



STATE OF NEW YORK
DEPARTMENT OF HEALTH

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Nirav R. Shah, M.D., M.P.H.
Commissioner

James W. Clyne, Jr.
Executive Deputy Commissioner

February 8, 2011

Dear Administrator:

As of February 9, 2011, Chapter 331 of the Laws of 2010 (commonly known as the Palliative Care Information Act), requires physicians and nurse practitioners to offer to provide terminally-ill patients with information and counseling concerning palliative care and end-of-life options. A patient has a terminal illness or condition, under the law, if the illness or condition is “reasonably expected to cause death within six months, whether or not treatment is provided.” Palliative care, as defined by the law, is “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.”

The law is intended to ensure that patients are fully informed of the options available to them when they are faced with a terminal illness or condition, so that they are empowered to make choices consistent with their goals for care and wishes and beliefs, and to optimize their quality of life. The law is not intended to limit the options available to terminally-ill patients. Nor is it intended to discourage conversations about palliative care with patients whose life expectancy exceeds six months. It is often appropriate to discuss palliative care with patients earlier in the disease progression.

Health care facilities, home care agencies, and hospice programs must provide patient care consistent with professional standards.¹ In addition, informed consent must be properly secured for health care services.² Accordingly, facilities, agencies, and programs are strongly encouraged to educate their affiliated physicians and nurse practitioners about the law's requirements and to put in place policies and processes that support compliance by their staff. A copy of the law is attached for your convenience. It can also be found at section 2997-c of the Public Health Law.

This letter provides a brief summary of the law and includes a series of questions and answers to provide guidance for practitioners. The summary and questions and answers, along with extensive resources for providers, will be posted on the Department of Health's website at: http://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/.

¹ PHL Articles 28, 36 and 40; 10 NYCRR §§ 415.15, 763.4, 763.11, 766.2, 793.1.

² PHL §§ 2803-c; Education Law § 6530(26); 10 NYCRR §§ 415.3, 415.11, 415.15, 763.2, 766.1, 794.1; *see also* PHL §2805-d.

Thank you for your prompt attention to this very important issue, and your continued commitment to high-quality care for terminally-ill patients.

Sincerely,

A handwritten signature in black ink, appearing to read "Mark L. Kissinger". The signature is written in a cursive style with a horizontal line at the end.

Mark L. Kissinger
Deputy Commissioner
Office of Long Term Care

Summary of the Law

Public Health Law section 2997-c requires the “attending health care practitioner” to offer to provide patients with a terminal illness with information and counseling regarding palliative care and end-of-life options appropriate to the patient, including:

- Prognosis;
- Range of options appropriate to the patient;
- Risks and benefits of various options;
- Patient’s “legal rights to comprehensive pain and symptom management at the end of life.”

The information and counseling may be provided orally or in writing.

- The attending health care practitioner may arrange for information and counseling under this section to be provided by another professionally qualified individual.
- If the attending health care practitioner is “not willing to provide the patient with information and counseling,” he/she must “arrange for another physician or nurse practitioner to do so,” or must “refer or transfer the patient to another physician or nurse practitioner.”

When the patient lacks medical decision-making capacity, the information and counseling must be provided to the person who has authority to make health care decisions for the patient.

Definitions:

- **"Appropriate"** means 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"** means 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 under this section, unless they agree to assign that responsibility to one of them.
- **"Palliative care"** means 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 under article forty of [the Public Health Law].
- **"Terminal illness or condition"** means an illness or condition which can reasonably be expected to cause death within six months, whether or not treatment is provided.

QUESTIONS AND ANSWERS ABOUT PALLIATIVE CARE, HOSPICE, AND THE PALLIATIVE CARE INFORMATION ACT

1) Question: What is palliative care?

Answer: Palliative care, as defined by the law, is “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.” PHL §2997-c.

The Palliative Care Information Act focuses on patients with a medical condition that is expected to cause death within six months, and does not require counseling about palliative care and end-of-life options for other appropriate patients. However, it is important to recognize that palliative care is not just for people who are about to die. Many people assume that palliative care and chronic disease management or disease-modifying therapies are mutually exclusive, but they are not. Palliative care may be provided concurrently with life-prolonging care or as the main focus of care.³

2) Question: Is palliative care the same thing as hospice?

