



Testimony of Paul Malley, President of Aging with Dignity

New York State Senate Committee on Aging Public Hearing
"America's Affordable Health Choices Act of 2009
and Its Impact on Senior Citizens"
New York City – September 8, 2009

Chairman Diaz and members of the New York Senate Committee on Aging, I am pleased to have the opportunity to contribute to this important conversation and I thank you for focusing attention on the impact of proposed health care reform measures on senior citizens. My name is Paul Malley and I am President of the national nonprofit organization Aging with Dignity, based in Tallahassee, Florida. Aging with Dignity has championed the cause of advance care planning for more than 12 years, during which time we have helped more than 13 million Americans discuss and plan for the kind of care they would want at the end of life. I thank you for focusing this hearing especially on Section 1233 of the current U.S. House Resolution 3200. As advocates for quality end-of-life care and advance care planning, we wholeheartedly support the concept of patients consulting with their doctors in these matters. While we support this concept overall, we have serious concerns about the practical implications of the current Section 1233 on seniors and other vulnerable populations.

Aging with Dignity Background

Aging with Dignity was founded in 1996 with generous support from the Robert Wood Johnson Foundation and others concerned with improving end-of-life care and protecting the dignity of all Americans as they age. We remain a private, nonprofit, and nonpartisan organization that has never taken federal or state grant dollars.

Our organization was founded by Jim Towey, who was legal counsel to Mother Teresa of Calcutta for 12 years until her death. He also worked in her missions in Calcutta and Tijuana, and for a year, as a full time live-in volunteer at her home for AIDS patients in Washington, D.C. It was this experience of caring for those near the end of life that inspired Jim to found Aging with Dignity.

Aging with Dignity is the creator and distributor of the advance directive Five Wishes, which is the closest thing there is in America to a national advance directive/living will. Five Wishes currently meets the legal requirements of 40 states, including New York, and it is useful in all 50 states in beginning and structuring end-of-life discussions that result in a completed advance directive. It is unlike all other advance directives in that it is easy to understand and use and includes the personal, family and spiritual issues that people say matter most to them.

Since its national introduction in 1998, some 15,000 partner organizations have distributed more than 13 million copies of Five Wishes in all 50 states and overseas. These organizations include places of worship, physicians, hospitals, hospices, health systems, attorneys, financial planners and others. Here in New York more than 400 organizations have distributed Five Wishes around the state – the City of Yonkers provided it to employees, and a few years ago even MTV provided Five Wishes for its young workforce.

In 2006 we received a grant from the United Health Foundation to make Five Wishes available to groups whose first language is not English. Today, Five Wishes is available in 23 languages and in Braille. This is especially important in a diverse country where 47 million people (18%) speak a language other than English at home – and even more so in the State of New York where about 30% of people speak languages other than English at home – and 13% speak English “less than very well.”¹

We believe Five Wishes has literally changed the way people talk about and plan for end-of-life care. In my 11 years at Aging with Dignity – seven years as the organization’s president – I have given countless advance care planning workshops at senior centers, workplaces, hospitals, places of worship, colleges, and other venues. It is clear that when people talk about caring for someone at the end of life, they want to talk about what matters most to them: their family relationships, comfort, human dignity, and spirituality. For too long the advance care planning conversation focused only on the issues that matter to doctors and lawyers – life support treatment and powers of attorney. It is no wonder that most people have not completed an advance directive. That is the change that Five Wishes brought to the table. It took what was an abstract legal and medical process and reframed the discussion and document in terms that make sense to people, regarding the issues that matter most. When the document is easier to understand, it becomes easier to have the all-important conversation about end-of-life preferences with loved ones and doctors.

Impact of H.R. 3200 – Section 1233

The proposed House health care legislation encourages these conversations between doctor and patient, and while we believe that this is important and good, that conversation should come after one already held in the living room between the patient, spouse and family. People tend to avoid this conversation if the discussion is centered around feeding tubes, comas, ventilators and terminal illness. In contrast, they are much more comfortable talking about it when the conversation deals with how they wish to be cared for, or how they would want their pain managed, or what things are important in their life that they want people to know.

Legal and medical decisions are important, but these are the topics that speak to the person’s God-given dignity and value as a person. It is important that we care for people, not because it is cost-effective, but because relieving pain and curing illness are worthy goals of a compassionate society.

¹ Shin HB, Bruno R. Language Use and English-Speaking Ability: 2000. U.S. Department of Commerce Census Bureau, October 2003.

