

Advance Care Planning in Canada:
National Framework

January, 2012



Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

Advance Care Planning in Canada: National Framework



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Advance Care Planning in Canada: National Framework

Preamble and Assumptions

This document is the beginning of a national framework for advance care planning in Canada. Over the next months, this Framework outline will be revised and populated based on consultations with stakeholders across the country.

The 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 — who, along with experts in the field, are a group that represents national professional organizations and non-governmental groups concerned with advance care planning. The members of this group are found on the inside of the front cover.

In Canada, we have a number of different systems and jurisdictions that are responsible for health, justice, and social services. Therefore, there is a need for the Framework to be flexible enough to be adapted for these various systems and/or jurisdictions. However, no matter what the system or jurisdiction, there are common principles that underlie advance care planning. Therefore, these guiding principles are articulated in the Framework.

Laws vary from jurisdiction to jurisdiction in this regard, and questions remain as to whether a health care practitioner can administer or withdraw treatment of an incapable person without the consent of his or her substitute decision maker.

Across the country, there are different legal points of view with regard to the use of written advance care plans and the need for health care providers to consult with substitute decision makers to obtain consent to treatment when a person lacks capacity. This Framework does not purport to be the final legal word on this issue. However, the approach taken in this Framework is one that can be applied in all jurisdictions: if a person is not capable of consenting to treatment (including the withdrawal of treatment), then consent must be given on his or her behalf by a substitute decision maker. Such substitute consent must be in keeping with an individual's wishes and their advance care plan since that is the expression of his or her wishes. It is critical that professionals and individuals/families be familiar with the specific legislation in their jurisdiction.

This advance care planning Framework is seen through a health lens recognizing and building on the interaction with the legal and ethical frameworks across the country and professions. It is important that this Framework give guidance to how we would operationalize advance care planning in a defined healthcare system. In addition, the Framework will attempt to articulate how this health lens communicates with the legal and ethical systems/frameworks across the country and across professions.

The Framework includes a number of recommendations for action. These recommendations are addressed to a wide audience — governments at all levels, the non-governmental sector, and health-care, legal, and social services professionals. All of whom have a responsibility in supporting advance care planning in Canada.

Important Definitions

Advance Care Planning (ACP): ACP is the development and expression of wishes for the goals of medical treatment and the continuation or discontinuation of such treatment and care. It involves discussions with family and friends with whom the person has a relationship, and may involve healthcare providers, and/or lawyers who may prepare wills and powers of attorney. Advance care planning also involves naming a substitute decision maker (SDM).

Advance Care Plan: An Advance Care Plan is a written document setting out a person's wishes with respect to medical treatment or personal care, and may include detailed instructions as well as expressions of the person's values, beliefs and goals of care. The Advance Care Plan will inform the person's SDM with respect to treatment or care decisions. It may be provided to the healthcare professionals or others, but it is not a substitute for consent to treatment or personal care.

Advance Directive: An Advance Directive is a capable person's documented expression of wishes with respect to the continuation or discontinuation of medical treatment. If applicable in the circumstances, an Advance Directive will direct substitute decision makers as to how to give or refuse consent on the person's behalf when the person is no longer capable for the particular care or treatment decision. If no known substitute decision maker is available, the Advance Directive will direct healthcare professionals and the substitute decision maker of last resort (i.e. the Public Guardian and Trustee) in the event the person becomes incapable. The preparation of an Advance Directive may be one part of the ACP process.

Capacity and Incapacity: A person is capable of giving or refusing consent to care or medical treatment if he or she is able to understand the information relevant to making a decision with respect to the care or treatment and is able to appreciate the reasonably foreseeable consequences of that decision or lack of decision. A person is incapable if he or she is not able to understand the information relevant to a medical decision or if he or she is not able to appreciate the reasonably foreseeable consequences of such decision. Capacity is to be assessed by the health care practitioner who is proposing the treatment or plan of treatment (which may include the withdrawal of treatment). A person will be able to appreciate the consequences of the decision if he or she is able to acknowledge that the condition for which treatment is recommended may affect him or her, to understand how the proposed treatment or lack of treatment could affect his or her quality of life, or to explain why he or she is making a decision in a manner that aligns with the person's previously expressed values — this provides another check on capacity. Where a decision contradicts the person's previously expressed values or beliefs, this may indicate that the person is unable to appreciate the consequences of the decision.

