

State Palliative Care Definition and Standards

Background

Codifying a definition of and standards for palliative care in your state can help ensure that stakeholders have a shared understanding of what palliative care means, and create a foundation for future policies on care delivery, quality, payment, and accountability. This document provides an overview of core elements that should be included in a palliative care definition and standards, supported by examples. It is intended for informational purposes only and should not be construed as legal advice; please consult experts in your state as appropriate.

Definition

A good definition will describe the goal of palliative care (i.e., provide relief from the symptoms and stress of a serious illness and improve quality of life), note that it is provided by an interdisciplinary team, and clarify that it *can be provided along with curative treatment at any stage of serious illness.* Take care when considering where to insert the definition, as including it under hospice statute or regulations alone may perpetuate misunderstandings about what palliative care is and who should receive these services.

Example Definitions

Centers for Medicare and Medicaid Services (CMS)ⁱ

"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.

National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Careⁱⁱ

Beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care providers.

Center to Advance Palliative Care (CAPC)ⁱⁱⁱ

Palliative care, and the medical sub-specialty of palliative medicine, is specialized medical care for people living with serious illness. It focuses on providing 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.

Palliative care is provided by a team of palliative care doctors, nurses, social workers and others who work together with a patient's other doctors to provide an



extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

Colorado^{iv}

"Palliative Care" means specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain and stress of serious illness, whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of physicians, nurses and other specialists who work with a patient's other health care providers to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness and can be provided together with curative treatment. Unless otherwise indicated, the term "palliative care" is synonymous with the terms "comfort care," "supportive care," and similar designations.

Maryland

"Palliative care" means specialized medical care for individuals with serious illnesses or conditions that:

- (a) Is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness or condition, whatever the diagnosis;
- (b) Has the goal of improving quality of life for the patient, the patient's family, and other caregivers;
- (c) Is provided at any age and at any stage in a serious illness or condition; and
- (d) May be provided along with curative treatment.

"Palliative care program" means an interdisciplinary team that provides palliative care services.

Standards

Standards describe the services that must be provided in order to be considered palliative care. At a minimum, palliative care services must include:

- Provision of, or access to:
 - Interdisciplinary team, comprising physician, nurse, social worker, and chaplain
 - o At least one prescriber holding certification in palliative care
 - Additional health care professionals as needed
- Comprehensive assessment and management of the patient's symptoms
- Communication on patient and family priorities for care, often referred to as 'goals of care' conversations, and advance care planning
- Provision of, or access to, meaningful and timely 24/7 response to patient and family crises



Licensed entities over a certain size providing palliative care should have written policies and procedures for the comprehensive delivery of these services. Stakeholders may incorporate attention to psychological and psychiatric, social, spiritual, and cultural aspects of care as appropriate (see the NCP Guidelines^{vi} for more information); however, it is important to ensure that standards not be so onerous as to be unachievable.

Example Standards

Coloradovii

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.

Maryland^{viii}

Note: Specific to Hospital Settings.

Palliative Care Services.

(1) The hospital shall counsel the palliative care patient or their authorized decision maker regarding:

- (a) Health options;
- (b) Pain management options;
- (c) Prognosis;
- (d) Risk and benefits of treatment;
- (e) Availability of grief and bereavement services;
- (f) Psychological services;
- (g) Availability of spiritual care counseling through the hospital or outpatient providers; and
- (h) Hospice services.

(2) Referrals. The palliative care program shall make and document appropriate and timely referrals to:

(a) Inpatient or outpatient bereavement providers;



- (b) Psychological services for the palliative care patient and the patient's family;
- (c) Inpatient or outpatient spiritual care services; and
- (d) Hospice when appropriate or upon request of the patient or the patient's authorized surrogate decision maker.

(3) Pain and Symptom Management. The hospital shall:

- (a) Conduct and document pain and symptom assessments using available standardized scales to appropriately manage a palliative care patient's symptoms;
- (b) Provide adequate and appropriate dosage of analgesics and sedatives to meet the needs of the palliative care patient; and
- (c) Educate the patient and the patient's family about the use of opioids during end-of-life care.

