



Hospice & Palliative Care Association of NYS

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**New York State Senate
Committee on Aging**

**Public Hearing on HR 3200:
America's Affordable Health Choices Act of 2009
Section 1233, Advance Care Planning Consultation**

September 8, 2009

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Senator Diaz, committee members, thank you for the opportunity to address section 1233, Advance Care Planning Consultation of HR 3200, America's Affordable Health Choices Act of 2009. I am Kathy McMahon, President and CEO of the Hospice and Palliative Care Association of New York State. Our mission is to promote the availability and accessibility of quality hospice and palliative care for anyone in New York State confronted with life-limiting illness.

Hospice and palliative care provide a comprehensive, inter-disciplinary approach to care—pain and symptom management, psycho-social support, spiritual care, and bereavement. Hospice and palliative care bring a whole team—physician, nurse, social worker, home health aides, pastoral care, volunteers, bereavement counselors—to the patient and family.

I thank the New York State Legislature for their ongoing support of hospice and palliative care, which they have shown by: passage of the Palliative Care Education and Training Act, the inclusion of hospice in the Child Health Plus and Family Health Plus programs, a soon to be implemented hospice quality initiative, and the recent addition of pediatric palliative care services to the Care at Home I & II Medicaid Waiver.

We were told that the purpose of today's hearing was for fact finding. However, before I begin my testimony, I feel compelled to express my amazement at one untruth that has

been presented as fact. THERE ARE NO DEATH PANELS! I hope that my testimony will help set the record straight.

Although the Hospice and Palliative Care Association of New York State has not taken an official position on HR 3200, we have long supported the use of advance care planning to ensure a patient's choices are respected and honored. We partner with United Hospice of Rockland to promote "Assuring Your Wishes," (www.assuringyourwishes.org), a website providing information and instruction on the completion of advance directives as well as secure on-line storage of documents.

In recent months the term "advance care planning" appears to have been terribly mischaracterized. For in nearly everything we do...we plan in advance.

If you are taking a trip, for example, from Long Island to Watertown, you would prepare yourself—you'd buy a map or go online to print step-by-step directions and a map or use your trusty GPS—But you'd have a plan. You'd choose the way you want to get there—highway or scenic route, toll roads or not, etc.

Your advance care plans—your living will, your health care proxy, your DNR—are your life plans, your road map for how you want to LIVE. For every moment of your life. No matter how seriously ill you become. To illustrate why these decisions are so important

and why they need to be made in consultation with a patient's primary care or attending physician, let me share the story of Judy.

Judy was a 64 year-old breast cancer survivor. In November of last year she was diagnosed with cervical cancer. She had a team of wonderful oncologists whom she trusted implicitly; they had treated her when she beat breast cancer. Together they decided on an aggressive treatment plan. Judy had just a few specific wishes as she faced this life-threatening situation. She wanted to attend and enjoy the May 2nd bridal shower she had so lovingly planned for her niece, Amy; and she wanted to be present at Amy's wedding on August 8th.

Judy completed her chemo in April and called her family to share the good news that she was cancer-free. She was jubilant, though still very tired and still suffering from a variety of troubling symptoms—all supposedly a result of the chemotherapy. The bridal shower arrived; Judy attended...but became ill during the event. Her symptoms—nausea, vomiting, diarrhea and pain—escalated and were not being managed. Just a month later Judy was told that the cervical cancer had metastasized to both lungs, her stomach, and groin. A family meeting was held and her oncologist said the cancer was not curable but it was treatable. Plans were made for her to go to a nursing home for rehabilitation with plans for her to start chemotherapy as soon as she was strong enough. But Judy did not regain her strength. She spent the next two months shuttling between several nursing homes for rehabilitation and the hospital for lengthy acute care

stays to address escalating pain and symptoms, including blood clots. Attempts to get Judy home were not successful. Her last hospital stay was marked by great fear and frequent crying. Judy went to a nursing home on hospice care on August 12th. She died at 2:00 a.m. on August 20th, the day I received the invitation to present testimony at this hearing.

Please think about Judy when you consider these points....About REAL advance care planning:

- The consultation provision in HR 3200 gives patients information that will help them make their own informed decisions about their care...
 - It covers the broad spectrum of care and options available to patients when facing a life-limiting illness;
 - The consultation is with the physician, physician assistant or nurse practitioner who is serving as the patient's primary care provider;
 - Research has shown that patients and family caregivers enjoy a much higher quality of life when patients discuss all of their options for care with their physician.
- The advance care planning consultation would be VOLUNTARY. It is not required. It certainly is not coerced.
 - The advance care planning consultation would be reimbursable under Medicare, just like any other existing Medicare consultation.

