

## **Assuring Choice for Seriously and Progressively Ill Patients**

### **Summary**

Informed consent is the gold standard for making choices in health care in the United States. Informed consent directly supports patients and families to better fulfill their health care goals 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.<sup>1</sup> 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, which are its primary aims. 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.**

### **Issue:**

- 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<sup>2</sup> and 1,500 hospital-based palliative care programs.<sup>3</sup>
- Professional nursing care is critical to achieving the patients', families', and communities' goals of care at the end of life.<sup>4</sup>

### **Rationale:**

- Americans worry that they might not be told about all treatment options during serious illness.<sup>5</sup>
- Americans are not aware of palliative care.<sup>5</sup>
- Palliative care nurses are expert in communicating with and supporting seriously and progressively ill Americans and their families.

### **Recommendation:**

- Include in future legislative language 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, with membership of nearly 11,000 palliative care nursing professionals. Contact us to learn more about delivery of high quality palliative care nursing.

<sup>1</sup>National Consensus Project. (2009). Clinical Practice Guidelines for Quality Palliative Care. Available at: <http://www.nationalconsensusproject.org/>

<sup>2</sup>National Hospice and Palliative Care Organization. (2012). NHPCO Facts and Figures: Hospice Care in America. Available at: [http://www.nhpco.org/files/public/statistics\\_research/2011\\_facts\\_figures.pdf](http://www.nhpco.org/files/public/statistics_research/2011_facts_figures.pdf)

<sup>3</sup>CAPC. (2011). Growth of Palliative Care in US Hospitals: 2011 Snapshot. Available at: <http://www.capc.org/capc-growth-analysis-snapshot-2011.pdf>

<sup>4</sup>Hospice and Palliative Nurses Association. (2003). HPNA Position Statement: Value of Professional Nurse in End-of-Life Care. Available at: [http://www.hpna.org/pdf/PositionStatement\\_ValueOfProfessionalNurse.pdf](http://www.hpna.org/pdf/PositionStatement_ValueOfProfessionalNurse.pdf)

<sup>5</sup>CAPC. (2011). Opinion Research on Palliative Care. Available at: <http://www.capc.org/tools-for-palliative-care-programs/marketing/public-opinion-research/2011-public-opinion-research-on-palliative-care.pdf>