Answer: Hospice care is a type of palliative care for people who are likely to have six months or less to live. When medical treatments cannot offer a cure, hospice provides care, comfort and support for persons with life-threatening illnesses and their families.

Palliative care, by contrast to hospice, is appropriate at any stage of a serious illness, whether that illness is potentially curable, chronic or life-threatening. Palliative care is appropriate for a much broader group of patients than hospice and, unlike hospice, may be provided in conjunction with curative or life-prolonging treatment.

Both hospice and palliative care, offer a personalized plan of care, delivered by an interdisciplinary team, that incorporates what is important to the patient and his or her caregivers in order to achieve the best possible quality of life for patients and families.

3) Question: What types of practitioners are subject to the law?

Answer: Physicians and nurse practitioners, who are serving as a terminally-ill patient’s attending health care practitioner, are subject to the requirements of this law. Physician assistants and other health care professionals may also, consistent with their scope of

³According to the National Consensus Project for Quality Palliative Care:

“Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.

Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care with consideration of patient/family needs, preferences, values, beliefs, and culture. Evaluation and treatment should be comprehensive and patient-centered with a focus on the central role of the family unit in decision making.”

National Consensus Project for Quality Palliative Care (2009). *Clinical Practice Guidelines for Quality Palliative Care, Second Edition*, 6; see also World Health Organization, Definition of Palliative Care, available at: <http://www.who.int/cancer/palliative/definition/>.

practice, provide information and counseling about palliative care and end-of-life options, but are not required to do so under this law. When a patient with a terminal condition is treated by a physician assistant, the supervising physician must comply with the Palliative Care Information Act, if the physician or the physician assistant has “primary responsibility for the care and treatment of the patient.”

To identify an “attending health care practitioner,” see Question 7. For information about satisfying the requirements of this law by arranging for counseling by a qualified professional other than a physician or nurse practitioner, see Questions 12 and 13.

4) Question: What types of information should an attending health care practitioner offer a terminally-ill patient about palliative care in order to comply with the law?

Answer: The law requires that the attending health care practitioner offer to provide the patient with information and counseling regarding palliative care and end-of-life options appropriate to the patient, including:

- Prognosis;
- Range of options appropriate to the patient;
- Risks and benefits of various options;
- Patient’s “legal rights to comprehensive pain and symptom management at the end of life.”

The information and counseling must be “appropriate” to the patient, meaning it must be “consistent with applicable legal, health and professional standards; the patient's clinical and other circumstances; and the patient's reasonably known wishes and beliefs.” This includes, but is not limited to, the patient’s psychosocial circumstances and cultural and religious beliefs.

Research shows that the majority of patients in the advanced stages of a life-limiting illness and their family members want a great deal of information about their prognosis and options. However, a significant minority prefer only limited information. In addition, according to the literature, information needs, patient preferences, and options may need to be revisited as the disease progresses.⁴ Thus, patient preferences vary, and individualized assessment is necessary.

The Department recognizes that conversations with patients about the end-of-life are difficult and cannot be approached in a one-size-fits-all manner. The delivery of palliative care and end-of-life counseling need not, and should not, be the same for every patient. The

⁴ Tattersall, M.H., Gattelarri, M., Voigt, K., & Butow, P. (2002). When the treatment goal is not cure: Are patients informed adequately? *Supportive Care Cancer*, 10, 314-321.

Innes, S., Payne, S. (2009). Advanced Cancer Patients' Prognostic Information Preferences: A Review. *Palliative Medicine*, 23(1), 29-39.

Back, A.L., Anderson, W.G., Bunch, L., Marr, L.A., Wallace, J.A., Yang, H.B., & Arnold, R.M. (2008) Communication About Cancer Near the End of Life. *Cancer*, 113(7 Suppl), 1897-910.

Parker, S.M., Clayton, J.M., Hancock, K., Walder, S., Butow, P.N., Carrick, S., ... Tattersall, M.H.(2007). A Systematic Review of Prognostic/End-of-Life Communication with Adults in the Advanced Stages of a Life-Limiting Illness: Patient/Caregiver Preferences for the Content, Style, and Timing of Information. *Journal of Pain and Symptom Management*, 34(1), 81-93.

practitioner should be sensitive to the patient's emotional cues, preferences, and ability to absorb information. More than one conversation is often needed in order to provide the patient with an opportunity to understand and weigh his or her options.

