



TITLE

PALLIATIVE AND END-OF-LIFE CARE PROGRAMS AND SERVICES

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Provincial: Continuing Care

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NOTE: The first appearance of terms in bold in the body of this document (except titles) are defined terms – please refer to the Definitions section.

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OBJECTIVES

- To identify and promote accessible and consistent access to **palliative and end-of-life care** for **Continuing Care patients** and their **families**.
- To support publicly funded Continuing Care programs and settings to achieve compliance with the Continuing Care Health Service Standards (CCHSS).

PRINCIPLES

The Palliative and End-of-Life Care (PEOLC) Provincial Steering Committee compiled and developed principles for the *Palliative and End-of-Life Care Alberta Provincial Framework* (Appendix A: *Principles of Palliative Care*).

Palliative care including end-of-life care, is both a philosophy and an approach to care that enables all individuals with a life-limiting illness to receive integrated and coordinated care across the continuum. This care incorporates patient and family values, preferences and goals of care and spans the disease process from early diagnosis of life-limiting illness to end of life, including bereavement.

Palliative and/or end-of-life care patients are not defined by age, diagnosis or the length of time they may require service, but by their need for care.

A palliative approach to care can occur simultaneously with a curative approach or during treatment. Palliative care improves the quality of life for individuals of any age and at any stage of a life-limiting illness by helping to manage both symptoms and the side effects of treatment.

Palliative care is an approach to improve the quality of life for patients and families facing the problems associated with a life-limiting illness through the prevention and relief of suffering by

means of early identification, comprehensive interdisciplinary assessments and appropriate interventions.

End-of-life-care is care provided to patients and their families when they are approaching a period of time closer to death, which may be exemplified by an intensification of interdisciplinary services and assessments such as anticipatory grief support, and pain and symptom management.

APPLICABILITY

Compliance with this document is required by all Alberta Health Services employees, members of the medical and midwifery staffs, Students, Volunteers, and other persons acting on behalf of Alberta Health Services (including contracted service providers as necessary) within Continuing Care programs and settings.

ELEMENTS

1. Points of Emphasis

- 1.1 Medical assistance in dying events do not fall within the scope of this policy. Refer to the Alberta Health Services (AHS) *Medical Assistance in Dying Policy*.
- 1.2 Care after death does not fall within the scope of this policy. Refer to the established practices in the care setting, e.g., AHS *Patient's Death in the Home Care Setting* Guideline.

2. Assessment

- 2.1 All patients in Continuing Care shall be assessed by a health care professional using a standardized assessment tool for the care setting. Refer to Appendix B: *PEOLC Standardized Assessment Tools*.
 - a) Assessment shall occur upon patient admission to a care setting and change in level of care.
 - b) Reassessment shall be performed as per recommended frequency in accordance with the care setting requirements, individual patient need, and when there is a significant change in patient health status.
- 2.2 Secondary assessment tools shall be evidence based to support accurate assessment and communication amongst the interdisciplinary team. Refer to online at AHS Palliative and End of Life Care: Symptom Assessment Tools.

- a) Secondary assessment tools may vary based on:
 - (i) individualized needs of each patient and their family; and
 - (ii) specific tool(s) used within the care setting.
- b) Secondary assessments shall be performed in a timely manner that is responsive to the patient's needs and include members of the interdisciplinary team as required.

3. Palliative Care and End-of-Life Care Services

- 3.1 Patients and their family shall be offered care and services provided in the location best suited for the patient's care needs, in accordance with the patient's choice, to the greatest extent possible.
- 3.2 Patients and their family shall be engaged and included in care decisions in a sensitive, open and timely manner.
- 3.3 Palliative and end-of-life care and services shall be provided by the most appropriate health care provider working within their role, scope and competencies within the practice setting.
- 3.4 Patient care interventions are based on the patient's **assessed unmet needs**. Palliative and end-of-life care services should include, but are not limited to:
 - a) pain and symptom management;
 - b) psychosocial care;
 - c) grief, loss and bereavement supports;
 - d) respect for patient diversity and culture; and
 - e) spiritually sensitive care that maintains patient dignity.
- 3.5 Patients and their family shall be informed of and provided access to additional and relevant care and services available, which may include, but not be limited to:
 - a) consultation with health care professionals as required (i.e., Palliative Care Nurse, Palliative Physician, Social Worker, Spiritual care provider, etc.);
 - b) Emergency Medical Services (EMS), Palliative and End-of-Life Care Assess, Treat and Refer (ATR) program;
 - c) **Hospice** or designated Palliative and End-of-Life bed in an Acute Care or Continuing Care setting;

- d) services and supports provided by community agencies or programs;
- e) specialized services (e.g., pediatric palliative care);
- f) volunteer resources;
- g) palliative and end-of-life care resources and education materials accessible online at My Health Alberta Network: Palliative Care;
- h) brochures and printed education materials, as available in each care setting; and
- i) resources and education materials in print and accessible online at AHS Advance Care Planning: Conversations Matter.

