Advance Care Planning in Canada:

National Framework

for Consultation

Executive Summary

February, 2010

Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

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Executive Summary

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The Advance Care Planning in Canada:
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has been made possible through
financial contributions from:

The GlaxoSmithKline Foundation

Health Canada, through the Canadian Partnership Against Cancer

I. Introduction

Advance Care Planning (ACP) is a process of reflection and communication during which a person with decision-making capacity makes decisions regarding their future health and/or personal care in the event that they become incapable of consenting to or refusing treatment or other care. The process may involve discussions with healthcare providers and family and friends with whom the person has a relationship.

Because there have been many advances in medical technology, people with many complex diseases are living longer. As a result, healthcare decisions are becoming increasingly complex. Furthermore, under the law in Canada all individuals have the right to make their own care decisions. That is, individuals may engage in or refuse interventions and treatment as long as they are capable, regardless of previously documented plans or directives; and, capable adults have the right to express wishes, including oral or written advance directives that provide instructions about their healthcare choices during a time of future incapacity. Professionals across Canada have identified the importance of providing patient-centred care. Advance care planning promotes patient-centred care that focuses on respecting the patient's perspective on what matters most and then tailoring the care provided to support their preferences.

There is evidence in the literature that, among a number of patient populations, advance care planning discussions increase patient satisfaction with care. Recent research has concluded that advance care planning can affect patient outcomes and that end-of-life conversations between patients and physicians are associated with fewer life-sustaining procedures, lower rates of intensive care unit (ICU) admission, and less expensive medical care. The absence of ACP, in all its forms, was associated with worse patient ratings of quality of life in the terminal phase of their illness.

II. Why Do We Need a National Framework for Advance Care Planning?

In Canada, though there is general public support for advance care planning, only a minority engage in it. A number of groups across Canada are just beginning to understand the importance of ACP. There are pockets of strong expertise across Canada and other pockets with little knowledge. Information sharing is important across all of those jurisdictions. Raising the subject of advance care planning with people can be difficult for professionals/healthcare providers. Nevertheless, there is evidence to suggest that many consumers are eager to discuss advance care planning if they are given the opportunity in a supportive environment. Education, user-friendly tools, and resources are needed by professionals in all sectors and by consumers. There is a need to foster ongoing dialogue about advance care planning among the legal sector (including those who develop legislation), policy makers, healthcare providers, and consumers so that legislation, law, and policy can be legally and medically sound and socially responsive.

III. Goal of this National Framework

The goal of this national framework is to provide a model for advance care planning that can be used to guide all related activity, program development, and standards of practice across Canada.

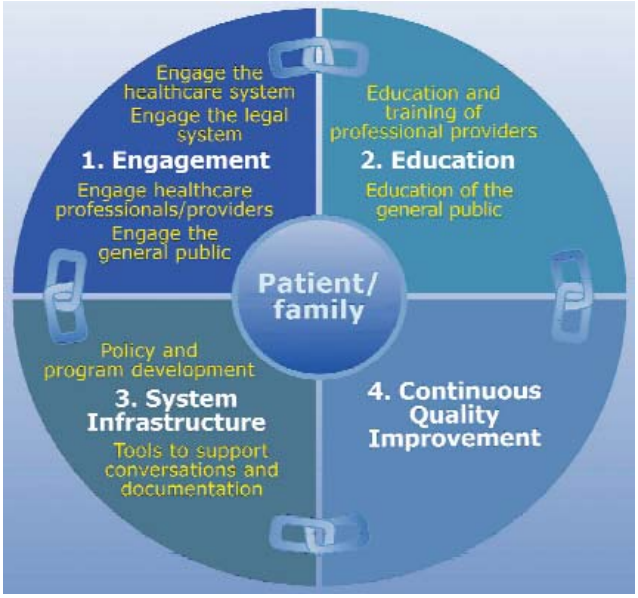
Implementing key recommendations in the framework will result in providing professionals/health-care providers with the tools they need to facilitate and engage in the process of advance care planning with their clients. It will raise the awareness of Canadians about the importance of advance care planning and equip them with the tools they need to effectively engage in the process. It will guide health system leaders/health authorities in their efforts to implement Advance Care Planning programs and services.

This national framework is being developed through a national consultative process that remains flexible and facilitates collaboration across sectors. This first draft of the Framework was developed by the Advance Care Planning in Canada: National Framework Project Task Group—a group that represents national professional organizations and non-governmental groups concerned with advance care planning and experts in the field.

IV. The Framework

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.

Framework for Advance Care Planning in Canada



Adapted with permission from Health Canada. Implementation Guide to Advance Care Planning in Canada: A Case Study of Two Health Authorities. March 2008. *http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/pal-liat/2008-acp-guide-pps/acp-guide-pps-eng.pdf*

Each block of the model is essential and all blocks must connect and function together in order for the model to be effective. There are a number of essential activities within each of the four basic building blocks.

