



Palliative Care and the Complex Care Patient

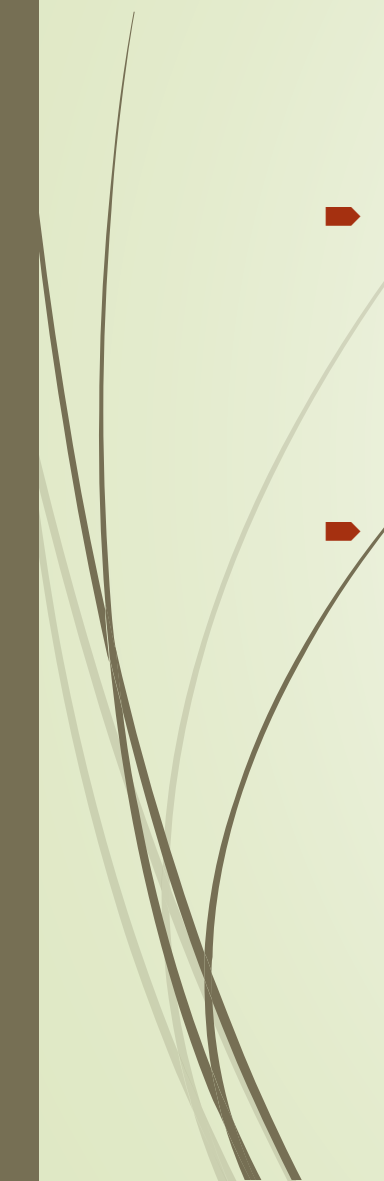
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Connecticut Palliative Care Advisory Council

- 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 eight times during 2019 and provided the Commissioner of Public Health a list of recommendations.
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Connecticut Palliative Care Advisory Council

- **Goal:**

- Improve access to quality palliative care for persons with serious illness in the state of Connecticut.

- **Objectives:**

- Analyze the current state of palliative care across the life span in the state of Connecticut and advise the Department of Public Health on matters relating to the improvement and accessibility of palliative care and the quality of life for persons, including children 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 information 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.



CT Advisory Council Recommendations 2018-2019

- The Council recommends to continue to work 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 ACS: American Cancer Society, CT Association for Healthcare at Home and CHA: CT Hospital Association) as well as other state agencies and payers to collect updated statistics on palliative care in the state to assure current data on the website.
- In 2018-2019 the Council focused on pediatric palliative care and identified a gap in services in the State. We heard examples of children dying in hospitals because there were no hospice agencies comfortable taking care of children. This led the council to develop a pediatric palliative care conference with the focus on educating champions from around the State in pediatric palliative care.



CT Advisory Council

Recommendations 2018-2019

- The Coalition for Serious Illness was created to form a Strategic Plan for Serious Illness care in Connecticut.
 - Including implementing a state wide definition of palliative care
 - Revising health professional licensure and/or continuing education requirements to include a minimum number of hours in the basic components of palliative care, i.e., communication, pain and symptom management
 - Requiring standardized policies and procedures around palliative care in hospitals, nursing homes and home as a condition of participation in the State Medicaid Program.
 - Expand public reporting of health plan quality measures to include relevant measures such as the number of days at home in the last 90 days of life.
 - Requiring Medicaid providers and managed care plans to collect functional and cognitive status on members to identify high risk members
 - Establish a means for Medicare and Medicaid new enrollees to have advance directives in place.

Definitions of Palliative Care

- **National Consensus Project for Quality Palliative Care**
- **Clinical Practice Guidelines – Fourth Edition**
 - Palliative care focuses on expert assessment and management of pain and other symptoms, assessment and support of caregiver needs and coordination of care. Palliative care attends to the physical, function, psychological, practical and spiritual consequences of serious illness. It is a person- and family- centered approach to care, providing people living with serious illness relief from the symptoms and stress of an illness. Through early integration into the care plan for the seriously ill, palliative care improves quality of life for the patient and family.
 - Palliative care is:
 - Appropriate at any stage of a serious illness, and is beneficial when provided along with treatments of curative or life-prolonging intent.
 - Provided over time to patients based on their needs and not their prognosis
 - Offered in all care settings and by various organizations, such as physician practices, health systems, cancer centers, dialysis units, home health agencies, hospices and long-term care providers.
 - Focused on what is important to the patient, family and caregivers, assessing their goals and preferences and determining how best to achieve them
 - Interdisciplinary to attend to holistic needs of the patient and their identified family and caregivers

Definitions of Palliative Care

➤ **WHO Definition of Palliative Care for Children**

- Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other pediatric chronic disorders (WHO; 1998a):
 - Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
 - It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
 - Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
 - Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
 - It can be provided in tertiary care facilities, in community health centers and even in children's homes.