Consent: The component elements of consent include:

- Voluntariness (e.g. lack of coercion)
- The requirement that consent be given by the patient or if the patient lacks capacity, the legally authorized substitute decision maker
- Reference to the particular treatment and administrator of the treatment
- Full information about the risks, benefits and side effects of the particular treatment; the alternatives to the particular treatment, including not having treatment, and the risks and benefits of these alternatives.

Public Guardian and Trustee/Québec Public Curator: The decision maker of last resort in some jurisdictions, who will make decisions for an incapable person where, no other SDM exists or where equally ranking SDMs disagree about a treatment decision.

Substitute Decision-Maker: or SDM is a person who will make decisions on behalf of person in circumstances where he/she is incapable of a particular care or treatment decision.

I. Introduction

I. Advance Care Planning

Advance Care Planning (ACP) is a process of reflection and communication in which a person with decision-making capacity expresses his or her wishes regarding his or her future health and/or personal care in the event that he or she becomes incapable of consenting to or refusing treatment or other care. The process should involve discussions with family and friends with whom the person has a relationship, and may involve healthcare providers, and/or lawyers who may prepare wills and powers — or the person who will make decisions on behalf of a person in circumstances where he/she is incapable of a particular care or treatment decision.

2. Why is Advance Care Planning Important?

There have been many advances in medical technology and people with many complex diseases are living longer. As a result, healthcare decisions are becoming increasingly complex. In this complicated environment, discussions regarding values, wishes, and preferences for care — on an ongoing basis — are critical.

The majority of Canadians die while receiving care from health professionals. And in fact, the majority of Canadians die of a chronic illness. There is a large proportion of persons who cannot make their own decisions when they are near death. Their loved ones will have a significant chance of not knowing their views without having discussed them in advance.

Under the law in Canada, all individuals have the right to make their own care decisions. That is, individuals have the right to engage in or refuse interventions and treatment as long as they are capable of the particular care or treatment decision and regardless of previously documented plans or directives. Furthermore, capable adults have the right to express wishes through 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 person-centred care.¹ Advance care planning promotes person-centred care that focuses on respecting an individual's perspective on what matters most and then tailoring the care provided to support those perspectives. Person-centred care offers people choices. It also supports peoples' rights to either consent to or refuse the treatment and care that is offered. In addition, advance care planning can decrease uncertainty, which decreases distress and anxiety for families, and moral distress for healthcare providers.

There is evidence in the literature that among a number of populations, advance care planning discussions increases patient satisfaction with their care. This includes people/patients with long-term conditions^{2 3 4 5 6} and those receiving care at the end of their lives.^{7 8 9 10 11} A recent systematic review

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of the evidence concluded that advance care planning can affect outcomes such as the completion of advance directives or powers of attorney for personal care, improvements in adherence to the individual's wishes, and patient and substitute decision maker satisfaction, understanding, and comfort.¹²

In recent studies, end-of-life conversations between patients and physicians were associated with fewer life-sustaining procedures and lower rates of intensive care unit (ICU) admissions. The absence of ACP, in all its forms, was associated with worse patient ratings of quality of life in the terminal phase of the illness, and worse ratings of satisfaction by the family during the terminal illness or in the months that follow death.¹³ The researchers concluded that increasing communication between patients and their physicians is associated with better outcomes and with less expensive medical care. Furthermore, these results were consistent with other studies showing that the greatest cost differences come from a reduction in acute care services at the end of life.¹⁴ The studies also reported that people with advanced cancer who had end-of-life conversations with physicians had significantly lower healthcare costs in their final week of life. Higher costs were associated with worse quality of death.¹⁵ A Canadian study found that systematically implementing an advance directive program in nursing homes resulted in fewer hospitalizations and less resource use.¹⁶

3. The Process of Advance Care Planning

Advance care planning is a process:

- Of reflection and communication about values, beliefs and goals of care;
- Of planning for a time when a person cannot make their own medical decisions;
- That involves discussions with friends, family and significant others, as well as professionals – healthcare, legal, etc.; and
- That may result in an advance directive.