5) Question: The law is intended to ensure that terminally ill patients are fully informed about their options for care. What types of options should be considered, and how should I frame them?

Answer: Therapeutic options include treatments for the serious illness and comorbidities—so-called disease-modifying therapies—and treatments and services that may be considered under the broad approach known as palliative care. Disease-modifying therapies may be undertaken to prolong life, reduce the complications of the disease, or aid in symptom control. Palliative care is a model of care that aims to reduce illness burden and suffering, support coping and adaptation, and maintain quality of life. Some key considerations are:

- Deciding among options should be guided by prognosis, the availability and medical appropriateness of disease-modifying therapy, and the patient's goals for care. For some patients, these decisions may also be guided by religious or cultural considerations concerning end-of-life care. Although studies have shown that prognostication is difficult, many patients value the knowledge that “time may be limited” or “people with this disease often have months, but not years.” To communicate about the medical appropriateness of specific therapies, physicians must have information about treatment availability, the evidence in support of effectiveness, and the risks or burdens that should be anticipated.
- The specific treatments or services that constitute palliative care may be provided alone or in conjunction with disease-modifying therapies. Specialist palliative care may be available for selected patients through consultation with a palliative care service, or if appropriate, referral to a hospice agency. For those illnesses with advanced disease-modifying therapies, such as cancer, congestive heart failure and chronic obstructive pulmonary disease, there often is a prolonged period during which the best therapeutic approach is one that simultaneously offers aggressive treatment for the disease and aggressive palliative care.
- The “palliative plan of care” should be sensitive to cultural and religious considerations and may target:
 - Pain and other symptoms
 - Psychiatric disorders or psychological concerns
 - Family disruption or distress, caregiver burden, or social isolation
 - Spiritual distress
 - Problems in coordinating care among many professionals or sites
 - Poor communication leading to uncertainty about the goals of care or to a lack of advance care planning (e.g., no living will, no Medical Orders for Life Sustaining Treatment (MOLST), no health care proxy)
 - Need for practical help at home.

- Patients (or if the patient lacks medical decision-making capacity, his or her authorized health care decision-makers) must consent to treatment. Informed consent requires that the patient or his or her decision-maker be given appropriate, accurate information about the risks and burdens and likely benefits of each treatment option. Consent to treatment, whether disease-modifying or palliative, should be informed by weighing risks and burdens against benefits.
- A discussion of options when patients are very ill should help the patient or his or her health care decision-maker understand that individuals vary in how they judge the balance between risks/burdens and potential benefits. Some patients prioritize comfort and support, and unless the benefits of treatment are very likely or very substantial, do not want down-sides like side effects or time away from home to compromise quality-of-life. Other patients choose substantial risk or burdens for even a small chance of benefit. The preferences and values of patients are critical in establishing treatment goals, and patients should be encouraged to communicate them to their physicians and other health professionals.

Discussions about options, therefore, must be individualized and guided by the availability and appropriateness of disease-modifying therapy; the need for palliative treatments and services; and an understanding of the patient's values, preferences and goals. It should be framed by a broad understanding of prognosis, gently shared with the patient and/or decision-maker as appropriate, and as accurate an analysis of risk/burden versus benefit as is possible, given the complexities of the situation. Discussion about options often requires multiple conversations.

6) Question: Are there any circumstances in which information and counseling about palliative care and end-of-life options need not be provided?

Answer: The information and counseling must be *offered*, but it need not be provided if the patient (or his/her authorized decision-maker, when the patient lacks medical decision-making capacity) declines the offer. If the offer is declined, the attending health care practitioner should document the decision in the medical record. The practitioner should renew the offer, as appropriate, consistent with changes in the patient's condition and the treatment options available to him/her.

7) Question: Who is the “attending health care practitioner?”

Answer: The attending health care practitioner is the physician and/or nurse practitioner who has primary responsibility for care and treatment of the patient with a terminal illness or condition. This may be the responsibility of more than one practitioner. For example, the patient's primary care practitioner and/or one or more specialists may all have primary responsibility for aspects of the patient's care. For more information about the attending health care practitioner's responsibilities when the patient is treated by several health care practitioners, see Questions 8, 9 and 10.

8) Question: If a patient receives care from several health care practitioners, are all of those practitioners required to offer palliative care and end-of-life information and counseling?

