



**REPORT TO THE COMMISSIONER OF PUBLIC HEALTH AND THE
CONNECTICUT GENERAL ASSEMBLY ON
Palliative Care**

PA 13-55

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Report to the DPH Commissioner and the Connecticut General Assembly

Palliative Care

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INTRODUCTION

In 2013, AAC An Advisory Council on Palliative Care was enacted as Public Act 13-55. (see Appendix 1)

This act establishes, within available appropriations, a 13-member Palliative Care Advisory Council within the Department of Public Health (DPH). The council must (1) analyze the current state of palliative care in Connecticut and (2) advise DPH on matters related to improving palliative care and the quality of life for people with serious or chronic illnesses.

The act, which became effective on October 1, 2013, requires the Council to begin annually reporting its findings and recommendations to the DPH commissioner and Public Health Committee, beginning in January, 2015.

The Council members include physicians, nurses and other health care providers with expertise in palliative and hospice care and one American Cancer Society representative or person experienced in advocating for people with serious or chronic illness and their families.

The members serve three-year terms without compensation and must elect a chairperson. The council must meet biannually and at the call of the chairperson or the request of either the DPH commissioner or a majority of the members.

The Council has met almost monthly though the law only requires semi-annual meetings from January 2014-December 2015. The early meetings have focused on the first charge in the law, to “analyze the current state of palliative care in the State”. Recognizing that confusion exists regarding what palliative care is and how it is a much broader concept than hospice care, the Council first developed a working definition of palliative care, in order to be speaking a common language and as a beginning step in educating healthcare practitioners and the public.

Many definitions were reviewed and the Council adopted the one from the National Consensus Project for Quality Palliative Care as being the most comprehensive. The Council also added three affirmations from the WHO definition feeling these were significant and instructive.

2014 WORKING DEFINITION OF PALLIATIVE CARE

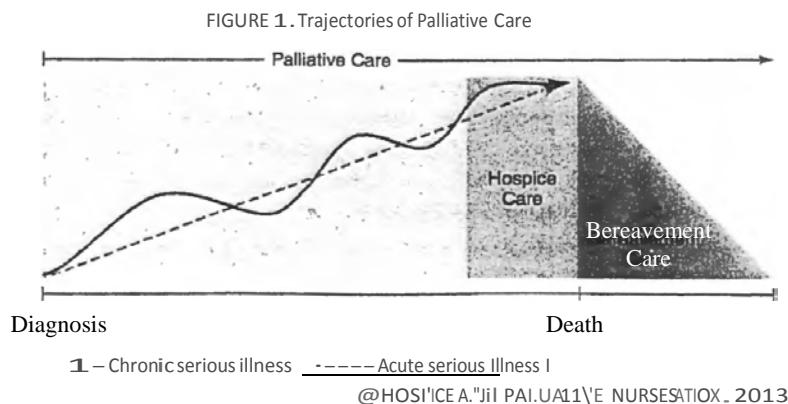
National Consensus Project for Quality Palliative Care Clinical Practice Guidelines – Third Edition

Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

The following features characterize palliative care philosophy and delivery:

- Care is provided and services are coordinated by an interdisciplinary team;
- patients, families, palliative and non-palliative health care providers collaborate and communicate about care needs;
- services are available concurrently with or independent of curative or life- prolonging care;
- patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death.

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. Palliative care affirms life by supporting the patient and family's goals for the future, including their hopes for cure or life-prolongation, as well as their hopes for peace and dignity throughout the course of illness, the dying process, and death.



WHO Definition of Palliative Care (excerpts)

Palliative care:

- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Will enhance quality of life, and may also positively influence the course of illness.

This working definition is posted on the DPH website under Topics A-Z “Palliative Care Advisory”. Minutes of Council meetings are also posted there.

Direct Link: <http://www.ct.gov/dph/cwp/view.asp?a=3117&q=537876>

The Council next attempted to set goals and objectives, based on the charges in PA 13-55, as a way to organize the group’s work. Much discussion occurred and the Council agreed on the following to guide the next phases of the assessment.

