Testimony

of

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It has been said that only two things in life are certain; I am here today to discuss one of the two.

Whether it is our own death, or that of a close friend or family member, each of us will in all likelihood eventually be faced with the agonizing decisions that impending death brings. When that moment arrives, I wonder how many of us have thought about the choices we would make for our own care and comfort at the end of life. What kind of medical treatment do we want? What don’t we want? How many of us have taken the time to put those choices in a legal document, so that when the time arrives, our families are not faced with decisions about things like breathing machines and tube feeding?

The truth is that when asked about the ideal picture of what our own deaths will look like, most of us share the same vision: to be free of pain, to be at home surrounded by family and friends and to have our wishes known and honored. Unfortunately, in Oklahoma and across the country, the opposite is occurring all too often. Most of us will die in a health care facility, pain that could be controlled and is not, and we are isolated from loved ones. As a health care consumer, and as an attorney general responsible for consumer protection, it troubles me greatly to think that for most of us, our last moments on earth will not meet that ideal standard. There simply must be a better way.

Recognizing that fact, I chose end-of-life health care as a presidential initiative during my term as President of the National Association of Attorneys General from 2002-2003. The cornerstone of the initiative centered on three regional listening conferences that provided an opportunity for attorneys general to hear compelling stories recounted by the mothers, brothers, children and spouses who were thwarted in efforts to fulfill the wishes of dying loved ones.

We challenged national experts to testify before assembled panels of attorneys general and to address the three questions repeatedly raised by consumers: “Will my pain be managed?” “Will my wishes be known and honored?” and “Will I receive competent care?”

These clinicians and health care advocates reported that some state legislatures and professional licensing boards are beginning to adopt policies to encourage better pain management, to clarify the role of opioid analgesics and to address physicians’ fears of being investigated for inappropriate prescribing of controlled substances. We also heard that there was a significant gap between policy and practice.

We heard from physicians and nurses who cited deficits in educational requirements in medical, nursing, social work and pharmacy schools for end-of-life health care. As consumers, we expect these professionals to be trained in pain management and be informed regarding health care choices, such as hospice. To the contrary, statistical studies reflect a lack of education as a major factor contributing to substandard care near the end of life. Doctors are trained to save life – to find cures, to restore health. To many of them, the death of a patient is a failure rather than an inevitable fact of nature. Some do not, therefore, study or prepare for their role in caring for the dying.

As attorneys general, we learned about the barriers that exist between the typical and the desired care as we are dying. These are barriers that must be removed if we are to improve end of life care.

Armed with the information we learned on the national level, I and some other attorneys general took what we had learned back home and worked to make improvements in the areas discussed and studied. These actions have been overwhelmingly popular with citizens in states including Arizona, Maine, Missouri, Oregon and Vermont.

In Oklahoma, I formed a state task force made up of 15 Oklahoma legal and health care professionals. In addition to the members of the task force, more than 70 members of an advisory committee worked to identify the existing legal, policy and educational barriers to quality end-of-life care in Oklahoma. This group heard from experts in areas of concern including advance directives, nursing facilities, hospitals, hospices, care for children and other issues.

Then the task force issued a series of recommendations to improve end-of-life care. Their work focused on changes that could be made in Oklahoma, and their continued work has led to the implementation of many of the task force recommendations.

In 2006, we worked to pass Oklahoma Senate Bill 1624, which improved the statutory advance directive form and acknowledged a patient’s unlimited right to accept or refuse life-sustaining treatment.

Also, the bill remedied an unconstitutional portion of Oklahoma law that limited a patient’s right to accept or refuse care to instances of illnesses diagnosed as terminal within six months or those patients deemed to be in a persistent vegetative state. The earlier law did not allow for patients whose terminal diagnosis exceeded the six-month time frame.

Additionally, Oklahoma is working to remove some of the educational barriers that persist. The Oklahoma Palliative Care Resource Center now provides training for doctors and nurses on palliative care, specifically focusing on pain management and other symptoms when a cure is no longer possible. The task force has created a written guide for health care professionals and citizens that contains guidance regarding Oklahoma's Advance Directive and other advance care planning information.

On another front, state attorneys general have also been working with the DEA on policies that will allow law enforcement to prosecute the diversion of prescription drugs without curbing doctors' abilities to prescribe pain killers to patients who suffer from constant pain. This is an important policy shift that we hope will ease the perception among doctors that prescribing painkillers will automatically draw the attention of prosecutors. I would seek your attention to this effort with the DEA for a balanced pain policy – pursuing wrong-doers while supporting physicians who are seeking to provide adequate pain management.

I would also draw your attention to two other areas where federal action could improve end-of-life care. First, physicians deserve adequate Medicare reimbursement for the time they take to discuss end-of-life decisions and advance care planning with their patients. The counseling that physicians provide about advance directives is as important as any test or procedure they might provide.

Second, the six-month terminal diagnosis that is required for the Medicare hospice benefit could be more permeable, allowing terminally ill hospice patients access to palliative treatments not currently allowed. There should not be an artificial division between ordinary medical care and hospice care.

I hope that the things I have done as attorney general create a better picture for everyone who will, one day, die in Oklahoma. By easing uncertainty among health care professionals and their patients, I believe our state is better equipped to meet the needs of its citizens.

While we are proud of the work that has been done, we recognize that there is much still to do. The right to choose our own courses of treatment as we near the end of life is one that should be honored and upheld at the highest level.

You are in a unique position to improve the life and death, of each and every American. As a public servant, I can think of no finer legacy than to reduce human suffering in this country. As a citizen and health care consumer, I offer my deepest gratitude for your efforts.