Advance care planning requires a number of conversations so that individuals can clarify and articulate their wishes for future care with their families. These conversations, which can happen at various times and stages, are fluid and dynamic. The conversations should occur in a non-stressful environment, where possible. What is important is that advance care planning should be a process rather than a single event.^{17 18 19} Some think that a DNR or do not resuscitate order constitutes advance care planning. Though it is part of ACP, ACP is much more than that. ACP involves conversations, preferences and defined wishes for the goals of medical treatment – the initiation, continuation and discontinuation of treatment. Advance care planning may result in the creation of an advance directive or living will or it may simply be a verbal account of previously expressed wishes.²⁰

Advance care planning also involves making choices about personal care, including wishes related to where one decides to be at the end of their life – for example, at home or in an institution.

Advance care plans and advance directives must be voluntary and focus primarily on principles and values. They are not 'tick boxes'. Consent to treat or refusal of treatment is still required, and must be obtained by the health care practitioner proposing treatment. Advance care plans or advance directives should be prepared only after consultation with a health care provider and may involve legal advice.

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The following is a summary of what the process of facilitating advance care planning can involve.²¹ With support from healthcare providers, the person doing advance care planning may engage in some or all of these process steps:

Focusing on principles and values

- Identifying the values and beliefs around end-of-life issues that are important such as:
 - Considering what makes their life meaningful;
 - Determining under what circumstances the burdens of treatment would outweigh any benefits of prolonging their life;
 - Assessing the quality of life that the treatment offers; and
 - Considering how one wants to live during the final stage of life (e.g. at home, pain free, etc.).

Considering personal care choices

- Determining what options for care and treatment could be considered along a disease trajectory.
- Using structured discussions with the care team and other resources to learn about the implications of possible medical treatments for the very ill or injured, such as artificial ventilation, nutritional support, hydration, and cardiopulmonary resuscitation (CPR).
- Taking into consideration the person's state of health and their goals for future healthcare including comfort care and life sustaining or prolonging measures, contemplate how treatment choices would reflect his or her values, culture, beliefs and goals, and affect quality of life.
- Participating in decision making regarding their goals of care so that the care the person receives honours their values, beliefs, wishes, culture, and faith.
- Specifying wishes regarding organ, gamete, tissue or whole body donation, and participating in research.

Discussing choices

- Providing him or her with an opportunity to express wishes for future treatment decisions and to identify which wishes are to be followed by substitute decision makers.
- Discussing these choices and wishes with those closest to him or her, particularly those who would be called upon to give or refuse consent to treatment and to make healthcare decisions for the person in the event of incapacity. This discussion enables loved ones to know the individual's wishes in different situations.
- Updating the advance care plan as is needed.

Obtaining legal advice

- While legal advice is not necessary to prepare an Advance Care Plan or to engage in advance care planning, a lawyer can provide advice which is integral to the planning process. A lawyer can explain the person's right to consent, issues of task and time-specific capacity, and the role of the SDM in giving consent. He/she can define wishes in an advance directive, consult on the selection of an appropriate SDM and/or hold a family meeting to facilitate the communication of wishes during the process of ACP. A person contemplating engaging in advance care planning is encouraged to consult with a lawyer.

In addition, there are many public legal education organizations across Canada that can help in providing the legal information necessary for advance care planning.

Choosing a substitute decision maker (SDM)

Choosing someone to act as a substitute decision maker if the time comes when he or she cannot make their own medical decisions and identifying that person in a written document (e.g., Power of

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Attorney for Personal Care or other instrument) will ensure that the person's decisions are made by the SDM of his or her choosing.

Documenting choices

- Documenting or having documented in the person's medical record or elsewhere, the person's discussions and the advance care plan will confirm the person's wishes and inform the SDM and health care team. (This would have to be done following the requirements of the legislation of the province/territory in which the person lives.)
- While not strictly necessary, the substitute decision maker may sign any written advance care plan and attest to having read, understood and discussed the document with the person making it. Signatures should be witnessed.
- Identifying where the written advance care plan is stored, attending to privacy concerns.