GOALS AND OBJECTIVES PALLIATIVE CARE ADVISORY COUNCIL

Goal: Improve palliative care and the quality of life for persons with serious illness in the state of Connecticut.*

Palliative care is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

Objectives

Analyze the current state of palliative care in the state of Connecticut and advise the Department of Public Health on matters relating to the improvement of palliative care and the quality of life for persons with serious illness.

Identify barriers and best practice standards for palliative care and incorporate them into Council recommendations.

Identify and facilitate educational opportunities for:

1. Medical personnel to understand and adapt best practice standards in their practice and within their institutions;
2. The public to understand and openly discuss palliative care as a normal part of life care, and provide a brochure that will enhance the public’s understanding of palliative care; and
3. Legislators to help them understand and support quality palliative care and distinguish it from hospice care.

* The council is utilizing the industry standard definition of “palliative care” which excludes the word “chronic” when describing patients and/or illnesses appropriate for palliative care. The focus is on patients with “serious” illness.

The Council has gathered preliminary data on CT healthcare practitioners who note palliative care as a specialty. The Council is hearing presentations from various CT hospitals and other stakeholders which have established “palliative care programs”. Many programs have an inpatient consultation element, some also consult in outpatient settings, and at least one is exploring home visiting. Some programs offer medical rotations or fellowship opportunities as well. After all presentations have been heard, the Council will develop a spreadsheet of common elements and gaps.

The Council is charged with assessing the state of palliative care in Connecticut, but barriers have been encountered in gathering data regarding where palliative care is being provided. Only two hospitals responded to a survey request to tell us about how they provide palliative care. The presentations are providing some of the hospital data. Data is available on home health agencies and hospices that provide palliative care. A sub-committee is also working on ways to assess palliative care practice in the primary care setting, long term care facilities and cancer centers.

The Advisory Council will continue to gather data on the current state of palliative care in CT. The group is refining the data – gathering questions and performance measures in order to more specifically describe the current services offered, as well as gaps in palliative care in terms of availability, access, and cost/reimbursement. This assessment must be detailed and complete in order to provide a baseline for recommendations to the Commissioner of DPH and the Legislature. The Council feels strongly about conforming our work and language to nationally accepted standards and definitions. This will foster a shared understanding. The Council expects to complete the assessment in 2015. Once complete, the Council will be in a position to provide advice to “the department...relating to the improvement of palliative care and the quality of life for persons with serious or chronic illnesses”.

The Advisory Council believes it is imperative to promote and support system changes that strengthens the quality and continuity of palliative care through partnerships with providers, faith based leaders and members across the state. Specific to all provider types implementation of a standardized screening tool for advanced illness is crucial. There must be inclusion of patients of all ages and phases of illness. The Council recognizes that palliative care provides individualized care across all domains of the patient and family, including the physical, psychosocial, spiritual/existential and cultural domains. Three sub-committees were established to explore the state of palliative care for each of the provider types. The three sub-committees met and developed a report of their findings and recommendations which were presented to the full Advisory Council. The recommendations were delineated into specific categories for each sub-committee which noted similarities across all provider types. These categories included standardization of care, reimbursement and workforce, and education.

FINDINGS AND RECOMMENDATIONS PALLIATIVE CARE ADVISORY COUNCIL

Standardization of Care

- All facilities and agencies who offer a palliative care program must at a minimum follow the NQF Consensus guidelines for quality palliative care. A Consensus Report www.nationalconsensusproject.org. This includes hospitals, nursing facilities and home care agencies.
- Hospitals with greater than 300 beds should strive to attain Joint Commission certification.
- Effective and timely screening of all patients must be conducted to insure appropriate referrals.
- Any organization that provides care to newborns and pediatric patients must have a means to provide palliative care and hospice.

Standardization of Care Rationale

- To ensure appropriate access to palliative care and hospice at the appropriate time and place.
- Collaboration and partnerships across the continuum to include long term care, hospitals, home health and hospice and physician offices to ensure that individual patient needs can be met. Although a palliative care program may be offered, there can be limitations based on capacity, staffing, and reimbursement.