Definition of Hospice Care

- Hospice care is Palliative Care but with a focus on serving and comforting patients and families at the end of their lives or **as the illness becomes terminal.**
- All Hospice care is considered Palliative but not all Palliative care is Hospice.
- Both Palliative Care and Hospice Care use an interdisciplinary team approach to focus on quality of life or "comfort care," including the active management of pain and other symptoms, as well as the psychological, social and spiritual issues often experienced with serious illness and at the end of life.



Eligibility

Palliative Care:

- Palliative care is for people of any age and at any stage in an illness, whether that illness is curable, chronic, or life-threatening.
- If you or a loved one are suffering from symptoms of a disease or disorder, be sure to ask your current physician for a referral for a palliative care consult.

Hospice Care:

- Specific to the Medicare Hospice Benefit, a patient is eligible for hospice care if two physicians (usually PCP and Hospice Medical Director) determine that the patient has six months or less to live if the terminal illness runs its normal course.



Gaps in Connecticut

- Lack of Statewide Palliative Care (PC) standards for both institutional and community services
- Shortage of pediatric palliative care community providers and coverage
 - Note: MA has a specific state-funded Pediatric Palliative Care benefit (I can get more details on this)
- Inadequate community palliative care coverage
 - Medicare requires homebound
 - Inconsistent private insurance coverage
 - No Medicaid palliative care benefit—especially home health social work services, chaplain/spiritual counseling
- Lack of standard approach to Advanced Care Planning
 - Medicare offers reimbursement but limited reimbursement for conversations that can and should be time consuming



Economic Impact

- Impact of Palliative Care
 - Decreased admissions
 - Greater patient and provider satisfaction
 - Decreased LOS
- For the Medicaid Population
 - 45% fewer hospital days
 - 30% fewer nursing home placements
 - 36% decrease in ED visits
 - 19.1% decrease in medical expenses PMPM

Zimbroff R, Ritchie C, Leff B, and Sheehan O. *Home-based primary and palliative care in Medicaid program: Sysematic review of the literature. JAGS 69:245-254, 2021.*



Economic Impact on our Pediatric Population

- Enrolled 132 seriously ill children on Medicaid
- Overall healthcare cost PEPM decreased by \$3331
- Decreased inpatient costs of \$4897 PEPM
- 50% reduction in average inpatient days per month
- ALOS went from 16.7 days to 6.5 days after enrollment

Gan D, et al. *Cost Analysis and policy implications of a pediatric palliative care program.* JPSM 52:329-335, 2016



Statewide Advance Care Planning

- Advance Directive: should be required for everyone 18 or older
 - Living will and Health Care Representative
- Advanced Care Plan: initial planning with diagnosis of a serious illness
- MOLST/POLST Forms: actual medical order for end of life care, usually in the final year of life

What other States are doing

➤ Massachusetts Coalition for Serious Illness Care

- Everyone in Massachusetts, 18 or older, has designated a health care decision-maker (health care proxy);
- Everyone in Massachusetts, 18 or older, has had a conversation (and continues to have conversations) with their proxy to communicate their goals, values and preferences for care at the end of life;
- All Massachusetts clinicians have appropriate training to facilitate high-quality communication with patients on advance care planning and serious illness;
- Everyone in Massachusetts facing a serious illness has had a high-quality, informed goals and values conversation with their care team;
- All Massachusetts health care providers have systems in place to elicit and document goals, values and preferences for patients with serious illness;
- All Massachusetts health care providers have systems in place to share patient goals, values and preferences across care settings, to ensure they are accessible regardless of place of care.



What other States are doing

- ▶ California Medi-Cal Bill

Effective January 1, 2018, when a member meets the minimum eligibility criteria for palliative care, MCPs must authorize palliative care without regard to age. Palliative care must include, at a minimum, the following seven services when medically necessary and reasonable for the palliation or management of a qualified serious illness and related conditions:

- ▶ Must include: advance care planning, palliative care assessment and consultation, plan of care, palliative care team access, care coordination, mental health services and pain and symptom management



What other States are doing

► Colorado

If palliative care is provided within a licensed healthcare entity, the licensee shall have written policies and procedures for the comprehensive delivery of these services. For each patient receiving palliative care, there shall be documentation in the plan of care regarding evaluation of the patient and what services will be provided. The licensee's policies and procedures shall address the following elements of palliative care and how they will be provided and documented:

1. Assessment and management of the patient's pain and other distressing symptoms; and
2. Goals of care and advance care planning; and
3. Provision of, or access to, services to meet the psychosocial and spiritual needs of the patient and family; and
4. Provision of, or access to, a support system to help the family cope during the patient's illness, and
5. As indicated, the need for bereavement support for families by providing resources or referral.



