



**TESTIMONY PRESENTED TO CONGRESSMAN DENNIS MOORE**

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**PRESIDENT AND CEO**

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Good morning, Congressman Moore. I am Myra Christopher, President and CEO of the Center for Practical Bioethics. It is good to see you again. Thank you for the opportunity to speak to you about provisions currently in HR 3200 regarding advance care planning.

As a member of the Center for Practical Bioethics, you are aware that the Center is a 501c3 organization that was incorporated in Kansas more than 25 years ago. We are not a political advocacy organization; we are an educational resource that has a great deal of experience and expertise in advance care planning and end-of-life care policy.

Since its beginning, the Center has encouraged all adults to do advance care planning, i.e., to think about their goals and values, to name a proxy (specifically a durable power of attorney for healthcare decisions) in the event they can no longer speak for themselves, and to talk to their loved ones and to their physician about their healthcare treatment preferences in those circumstances. We have worked at the local, state and national levels on these issues.

In 1990, we had the privilege to consult with then Senators Danforth and Moynihan to draft and introduce the Patient Self-Determination Act, federal legislation that requires all healthcare institutions that receive Medicare to inform patients about their rights to choose and refuse any medical or surgical treatment and to make advance directives.

For five years, we directed Community-State Partnerships to Improve End-of-Life Care, a national program of the Robert Wood Johnson Foundation that focused on state-wide policy

reform, including advance care planning. Other organizations with which we have worked on these issues include AARP, the American Bar Association's Commission on Law and Aging, the American Hospital Association, the National Association for Attorneys General, the Centers for Disease Control, and the Institute on Medicine among others.

And earlier this year we co-authored a Congressional report on advance care planning with the RAND Institute. It can be found at: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm>.

Various studies confirm that the vast majority of Americans (more than  $\frac{3}{4}$ ), believe that these rights – the right to make advance directives and to name someone they trust to act as their proxy in the event they lose the capacity to make healthcare decisions for themselves – are highly valued.

It is also the case that people want their physicians to have these conversations with them and that they think more highly of physicians when they raise these issues in the clinical context. We have always encouraged physicians to have advance care planning conversations with their patients. However, often we have heard caring, well-intended physicians say that they would like to have these conversations but they are more and more pressed for time AND that they are not compensated for their time when they actually do so.

We were, therefore, delighted when we saw that HR3200 would provide reimburse physicians when they had such conversations with their Medicare patients and that they would be reimbursed them for these conversations every five years and sometimes more often if their patient received a serious life-threatening diagnosis. This is completely congruent with what we have always advised because, as we all know, our goals and values can change – especially if our life circumstances change significantly.

Needless to say, we have been stunned and disheartened in the last few weeks by all the talk about bureaucrats promoting euthanasia, death panels, and doctors being told they could not provide life-sustaining treatment to old people. My colleagues and I have combed through HR3200 and related legislation that has been proposed in both the House and the Senate to make sure that we had not missed something.

We do think the structure of HR3200 is confusing in places and that there should be more distinction between advance care planning and establishing orders for life-sustaining treatment and have offered to help clarify the language.

We have also agreed to be present to the media and at as many public forums as possible to discuss this with those who have legitimate concerns or where there is confusion. However, we also believe that some of those who are speaking out on these matters are not confused. We are convinced that they are fear-mongers and demagogues who are trying to frighten frail, elderly, and sick people as a way of undermining healthcare reform.

Ironically, some of those who are the most well-known politically and have spoken out the loudest are also on record in the recent past promoting advance care planning. Consistency and truth-telling appears not to be of concern. We know that advance care planning improves care for the same people who are now being targeted with lies and deception for political purposes. It is unethical to use people as a means to an end, especially those who are vulnerable.

It is our hope that when you and your colleagues return to Washington in the next few days that you will not succumb to the political pressures to withdraw the advance care planning provisions of the pending legislation.

Aristotle once said, "Ethics is at least in part politics." We hope that "politics is at least in part about ethics."