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# End of Life Options—Striking A Balance

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# Stigma

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- Death denying society creates barriers
- Need for integrating palliative care- into routine advanced cancer care and with chronic disease management
- “A name change would achieve nothing without a fundamental shift in the manner in which palliative care is practised and portrayed.” (CMAJ, April 2016)

# Enter... Alberta Specific Definitions

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- Palliative and End of Life Care is provided throughout the continuum utilizing an interdisciplinary approach to meet the individualized needs of patients and their families/caregivers.
- Palliative Care aims to improve the quality of life of 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 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.
- Hospice is a designated non-tertiary space specifically providing End of Life Care.

# History of PEOLC in Alberta

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- Focus on increasing access in community since 1993
- Inception of programs in Calgary/ Edmonton in 95/96
- Other zone developments
- Variance in programs across AB
- The AHS PEOLC Framework

# Leg/ Reg Highlights

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- 1991 **Co-ordinated Home Care Program Regulation** supported by the **Provincial Policy Framework** (1993) resulting in improved access to and co-ordination of PEOLC services (later amended in 2003, 2007, 2012)
- **Public Health Act** (Part 2, Section 10)- States a RHA shall provide the health promotional, preventative, diagnostic, treatment, rehabilitative and palliative services, supplies, equipment and care that the regulations require to provide.
- 1999: Implementation of the **Alberta Palliative Care drug program**
- 2003, the **Nursing Homes Operation Regulation** was amended to reflect new LTC accommodation changes/ no charge to residents admitted to receive palliative care
- 2006 **CCHSS** required AHS to have operational policies and processes for PEOLC
- 2012 **Accreditation Canada Standards** for Hospice Palliative End-of-Life introduced
- 2014 **Ambulance Coverage** added to Blue Cross for palliative care patients
- 2016 **CCHHS** updated to include PEOLC