We believe that advance care planning must always put the patient first and allow people to state in their own words what kind of treatment they want or don't want in case of serious illness or impending death. While the doctor is a valuable resource, the decision on what to do or not do should be the patient's. When that decision is made it should be respected and the patient must be able to change his wishes at any time.

Advance Care Planning Communication

At the heart of good advance care planning is good communication, first within the family, and then between doctor and patient. It is never enough to just sign the advance directive and be done with it. We have always encouraged the follow-up conversation with the physician so that a person's wishes are fully understood. A communications study revealed that when doctors talk to patients about advance directives, the average conversation lasts 5.6 minutes and the doctor talks for two-thirds of this time.² Additionally, when doctors do talk to patients about advance directives, the discussion infrequently addresses patients' values and attitudes toward uncertainty, making the discussions less useful in decision making.³ It is also acknowledged that traditional advance directive documents may not effectively stimulate this form of physician-patient communication.⁴ Any new policies adopted should make it easier for these conversations to occur and provide the doctor with enough time to engage in true consultation. Section 1233 takes a step in the right direction by promoting patient-doctor communication. But the key is to make it a patient-centered process that gives the person the most control possible over his or her individual care. This is what Congress intended when it passed the original Patient Self-Determination Act in 1990.

Medical Orders vs. Advance Directives

The current House proposal threatens to undo all that progress and re-medicalize the discussion, essentially making patients spectators in their own health care decisions again. For example, the proposal says the physician-patient conversation shall include an explanation of the benefits of medical "orders for life sustaining treatments." This would enshrine and define the concept of orders for life sustaining treatment for the first time in federal law. The medical orders model has the potential to shift end-of-life decision making away from the patient. This is the mechanism many fear will lead to the patient feeling pressured into consenting to the doctor's orders.

The shift is important to understand. As it exists now, an advance directive expresses a patient's wishes regarding life support treatment if they become seriously ill and life support treatment would only delay the moment of death. The person can change his mind at any time. However, the orders for life sustaining treatment model results in a signed medical order that could state that no life support treatment, or antibiotics, or

² Tulskey JA, Fischer GS, Rose MR, Arnold RM. Opening the Black Box: How do Physicians Communicate about Advance Directives? *Ann Intern Med.* 1998;129:441-449.

³ Larson DG, Tobin DR. End-of-Life Conversations: Evolving Practice and Theory. *JAMA.* 2000;284(12): 1573-1578.

⁴ Singer PA, Martin DK, Lavery JV, Thiel EC, Kelner M, Mendelsohn DC. Reconceptualizing Advance Care Planning from the Patient's Perspective. *Arch Intern Med.* Vol 158. Apr 27, 1998: 879-884.

tube feeding, be offered the patient even if these treatments could help, and regardless of what family members may request. Once the order has been signed by a physician, it remains in effect until changed. This medical order model may be appropriate for someone close to death, but it is not at all appropriate for an otherwise healthy Medicare recipient. The distinction should be made clear in the legislation.

Supporters of the medical order model say it was developed in Oregon to overcome the limitations of do-not-resuscitate orders. It aims to convert treatment preference in to medical orders that can be followed by medical personnel regardless of where the patient is located.⁵

Unlike an advance directive that is triggered only in specific situations, the medical order does not depend on your health getting worse. It does not think ahead to future situations, it is only about the here and now. There is a huge difference between patients making decisions in their own words and on their own turf, and a process where the decisions are written in a medical order created by and for health care providers.

Because New York is one of the few states where these medical orders are already established, the doctors and residents of this state would be impacted by the requirement that doctors shall explain “the reasons why the development of such an order is beneficial to the individual...” I want to be very clear in my comments regarding medical orders. There are times when these orders can be very useful. Indeed, much work has been done on this issue in the State of New York regarding Medical Orders for Life Sustaining Treatment (MOLST). My objection is found in the requirement established in Section 1233 that doctors must tell Medicare patients about the benefits of these orders if they want to be reimbursed for the consultation, without regard to the condition of the patient and whether or not such an order is appropriate.

Physician as Salesman

We urge Congress to abandon any approach that waters down patient rights. It must also stop any attempts to inject the government into doctor-patient conversations. The current House proposal does indeed make the doctor-patient end-of-life discussion voluntary, not mandatory, but it overreaches inappropriately when it specifies what the doctor and patient must discuss in order for the doctor to be paid. It goes too far when it instructs the physicians to “include an explanation of the *benefits* of medical orders for life sustaining treatments.” The government should not put the doctor in the position of having to “sell” the patient on the benefits of medical orders for life sustaining treatment.

