



New York Palliative Care Information Act and Palliative Care Access Act Summary

Palliative Care Information Act

The Palliative Care Information Act (PCIA), Public Health Law, Section 2997-c, effective February, 2011, is a critically important patients' rights law and a model for the nation. Terminally ill patients now have a clearly defined right to receive information and counseling about their palliative care and end-of-life options, including hospice. This will enable them to make informed treatment decisions during the final months of their lives. The law states, in part:

If a patient is diagnosed with a terminal illness or condition, the patient's attending health care practitioner shall offer to provide the patient with information and counseling regarding palliative care and end-of-life options appropriate to the patient, including but not limited to: the range of options appropriate to the patient; the prognosis, risks and benefits of the various options; and the patient's legal rights to comprehensive pain and symptom management at the end of life; and information regarding other appropriate treatment options should the patient wish to initiate or continue treatment.

Definitions:

- "Palliative Care:" Health Care treatment, including interdisciplinary end-of-life care, and consultation with patients and family members, to prevent or relieve pain and suffering and to enhance the patient's quality of life, including hospice care.
- "Terminal Illness or Condition:" Reasonably expected to cause death within 6 months. "Appropriate." Consistent with applicable legal, health and professional standards, the patient's clinical and other circumstances ; and the patient's reasonably known wishes and beliefs.
- "Attending health care practitioner" a physician or nurse practitioner who has primary responsibility for the care and treatment of the patient. Where more than one physician or nurse practitioner share that responsibility, each of them has responsibility [to offer information and counseling], unless they agree to assign that responsibility to one of them.

Compliance:

- Offer to provide information and counseling:
 - Patient accepts:
- Provide information and counseling directly orally or in writing.
- Arrange for another physician, NP or professionally qualified person to provide the information and counseling;
- If unwilling to or does not feel qualified to provide information and counseling, refer to another physician or NP.
 - Patient declines:
- Patient is not provided with information.
- Information and counseling shall be provided to a person with authority to make health care decisions for the patient if the patient lacks decision making capacity.

If you are a patient who may have a terminal illness or a health care professional working with a patient whom you believe may have a terminal illness, and an attending health care practitioner has not yet offered information and counseling, then you may want to discuss this with the attending.

Studies Demonstrate the Need for the PCIA:

- Dying patients are not informed or sufficiently informed of diagnosis, prognosis and treatment options.
- The vast majority of dying patients in fact want to know their diagnosis and prognosis.
- The lack of physician-patient end-of-life discussions results in hospice referrals only very near death or not at all.
- EOL discussion patients have a better quality of life and better deaths and may even live longer.
- Costs are reduced.

Palliative Care Access Act (PCAA) effective September, 2011:

The PCAA: Expands on the PCIA, Public Health Law, Section 2997-d

- Applies to hospitals, nursing homes, home care agencies and enhanced and special needs assisted living residences.
- Applies to patients with advanced, life limiting conditions and illnesses who might benefit from palliative care (defined as in the PCIA).
- Requires providers to establish policies and procedures to provide these patients:
- Services with access to information and counseling concerning palliative care and pain management appropriate to the patient, and
- Facilitate access to appropriate palliative care and pain management consultations and services
- Provide the information and counseling to those lawfully authorized to make decisions for patients who lack capacity to make medical decisions.

According to the NYS Department of Health, “Like the PCIA, the PCAA is intended to ensure that patients are fully informed of the options available to them when they are faced with a serious illness or condition, so that they are empowered to make choices consistent with their goals of care, and wishes and beliefs, and to optimize their quality of life. The law is not intended...to discourage conversations about palliative care with patients who have distressing symptoms and serious conditions, but do not technically fall within the law’s requirements. Palliative care and disease-modifying therapies are not mutually exclusive. Patients may opt to pursue palliative care while also pursuing aggressive treatment. Palliative care may be provided together with life-prolonging or curative care or as the main focus of care.”

As with the PCIA, if you are a patient or a health care professional working with a patient to whom the PCAA applies, and access to information and counseling concerning palliative care and pain management has not been provided and/or access to appropriate palliative care and pain management consultation and services has not been facilitated by the health care facility, then you may want to discuss this with an appropriate health care professional in the facility.

Resources:

- New York State Department of Health website, questions and answers and guidance for practitioners, http://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/
- Hospice and Palliative Care Association of New York State, Palliative Care Information Act Resource Center, available to members, <http://www.hpcanys.org/members/PCIA/> or for CD purchase for non members.