4. Care Planning

- 4.1 **Advance care planning** shall be conducted in accordance with the AHS *Advance Care Planning and Goals of Care Designation Policy* suite.
- 4.2 The patient's **Goals of Care Designation** shall be accessible to the interdisciplinary team and any other involved **health care providers** to ensure the patient's choices are respected.
- 4.3 Each patient shall have an individualized care plan, developed by a health care professional, and accessible to the interdisciplinary team that:
 - a) addresses their physical, psychosocial and emotional needs;
 - b) aligns with their Goals of Care Designation;
 - c) contains other relevant wishes or instructions pertaining to the patient's palliative and end-of-life care goals (e.g., Personal Directive);
 - d) incorporates patient diversity, culture and spiritual beliefs and practices; and
 - e) identifies the health care provider responsible to perform interventions.
- 4.4 The interdisciplinary team shall review the patient's care plan for effectiveness based on patient assessment(s), patient goals or changes in Goals of Care Designation, and then revise the care plan to reflect the patient's current status and choices.

DEFINITIONS

Advance Care Planning means a process which encourages people to reflect and think about their values regarding clinically indicated future health care choices; explore medical information that is relevant to their health concerns; communicate wishes and values to their loved ones, their alternate decision-maker and their health care team; and record those choices.

Assessed unmet needs means the care requirements that remain after the strengths and resources of the patient and family and of the community have been considered in relation to the functional deficits identified on assessment. The assessment includes the patient's ability to learn the skills necessary for self-care and the willingness, ability and availability of the family and community to participate or learn.

Continuing Care means an integrated range of services supporting the health and wellbeing of individuals living in their own home, a supportive living or long-term care setting. Continuing care clients are not defined by age, diagnosis or the length of time they may require service, but by their need for care.

End-of-life care means care provided to an individual and their family when they are approaching a period of time closer to death, which may be exemplified by an intensification of services and assessments such as anticipatory grief support, pain, symptom management and comfort care.

Family(ies) means one or more individuals identified by the patient as an important support, and who the patient wishes to be included in any encounters with the health care system, including, but not limited to, family members, legal guardians, friends and informal caregivers.

Goals of Care Designation means a codified instruction that provides direction regarding general care intentions, specific health interventions, transfer decisions and locations of care, for a patient as established after consultation between the most responsible health practitioner, patient and when appropriate, alternate decision-maker.

Health care providers means any person who provides goods or services to a patient, inclusive of health care professionals, staff, students, volunteers and other persons acting on behalf of or in conjunction with Alberta Health Services.

Hospice means a designated non-tertiary space specifically providing End-of-life care.

Palliative care means an approach to improve the quality of life for patients and families facing the problems associated with a life-limiting illness through the prevention and relief of suffering by means of early identification, comprehensive interdisciplinary assessments and appropriate interventions.

Patient means an adult or child who receives or has requested health care or services from Alberta Health Services and its health care providers or individuals authorized to act on behalf of Alberta Health Services. This term is inclusive of residents, clients and outpatients.

REFERENCES

- Appendix A: *Principles of Palliative Care*
- Appendix B: *PEOLC Standardized Assessment Tools*
- Alberta Health Services Governance Documents:
 - *Advance Care Planning and Goals of Care Designation* Policy suite (#HCS-38)
 - *Patient's Death in the Home Care Setting* Guideline (#HCS-213-01)
 - *Medical Assistance in Dying* Policy (HCS-165-01)
- Alberta Health Services Forms:
 - *Goals of Care Designation (GCD) Order Form* #103547
- Alberta Health Services Resources:
 - *Advance Care Planning/Goals of Care Designation (ACP/GCD) Frequently Asked Question (FAQ) for the Health Care Professional*
 - *Provincial Palliative and End-of-Life Care Project Charter - EMS Assess, Treat and Refer*
 - *Palliative and End-of-Life Care Alberta Provincial Framework 2014*
 - *Symptom Assessment Tools*