The healthcare provider can help the person establish their treatment goals. The provider should also:

- Document discussions and decisions related to the person's advance care plan in the medical record and provide the person with a copy of any such plans to share, as they choose, with their family, loved ones, or substitute decision maker.
- Implement a process for periodically reviewing and updating the advance care plan and treatment decisions as the goals of care change.²²

It is important to remember that advance directives are evidence of an individual's prior wishes, but are not to be relied upon for consent. Consent is always required for each treatment or change in treatment, whether or not an advance directive exists. Advance directives do not function as the individual's or substitute's consent. Consent must be sought from the individual if capable, or the legally authorized substitute decision maker if the person is incapable of the decision in question. Health care providers cannot consent for their patients, nor rely on the advance directive in the absence of consent to or refusal of a particular treatment (except in an emergency where no SDM is available). There must be a clear determination of the individual's incapacity for the decision in question prior to obtaining consent from the substitute. There are mechanisms in place in the provinces/territories to determine who the substitute is if none has been named.

There is a legal framework to follow that includes the need for consent, with all its component elements which include:

- voluntariness (e.g. lack of coercion)
- the requirement that consent be given by the patient or if the patient lacks capacity, the legally authorized substitute decision maker
- reference to the particular treatment and administrator of the treatment
- full information about the risks, benefits and side effects of the particular treatment; the alternatives to the particular treatment, including not having treatment, and the risks and benefits of these alternatives.



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

There is considerable evidence that advance care planning is poorly done, often happening only at the very end of life when crises occur, or when life-sustaining treatments have been instituted despite issues of poor prognosis.

In 2000, the Canadian Senate report updating the *Quality End-of-Life Care: The Right of Every Canadian* identified that there were many problems with preparing advance directives in Canada, that the difficulties were primarily with the singular focus on advance directives, and it suggested moving towards the process of conversation or advance care planning. The report recommended that advance directions should be seen as part of an overall planning and communication process that helps people prepare for death in the context of being supported by, or making decisions with, their loved ones. The report stated,

“The preparation of an advance directive can facilitate discussions between people and their family, and provide guidance and support for substitute decision makers who must make the difficult decisions regarding life-sustaining treatment. If loved ones and medical professionals have engaged in a process of serious communication, the problems associated with the interpretation and application of advance directives are much less likely to occur. The passage to death is eased, the level of comfort rises, and the burden of care is lightened for the substitute decisions-maker.”²³

In Canada, though there is general public support for advance care planning, only a minority engage in it. According to a 2004 poll conducted by Ipsos-Reid on behalf of the Canadian Hospice and Palliative Care Association and GlaxoSmithKline:²⁴

- Eight in ten Canadians agreed that people should start planning for end of life when they are healthy.
- 70% of Canadians had not prepared a living will or Advance Directive.
- 47% of Canadians have not designated a substitute decision maker to make healthcare decisions for them if they are unable.
- Fewer than 44% Canadians have discussed end-of-life care with a family member.
- Although Canadians felt that end-of life care was an important discussion to have with a physician, only 9% had done so.

The literature supports these findings. A recent review of the literature²⁵ found that most of the general public (60-90%) is supportive of advance care planning^{26 27 28 29 30 31} but only 10 to 20% of the public in the US, Canada, and Australia have completed an advance care plan document of any kind.^{32 33 34 35}

There will be an increasing need to focus on advance care planning with the changing demographics. Most Canadians die in old age and most have two or more chronic diseases.³⁶ The leading causes of death in Canada are diseases of the circulatory system (about 35%), neoplasms (tumors or cancers) (about 28%) and diseases of the respiratory system (about 10%)³⁷. These chronic illnesses account for 73% of all Canadian deaths. And chronic disease is on the rise. For example, the number of people living with Alzheimer’s disease and related dementias is expected to double to 1.1 million people by 2038, when almost 3% of the population will have some form of dementia.³⁸

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A number of groups across Canada are just beginning to understand the importance of ACP. A review of the status of advance care planning across Canada has concluded that there are pockets of strong expertise across Canada but other pockets with little knowledge. Information sharing is important across all of those jurisdictions.^{39 40} These reviews concluded that raising the subject of advance care planning with people can be difficult for professionals/healthcare providers. Nevertheless, there is evidence to suggest that many patients 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 patients and families and by professionals in all sectors. There is a need to foster ongoing dialogue about advance care planning among patients/families, the legal sector (including those who develop legislation), policy makers and healthcare providers so that legislation, law and policy can be both legally and medically sound and socially responsive.