Answer: All physicians and nurse practitioners who have primary responsibility for care and treatment are subject to the law's requirement to offer palliative care and end-of-life information and counseling. However, when there is more than one health care practitioner primarily responsible, the law allows them to agree to assign that responsibility to one of them. The assignment should be reflected in the patient's medical record.

A patient may have many conditions and several health care providers with primary responsibility for particular aspects of his/her medical care. For example, a patient who has congestive heart failure and end-stage renal failure may be under the care of an endocrinologist, a nephrologist, cardiologist, and an internist or family practice practitioner. Unless they agree to assign the responsibility to offer information and counseling regarding palliative care and end-of-life options to one of them, each has primary responsibility for the patient and, therefore, must provide information regarding palliative care options.

9) Question: If a primary care practitioner diagnoses a terminal condition and refers the patient to a specialist, must the primary care practitioner offer to provide palliative care information and counseling?

Answer: It depends on whether the primary care practitioner's role is only diagnosis and referral to another practitioner who assumes primary responsibility for the patient, or whether the primary care practitioner provides, or expects to provide, ongoing care or care coordination for the patient.

If the primary care practitioner's only role in the patient's care is diagnosis and referral, then the primary care practitioner does not have "primary responsibility" for the patient's care and is not required to offer information and counseling concerning palliative care and end-of-life options. On the other hand, if the primary care practitioner provides, or expects to provide, ongoing care or care coordination for the patient and reasonably expects that the patient's condition will cause death within 6 months, he or she must offer to provide information about palliative care and end-of-life options, or reach an agreement with the patient's specialist that the specialist will assume that responsibility. For more information about the responsibilities associated with treating a patient who receives care from more than one attending health care practitioner, see Question 7 and 10.

10) Question: If the patient receives care from more than one attending health care practitioner, and they agree to assign to one of them the responsibility to offer information and counseling concerning palliative care and end-of-life options, should the agreement be documented?

Answer: Each attending health care practitioner for a given patient should document in the patient's medical record the identity of the practitioner who was assigned, and agreed to accept, the responsibility to offer the information and counseling.

11) Question: Is there more than one way for an attending health practitioner to comply with the law?

Answer: The law requires attending health care practitioners to *offer* information and counseling concerning palliative care and end-of-life options to terminally ill patients. If the offer is accepted, the law provides four alternatives for the attending health care practitioner:

- He or she may provide the information and counseling directly; or
- He or she may reach an agreement with another attending health care practitioner who is treating the patient that the other practitioner will provide the information and counseling; or
- He or she may “arrange for” information and counseling . . . to be provided by another professionally qualified individual” (PHL §2997-c(2)); or
- If the attending health care practitioner is not willing to provide the required information and counseling, he or she must “refer or transfer the patient to another physician or nurse practitioner willing to do so” (PHL §2997-c(3)).

For more information about arranging for information and counseling by another professionally-qualified individual, see Questions 12 and 13.

12) Question: What is a “professionally-qualified individual?”

Answer: A “professionally-qualified individual” is a health care professional who is qualified by training and experience to provide information and counseling to terminally-ill patients concerning prognosis, options, risks and benefits of options, and the patient’s legal rights to pain and symptom management at the end of life.

13) Question: May an attending health practitioner refer or transfer a patient to a trained social worker or nurse for palliative care and end-of-life counseling?

Answer: The law allows an attending health care practitioner to “refer or transfer” the patient for counseling only to another physician or nurse practitioner. The legislation does not authorize a referral or transfer to other types of health care professionals.

However, an attending health practitioner may “arrange for” the delivery of information and counseling by other professionally qualified individuals, as well as by a physician or a nurse practitioner. (See Question 12 for a description of a “professionally-qualified individual.”)

An attending health practitioner “*arranges for*” counseling by a professional other than a physician or nurse practitioner, if the counseling is part of the plan of care of the attending physician or nurse practitioner – i.e., he or she coordinates the counseling, communicates with the other professional concerning the patient’s condition and treatment options, assures that the outcomes of the counseling (including the patient’s goals for care and treatment preferences) are included in the plan of care, and will translate the goals for care and treatment preferences into appropriate medical orders.

