

Speak Up

Start the conversation
about end-of-life care

Advance Care Planning

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Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

Webinar Overview



- **Advance Care Planning in Canada project**
- **The meaning and importance of advance care planning.**
- **National Framework: Core Elements**
- **Tools**
- **Speak Up: Start the Conversation about end-of-life care**



National Project

Advance Care Planning in Canada: National Framework and Implementation

- Is a project of the Canadian Hospice Palliative Care Association
- In its third year
- Overseen by a national Task Group – interprofessional and representing many jurisdictions



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National Task Group

- ACP Experts/Communications experts
- Alberta Health Services - Calgary Area
- Canadian Bar Association
- Canadian Cancer Society
- Canadian Hospice Palliative Care Association
- Canadian Lung Association
- Canadian Medical Association
- CNA: Palliative Care Nurses Interest Group
- Canadian Society of Palliative Care Physicians
- CARENET
- College of Family Physicians of Canada
- Fraser Health, British Columbia
- Funders: The GlaxoSmithKline Foundation and The Canadian Partnership Against Cancer



Advance Care Planning in Canada – Long Term Project Goals

- To raise the awareness of Canadians about the importance of advance care planning and to equip them with the tools they need to effectively engage in the process.
- To prepare professionals/health care providers with the tools they need so they can facilitate and engage in the process of advance care planning with their clients.



Project Activities

- Needs assessment – literature review and environmental scan to identify the components of a *National Framework* and tools
- Developing draft *National Framework* through national consultation
- Review of existing tools for professionals to facilitate ACP with patients and families
- Two national roundtables to seek guidance on *Framework* and tools development
- Speak Up – a national awareness campaign
- Research activities



Advance Care Planning: Definition



Advance Care Planning (ACP) is a **process** of reflection and communication. It is a time when a person (who is capable) reflects on their values and wishes, and lets others know their future health and personal care preferences in the event that they become incapable of consenting to or refusing treatment or other care.



Advance Care Planning: Definition



- A process of reflection and communication about values, beliefs and goals of care
- A process of planning for a time when a person cannot make their own medical decisions
- A process that involves discussions with healthcare professionals and significant others
- A process that may result in an advance directive



Advance Care Planning is not meant to be:



- One conversation about treatment options with a physician or other healthcare professional
- Strictly refusal of medical treatments
- A document/form family or healthcare professionals are unaware of nor have access to
- Conversations with only a closest family member that are not shared with others



Why is ACP Important?

Individuals who engage in advance care planning and/or appointed a substitute decision maker:

- Are much more likely to have their end-of-life wishes known and followed
- Have family members who had significantly less stress and depression
- Are more satisfied, as were their families and substitute decision makers
- Have fewer life-sustaining procedures and lower rates of intensive care unit (ICU) admissions
- Have a better quality of life and death
- Have less costly care in last weeks of life

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What is the need in Canada?



2004 Ipsos-Reid poll

- 70% of Canadians had not prepared a living will or advance care plan,
- 47% of Canadians had not designated a Substitute Decision Maker to make healthcare decisions for them if they are unable.
- Less than 44% of respondents had discussed end-of-life care with a family member



What is the need in Canada?

- Few strong pockets of ACP expertise across Canada.
- Most provincial and territorial governments have established **legislation** related to advance directives, but there are only a few areas in Canada that have established ACP **programs** within their organizations or jurisdictions.
- Focus often on documents rather than **conversations**.
- **Language** used with regard to ACP varies across jurisdictions, provinces/territories and care settings continues to vary significantly. This can cause confusion among the public and in the care setting.



ACP: National Framework - Goal



- To provide a **model** for advance care planning that can be used to guide related activity, program development, and practice **across Canada**.



