medical records when important decisions need to be made, ***we want them to consult us*****.** We know our loved ones best. We are the ones with loyalty to them, and to them alone. We may need help understanding a difficult prognosis and talking through the options and possibilities. But when it comes to end-of-life decisions, we want providers to trust us to make the right choices for ourselves and those who we love.

Based on all that I have seen and heard from healthcare providers, they are very happy when patients are well-informed, decisions are made in advance, and families are in agreement with the plan.  This scenario is possible when people are allowed to make their own decisions, in their own terms and on their own turf.
Most importantly, it accomplishes the goal to which we all aspire:  caring well for every person, and maintaining the human dignity of every person at the end of life.

As our healthcare provider networks build new systems to support advance care planning, it would be wise to learn from the past.  We cannot afford to spend the next decade or more building medical or legal frameworks that ignore the very things that matter most to individuals and families.  We should consider what similar congressional hearings or roundtables like this may occur in the future if large amounts of money and time are devoted to building systems that people do not like and do not use.

Mr. Chairman, I conclude these remarks by thanking you and your colleagues for holding this roundtable.  This is the very thing that is needed, and I look forward to the discussion.