(4) Other Services. The hospital shall provide to palliative care patients, their families, and their unlicensed caregivers:

- (a) Education and support about how to safely care for the patient at home or in an alternate residential setting as appropriate; and
- (b) Information, education, and training materials that are culturally and linguistically appropriate and meet the needs of the patient.

(5) Imminent Death. The palliative care team shall document and counsel the patient, the authorized decision maker, the patient's family, and the interdisciplinary care team about the active dying phase and imminent death as appropriate.

(6) Hospice. The palliative care program shall document the counseling and referral of patients to hospice in the medical record.

(7) MOLST. The hospital shall comply with the procedures and requirements of the Medical Orders for Life-Sustaining Treatment Form, which is incorporated by reference at COMAR 10.07.21.

(8) Interpreter services. The hospital shall ensure interpreter services are available and accessible to the palliative care program

California^{ix}

Note: Specific to Community-Based Settings.

The California Advanced Illness Collaborative (CAIC) developed Consensus Standards for Community-Based Palliative Care; while these have <u>not</u> been codified, they were aligned with state policy at the time of publication. These standards included patient eligibility criteria, descriptions of providers, disenrollment criteria,



and metrics (see complete document for more information). Essential services included:

- A. Assessment
 - 1. A comprehensive palliative care assessment, to include physical, psychological, social, and spiritual needs, and functional status. This must include ongoing assessment of need for community-based palliative care services.
 - 2. Development of an individualized care plan to identify problems and document a plan of care to address symptom management, goals of care, care coordination and to provide an extra layer of support.
 - 3. Assessment of caregiver needs, making appropriate referrals to community-based services such as support groups, caregiver respite, and grief/bereavement services.
- B. Clinical Services
 - 1. In-person or telehealth/telemedicine visits or telephonic contacts by an interdisciplinary team. Services shall be adjusted to meet patient needs for care.
 - 2. Medication management and reconciliation.
 - 3. Availability of symptom management services 24 hours/day, 7 days a week.
 - 4. Advance Care Planning discussions and appropriate documentation, including identification of surrogate decision maker and completion of POLST forms, where appropriate and desired.
 - 5. Caregiver education on aspects of in-home care.
- C. Care Coordination and Communication
 - 1. Collaboration with patient, family and other treating medical providers.
 - 2. Care coordination to assist eligible member in navigating of the medical system, including navigating transitions across settings and benefits, in collaboration with health plan partner.
 - 3. Coordination with health plan partner to support palliative care patient access to appropriate services as necessary and appropriate for eligible member, in a timely manner.
 - 4. Education on hospice services.

ⁱ <u>https://www.cms.gov/Medicare/Provider-Enrollment-and-</u> <u>Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-12-48.pdf</u>

ⁱⁱ <u>https://www.nationalcoalitionhpc.org/ncp-guidelines-2018/</u>

iii https://www.capc.org/about/palliative-care/

^{iv} <u>http://www.sos.state.co.us/CCR/GenerateRulePdf.do?ruleVersionId=5623&fileName=6%20CCR%201011-1%20Chap%2002</u>

v https://health.maryland.gov/ohcq/Documents/Palliative%20Care_10.07.01.31_5_18_2016.pdf



^{vi} <u>https://www.nationalcoalitionhpc.org/ncp-guidelines-2018/</u> ^{vii} <u>http://www.sos.state.co.us/CCR/GenerateRulePdf.do?ruleVersionId=5623&fileName=6%20CCR%201011-</u> <u>1%20Chap%2002</u>

viii <u>https://health.maryland.gov/ohcq/Documents/Palliative%20Care 10.07.01.31 5 18 2016.pdf</u> ix <u>https://coalitionccc.org/wp-content/uploads/2017/11/CAIC-Standards-for-CBPC-Oct-2017.pdf</u>