

Good morning. Thank you all for coming today to be part of a discussion I consider to be a vital one: choice and dignity at the end of life. It's a discussion that makes many people uncomfortable, – understandably so – but anyone who has been there through the death of a loved one knows how important it can be. To me, this is really a discussion about free will, the touchstone of this country, and the opportunity to express one's free will at the end of life, a point when there is such a premium on dignity.

Individuals at the end of life are vulnerable. Many of them are unable to communicate, and few are in a position to argue with a bureaucracy. We owe them an opportunity to make their wishes known, and to have those wishes respected. How much treatment do I want? Where do I want to be? How much pain do I wish to endure? These are wishes that should be honored.

It is particularly important to honor those wishes at the end of life because the ramifications of not doing so are so grim. Too many of us have witnessed a death taken over by machines and medicine, turning a human being into a mess of tubes and wires, all humanity and dignity stripped away. The late American political writer Stewart Alsop, while he was dying, wrote, "A dying man needs to die, as a sleepy man needs to sleep, and there comes a time when it is wrong, as well as useless, to resist." If someone chooses not to "resist" death, he or she has the right to make that decision, and to see it honored.

There are, therefore, two broad policy questions that I hope this hearing will address. First, how can we make sure that Americans carefully think about, and communicate, and document how they want to be treated at the end of life? Many people fail to complete advance directives because they believe they are difficult to execute, or that they'll just be ignored. Many are reluctant to discuss death or plan for the end of life, and many think that completing a form is unnecessary because a loved one will know what to do. Currently, only between 18 and 30 percent of Americans have completed some type of advance directive. Acutely ill individuals complete advance directives at only slightly higher rates: 35% of dialysis patients and 32% of COPD patients. Even among terminally ill patients, fewer than 50 percent have an advance directive included in their medical record.

The second policy question I hope this hearing will address is: how do we help documented wishes actually get translated into a plan of care with a provider? How can we make sure, for example, that EMS workers don't resuscitate a patient against the patient's documented wishes, that doctors can comfortably provide adequate pain medication to patients in need, or that patients can receive palliative care wherever they are? Currently, roughly 70 percent of physicians whose patients have advance directives do not know about them. This is a fundamental disconnect. It is particularly troubling in light of the fact that physicians accurately predict their patients' preferences regarding their care about 65 percent of the time. We need to improve the link between patient wishes and services rendered.

Fortunately, we have invited some superb individuals to help us wade through these questions from a variety of perspectives.

Joseph O’Conner has been the chair of the American Bar Association’s Commission on Law and Aging since 2005. The Commission has been involved in end-of-life legal research and implementation of appropriate end of life policies for the past 29 years. Mr. O’Connor is a partner in the law firm of Bunger & Robertson in Bloomington, Indiana. He has served the Indiana State Bar Association in various capacities, including as its president.

Dr. Diane Meier is the Director of the Center to Advance Palliative Care, a national organization devoted to increasing the number and quality of palliative care programs in the United States. She is also Director of the Lilian and Benjamin Hertzberg Palliative Care Institute, and Professor of Geriatrics, Internal Medicine, and Medical Ethics at the Mount Sinai School of Medicine in New York City. She is the Principal Investigator of an NCI-funded five-year multisite study on the outcomes of hospital palliative care services in cancer patients. Dr. Meier is also a recent recipient of a MacArthur Foundation Fellowship, or “genius grant,” for her leadership and innovation in promoting high-quality palliative care. Congratulations on this tremendous accomplishment, Dr. Meier!

Dr. Joan Teno is a Professor of Community Health and Medicine, and Associate Director of the Center for Gerontology and Health Care Research, at the Brown Medical School. She is a health services researcher, hospice medical director, and board-certified internist with added qualification in Geriatrics and Palliative Medicine. Dr. Teno has served on numerous advisory panels including the Institute of Medicine, World Health Organization, American Bar Association and as grant peer reviewer for the National Institutes of Health. She is also an Associate Medical Director at Home and Hospice Care of Rhode Island.

Drew Edmondson has served as the Attorney General of Oklahoma since 1994. Attorney General Edmondson has made high-quality end-of-life care a priority during his tenure, and thanks to advocacy from his office, the past three Oklahoma governors have all endorsed and participated in a statewide “Palliative Care Week” aimed at raising awareness about end-of-life decision making. Attorney General Edmondson has also convened legal experts, health care providers, and community leaders to form the Oklahoma Attorney’s General Task Force on End-of-Life Health Care, which continues to study this issue in the state and advocate for reforms. Attorney General Edmondson served as the president of the National Association of Attorneys General (NAAG) 2002-2003. He selected end-of-life care as his presidential initiative and organized three regional listening conferences for AGs to hear stories about end-of-life care needs and initiatives taking place in various states.

Finally, Dr. Patricia Bomba is the Vice President and Medical Director of Geriatrics for Excellus Health Plan, Inc. and subsidiaries of The Lifetime Healthcare Companies. In her current role, she serves as a geriatric consultant on projects and program development

affecting seniors. She is a nationally recognized palliative care and end-of-life expert who designs and oversees the implementation of community projects. Dr. Bomba is New York State's representative on the National POLST Paradigm Task Force, a multistate collaborative. She has also served as a New York State Delegate to the White House Conference on Aging and as a member of the Review Committee of the National Quality Forum's "Framework and Preferred Practices for a Palliative and Hospice Care Quality" project.

As a reminder, I ask of the witnesses to please limit his or her testimony to 5 minutes. You will certainly have an opportunity to speak further during the questioning period, and your full statements may be submitted into the Congressional record.

Last but not least, I want to thank Chairman Kohl for allowing me to chair this hearing, and with that, I would like to like to turn it over to him to introduce our first witness, Joan Curran of Wisconsin.