# Government & AHS-Roles

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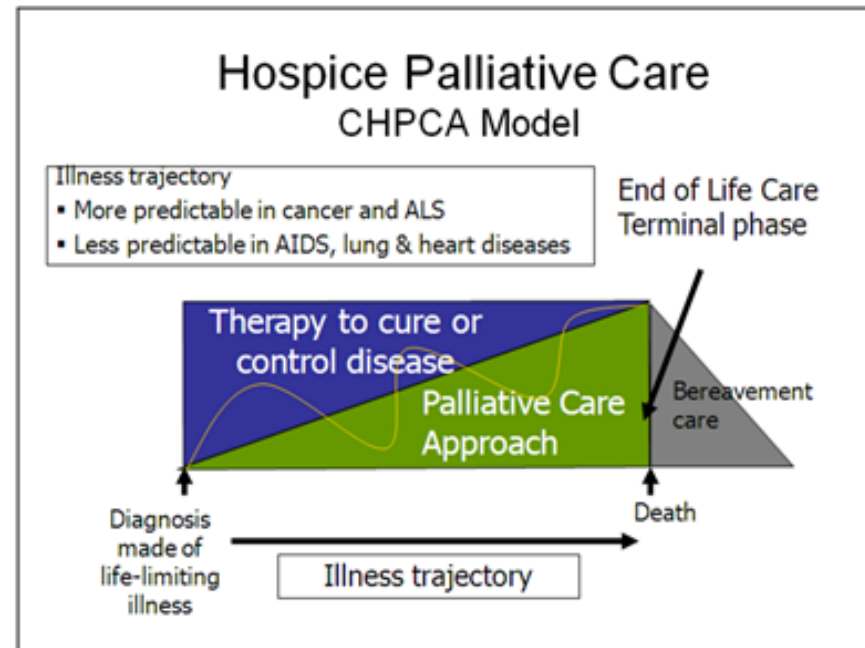
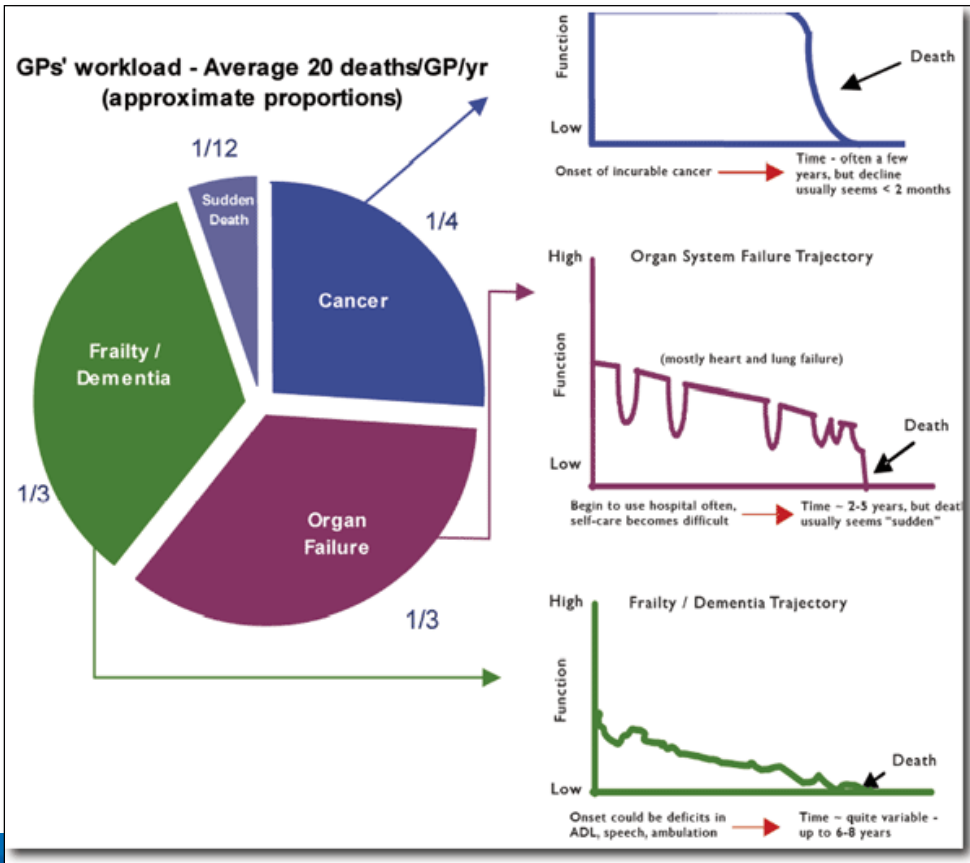
- Alberta Health is the ministry that sets policy, legislation and standards for the health system in Alberta. The ministry allocates health funding and administers provincial programs (E.g. Alberta Health Care Insurance Plan)
- Alberta Health Services manages the delivery of health services, allocates workforce and funding resources to support health service delivery, and implements operational policy. Their mandate includes determining “priorities in the provision of health services in Alberta and allocating resources accordingly” while the government is “responsible for the legislative, regulatory and policy frameworks in which AHS operates”
- Alberta Health Services works with Alberta Health to define measures for compliance at the operational level.

# Context Setting

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- ~24,000/ year-15% die suddenly while 85% will require *some form* of PEOLC prior to death
- >75% of cancer patients require more specialized palliative care services
- Historically ~85% of patients in PEOLC programs are cancer patients
- Non-cancer cohorts increasing over time--~18-25% depending on location
- GPs case load >cases of chronic illness than Cancer