Typically, a social worker would not have sufficient medical training to provide the information and counseling required under the law. However, a social worker may be helpful in supplementing the required medical information and counseling. A social worker could assist the patient in identifying and articulating his/her goals for care, and values concerning the end of life, and in selecting among treatment options based on those goals and values. Similarly, for patients whose values are informed by religious considerations, a member of the clergy selected by the patient may be helpful in advising the patient about the teachings of his/her religion concerning end-of-life care and how those teachings relate to the patient's particular situation. If a patient appears to need assistance in deciding among options, attending health care practitioners may want to ask patients whether a consultation with a social worker or a member of the clergy would be helpful.

14) Question: How does the attending health care practitioner determine whether a patient's condition is reasonably expected to cause death within 6 months?

Answer: PHL section 2997-c does not address this question. The determination is based on the clinical condition of the patient, including his/her primary diagnosis and co-morbidities, utilizing the knowledge and experience of the practitioner. The Department does not expect practitioners to predict prognosis precisely in each case. Even when clinical research identifies criteria that support particular prognoses, the criteria typically define "a range of probabilities for mortality in a specific population."⁵ Clinical judgment is necessary at each stage of an illness to determine the patient's prognosis.⁶

There are many sources of guidance available to practitioners. Since the Medicare definition of terminal illness for purposes of determining eligibility for hospice⁷ is very similar to the definition used in PHL 2997-c, one resource for practitioners is the Medicare fiscal intermediary's local coverage determination for hospice – Determining Terminal Status (L25678). The local coverage determination provides detailed guidelines based on clinical variables with general applicability and disease-specific clinical variables.⁸

According to the *Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases*, published by the National Hospice Organization, in assessing a patient's prognosis, health care practitioners should evaluate "the whole person and the entirety of the illness." A patient may "have multiple medical problems, none of which individually amount[s] to a terminal *diagnosis*, but when take together indicate a terminal *condition*."⁹ Non-medical factors, such as the patient's decision to reject aggressive treatment may also indicate a

⁵ *Medical Guidelines For Determining Prognosis In Selected Non-Cancer Diseases* (2d ed.). The National Hospice Organization, 1996, available at <http://aspe.hhs.gov/daltcp/reports/impquesa.htm#appendixC>.

⁶ *Ibid.*

⁷ Under the Medicare conditions of participation for hospice, a patient is "terminally ill" if he or she "has a medical prognosis that his or her life expectancy is 6 months or less if the illness runs its normal course." 42 CFR §418.3.

⁸ Available at: [https://www.cms.gov/medicare-coverage-database/details/lcd-details.aspx?ContrNum=00450&ContrTypeId=3&LCDId=25678&ver=33&ContrId=89&Cntretr=89&name=National+Government+Services%2c+Inc.+\(00450%2c+RHHI\)&s=41&bc=BBAAAAEAAAA&](https://www.cms.gov/medicare-coverage-database/details/lcd-details.aspx?ContrNum=00450&ContrTypeId=3&LCDId=25678&ver=33&ContrId=89&Cntretr=89&name=National+Government+Services%2c+Inc.+(00450%2c+RHHI)&s=41&bc=BBAAAAEAAAA&).

⁹ *Medical Guidelines*, *supra*, note 3.

terminal diagnosis. Clinical judgment, based on both medical and nonmedical factors, is necessary to evaluate a patient's prognosis.¹⁰

In any event, it is often appropriate to discuss palliative care options with seriously-ill patients earlier in the disease progression, when the patient's is expected to live more than six months. In one recent study, early delivery of palliative care prolonged the lives of patients with metastatic, non-small cell lung cancer.¹¹ More research is needed to provide a better understanding of the relationship between palliative care and life expectancy. For more information, see Question 15.

15) Question: When should the offer of palliative care information and counseling be made?

Answer: Under the Public Health Law section 2997-c, palliative care information must be offered at the point in time that the physician or nurse practitioner reasonably expects the patient's condition to cause death within six months, whether or not treatment is given.

Given the uncertainty inherent in an individual's prognosis, it is often appropriate to discuss palliative care options with seriously-ill patients earlier in the disease progression, when the patient's lifespan is expected to exceed six months. Early introduction of palliative care optimizes the patient's quality of life and empowers the patient to prepare for the possibility that treatment may fail and to make the most of his/her remaining time, even if he or she continues to pursue curative treatments or life-prolonging care. In fact, palliative care may, itself, extend a patient's lifespan. According to one recent study, early delivery of palliative care prolonged the lives of patients with metastatic, non-small cell lung cancer.¹² More research is needed to provide a better understanding of the relationship between palliative care and life expectancy.