1. Engagement
   - 1.1 Engage the healthcare system
   - 1.2 Engage the legal system
   - 1.3 Engage healthcare professionals/providers
   - 1.4 Engage the research community
   - 1.5 Engage the general public
2. Education
   - 2.1 Education and training of professionals/providers
   - 2.2 Education of the general public
3. System Infrastructure
   - 3.1 Policy and program development
   - 3.2 Tools to support conversations and documentation
4. Continuous Quality Improvement

1. Engagement

GOAL:
To engage all relevant systems/organizations/governments, professionals, providers, and the general public in planning for, and implementing, advance care planning in Canada.

1.1 Engage the healthcare system

Advance care planning can be integrated into the continuum of care – primary care; diagnosis of a chronic illness; and diagnosis of a serious and progressive illness. Evidence has shown that leadership and organizational support within the health care system are critical to the implementation of advance care planning. ACP is best facilitated by a combination of professionals – including physicians – initiating and having the discussions, combined with educational materials repeatedly over time. While research is developing regarding advance care planning, there remain many unanswered questions.

Recommendations to engage the healthcare system

1.1.1 Provincial/territorial ministries of health develop strategies to implement advance care planning programs within their jurisdictions that are modeled after the National Framework and reflect their own legislative environments and health and social service frameworks.

1.1.2 Advance care planning be integrated into the health care delivery system at the local level among local/regional health authorities at all points along the continuum and in all settings.

1.1.3 Funding must be available to encourage health care professionals – particularly those who bill on a fee for service basis – to spend the requisite time engaging in this process with patients and family members. A specific code in fee schedules for provincial/territorial health insurance plans is crucial to engagement.

1.1.4 Develop a research agenda in Canada that identifies the priorities for research in advance care planning.

I.2 Engage the legal system

In Canada, capable adults have the right to make oral or written advance directives that provide instructions about their health care choices during a time of future incapacity. Furthermore, over the past 15 to 20 years, legislation has been enacted in almost all provinces and territories across Canada to codify the right of a capable adult to make arrangements about personal choices for future health care. One of the challenges faced by Canadians is that these laws are not harmonized. In some jurisdictions, legislation enables a capable adult to appoint another person or persons to make decisions for him or her in the event of incapacity. Provinces and territories provide legal recognition for different forms of written advance directive. Since laws differ across the country, professionals must know what the law says in their own province/territory. Increasingly, Canadians are putting what they want for future care in writing in formal signed documents. A written document can be a helpful record of the person's wishes. It is important to note, however, that advance care planning encompasses more than written documents.

Recommendations to engage the legal system

1.2.1 Conduct a cross-Canada review and analysis of the provincial/territorial legislation that is relevant to advance care planning – including an analysis of enablers and barriers.

1.2.2 Develop and maintain provincial/territorial primers for clinicians regarding the laws influencing advance care planning in their jurisdiction.

1.2.3 Develop/adapt and disseminate materials that assist legal professionals to recognize their role in advance care planning.

I.3 Engage healthcare professionals/providers

Most health care professionals have a positive attitude towards advanced care planning. However, the majority do not engage in it. While there may be barriers to health care professionals engaging in advance care planning, as a profession they recognize the value and need for advance care planning. Health care professionals have ethical obligations to honour a person's advance care choices wherever possible and to know the legal requirements – as stated in their Codes of Ethics. There are several reasons why professionals are reluctant to engage in the ACP discussion. These include discomfort with end-of-life discussions, fear of legal repercussions, time constraints, and limited reimbursement.

Recommendations to engage healthcare professionals/providers

1.3.1 Develop/adapt and disseminate materials that assist healthcare professionals to recognize their role in advance care planning and offer it as part of routine clinical practice. These professionals include: physicians – family physicians and specialists; registered nurses and nurse practitioners – in acute, community, chronic and long-term settings; spiritual care counsellors; social workers; and case managers.

1.3.2 Develop/adapt and disseminate materials that inform healthcare professionals of the evidence relating to advance care planning and engage them in the process to develop a research agenda that will address unanswered questions.

1.3.3 Encourage relevant professional associations to engage their members in addressing advance care planning and the barriers related to advance care planning.

I.4 Engage the general public

One of the major barriers to advance care planning is the lack of understanding among the general public that advance care planning is a process and encompasses much more than the generation of advance directives or living wills. Engaging our Canadian communities in advance care planning will involve raising awareness, initiating dialogue, and connecting people to the resources, mechanisms, and organizations involved in ACP. This will involve a number of strategies – dissemination of printed materials and resources through healthcare contacts, non-governmental organizations, community settings, and Web presence.

Recommendations to engage the general public

1.4.1 Engage in a public awareness campaign to assist the general public in recognizing the importance of advance care planning and its relevance to their situation.