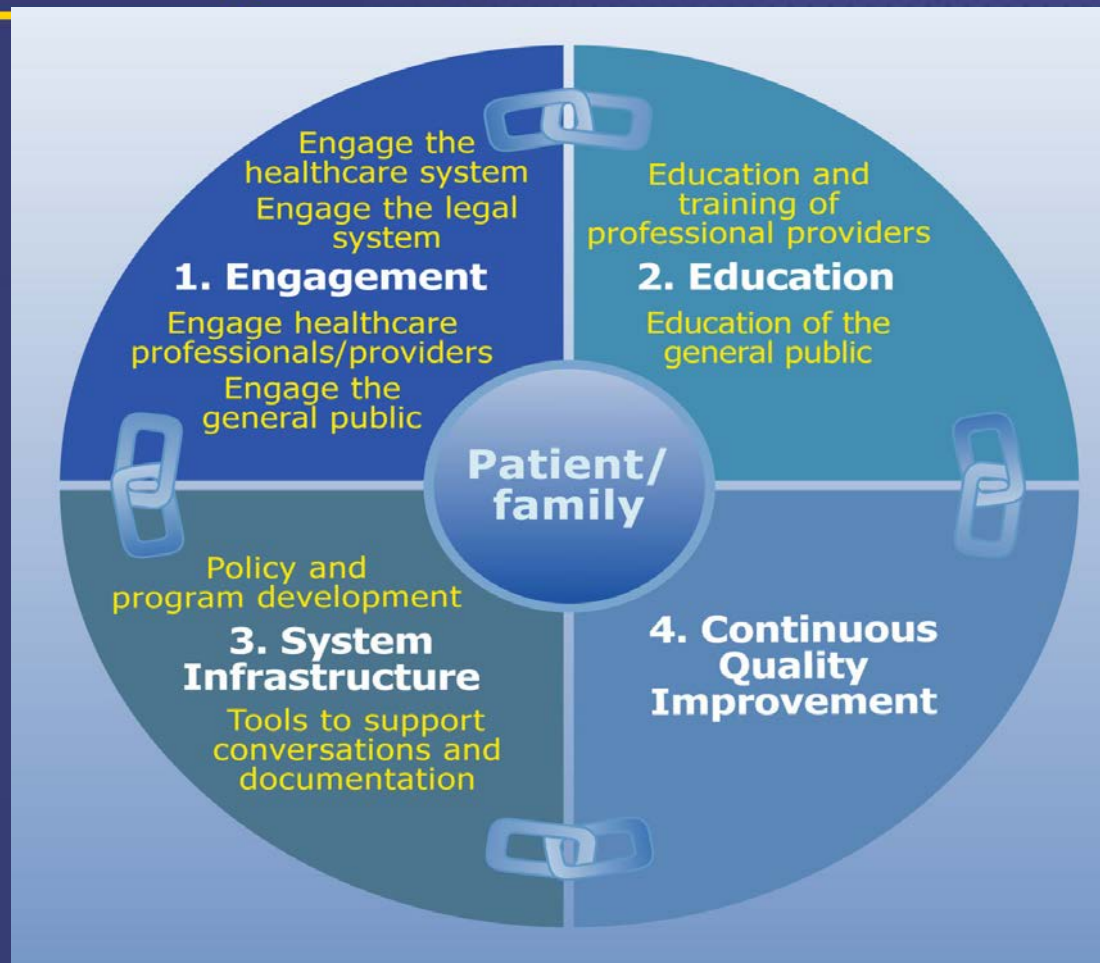
ACP Framework: Overview



The *National Framework* for advance care planning in Canada is based on a model that features the patient and family at its centre, and is composed of four basic building blocks—engagement; education; system infrastructure; and continuous quality improvement.



ACP Framework: Overview



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ACP Framework Consultation

- First round of the consultation Winter, 2010
 - National non-governmental organizations – health, legal
 - National professional organizations – medicine, nursing, law social work, pastoral care, etc.
 - Provincial/territorial governments
- Second round of consultation – Fall, 2010
 - Local/regional health authorities
 - Provincial/territorial professional associations/colleges
 - Non-respondents from round 1
- Two face-to-face roundtables



Underpinning: Research

- Setting the agenda for ACP research in Canada
- ACCEPT Study:
 - Multi-centre study
 - Daren Heyland and Doris Barwich, Co PIs
 - Funded through the CIHR
 - Evaluate how advance care planning, a process of documenting and communicating end of life care wishes, can improve the quality of end of life care for seriously ill Canadians and their family members and at the same time, reduce costs for our health care system



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Speak Up



- National advance care planning campaign
- Includes Advance Care Planning Day – April 16, 2012
- Provides a web portal with resources for the public, professionals and community organizations/agencies



Target Audiences



- Health care professionals
- Community health-related organizations/associations
- Individuals – middle aged and seniors
- Caregivers
- Media
- Policy/decision makers



Website

For:

- Patients and families
- Professionals
- Community organizations / agencies / programs
- Researchers

www.advancecareplanning.ca



Toolkits for patients and families



- Why plan for end of life care?
- What is an advance care plan?
- Workbook to assist in having the conversations
- Wallet card to name substitute decision maker



Wallet Card

In Case of Medical Emergency

I have a **Substitute Decision Maker** who can speak for me if I am unable to communicate my wishes regarding medical care:

Substitute Decision Maker: _____

Tel: _____

Alternative Tel: _____

Relationship to me: _____

Signature: _____ **Date:** _____



Toolkits for patients and families



Tips on how to make a plan

- Think about what's right for you
- Learn about end of life care options and treatments
- Determine who will make decisions on your behalf
- Have/begin the conversation
- Write down your wishes
- Review your plan regularly



Hot off the Press!



Advance Care Planning Workbook



Toolkits for agencies – get involved!



- Campaign kit
- Templates for posters, ads, news releases
- Bookmarks
- Wallet cards
- Broadcast PSA script
- FAQs on advance care planning
- Articles for newsletters or websites
- **Brand New – Video**



Toolkits for Professionals



- About advance care planning
- Tools to get the conversation going
- Tools to facilitate advance care planning
- Resources in different jurisdictions
- References/research materials



Advance Care Planning Resource Commons

The Advance Care Planning Commons enables each of us to share resources and to learn from each other's experience.



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Advance Care Planning Resource Commons

- A repository for sharing and uploading resources.
- Provides professionals – health, legal and planning with the resources they need to learn about advance care planning and to effectively engage in ACP.



Facilitating Advance Care Planning: An Interprofessional Education Program



Educating Future Physicians
in Palliative and End-of-Life Care

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Advance Care Planning Resource Commons: Sample Tools

Facilitating Advance Care Planning: An Interprofessional Education Program: Curriculum Materials

- Competency-based educational program/module on ACP
- Targets health care professionals across a range of disciplines and at all levels (undergraduate, postgraduate and continuing professional development).
- The curriculum details the steps in the ACP
- Addresses the importance of building organizational capacity for ACP including guidelines for policy development.
- Curriculum Materials and a Trainer's Guide



Social Marketing



- Online presence and promotion
- Website promotion via links, news stories, sharing sites, etc.
- Facebook / Twitter presence
- Videos / Youtube channel



Media and Partnerships



- Media pitches / story backgrounders
- News releases
- Radio shows
- Partnerships with NGOs, governments and service providers



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**It's about a conversation.
It's about choices.
It's how we care for each other.**

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