The precise moment for the offer of palliative care information and counseling, and the nature of the information provided, are dependent on the patient's individual circumstances, including his or her physical and mental condition. The practitioner should be sensitive to the patient's emotional cues and ability to absorb information. More than one conversation is often needed in order to provide the patient with an opportunity to understand and weigh his or her options. The practitioner may want to extend an offer to provide the information and, if the patient agrees, schedule the counseling for a subsequent session when a family member, close friend, or other advisor selected by the patient, is available to participate.

16) Question: If palliative care information and counseling is offered once, should it be offered again?

Answer: The legislation does not address this question. However, it is important to recognize that patients' needs and desire for information may change over time. Palliative

¹⁰ *Ibid.*

¹¹ Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admane, S., Jackson, V.A., ... Lynch T.J. (2010). Early Palliative Care for Patients with Metastatic Non-Small Cell Lung Cancer. *The New England Journal of Medicine*, 363, 733-42.

¹² Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admane, S., Jackson, V.A., ... Lynch T.J. (2010). Early Palliative Care for Patients with Metastatic Non-Small Cell Lung Cancer. *The New England Journal of Medicine*, 363, 733-42.

care information and counseling should be offered as often as necessary to assure that the patient has the information he or she wants at each stage of his or her illness and to permit appropriate control of the patient's symptoms and optimize his/her quality of life. For example, as the patient's condition changes or the availability of social supports changes, the patient and his/her family may need to re-evaluate the treatment plan.

17) Question: Should the offer of palliative care information and counseling be documented?

Answer: Yes, it is appropriate to document the offer for a number of reasons, including: to serve as a reminder of the timing of the offer so that it can be renewed as appropriate, to alert other health care practitioners treating the patient that the offer was made and when, to support reimbursement claims related to the counseling, and to respond to an allegation that the offer was not made.

18) Question: May an attending health care practitioner comply with the law by simply providing the patient with a list of palliative care resources or a link to a website?

Answer: The law allows the practitioner to provide information and counseling orally or in writing. However, the information and counseling must be "appropriate to the patient." "Appropriate" is defined in the law to mean that the information must be consistent with professional standards, the patient's condition and circumstances, and the patient's reasonably know wishes and beliefs. Practitioners are encouraged to engage in a dialogue with the patient about his/her diagnosis, prognosis, goals for care, options for life-prolonging and palliative care, and treatment preferences. Written and web-based materials often serve as excellent supplements to conversations about palliative care and end-of-life issues.

Alternatively, an attending health care practitioner may:

- arrange for counseling to be provided by another professionally-qualified individual, if the attending health care practitioner coordinates the counseling, communicates with the counseling professional concerning the patient's condition and treatment options, will assure that the outcomes of the counseling (including the patient's goals for care and treatment preferences) are reflected in the plan of care, and will translate the goals for care and treatment preferences into appropriate medical orders; or
- refer or transfer the patient to another physician or nurse practitioner.

For more information about options available to attending health care practitioners who would like to arrange for counseling by another professionally-qualified individual or would prefer to refer patients to another physician or nurse practitioner, see Questions 11 and 13.

19) Question: What are the patients "legal rights to comprehensive pain and symptom management at the end of life?"

Answer: The Palliative Care Information Act does not define these rights. However, patients have a right to expect medical care that is competent and consistent with professional standards. The Board for Professional Medical Conduct "encourages and expects physicians to view effective pain management as a part of quality medical practice for all patients with

pain, acute or chronic, including pain as a result of terminal illness.”¹³ In “Pain Management – A Guide for Physicians,” the Board stresses:

An adequate assessment of the patient and the pain should be performed and documented. Pain should be considered a fifth vital sign that is viewed as a fundamental assessment of well-being which is regularly monitored.¹⁴

Attending health care practitioners should offer terminally-ill patients information about the array of options for controlling their pain and symptoms. This includes information about treatments for shortness of breath, fatigue, and nausea and loss of appetite, among others.

20) Question: In certain cultures, discussions about the end-of-life are considered taboo. Is there a cultural exemption from this requirement?

Answer: The law does not provide an exemption from its requirements based on cultural considerations. Information and counseling about palliative care and end-of-life options must be offered, but if the patient declines the offer, the attending health care practitioner is not required to provide it. The patient’s decision to decline the information and counseling should be documented in the medical record.

