Palliative and End of Life Care Alberta Provincial Framework: What does this mean for Albertans

Grey Matters Conference
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*Presenters:*
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Who we are

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Presentation Objectives

• Provide an overview of:
  – Advance Care Planning
  – Palliative and End of Life Care Alberta Provincial Framework
• 36 initiatives that have been recommended
• How will we implement these initiatives?
• What’s happening next?
100% of us in this room will die
Maybe 70% will lack capacity at that time
What we already know

- We can expect to die with 2 or more chronic diseases after a few years in state of “vulnerable frailty”
- Only 20% will die with a recognizable “palliative” phase
- ~70% Canadians die in hospital, 20% in ICU
- At time of death:
  - 42.5% require decision-making
  - 70.3% lack capacity

(Silveira et al. NEJM 2010; 362:1211)
Levels of ACP in Canada

- Only 14% of Canadians had heard of ACP
- Half have communicated preferences to family members
- Only 9% have talked with their Health Care Provider
- 19% have written an Advance Care Plan
- 46% had formally designated a decision maker
- Some regional differences
  Western provinces > East and Atlantic Canada

Source: Ipsos Reid Canadian public opinion poll
March 2012: 1,021 respondents
The Advance Care Planning/Goals of Care Designation (ACP/GCD) project aims to establish and implement standardized provincial processes for advance care planning and the determination of goals of care with patients across the care continuum.
April 1, 2014 Province Wide Adoption

- Promote best practice conversations
- Develop Provincial tools/resources
- Enhance clinical practice through education
- Ensuring that all appropriate Albertans receive a Green Sleeve and are made aware of ACP and GCD
Advance Care Planning

- **Think** about your values and wishes
- **Learn** about your own health
- **Choose** someone to make decisions and speak on your behalf
- **Communicate** your wishes and values about health care
- **Document** in a Personal Directive
Goals of Care Framework

Goals of Care Designation provides direction regarding:

- *specific health interventions*,
- *transfer decisions*,
- *locations of care*,
- *general intent of care*
ACP / GCD Resources

GOALS OF CARE DESIGNATIONS

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- R: Resuscitative Care
- M: Medical Care
- C: Comfort Care

- Can consider, if required for symptom control

www.albertahealthservices.ca
Key motivators

• Ideal information to support good decision-making
• Modernized platform for categorizing and communicating care focus
• Better transmission of information during patient transitions
• Patients as Partners in decision-making
• Acceptability, effectiveness, efficiency, safety, appropriateness
Focus

- It is about the conversation
- Joint decision-making
  - Patient/family expertise
  - Clinician expertise
- In the case of dispute, a mechanism for resolution
A simple aim…

• The aim is to provide Albertans with decision making information in order to guide a person, treatment team, family, and or agent to make the best decision possible, when a decision point is required.
Alberta Health Services is investing in Palliative and End of Life Care (PEOLC) as part of the overall goal of providing choice and equity for Albertans.
Achievement Path

The Foundational Roadmap objectives will be achieved through various staged projects and initiatives.
The Conceptual Framework development was built on evidence informed best practice with the goal of one harmonized Palliative and End of Life Provincial Program that is equally accessible and equitable for all Albertans.
## Timelines

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<th>Milestones/Quarter</th>
<th>Apr 13</th>
<th>May 13</th>
<th>Jun 13</th>
<th>Jul 13</th>
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### Planning, Strategy Development, Framework Development
Completed March 2014

### Implementation & Operational Impacts
April 2014 and Beyond
Provincial Palliative and End Of Life Innovations Steering Committee (PPAL/EOL ISC)

- Inclusive of all fundamental stakeholders
- To strengthen, formalize and implement initiatives
- Designate appropriate representation on Working Groups
Definitions and Framework Principles

• Definition – Philosophical and Administrative

• Principles
  1. Patient & Family Centered
  2. Equitable & Accessible
  3. Collaborative & Integrated Team Service Delivery
  4. Communication and Information Sharing
  5. Safe, Ethical & Quality Care
  6. Sustainable & Accountable
  7. Governance and Administration
  8. Research, Education and Advocacy
Current State

- **Illness Trajectory Model**
  Palliative and End of Life Care:
  is a continuum of care from the time of diagnosis of a life-limiting illness through to the time of death and into Bereavement. It demonstrates that a palliative approach to care can occur simultaneously with a curative approach or during treatment.