Federal Usurpation

We believe that state legislatures should also be very concerned over federal usurpation of state powers, which are part of this legislation. The U.S. House legislation carefully defines how states are to adopt the medical orders for life sustaining treatment;

⁵ Hickman SE, Nelson CA, Moss AH, Hammes BJ, Terwilliger A, Jackson A, Tolle SW. Use of the Physician Orders for Life Sustaining Treatment (POLST) Paradigm Program in the Hospice Setting. *Journal of Palliative Medicine* 2009; 12(2). 133-141.

how such policies should be formed; what organizations must be part of the committee; and how and where the orders will be honored. These are properly the realm of state lawmakers and their departments of health, not members of Congress or the Secretary of Health & Human Services.

We can easily see how a federal regulator, under the rubric of “quality improvement,” could, over time, ratchet up the control it exerts over its affiliated providers.

It is curious that with so much attention given to mandating the details of the medical order model, one very important question remains unanswered. For whom is the medical order appropriate? The current provision requires doctors wanting reimbursement to tell Medicare patients about the benefits of these medical orders. However, these orders are intended for people who already have an advanced chronic illness, for whom the prognosis is measured in 1 to 2 years.⁶ That certainly does not include every Medicare recipient. Should the Congress decide to use this opportunity to define the medical order model for the first time in federal law, it should include in its mandate for the states the distinction that these medical orders are only intended for people near the end of life.

Assisted Suicide?

Still another concern is that the legislation also instructs the physician to include “the continuum of end-of-life services and supports available,” including providing a list of state and national informational “clearinghouses.” Doctors should absolutely talk about the benefits of hospice and palliative care as part of the continuum. Physicians should refer patients to hospice as soon as appropriate – often the referral happens too late for the patient to receive the full benefit of this high-quality care. The full “continuum” provision sounds innocent enough, but such a list or clearinghouse would likely include options recommended by groups like the Hemlock Society, now euphemistically calling itself “Compassion & Choices.” Advocates of physician-assisted suicide successfully argued for this type of requirement in California, knowing that if assisted suicide is legalized doctors will be forced to tell patients about the option as part of the “continuum.” The House legislation would impart a similar requirement on physicians when they have a Medicare-reimbursable consultation on advance care planning. This has already suddenly become a very real issue in the states of Washington, Oregon and Montana.

When the government has a vested interest in holding down costs, is it beyond the realm of possibility to imagine it encouraging citizens to forego care? Recall the woman in Oregon who last year was told by state-administered Oregon Health Plan that it wouldn't pay for her cancer treatment, but would pay for her suicide drugs. I cite this reference because this fear is what drives all the talk and concern about “death panels” and “death books.” It is a very real fear that this legislation needlessly stokes. Indeed, the Hemlock Society has publically stated that passage of this portion of the legislation is its highest legislative priority.

⁶ Meier DE, Beresford L. POLST Offers Next Stage in Honoring Patient Preferences. *Journal of Palliative Medicine*. April 2009, 12(4): 291-295.

Vulnerable groups

Studies estimate that about one-quarter of the U.S. adult population is functionally illiterate. Even higher numbers of people have difficulty understanding most health documents. This is not confined to small pockets of the population. Specifically, research shows that many independent, community-dwelling elderly people do not have the literacy skills necessary to function adequately in the health care environment.⁷

Vulnerable populations – the disabled, those with expensive-to-treat conditions, the uninsured, people with cognitive impairments, people with no or few family members and those with low health literacy – also have good reason for concern. They rightly fear the logical conclusion of any discussion that frames life in terms of its quality or its value to others. This is what the recent concern over the VA’s use of “Your Life, Your Choices” is all about. If what it advocates becomes the norm, it will have an immediate impact on New York’s 1.1 million veterans (many of whom receive care in New York’s 12 VA medical centers), and ultimately on every New Yorker and every American.

I am familiar with “Your Life, Your Choices” because our founder Jim Towey and I were the first to raise concerns about it in 2007. Due to the flawed content, it was removed from circulation in November 2007 and remained that way until recently. Last month “Your Life, Your Choices” appeared again on the VA website along with a new edition of the VA handbook on advance care planning that instructs physicians to refer patients to “Your Life, Your Choices.”