Reimbursement & Workforce

- Recommend to Private insurance payer to provide palliative care benefit across all settings, including hospitals, nursing facilities, and home care agencies.
- The State Innovation Model (SIM) and other payment reform plans e.g. Accountable Care Organizations (ACOs) need to include palliative care and hospice care across the continuum of care coordination.
- Consideration must be given to staffing in long term care facilities and provisions for additional resources provided to insure consistency and familiarity.
- In Long Term Care whenever possible, the Council recommends the use of Registered Nurses as fiscally feasible due to their ability to perform comprehensive palliative care assessments.

- Increase access to palliative care to Title 19 patients to across all settings, including in nursing facilities and home care agencies (Requires legislative changes).
- Advocate on the Federal level for specific Medicare reimbursement for Home Care palliative care services to eliminate the homebound requirement.

Reimbursement & Workforce Rationale

- Private insurance coverage regulations and/or guidelines vary tremendously and often lack reimbursement for palliative care across payment plans.
- There should be two quality outcome tracks developed, one for restorative care and one for palliative and/or hospice care. As both patients need that level of care, but will have different goals and outcomes, and need to be evaluated through a different quality lens. A second quality outcome track should be developed to measure the quality of care for the palliative population, knowing that the disease trajectory is much different. For example, weight loss in long-term care patients results in burdensome interventions that do not support patients' goals and values.
- The Medicare Home Health benefit requires the patient to be homebound and receive a skilled service. Patients will be reluctant to use the Home Health benefit because of the homebound requirement, which diminishes quality of life, therefore excluding them from needed services.

Education

- Mandate two hours Continuing Medical Education (CME) for physicians, physician assistants, APRN's, social work and pharmacists in pain management and palliative care.
- Collaborate with the Department of Higher Education to achieve the goal of standardized education for all schools providing education to physicians, nurses, social workers, pharmacist and other healthcare providers, to ensure that education on palliative and hospice care is provided.
- Encourage any agency/institution that provides palliative care to fully educate all staff involved in providing care.
- Utilize a "performance status" versus diagnosis in determining the need for palliative care.
- Explore funding for palliative care through legislation.
- Develop a statewide website to evaluate the systematic approach to monitor, disseminate and utilize data to advocate for high-quality palliative care.
- Encourage healthcare providers to spotlight palliative care initiatives.

- Develop an affordable “train the trainer” program where trained educators could offer accessible and affordable education to staff in all levels of care.
- Increase public awareness through a public education initiative that defines palliative care.

Education Rationale

- Specialized education needs to be considered for palliative care in general versus the resident with end stage dementia and/or the pediatric patient to insure patient centered care.

Advance Care Planning

- Advance Care Planning education is necessary to address treatment options including both palliative care and hospice care.
- All patients with serious illnesses have advanced care planning in place.
- The State of Connecticut establish of an electronic database for advance directives to be able to allow for portability of documents across the state.

APPENDIX 1



Substitute Senate Bill No. 991

Public Act No. 13-55

AN ACT CONCERNING AN ADVISORY COUNCIL ON PALLIATIVE CARE.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

Section 1. (NEW) (*Effective October 1, 2013*) (a) There is established, within available appropriations, within the Department of Public Health, a Palliative Care Advisory Council. The advisory council shall: (1) Analyze the current state of palliative care in the state; and (2) advise the department on matters relating to the improvement of palliative care and the quality of life for persons with serious or chronic illnesses.

(b) The advisory council shall consist of the following members:

(1) Two appointed by the Governor, one of whom shall be a physician certified by the American Board of Hospice and Palliative Medicine and one of whom shall be a registered nurse or advanced practice registered nurse certified by the National Board for Certification of Hospice and Palliative Nurses;

(2) Seven appointed by the Commissioner of Public Health, each of whom shall be a licensed health care provider, with each appointee having experience or expertise in the provision of one of the following: (A) Inpatient palliative care in a hospital; (B) inpatient palliative care in a nursing home facility; (C) palliative care in the patient's home or a community setting; (D) pediatric palliative care; (E) palliative care for young adults; (F) palliative care for adults or elderly persons; and (G) inpatient palliative care in a psychiatric facility;

(3) One appointed by the speaker of the House of Representatives, who shall be a licensed social worker experienced in working with persons with serious or chronic illness and their family members;

