

Statement for the Record
By The
Hospice and Palliative Nurses Association
For the Select Committee on Aging
U.S. Senate
Hearing Convened on June 13, 2012

**Hearing Title: “Empowering Patients and Honoring Individuals’
Choices: Lessons in Improving Care for
Individuals with Advanced Illness”**

On behalf of the Hospice and Palliative Nurses Association (HPNA), the nation's only professional nursing organization dedicated to promoting excellence in hospice and palliative nursing care, we commend Senator Sheldon Whitehouse for convening this hearing and very important, yet often ignored, discussion addressing aging, advanced illness and honoring individuals' choices. This issue is at the foundation of much of the work of HPNA and its 11,000 members in all 50 states. We thank you for the opportunity to submit a statement for the record and would like to further offer our expertise to the Senate Select Committee on Aging for any future activity on these critical patient issues.

Summary

The assurance of choice for seriously and progressively ill patients is one of the core missions of HPNA. Informed consent is the gold standard for making choices in health care in the United States. Informed consent directly supports patients and families by presenting all treatment and care options in a balanced manner and supporting the individual and his/her family to make their own choices. Nowhere is this more important than in the care of people with life limiting conditions. Patients have a right to know all of their treatment options at the time of the diagnosis and at each treatment juncture, and to be provided with consultations that help them make informed choices that match their goals.

Palliative care is a philosophy of and system for delivering patient-centered, interdisciplinary care to persons with serious, progressive illness. It includes a focus on quality of life, function, decision making and opportunities for personal

growth. Palliative care can be provided concurrently with disease-modifying treatments and provides assistance in identifying health care goals, system navigation, and aggressive pain and symptom management.

Growing research evidence demonstrates that palliative care supports patient choice and improves quality of life. Patients who understand all of their treatment options may choose to forego medical treatments that are not aligned with their goals for care or that they consider too burdensome. While not its primary aim, palliative care reduces costs of care by supporting patients' treatment choices that match their personal goals and values. All patients with life limiting conditions should be informed about palliative care along with other medical treatment options to support them through one of life's most difficult challenges. **Palliative care is an important and still underutilized treatment option.**

Issues:

- Informed consent must include balanced information about all treatment options.
- Patients who don't receive open, honest communication about severity of illness and medical treatment options often suffer unnecessarily with poorly managed pain and symptoms, anxiety and no support to plan ahead for future care when they are no longer able to voice their wishes.
- Palliative care is underutilized, yet is available broadly across the United States through more than 5,000 hospice programs and 1,500 hospital-based palliative care programs.
- Professional nursing care is critical to achieving the patients', families', and communities' goals of care at the end of life.

Rationale:

- Americans worry that they might not be told about all treatment options during serious illness.
- Americans are not aware of palliative care.
- Palliative care nurses are expert in communicating with and supporting seriously and progressively ill Americans and their families.

Recommendations:

- Include in future legislative and regulatory policies a requirement that advance practice nurses and physicians offer seriously, progressively ill patients information and counseling concerning palliative and end of life options for care and treatment.
- HPNA is the authority of palliative care nursing and as such, stands ready to participate in initiatives to enhance patient choice and access to quality palliative care.