VERSION HISTORY

Date	Action Taken
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APPENDIX A

Principles of Palliative Care

- 1. Patient and Family-Centred:** It is important that patients and families are placed at the centre of their care to foster participation and collaboration. They will be empowered to make informed choices, and their needs, culture, values, religion, language and preferences are respected and honored. The patient and family's capacity to cope will be recognized allowing a flexible approach to care.
- 2. Equitable and Accessible:** All Albertans should have equitable and timely access to quality interdisciplinary PEOLC services despite illness or geography. It is not the intention that the same services will necessarily be provided in all settings but that the access to expertise will be equitable across Alberta. Timely access to PEOLC services and programs will be facilitated by system processes for patients and providers at all levels of health care.
- 3. Collaborative and Integrated Team Service Delivery:** In order to meet the individual needs of patients and families comprehensive interdisciplinary teams with varying skills and knowledge are required to safely and effectively care for Albertans who are palliative or are at the end of life. The systems of care including providers, policy makers, educators and organizations that can influence programming need to share information about practices that promote the best possible outcomes for patients and families.
- 4. Communication and Information Sharing:** There is a need for improved structured options including information technology for knowledge transfer at all levels (patient and family, service delivery and system) and the use of common tools, language, and utilization of the most appropriate documentation to support seamless transitions of patients, to convey appropriate information, and, to safely manage patient and family issues.
- 5. Safe, Ethical and Quality Care:** Comprehensive assessments by adequately skilled professionals and providers are at the heart of quality and ethical care delivery. The provision of care that is appropriate to all domains including physical, psychological, emotional, social and spiritual requires knowledge and tools related to assessment in these areas. Practice that promotes consistency, coordinated activities, and collaborative approaches with minimal duplication will foster best outcomes.
- 6. Sustainable and Accountable:** Adequate and appropriate resources will be available for PEOLC programs and services for both cancer and non-cancer patients, their families and their health care providers with the goal of providing the right care at the right place at the right time. A mixture of structure, process and outcome indicators established for PEOLC services are needed to measure symptom improvement, accessibility of services and equitable distribution of services across Alberta.
- 7. Governance and Administration:** Clearly defined governance and administration models are required to ensure accountability and to support the development of PEOLC programs. Exploring palliative care from a public health, health promotion perspective and aligning palliative care with a population needs approach is important for future planning. Broad-based governance includes community representatives, caregivers, service providers, patients and families.
- 8. Research, Education and Advocacy:** High quality PEOLC that is supported by the best available evidence positively impacts quality of life. Continued learning and education should work toward information, research and advocacy for the development and maintenance of public policy, palliative care standards and resources to improve the delivery of palliative care.

Clearly defined programs and activities will help support providers and improve patient outcomes.

Source: *Palliative and End-of-Life Care Alberta Provincial Framework 2014*

APPENDIX B

PEOLC Standardized Assessment Tools

The following standardized assessment tools are used in one or more Continuing Care and Hospice setting, but are not limited to those listed here.

Adult Tools – Specific to Clinical Care Area

Resident Assessment Instrument – Home Care (RAI-HC)
Resident Assessment Instrument – Minimum Data Set 2.0 (RAI-MDS 2.0)
Victoria Hospice Palliative Performance Scale (PPS)
Edmonton Symptom Assessment Scale-Revised (ESAS-R)
Palliative Outcome Scale (POS)
Palliative Outcome Scale (POS)-modified
Home Care End of Life (EOL) Comprehensive Assessment
Agape Hospice Family Survey
Bereavement Risk Assessment Tool (Victoria Hospice Society 2008)
Complexity Tool (Grief Assessment)
Eastern Cooperative Oncology Group Performance Status (ECOG)
Edmonton Classification System for Cancer Pain (ECS-CP)
Palliative Prognostic Index (PPI)
Palliative General Physical Assessment (Meditech)
Death at Home: Expected (Meditech)
End of Life Prearrangement (Meditech)
Palliative Care Intake (Meditech)
Palliative Psychosocial Assessment (Meditech)

Pediatric Tools – Specific to Clinical Care Area

Pediatric Client Comprehensive (Meditech)
Palliative General Physical Assessment (Meditech)
End of Life Prearrangements (Meditech)