- (4) One appointed by the president pro tempore of the Senate, who shall be a licensed pharmacist experienced in working with persons with serious or chronic illness;
 - (5) One appointed by the minority leader of the House of Representatives, who shall be a spiritual counselor experienced in working with persons with serious or chronic illness and their family members; and
 - (6) One appointed by the minority leader of the Senate, who shall be a representative of the American Cancer Society or a person experienced in advocating for persons with serious or chronic illness and their family members.
- (c) All appointments to the advisory council shall be made not later than December 31, 2013. Advisory council members shall serve three-year terms. Any vacancy shall be filled by the appointing authority.
- (d) Members shall receive no compensation except for reimbursement for necessary expenses incurred in performing their duties.
- (e) The members shall elect the chairperson of the advisory council from among the members of the advisory council. A majority of the advisory council members shall constitute a quorum. Any action taken by the advisory council shall require a majority vote of those present. The first meeting of the advisory council shall be held not later than December 31, 2013. The advisory council shall meet biannually and at other times upon the call of the chairperson, upon the request of the Commissioner of Public Health or upon the request of a majority of the advisory council members.
- (f) Not later than January 1, 2015, and annually thereafter, the advisory council shall submit a report on its findings and recommendations to the Commissioner of Public Health and the joint standing committee of the General Assembly having cognizance of matters relating to public health, in accordance with the provisions of section 11-4a of the general statutes.

Council Members include:

1. (a) one physician certified by the American Board of Hospice and Palliative Medicine and (b) one registered nurse or advanced practice registered nurse certified by the National Board for Certification of Hospice and Palliative Nurses, both appointed by the governor;
2. seven licensed health care providers with experience or expertise in (a) inpatient palliative care in a hospital, nursing home, or psychiatric facility, (b) palliative care in a patient's home or community setting, (c) pediatric palliative care, or (d) palliative care for young adults, adults, or the elderly, all appointed by the DPH commissioner;
3. one licensed social worker experienced in working with people with serious or chronic illness and their families, appointed by the House speaker;

4. one licensed pharmacist experienced in working with people with serious or chronic illness, appointed by the Senate president pro tempore;
5. one spiritual counselor experienced in working with people with serious or chronic illness and their families, appointed by the House minority leader; and

Approved May 28, 2013

APPENDIX 2

Palliative & Hospice Care Benchmark Data

Benchmark data	Source	Webpage	CT data	National data	Comments
Professional certification:					
Physicians	American Board of Medical Specialties	http://www.certificationmatters.org/Home.aspx	140 physicians		Not all practice in CT
Nurses	National Board for Certification of Hospice & Palliative Care Nurses	http://www.nbchpn.org	Total nurses: 266 Advanced Certified RN 22 Certified RN 187 Pediatric 3 LPN 15 NA 37 Admin 2 Perinatal loss care 0		
Social Workers	National Association of Social Workers				
Other:					
Palliative Care Services available in CT Hospitals	Center for the Advancement of Palliative Care	http://www.capc.org/reportcard/home/CT/RC/Connecticut	Grade B in 2011 Palliative care services available in: 72% of all hospitals 100% of hospitals with >300 beds	63% 85%	72% NE states 100% NE states
Advanced Certification in Palliative Care	JAHCO Gold Seal	http://www.jointcommission.org/certification/palliative_care.aspx http://www.qualitycheck.org/consumer/searchQCR.aspx#	2 Hospitals – The CT Hospice and Danbury Hospital		Other hospitals are applying

Benchmark data	Source	Webpage	CT data	National data	Comments
Medicare Hospice Utilization Data 2012	Hospice Analytics report	CAHCH webpage			
Medicare Hospice Beneficiary Admissions			12,906 52% of Medicare deaths	1,257,735 62% of Medicare deaths	
Medicare Hospice Beneficiary Deaths			10,271 41.7% of Medicare deaths	897,379 44.4% of Medicare deaths	
Medicare Hospice Mean Days / Beneficiary			50 Days	71 Days	
Medicare Hospice Median Days / Beneficiary			14 Days	25 Days	