



**REPORT TO THE COMMISSIONER OF PUBLIC HEALTH
AND THE CONNECTICUT GENERAL ASSEMBLY ON
PALLIATIVE CARE**

2017 REPORT

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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.portal.ct.gov/DPH/Government-Relations/Palliative-Care-Advisory-Council/Palliative-Care-Advisory-Council>

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.

INTRODUCTION

Section 19a-60 (Appendix 1) of the General Statutes requires the Department of Public Health to establish, within available appropriations, a Palliative Care Advisory Council to analyze the current state of palliative care in Connecticut; and advise the department on matters relating to the improvement of palliative care and the quality of life for persons with serious or chronic illnesses. The Commissioner of Public Health is also required to submit a report to the joint standing Committee on Public Health beginning on January 1, 2015, and annually thereafter, regarding the Palliative Care Advisory Council's recommendations.

The Palliative Care Advisory Council first convened in 2013 and consists of 13 members which include physicians, nurses and other health care providers with expertise in palliative and hospice care, as well as, an American Cancer Society representative or person experienced in advocating for people with serious or chronic illness and their families.

The Council met seven times during 2017 and provided the Commissioner of Public Health a list of recommendations. The recommendations from the Council are reflected below. The Department is in agreement with all of the recommendations from the Council.

RECOMMENDATIONS FROM THE COUNCIL:

In order to accomplish implementation of their recommendations to improve palliative care and quality of life for persons of all ages with serious illness in the state of Connecticut, the Council recommends the following.

The Palliative Care Advisory Council recommends a continued partnership with the Connecticut Hospital Association (CHA) Care Decisions Connecticut Advisory Group. The Care Decisions Advisory Group includes representatives from Long Term Care, home care, emergency medical services, hospitals, hospices, patient and family organizations, Cancer Society, Connecticut QIO, Connecticut State Medical Society, DPH, DSS and payer organizations. The Care Decisions Advisory Group is charged with developing an evidence-based, compassionate, statewide end-of-life care strategy, in collaboration with the continuum of care partners, and facilitation of statewide adoption of guidelines for practice improvement in palliative care. The Care Decision Committee and the Palliative Care Advisory Council have common goals and a partnership that will allow for collaboration of resources, provide greater access for the public through website utilization, marketing, and sharing best practices and national standards. Further, the Chair of the Palliative Care Advisory Council also sits as the Co-chair of the Care Decision Committee which facilitates consistent communication.

The Advisory Council remains committed to its recommendations including palliative care continuing education for licensed health care professionals. The Council recommends the training be comprised of two hours of education every two years in the areas of chronic disease management, symptom management, end of life management, and advanced care planning. In order to facilitate the implementation of mandated continuing education, the Advisory Council Recommends rewording the current requirements to include chronic disease management and topics related to palliative care. The Advisory Council has also recommended to the state medical,

pharmacy, social work and nursing organizations to include topics on palliative and end-of-life care at their annual conferences.

The Council recommends working with professional organizations (CAPC: Center to Advance Palliative Care, AMA: American Medical Association, CT APRN's, NASW: National Association of Social Workers, CPA: Connecticut Pharmacy Association and CHA: CT Hospital Association) as well as other state agencies (DSS) to collect updated statistics on palliative care in the state to assure current data on the website.

In addition to these recommendations, for the Public Health Committee's information, is Appendix 2 which provides the most current 2017 benchmark data collected by the Palliative Care Advisory Council regarding state of palliative care and hospice in Connecticut.

APPENDIX 1



Statutory Reference:

Sec. 19a-60. Palliative Care Advisory Council. Duties. Members. Report. (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.

APPENDIX 2

Palliative & Hospice Care Benchmark Data 2017

Appendix 2 represents benchmark data collected by the Palliative Care Advisory Council. The data provides statistics on professional certification, advanced certification in palliative care, palliative and hospice services available in Connecticut’s hospitals, Medicare hospice utilization data, Medicare hospice deaths compared to total Medicare deaths, and Medicare hospice mean and median days of care. This benchmark data was first included in the 2013 Palliative Care Report to the Commissioner of Public Health. Appendix 2 represents data available in 2017 on the state of palliative care and hospice in Connecticut.

Although the data represents an improvement in palliative care in hospitals, only 2 hospitals have achieved the Joint Commission Gold Seal for advanced certification in palliative care. Medicare Hospice utilization in Connecticut has slowly been improving over the past three years. The Medicare hospice benefit median length of stay remains amongst the lowest in the nation, but now we share that spot with three other states. This year saw a rise in the number of nurses certified in hospice and palliative care, but we still have not returned to 2015 numbers. In 2017, Medicare posted Hospice Compare on line. This site allows patients, family members, and health care providers to get a snapshot of the quality of care each hospice provides. Hospices are compared based on important indicators of quality. However, the data and the agencies listed for Connecticut are not completely relevant or accurate as yet.