- **Current State Analysis**
  Involved 3 main components:
  - Systematic Literature Review
  - Data Mining for Quantitative Information
  - Qualitative Questionnaires and Primary Care Network Surveys

(Adapted by the Canadian Hospice Palliative Care Association model, Pereira (2008).)
Literature Reviews

- Within publications across Canada, North America and Internationally.
- Through the UofA supported by a ACF grant
Canadian Frameworks
International Frameworks
Patient and Family Engagement

Avenues:
– Patient and Family Advisory Group
– Patient Engagement Research (UofC) Focus Groups

Feedback:
– Clinician based, needs more focus on Patients and Families
– Needs tools to decode the framework so that non-experts can understand the purpose and goals
Other Engagement and Feedback

Framework has been circulated throughout:

- AHS
- All SCNs
- AHPCA
- CHPCA
- Government Ministries (ie. Alberta Health)
- Academic Institutions
- Contract providers
- BC, Ontario
- Cancer Control
- Primary Care
Conceptual Framework Development Project Phases

I. Current state analysis and report
   - Clinical services, programs, care models, and incorporated resources (within and external to Alberta)
   - Data & statistics (zone, provincial)
   - Literature review

II. Develop a Conceptual Framework

III. Refine, finalize, and obtain endorsement of the Conceptual Framework

IV. Create a Program Charter; inclusive of projects and initiatives identified within the Conceptual Framework
36 Initiatives have been recommended

Focus areas that are all foundational to the program

1. Practice and Standards
2. Education and Awareness
3. Program Development
4. Partnerships and Innovation
5. Communication
What we are currently working on

Step 1: Planning and Chartering

Step 2: Development and Implementation

Step 3: Launch and Evaluation

Development of Provincial Palliative and End of Life Care Program
Year 1 - Initiatives

Establish

Partnerships & Innovation

- As part of a provincial PEOLC program develop direct links with the Primary Care Networks and Family Care Clinics within local communities and partner with provincial stakeholders building strong relationships with those who can support provision of PEOLC in local communities, such as contracted partners in Long Term Care, Supportive Living and Home care as well as community organizations.

- Create synergies amongst existing organizations/services within Alberta (e.g. Chronic Disease Management, Community services, Covenant Health, FCC’s, Home Care, PCN, Primary Care Services, SCN, TOP, and secondary levels of Care). These partnerships need to be supported with education and practice guidelines that are evidence-based, standardized and easily accessible. These linkages will be evident in that knowledge is transferred, and there are both a seamless point of entry and seamless transitions for patients.

- Establish a provincial PEOLC Practice and Innovations Council (PIC) that is focused on identifying, trialing, and implementing innovative ways to deliver care within the community settings across all areas within Alberta; create alliance with Alberta Health through the PIC to maintain alignment with public messaging around PEOLC.

- Identify and develop connections to other patient centered initiatives in the province, reinforcing the concept throughout health care, and minimizing the impact of change by building on existing language and concepts, and aligning palliative care with other programs and services incorporating environmental supports and flexibility in care.
### Year 1 – Initiatives cont

#### Launch

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<td>♦ Develop a one stop information portal that includes information on equipment, medication access with links to other programs and information sources such as Virtual Hospice, Caregiver College, on line grief and bereavement resources for both pediatrics and adults.</td>
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<td>♦ Inventory existing resources that have already been developed (other than LEAP). Partner with national organizations offering educational resources, as well as educational institutions such as universities within Alberta, to develop an innovative and collaborative plan to establish and support minimum standards of education and ongoing education for those working directly in PEOLC therefore, improving quality of care for patients locally (4;14;18;22).</td>
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<td>♦ Build on the established education programs, procedures, and access to tools within each zone and leverage existing infrastructure by identifying all forms of PEOLC educational resources available across Alberta, standardize the methods under a provincial focus, and create tools and programs for making the resources easily accessible for care providers across all geographies to decrease duplication of creation of similar resources developed in isolation. A central repository that is maintained/updated regularly for sharing family resources or allowing central access online for patients and families is to be developed to provide readily accessible resources and there is a need to expand and evaluate virtual education (1;9;22) 32.</td>
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Year 1 – Initiatives cont

Scope and design (SCN's involvement)

**Practice & Standards**
- Identify current local best practices, design a provincial standard, and implement practice standards, guidelines and protocols to assess and manage POELC symptoms (including dementia) for primary and secondary level care providers (1;2;18;22).
- Identify and agree on a set of provincially standardized common screening, assessment tools, and guides to practice. Some examples of these tools are: (ESAS-r, Palliative Performance Scale, Collaborative Care Plans, and Symptom Management Guides to Practice) (2;13;14;18;22).

**Program Development**
- Formalize and expand the EMS program across Alberta.
- Working off the success of the programs within zones that offer 24/7 services; standardize access points and spread 24/7 on call PEOLC consult services for adults and pediatrics for primary care practitioners, care givers, patients and families to support care within the community including strategies that support rural/remote practitioners such as regular rounds by Telehealth, allowing for interdisciplinary access in areas where it is limited, and building capacity as knowledge and skills are transferred to local practitioners.

**Communication**
- Enhance and provincially standardize both the referral and the transition communication processes ensuring concordance with requirements from Accreditation Canada (52) and including identifying possibilities within electronic health records or paper based processes that follow the patient as they move through the system including exploring the option feasibility, and potential benefits of a provincial registry. (13;18;24;26;32;39).
Overall Strategy

- Primary care level providers need to help support people to plan for end of life.
- Accessing services and resources to support people to die at home.
- Helping people, not just patients, navigate the system.
Questions

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www.conversationsmatter.ca

Thank you