Information about palliative care and end-of-life options should be offered and delivered in a manner that is sensitive to cultural and religious beliefs. Health care practitioners should be informed about the common beliefs, traditions, and values of the groups they see regularly in their practices. However, they should be careful to recognize that there is great diversity within groups and should treat patients as individuals.¹⁵ The beliefs and practices common in a particular group are not necessarily shared by every member of that group. Therefore, practitioners should not assume, based on a patient’s race, ethnicity, religion, or national origin, that he or she would accept or decline information about palliative care and end-of-life options. Practitioners should elicit the patient’s own perspectives on issues such as goals for care, care management, medical decision-making, role of family members, and the end of life, and respond accordingly.¹⁶

The offer of information and counseling required by the Palliative Care Information Act is clinical in nature, not spiritual or religious. Practitioners should understand that patients may request guidance from clergy or other community leaders in order to make treatment decisions that are consistent with their traditions and religious beliefs.

21) Question: Some health care practitioners may be concerned that discussing the end-of-life may be too distressing for some patients and their caregivers. Is there a therapeutic exemption for such patients?

Answer: No. The law does not provide a therapeutic exemption from its requirements.

¹³ *Pain Management: A Guide for Patients*. (2010) from New York State Board for Professional Medical Conduct is available at <http://health.ny.gov/publications/4180.pdf> .

¹⁴ *Ibid.*

¹⁵ LaVera, M., Marchall, P.A., Lo, B., & Koenig, B.A. (2002). Strategies for Culturally Effective End-of-Life Care. *Annals of Internal Medicine*, 136, 673-670.

¹⁶ *Ibid.*

It is normal for patients and family members to express grief about a serious, life-limiting illness. Nevertheless, research shows that the majority of patients in the advanced stages of a life-limiting illness and their family members want a great deal of information about their prognosis and options. A significant minority, however, prefer only limited information. In addition, according to the literature, information needs change as disease progresses.¹⁷ Thus, patient preferences vary, and individualized assessment is necessary.

Accordingly, Public Health Law section 2997-c requires that health care practitioners offer information and counseling. The patient (or if the patient lacks medical decision-making capacity, the patient's authorized decision-maker) is entitled to decline the offer. Attending health care practitioners can adjust their approach with patients who do not want information about prognosis, palliative care and end-of-life options, by offering to provide the information and giving the patient an opportunity to decline it or to ask for limited information only.

If the patient declines the offer of information about palliative care and end-of-life options, the attending health care practitioner is not required to provide the information. The patient's decision to decline the information and counseling should be documented in the medical record.

In any case, information about palliative care and end-of-life options should be delivered in a manner that is sensitive to the patient's cues, frame of mind and need for hope. Practitioners may seek to encourage hope, while helping the patient to prepare for the possibility that treatment may fail.¹⁸

22) Question: When the patient lacks capacity to make medical decisions, who should receive the offer of counseling concerning palliative care and end-of-life options?

Answer: The person who is legally-authorized to make medical decisions for the patient.

- For adult patients, the medical decision-maker is typically the health care agent designated in a health care proxy. If there is no health care proxy, and the patient is in a hospital or nursing home, the appropriate surrogate under the Family Health Care

¹⁷Tattersall, M.H., Gattelarri, M., Voigt, K., & Butow, P. (2002). When the treatment goal is not cure: Are patients informed adequately? *Supportive Care Cancer*, 10, 314-321.

Innes, S., & Payne, S. (2009). Advanced Cancer Patients' Prognostic Information Preferences: A Review. *Palliative Medicine*, 23(1), 29-39.

Back, A.L., Anderson, W.G., Bunch, L., Marr, L.A., Wallace, J.A., Yang, H.B., & Arnold, R.M. (2008) Communication About Cancer Near the End of Life. *Cancer*, 113(7 Suppl), 1897-910.

Parker, S.M., Clayton, J.M., Hancock, K., Walder, S., Butow, P.N., Carrick, S., Tattersall, M.H.(2007). A Systematic Review of Prognostic/End-of-Life Communication with Adults in the Advanced Stages of a Life-Limiting Illness: Patient/Caregiver Preferences for the Content, Style, and Timing of Information. *Journal of Pain and Symptom Management*, 34(1), 81-93.