1.4.2 Develop/adapt and disseminate materials that assist the general public in recognizing the importance of advance care planning and its relevance to their situation.

1.4.3 Develop/adapt and disseminate materials that assist provincial, territorial, local and regional organizations with engaging their local communities in advance care planning.

2. Education

GOAL:
To educate healthcare, legal, and social service professionals and the general public about advance care planning.

2.1 Education and training of professionals/providers

In spite of the importance of the engagement of healthcare professionals in advance care planning, they often lack the preparation and the support to actively initiate the process. In order for an ACP initiative to be successful, healthcare providers must have the knowledge and clinical skills required to ensure a consistent application of program elements. Facilitation of advance care planning conversations is essential to the success of the communication, reflection, and decision making undertaken by patients and those close to them. All healthcare team members require education and support to facilitate these conversations and, this must become part of the core skill set for all clinicians.

Recommendations for education and training of professionals/providers

2.1.1 Integrate education regarding advance care planning into the undergraduate and graduate education of all relevant healthcare and legal professionals.

2.1.2 Develop and support role models and mentors in healthcare settings.

2.1.3 Develop online continuing medical education (CME) modules for professionals in advance care planning.

2.1.4 Invite all professional groups and organizations to post their existing tools on the Web so that they can be easily accessed by others.

2.1.5 Provide training for practicing healthcare and legal professionals – both basic education and continuing education.

2.2 Education of the general public

Advance care planning is a relatively new concept to the general public. One of the major barriers to ACP is the lack of understanding among the general public that advance care planning is a process and encompasses much more than the presence of advance directives or living wills.

Recommendations for education of the general public

2.2.1 Develop/adapt public education materials regarding ACP for the general public and disseminate in a wide variety of media.

2.2.2 Develop standard toolkits that can be shared across Canada and adapted locally.

2.2.3 Develop, and make available for the general public, online and toll-free resources in ACP.

3. System Infrastructure

GOAL:
To create infrastructure in the health and legal systems that facilitate organizations, professionals, and the general public's engagement in advance care planning in Canada.

3.1 Policy and program development

Evaluation research has identified critical keys to success and challenges when implementing advance care planning programs. There is consensus, based on Canadian experience and the literature, regarding what constitutes the essential program elements that need to be incorporated into any advance care planning initiative. They are organizational commitment; guiding principles and value statements; public awareness; healthcare provider education and training; system infrastructure support; sector integration; and evaluation.

Recommendations for policy and program development

3.1.1 Provincial/territorial ministries of health develop policies and programs to support the implementation of advance care planning programs within their jurisdictions based on Canadian and international experiences and are reflective of their own legislative environments and health and social service frameworks.

3.1.2 Local/regional health authorities and their institutions and agencies develop policies and programs to support the implementation of advance care planning programs.

3.1.3 Specific standards relating to advance care planning be integrated into the accreditation guidelines for all aspects of acute care; long-term care; hospice/palliative care; and community care.

3.2 Tools to support conversations and documentation

In order for professionals and the public to engage in advance care planning they require a number of tools. As well, in order to ensure that the advance care plan follows the patient and family throughout their experience with the system, tools are required to enable documentation. Tools can include quick reference guides and tools that support advance care planning conversations and documentation of ACP outcomes. This allows for a consistent approach to engaging clients and consistent reporting of conversations and outcomes. A small number of jurisdictions have developed advance care planning tools for healthcare providers and patients.

Recommendations for tools to support conversations and documentation

3.2.1 Adapt/develop evidence-based tools to support and enable healthcare providers and legal professionals to engage in advance care planning effectively that can be available and utilized across Canada.

3.2.2 Adapt/develop evidence-based tools to support and enable the general public to engage in advance care planning effectively that can be available and utilized across Canada.

3.2.3 Encourage the sharing of tools across jurisdictions and agencies.

3.2.4 Encourage/support research activities that demonstrate the effectiveness of tools in supporting healthcare providers and legal professionals to engage in advance care planning.

4. Continuous Quality Improvement

GOAL:
To evaluate all advance care planning initiatives in Canada based on structure, process, and outcomes indicators.

Continuous quality improvement is best integrated into advance care planning from the beginning of program development. The elements of continuous quality improvement include a corporate culture that promotes quality improvement as a key component of evidence-based practice; development and testing of measurement and evaluation tools; development of performance indicators; mechanisms for sharing what is learned from evaluation; and ongoing incorporation of evaluation results into practice. ACP programs in Canada are still in the early stages of development. The evidence noted in the literature is just developing at this point in time with respect to its impact on patient and family outcomes. Programs must incorporate evaluation and continuous quality improvement.

Recommendations for continuous quality improvement

4.1.1 Develop a research agenda in Canada relating to advance care planning – identifying the priorities for research.

4.1.2 Develop/adapt a continuous quality improvement framework for jurisdictions to use when implementing advance care programs in Canada.