<https://www.medicare.gov/hospicecompare/> There is not yet a means of comparing palliative care providers/agencies. The Center to Advance Palliative Care continues to collect data and create benchmarks around quality palliative care.

Benchmark Palliative Care data is difficult to compile and the Advisory Council will continue to compile the latest national and state data on a yearly basis.

Benchmark data	Source	Webpage	CT data	National data	Comments
Professional certification	January 1, 2018 data.				
Physicians	American Board of Medical Specialties	http://www.certificationmatters.org/Home.aspx	157 physicians (increase of 10)	2017 >6000	Not all these 157 physicians practice in CT
Nurses	National Board for Certification of Hospice & Palliative Care Nurses	http://www.nbchpn.org	Total CT nurses certified: 2015: 267 2016: 221 2017: 252 (increase of 31)	18614 Total Nation	

Benchmark data	Source	Webpage	CT data	National data	Comments
			December 2017 CT numbers:		
			Advanced Certified Hospice Palliative Nurse RN 33 (increase of 3)	1679 total ACHPN	
			Certified Hospice and Palliative RN 182 (increase of 22	11587 CHPN	
			Certified Hospice and Palliative Pediatric RN 2 (no change)	234 CHPPN	
			Certified Hospice and Palliative LPN 9 (increase of 1)	971 CHPLN	
			Certified Hospice and Palliative NA 21 (increase of 1)	3619 CHPNA	
			Certified Hospice and Palliative Admin 2 (Increase of 1)	348 CHPNA	
			Certified Perinatal Loss 3 (increase of 3)	189 CPLC	
Social Workers	National Association of Social Workers	https://www.socialworkers.org/	11 ACHP-SW	754 ACHP-SW	
Palliative Care Services available in CT Hospitals	Center for the Advancement of Palliative Care	http://www.capc.org/reportcard/home/CT/RC/Connecticut	Achieved Grade A in 2014: 84% (21 programs in 25 hospitals) Improved from Grade B in 2011: 72% (18 PC programs in 25 hospitals)	In 2014: New England States had Grade A: 72.3% National had Grade B: 66.5%	2014 is the most recent report
Advanced Certification in Palliative Care	The Joint Commission Gold Seal	http://www.jointcommission.org/certification/palliative_care.aspx	2 Hospitals – The CT Hospice and Danbury Hospital	91 organizations are certified nationwide	Other hospitals are applying

Benchmark data	Source	Webpage	CT data	National data	Comments
		http://www.qualitycheck.org/consumer/searchQCR.aspx#			
Medicare Hospice utilization data from 2015	Hospice Analytics report	http://www.cthealthcareathome.org/page/Data_Resources			
Medicare Hospice Deaths/ Total Medicare Deaths			2013: 42.8% 2014: 44.4% (#29) 2015: 44.7% (#31)	2013: 45.4% 2014: 45.9% 2015: 46.6%	
Medicare Hospice Mean Days / Beneficiary			2013: 50 Days 2014: 49 Days 2015: 50 Days (#48)	2013: 70 Days 2014: 69 Days 2015: 69 Days	
Medicare Hospice Median Days / Beneficiary			2013: 14 Days (#51) 2014: 14 Days (#51) 2015: 15 Days (#48)	2013: 24 Days 2014: 23 Days 2015: 23 Days	

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APPENDIX 3

Resources for Palliative Care

State Resources

- ❖ **Connecticut State Palliative Care Advisory Council Website:** <http://www.ct.gov/dph/cwp/view.asp?a=3117&q=537876>
- ❖ **Care Decisions Connecticut:** <https://caredecisionsct.org/>
Care Decisions Connecticut was created by the Connecticut Hospital Association, in collaboration with healthcare partners across the continuum of care and state government. The goal of Care Decisions Connecticut is to integrate patient-directed care strategies to improve palliative/hospice care and quality of life for persons in Connecticut with serious illnesses.
- ❖ **Connecticut Association for Healthcare at Home (CAHCH):** <http://www.cahch.org>
The Connecticut Association for Healthcare at Home is the largest member group of home health and hospice care leaders championing home-based solutions to foster cost-effective, person-centered healthcare in the setting people prefer most - their own home. Hospice agencies are listed at: <https://m360.cthealthcareathome.org/frontend/search.aspx?cs=3222>
- ❖ **Connecticut Coalition to Improve End of Life Care:** <https://www.ctendoflifecare.org/>
The mission of the Coalition is to improve the care of people who are dying and their families in the state of CT and to ensure that every individual has information about and access to compassionate, quality end-of-life care.
- ❖ **Connecticut Cancer Partnership:** <http://ctcancerpartnership.org/>
The Connecticut Cancer Partnership is a broad and diverse coalition of individuals and organizations representing stakeholders in Connecticut's cancer community. Its overall goal is to reduce the burden of cancer (incidence, morbidity, mortality, and disability) and to improve the quality of life of people with cancer in Connecticut. The 20014 -2017 Connecticut Cancer Plan includes sections addressing both palliative care and hospice care needs in the state. CT Cancer Partnership: Palliative & Hospice Committee
- ❖ **Connecticut Charter Oak Chapter HPNA:** <https://cthpna.nursingnetwork.com/>
Chapter Mission: To uphold the HPNA mission of leading the way to promote excellence in the provision of palliative nursing care through leadership development, education, and the support of research in the field at the State level.