What Connecticut is doing

➤ Connecticut

- Held Palliative Care Serious Illness Summit in late 2019
- Began Serious Illness Coalition summer 2020 with goals to improve serious illness care in CT through legislation, policy, and education
 - 3 work groups formed
 - Advanced Care Planning
 - Pediatric Palliative Care
 - Legislative/Policy

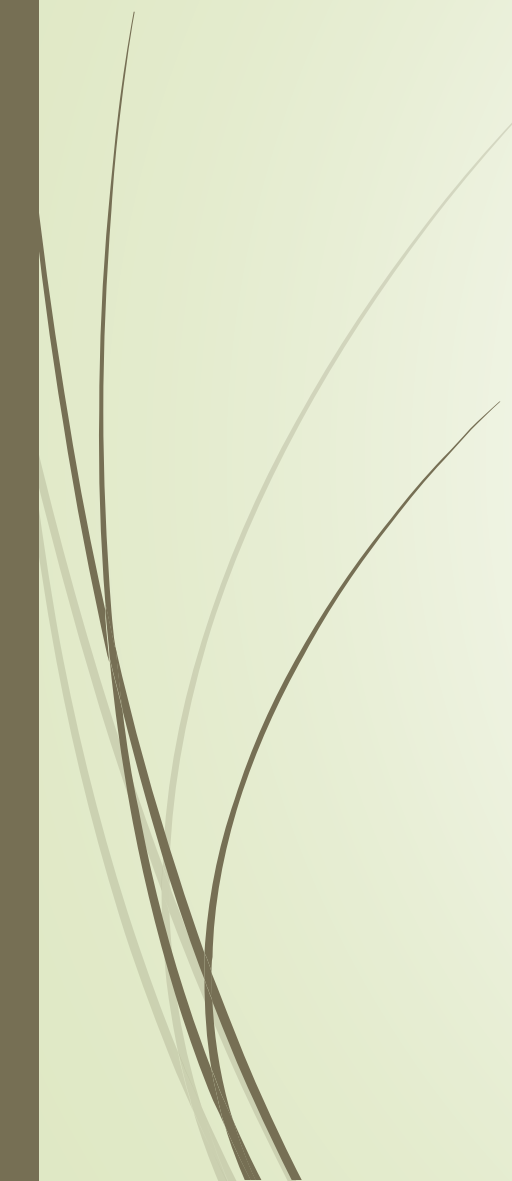


CAPC Resources: Serious Illness Quality Alignment Hub

- The Serious Illness Quality Alignment Hub (“the Hub”) was a coordinated effort to develop a [national strategic plan](#) to incentivize the delivery of high-quality care for people living with a serious illness.
- The Hub – led by CAPC, in collaboration with the [National Quality Forum](#)– was funded by the Gordon and Betty Moore Foundation. It completed four work streams:
 - **Needs Assessment:** investigating operations and opportunities across multiple levers of accountability
 - **Accountability Committee:** assessing and prioritizing opportunities to strengthen accountability, by feasibility and likely impact, across each of the levers
 - **Quality Measurement Committee:** cataloging measures and making recommendations to address measurement gaps
 - **National Serious Illness Projects:** coordinating and aligning multiple national efforts to improve standards and measures in the care of people living with serious illness



CAPC Resources: Serious Illness Quality Alignment Hub

- Goal 1 – Increased state-level efforts driving availability and oversight of high-quality care for people living with serious illness
 - Goal 2 – Increased private payer efforts driving access and standardization of specialty palliative care services
 - Goal 3 – Create a sustainable body that continuously drives quality measure development and promotes relevant quality measure adoption across accountability systems
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Recommendations for Connecticut

- Educate and require advance directives for all Medicaid recipients 18 and older
 - Including education using The Conversation Project
 - Require education on advance directive conversations for provider who see Medicaid patients
- Provide a palliative care benefit to commercial insurance and Medicaid patients
 - Coverage should include the interdisciplinary team: social work, spiritual care and others as appropriate
 - Implement a pediatric palliative care program



Thank you all for all you do!!!