- Beneficiaries could elect to have the consultation once every 5 years or when they face significant change in their health status. The key points here are that these advance care planning consultations are VOLUNTARY ... and they offer people options; they give patients the FREEDOM to choose the care that is best for them and their loved ones.
- Advance care planning discussions before the patient finds him or herself in a medical crisis will help ensure that the patient gets the care he or she wants.
- One of the most frequent comments that hospice providers all across New York State and all across the nation hear from family members is: “Why didn’t we know about hospice sooner?” Hospice and palliative care are just two options that would be discussed in an advance care planning consultation.
- The irony here is that research published just last year by Stephen Connor, Ph.D., and colleagues, presented convincing proof that patients who elect hospice care actually tend to live longer than patients with the same diagnosis and the same acuity who don’t elect hospice care.
- So, to set the record straight, advance care planning involves:
 - Understanding your healthcare choices;
 - Thinking about your choices in light of what is important to you, your family and the values you share;
 - Talking about your decisions with your loved ones and your doctors;
 - Writing down your plans in Advance Directives so they will be ready if needed.

- And it's important to remember that...
 - Your advance care plans can be changed as your medical and/or personal situation or wishes change;
 - Advance care planning is done over time and is not a single conversation;
 - Decisions like these are always best considered before there is a health crisis.

Advance care planning is a gift to your family. When serious illness threatens, it allows families to spend precious moments with their loved ones—not fighting about what a patient who no longer can speak for himself/herself may or may not have wanted.

It's important to remember that advance care planning has absolutely NOTHING to do with limiting care. It's NOT about hastening death. It's NOT about taking choice away from the patient. It's NOT about saving money!

So think again about Judy. She did not have a conversation with her trusted doctors that outlined her options and would have empowered her to make informed decisions about her own care. And the result was that her care did not include hospital-based palliative care. And only included hospice care in the very last week of her life. Until Judy went on hospice, her pain and symptoms were not aggressively managed. She suffered greatly—not just physically, but emotionally and spiritually as well. She did not get either of her final two wishes—to go home and to attend her niece's wedding. By

not having an advance care planning consultation, Judy's care was limited, and she did not have real choices. Her care was decided by what her insurance would cover.

My questions to you and your colleagues Senator Diaz are: Why shouldn't patients like Judy have their choices explained to them? Why shouldn't they have all the information they need to make thoughtful decisions about their lives? Why shouldn't they have the time to express what they want to their primary care provider?

Judy was not some faceless patient in a large academic medical center. Judy was my sister-in-law, the aunt who was so incredibly thoughtful and attentive to my son and daughter and two grandchildren. It absolutely breaks my heart that, despite my long-distance coaching via many phone calls to Judy, family, social workers and nurses, Judy did not get a palliative care consultation (the hospital social worker didn't know what my brother-in-law was talking about) and when Judy did elect hospice care her organs were already shutting down. She did not go home; she did not go to Amy's wedding. The fact that we weren't able to honor her last two wishes truly haunts me.

Now let me share the story of another patient, Mary. Dr. Diane Meier of Mt. Sinai Hospital and the Center to Advance Palliative Care in New York City has given me permission to share Mary's story. Mary was a 59-year-old New Yorker diagnosed with lung cancer and initially given 6-12 months to live. Under the care of an oncologist from NYU, Mary actually lived for five years and was able to maintain a good quality of life

throughout that time. In the last 14 months of Mary's life, as her symptoms worsened, Dr. Meier provided palliative care—managing her pain and controlling other debilitating symptoms. With only days left in Mary's life, Dr. Meier helped counsel Mary to refuse a last futile round of chemotherapy delivered directly into the brain that no one thought was likely to help her live longer or enjoy a better quality of life in the time she had left. Thanks to the compassionate care she received, Mary died at home in the company of her husband and daughter, under the care of one of New York's excellent hospices.

In conclusion, New York State has a strong history of supporting access to quality hospice and palliative care. Advance care planning helps make hospice and palliative care more accessible to your constituents. It's worth emphasizing that the advance care planning consultation proposed in HR 3200 is voluntary. Advance care planning offers people options. Advance care planning gives patients the freedom to choose the care that is best for them and their loved ones. Advance care planning provides a roadmap for how you want to live. Research has shown that: 1) patients and family caregivers enjoy a much higher quality of life when patients discuss all of their options for care with their physicians; and 2) patients who elect hospice care actually tend to live longer than patients with the same diagnosis and the same acuity who don't elect hospice care.

I welcome any questions you may have. Thank you for your time.

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