U.S. Veterans Administration – “Your Life, Your Choices”

“Your Life, Your Choices” is a massive taxpayer-funded guide that turns good advance care planning upside down and gives it a bad name. Its focus is on situations when, faced with a disability or serious illness, people may consider life not worth living. For example, it asks veterans to consider if life is worth living if they can’t walk, can’t meaningfully contribute to their family, are a financial burden, live in a nursing home, or can’t “shake the blues.” After this exercise, veterans are asked to write down their decisions about medical care and decide at what point they would rather forego medical treatments. In other words, it frames the discussion in such a way that it asks them at what point their life just isn’t worth living anymore.

The context in which veterans are guided to make end-of-life decisions is significant because the way questions are asked and framed impacts the answer. When given the same case scenario with different descriptions of the intervention, seventy-seven percent of elderly people in one study changed their minds at least once. When the language was phrased negatively, they were more inclined to forego medical intervention.⁸

⁷ Parker, R. Health Literacy: a Challenge for American Patients and their Health Care Providers. Health Promotion International, Oxford University Press. 2000 Vol 15 No 4: 277-283.

⁸ Fagerlin A, Schneider CE. Enough: The Failure of the Living Will. The Hastings Center Report, Vol 34, 2004.

This standard for medical decision making – a “life not worth living” approach to advance care planning – should have no place in any health care system, and certainly not one set up to serve those who have served in the nation’s armed forces. Indeed, the fingerprints of the assisted suicide movement are all over “Your Life, Your Choices.” Its authors are prominent figures in the movement and are on the record favoring assisted suicide and health care rationing.⁹ and¹⁰ Most prominently, lead author Dr. Robert Pearlman signed an amicus brief arguing in favor of assisted suicide in the landmark case of *Vacco v. Quill*, which originated in the State of New York and was decided by the U.S. Supreme Court. His legal brief argued “that the right to physician-assisted suicide should be recognized by this Court as a fundamental right.” Dr. Pearlman is entitled to his opinions, but his support of assisted suicide has found its way into VA policy and resources. In fact, the 2007 edition¹¹ of this supposedly even-handed and “mainstream” advance care planning guide lists only the Hemlock Society’s *Compassion & Choices* as a reference for advance directives.

A Bad, New Standard

The real danger “Your Life, Your Choices” poses is that if its approach to advance care planning and medical decision-making is deemed “mainstream” by bioethicists and other such experts, soon it will take hold and will be widely adopted as the standard across other health systems. This approach is in direct contradiction to the dignified care provided by palliative care professionals, including many at VA hospices and medical centers. Thus, instead of you making health care decisions based on diagnosis of a terminal illness, the new standard will become “when is your life not worth living anymore?” This “right to die” will become a right these vulnerable groups will get first.

Disability rights groups and others have long been suspicious of advance directives because they fear it will become a means to deny them care. They are not comforted when the VA guide casually asks them, “what does ‘being a vegetable’ mean to you?” Nor are they unconcerned when an American Medical Association ethicist asks them, as was stated in a recent newspaper story, to contemplate their “place in life.” It’s not for the government or any piece of legislation to ask that question. The approach the VA is taking and the overreaching nature of the House legislation on advance care planning will reintroduce fear and suspicion and chill the very discussions they seek to encourage.

Conclusion

In conclusion, our main concern is that people remain the primary decision-makers in their care. We believe people should decide this issue for themselves, and that it should not only be left to bioethicists, lawyers and bureaucrats.

⁹ Jecker NS, Pearlman RA. Ethical Framework for Rationing Health Care. *J Med Philos.* 1992 Feb;17(1): 79-96.

¹⁰ Pearlman RA, Starks H. Why do People Seek Physician-Assisted Death? in Quill TE, Battin MP. Physician-Assisted Dying: The Case for Palliative Care & Patient Choice. Johns Hopkins University Press. 2004.

¹¹ Pearlman R, Starks H, Cain K, Cole W, Rosengren D, Patrick D. Your Life, Your Choices: Planning for Future Medical Decisions. U.S. Department of Veterans Affairs. Second edition. June 11, 2007.

I would encourage every adult to talk with their doctor about advance care planning; and I would support public policies that encourage such discussion. It is wonderful that advance care planning is now discussed as part of the “Welcome to Medicare” consultation with a physician. That was a positive step forward that we supported. In the same fashion, we would support a simple provision that makes an advance care planning consultation reimbursable under Medicare. Patients should talk to their doctors about this. But the contents of the conversation should not be dictated by provisions of section 1233 of a health care affordability bill. And this federal legislation should not be used as a state mandate for the medical orders model, complete with the structure, policies, and implementation practices already decided.

The issue is a small piece of the much bigger puzzle of health care reform. Still, the impact of this provision will have long and lasting implications on how we care for people near the end of life and how we talk about health care decision-making.