National Resources

- ❖ **National Consensus Project for Quality Palliative Care(NCP):**
<http://www.nationalconsensusproject.org>
"The purpose of the National Consensus Project for Quality Palliative Care is to promote the implementation of **Clinical Practice Guidelines** that ensure care of consistent and high quality, and that guide the development and structure of new and existing palliative care services."
- ❖ **NCP Clinical Practice Guidelines for Quality Palliative Care 3rd edition 2013.**
The Clinical Practice Guidelines for Quality Palliative Care promote quality palliative care, foster consistent and high standards in palliative care, and encourage continuity of care across settings.
https://www.hpna.org/multimedia/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf
- ❖ **NCP Clinical Practice Guidelines 4th Edition** is scheduled for publication summer 2018. The goal of the 4th edition of the NCP Guidelines is to improve access to quality palliative care for all people with serious illness, regardless of setting diagnosis, prognosis, or page.
<https://www.nationalcoalitionhpc.org/ncp-guidelines-2018/>

National Consensus Task Force members

- ❖ **American Academy of Hospice & Palliative Medicine (AAHPM):** <http://www.aahpm.org>
The Academy is the professional organization for physicians specializing in hospice and palliative medicine and is dedicated to expanding access of patients and families to high quality palliative care, and advancing the discipline of Hospice and Palliative Medicine, through professional education and training, development of a specialist workforce, support for clinical practice standards, research and public policy.
For details about board certification in hospice & palliative medicine:
<http://www.aahpm.org/certification/default/index.html>
- ❖ **Center to Advance Palliative Care (CAPC):** <http://www.capc.org>
CAPC provides health care professionals with the tools, training and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings.
CAPC maintains a state by state report card on access to palliative care in our nation's hospitals. Find the CT report at: <http://www.capc.org/reportcard>
- ❖ **Hospice & Palliative Nurses Association (HPNA):** <http://www.hpna.org>
HPNA is the nation's largest and oldest professional nursing organization dedicated to promoting excellence in palliative nursing care.
For details about board certification in hospice & palliative nursing care:
<http://www.nbchpn.org>

- ❖ **National Association of Social Workers (NASW):** <http://www.socialworkers.org>
NASW is the membership organization for social workers. It has developed standards for social work practice in palliative & end of life care, and offers specialty certification.
- ❖ **Hospice & Palliative Care Organization (NHPCO):** <http://www.nhpc.org>
NHPCO is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end of life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones.
- ❖ **National Palliative Care Research Center (NPCRC):** <http://www.npcrc.org>
NPCRC is committed to stimulating, developing, and funding research directed at improving care for seriously ill patients and their families.
- ❖ **Social Work Hospice & Palliative Care Network (SWHPN):** SWHPN is a network of psychosocial hospice and palliative care professionals dedicated to advancing best practices in palliative and hospice in caring for those with serious illness, and advancing the field on behalf of those caregivers. www.swhpn.org

Other National Resources for Palliative Care

- ❖ **Mapping Community Palliative Care Project:** <https://mapping.capc.org/>
Mapping Community Palliative Care is building a comprehensive inventory of community palliative care programs across health care settings.
The project will support the expansion of community palliative care by identifying models of service delivery and providing summary and comparative data for the field. And it will make it easier for patients, families, caregivers, and practitioners to find palliative care services in their community.
If you are a community-based palliative care program, put yourself on the map!
- ❖ **Get Palliative Care:** <https://getpalliativecare.org/provider-directory/>
The Palliative Care Provider Directory is a resource to help locate palliative care in different areas of the country.
- ❖ **Hospice Compare:** <https://www.medicare.gov/hospicecompare/>
Hospice Compare reports information on hospices across the nation and allows patients, family members, and health care providers to get a snapshot of the quality of care each hospice provides. You can compare hospices based on important indicators of quality, like the percentage of patients checked for pain or who are asked about their preferences for life-sustaining treatment.