# Illness Trajectories





# Preferences for Dying Survey?

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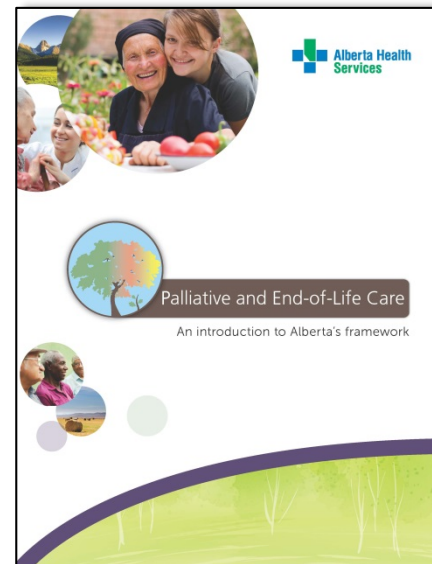
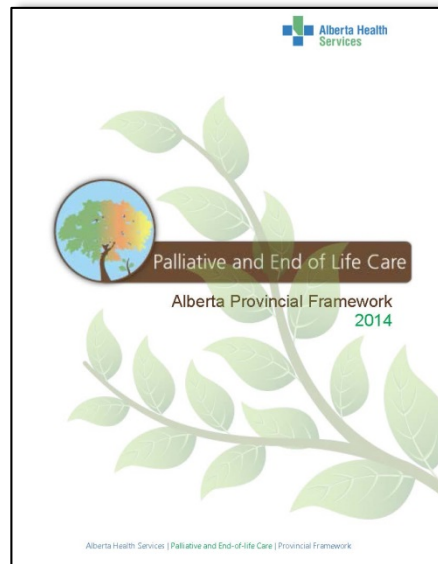
- More people talk to their family than their health care team about wishes
- 76% of Albertans want to die at home-survey indicates ~57% died in hospital
- Those who did not die in their place of preference had many different reasons

CHPCA, What Canadians Say: The Way Forward Survey Report, for The Way Forward initiative, Harris/Decima: 2013



# Palliative and End of Life Care Alberta Provincial Framework 2014

- <http://www.albertahealthservices.ca/about/Page10774.aspx>
- Framework development was a collaborative effort involving multiple stakeholders





Palliative and End of Life Care

ADVANCE CARE PLANNING | GOALS OF CARE  
**CONVERSATIONS  
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A GUIDE FOR MAKING HEALTHCARE DECISIONS

# 36 Recommended Initiatives



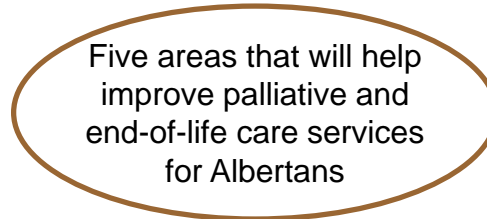
## Program Development

- Emergency medical staff trained with appropriate knowledge
- 24/7 access to information and support
- Advance care planning
- Home care offering similar services across the province



## Education and Awareness

- Increase knowledge of care providers across all health care sectors
- Home care services built around peoples' needs
- Helping patients and caregivers find the right information
- More teams with right skills in home care and other care settings



Five areas that will help improve palliative and end-of-life care services for Albertans



## Partnerships and Innovation

- Government, communities and AHS working together on policies
- Establish experts and funding for long-term developments
- Specialists helping primary care with management complex illnesses
- Do research that tells us how to measure, how to improve and be consistent



## Practice and Standards

- Tools and supports for physicians and other providers in communities
- Use technology to support providers in remote care
- Standards for care across Alberta



## Communication

- Better understanding of the benefits of palliative and end-of-life care
- Improved awareness of how to access services
- Better planning for future health issues
- Timely expert support and safe transitions for patients in health-care locations