¹⁸ Back, A.A., Arnold, R.M., & Quill, T.E. (2003). Hope for the Best, and Prepare for the Worst. *Annals of Internal Medicine*. 138, 439-443.

Steinhauser, K., Christakis, N., Clipp, E., McNeilly, M., McIntyre, L., & Tulsky, J. (2000). Factors considered important at the end of life by patients, families, physicians and other care providers. *Journal of the American Medical Association*, 28, 4(19), 2476-2482.

Decisions Act (Public Health law Article 29-cc) is the decision-maker. Sometimes, there is a living will or Medical Orders for Life-Sustaining Treatment (MOLST) form that will reflect the patient's treatment preferences.

- For minor patients, the medical decision-maker is typically the parent. It is usually best to get both parents involved, if possible.
- For patients with a developmental disability, there may be a surrogate appointed pursuant to the Surrogate Court Procedure Act.
- For patients with a mental illness, there may be a guardian authorized to make medical decisions under Article 81 of the Mental Hygiene Law.

Reliance on a health care agent, surrogate or guardian to make health care decisions requires a determination by a physician and another health care practitioner that the patient lacks capacity to make such decisions (in some cases, a determination by two physicians is required). The rules governing capacity determinations and consent by health care agents, surrogates, and guardians are complex. Seek legal counsel, if you are not familiar with these requirements.

23) Question: What are the penalties for failure to comply with this requirement?

Answer: Violations of the Public Health Law are punishable by a civil penalty of up to \$2,000. This penalty may be increased to up to \$5,000 for repeat violations within 12 months that were a serious threat to health and safety of the individual or individuals involved. A willful violation of the Public Health Law is punishable by a term of imprisonment of up to 1 year and/or a fine of up to \$10,000. In addition, a willful or grossly negligent failure to comply with substantial provisions of state laws governing the practice of medicine, or repeated occasions of negligence, can trigger a medical misconduct action

LAWS OF NEW YORK, 2010

CHAPTER 331

AN ACT to amend the public health law, in relation to a patient's right to palliative care information

Became a law August 13, 2010, with the approval of the Governor.
Passed by a two-thirds vote.

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. The public health law is amended by adding a new section 2997-c to read as follows:

§ 2997-c. Palliative care patient information. 1. Definitions. As used in this section, the following terms shall have the following meanings, unless the context clearly requires otherwise:

(a) "Appropriate" means consistent with applicable legal, health and professional standards; the patient's clinical and other circumstances; and the patient's reasonably known wishes and beliefs.

(b) "Attending health care practitioner" means 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 under this section, unless they agree to assign that responsibility to one of them.

(c) "Palliative care" means 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 under article forty of this chapter.

(d) "Terminal illness or condition" means an illness or condition which can reasonably be expected to cause death within six months, whether or not treatment is provided.

2. 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. The information and counseling may be provided orally or in writing. Where the patient lacks capacity to reasonably understand and make informed choices relating to palliative care, the attending health care practitioner shall provide information and counseling under this section to a person with authority to make health care decisions for the patient. The attending health care practitioner may arrange for information and counseling under this section to be provided by another professionally qualified individual.

3. Where the attending health care practitioner is not willing to provide the patient with information and counseling under this section, he or she shall arrange for another physician or nurse practitioner to

EXPLANATION--Matter in *italics* is new; matter in brackets [-] is old law to be omitted.

do so, or shall refer or transfer the patient to another physician or nurse practitioner willing to do so.

§ 2. Paragraph (f) of subdivision 1 of section 207 of the public health law, as added by chapter 573 of the laws of 2008, is relettered paragraph (g) and a new paragraph (h) is added to read as follows:

(h) Palliative care options for patients with a terminal illness or condition.

§ 3. The department of health shall consult with the New York state palliative care education and training council, as established in subdivision 6 of section 2807-n of the public health law, in developing educational documents and rules and regulations related to this act.

§ 4. This act shall take effect immediately, provided that section one of this act shall take effect one hundred eighty days after it shall have become a law.

The Legislature of the STATE OF NEW YORK **ss:**

Pursuant to the authority vested in us by section 70-b of the Public Officers Law, we hereby jointly certify that this slip copy of this session law was printed under our direction and, in accordance with such section, is entitled to be read into evidence.

MALCOLM A. SMITH
Temporary President of the Senate

SHELDON SILVER
Speaker of the Assembly