## Key Initiatives Completed to Date

- ☑ 24/7 Palliative Physician on-call for Primary Care physicians caring for Pediatrics and adult PEOLC patients available province wide
- ☑ Launch of Provincial PEOLC Website (Phase 1 and Phase 2)
- ☑ Capacity and forecast planning for hospice spaces across Alberta
- ☑ Initial Key PEOLC indicators published on AHS Tableau Dash Board
- ☑ Bereavement directory for Albertans to find support and services in their own communities
- ☑ A preliminary draft Resource Guide for Community-based PEOLC: An initial response to surveyed community groups and PEOLC organizations in Alberta
- ☑ Advance Care Planning / Goals of Care Designation (ACP / GCD) Policy – year one review completed
- ☑ EMS PEOLC ATR Phase 1 implementation
- ☑ Developed AHS Provincial Volunteer Resource Training and Facilitator Manuals



# Key Initiatives in Progress

- EMS PEOLC ATR Phase 2 implementation
- Implementation of recommendations to improve Bereavement care in Alberta
- Enhance and revise the initial draft of Resource Guide for Community-based PEOLC: An initial response to surveyed community groups and PEOLC organizations in Alberta
- Provincial Expected Death in the Home Guidelines
- Clinical Knowledge Clinical Management (CKCM) – three clinical knowledge topics:
  - ACP/GCD
  - Provincial Palliative Sedation guidelines
  - End of Life Care guidelines
- Capacity planning and forecasting for acute Palliative beds and Palliative Home Care
- Development of additional PEOLC indicators published on AHS Tableau Dashboard



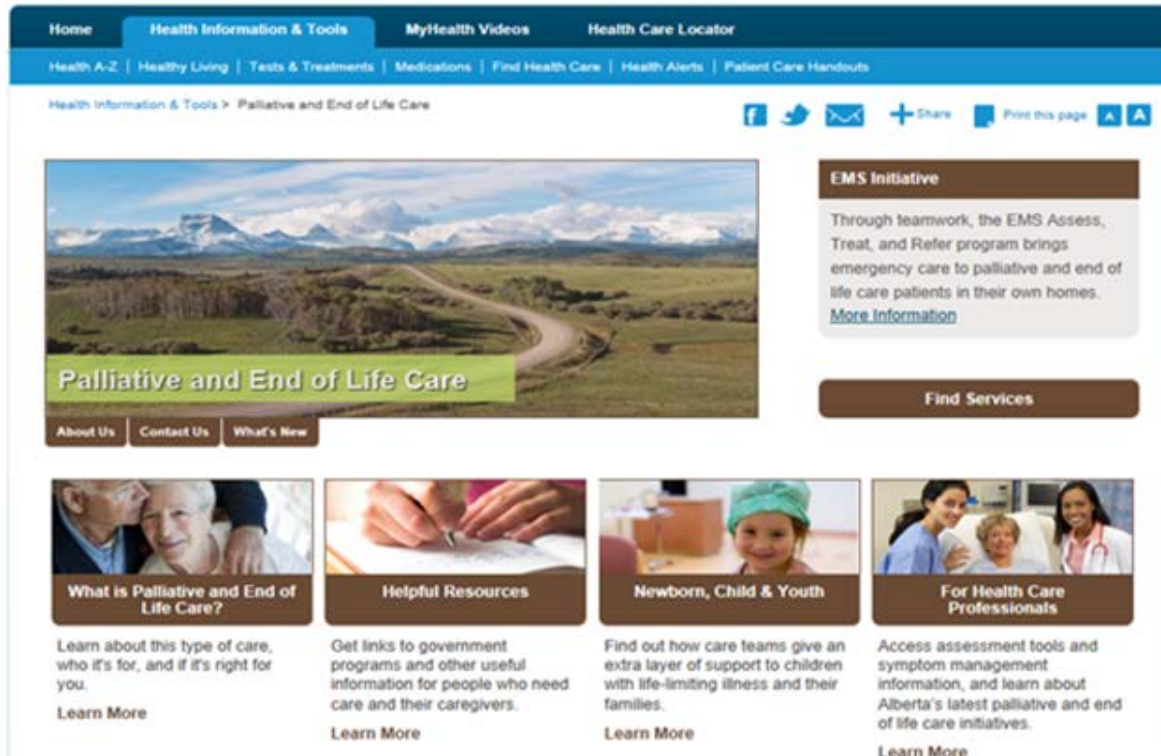
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# PEOLC Provincial Website

<https://myhealth.alberta.ca/palliative-care>

  
MyHealthAlberta.ca



The screenshot shows the MyHealthAlberta.ca website interface. At the top, there is a navigation bar with links for Home, Health Information & Tools, MyHealth Videos, and Health Care Locator. Below this is a secondary navigation bar with links for Health A-Z, Healthy Living, Tests & Treatments, Medications, Find Health Care, Health Alerts, and Patient Care Handouts. The main content area is titled "Health Information & Tools > Palliative and End of Life Care". On the right side, there are social media icons (Facebook, Twitter, Email) and a "Share" button. The main content features a large image of a winding road through a mountainous landscape with the text "Palliative and End of Life Care" overlaid. Below this image are three buttons: "About Us", "Contact Us", and "What's New". To the right of the main image is a box titled "EMS Initiative" with text describing the program and a "More Information" link. Below this is a "Find Services" button. At the bottom, there are four columns of content, each with a small image, a title, a brief description, and a "Learn More" link:

- What is Palliative and End of Life Care?**: Learn about this type of care, who it's for, and if it's right for you. [Learn More](#)
- Helpful Resources**: Get links to government programs and other useful information for people who need care and their caregivers. [Learn More](#)
- Newborn, Child & Youth**: Find out how care teams give an extra layer of support to children with life-limiting illness and their families. [Learn More](#)
- For Health Care Professionals**: Access assessment tools and symptom management information, and learn about Alberta's latest palliative and end of life care initiatives. [Learn More](#)



# On the Horizon...

- Clinical Knowledge Clinical Management working on several topics
- Priority setting (ISC) includes more provincial work on pathways, policy and places where we die
- AHS collaborating with Alberta Health to examine the most appropriate model to enable equitable access for PEOLC in Alberta (HTA)



# Importance of planning upstream

- Benefits of ACP
- ACP in health care setting-chronic disease prognostication challenges
- Integrating CDM with PEOLC-the benefits
- Role of primary care/ challenges in this sector





# ACP/GCD Level 1 Policy and Procedure

- A process of deliberation, documentation and communication of peoples preferences regarding health care.
- Better prepares capable people and family members for in-the-moment decision making.
- Researched benefits for patients, families, providers and the system of health care.
- Increases completion rates of PD's/ O&TD.
- [www.conversationsmatter.ca](http://www.conversationsmatter.ca)
- Status: 1 Year Review Process Concluded & revised policy approved at COEC level



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# [Conversationsmatter.ca](http://Conversationsmatter.ca)

## Conversations Matter - It's about decisions and how we care for each other



**Advance Care Planning** is a way to help you think about, talk about and document wishes for health care in the event that you become incapable of consenting to or refusing treatment or other care.

You may never need your advance care plan - but if you do, you'll be glad that it's there and that you have had these conversations, to make sure that your voice is heard when you cannot speak for yourself.

**Goals of Care Designation** is a medical order used to describe and communicate the general aim or focus of care including the preferred location of that care.

Although advance care planning conversations don't always result in determining goal of care designation, they make sure your voice is heard when you cannot speak for yourself.

**Contact Us**

[conversationsmatter@albertahealthservices.ca](mailto:conversationsmatter@albertahealthservices.ca)

**Information For**

Patients & Families

Health Professionals

**Start the Conversation**

Interactive Guide



Website for Patients/Families and  
Health Care Providers

Mobile App

# PEOLC Pan-Canadian Approach

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## Canadian Partnership Against Cancer Top Priorities:

- Education
- Integration
- Advance Care Planning

# Summary/ Intro to MAID

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- PEOLC in Bill C14
- Convergence/ divergence of PEOLC with MAID
- AHS readiness
- Need for balance-access and safeguards