The fact that existing written advance directives⁴¹ are not adequately prepared or utilized indicates that many people and professionals have not participated in *effective* advance care planning. A review conducted in the U.S. found that less than 50% of the people studied who were severely or terminally ill had an advance directive in their medical record; only 12% of those with an advance directive had received input from their physician in its development; and having an advance directive did not increase documentation in the medical chart regarding their preferences for care.³⁹

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 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 result in providing professionals/healthcare providers with access to the tools they need to facilitate and engage in the process of advance care planning with their clients. It will guide health system leaders/health authorities in their efforts to implement Advance Care Planning programs and services.

I. Guiding Principles Related to Advance Care Planning

The following principles guide all aspects of advance care planning:

Individual respect

- Each person is intrinsically valuable, unique, and has the moral right to autonomous decision-making.
- Advance care planning is guided by the quality of life individuals have assessed as acceptable for themselves.
- Healthcare professionals enter into a therapeutic relationship with patients and families based on mutual respect for the inherent dignity and integrity of all parties.
- Advance care planning must occur within the context of, and with respect for, an individual's (patient's) and family's personal, cultural, and religious values, beliefs and practices regarding the quality of life and dying, their developmental state, and preparedness to deal with the dying process.
- Advance care planning is only facilitated when the patient and family are prepared to accept it.

Need for support and collaboration

- Advance care planning conversations can be difficult and support is often needed for individuals (patients), families, substitute decision makers and care providers so that they can engage in these discussions in a meaningful way.
- Advance care planning requires collaboration and integration across many sectors — health, social, and legal.

Professional and legal responsibilities

- Whenever possible, professional and healthcare providers should engage in conversations regarding advance care planning with individuals (patients), substitute decision makers and families, according to the ethical/legal framework of their profession and the laws of their jurisdictions.
- Healthcare providers have a responsibility to practice within the policies and laws/legal framework of their institution and jurisdiction. Whenever possible, they should inform themselves of the laws/legal framework surrounding advance care planning in their jurisdiction.



Self-reflection

- The ability for healthcare providers to engage in meaningful advance care planning will be influenced by their ability to reflect on their own experiences and values.

Quality of advance care planning activities

- Advance care planning programs and tools should be informed by the highest quality of available evidence. Ongoing evolution of advance care planning programs should be guided by emerging research in this area.
- All advance care planning activities are guided by the following:
 - The ethical principles of autonomy, beneficence, nonmaleficence, fidelity, justice, truth-telling and privacy and confidentiality;
 - Standards of practice that are based on generally accepted principles and norms of practice across the country, and standards of professional conduct for each discipline;
 - Policies and procedures that are based on the best available evidence or opinion-based preferred practice guidelines; and
 - Data collection/documentation guidelines that are based on validated measurement tools.

Ongoing education

- Introductory and ongoing education of individuals (patients), families, caregivers, professionals and stakeholders is integral to the continuing provision and progression of quality advance care planning.

Framework for consent

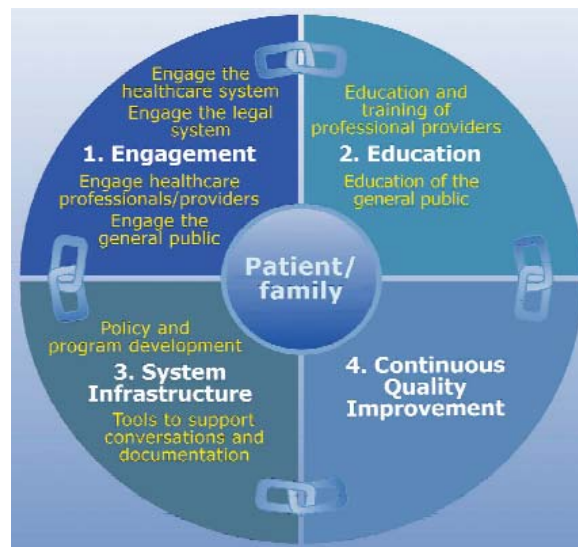
- The legal framework to follow for ACP includes the need for consent, with all its component elements which include:
 - voluntariness (e.g. lack of coercion)
 - the requirement that consent be given by the patient or if the patient lacks capacity, the legally authorized substitute decision maker
 - reference to the particular treatment and administrator of the treatment
 - full information about the risks, benefits and side effects of the particular treatment; the alternatives to the particular treatment, including not having treatment, and the risks and benefits of these alternatives.

IV. The Framework

The Framework builds on work that has been done in Canada regarding advance care planning. The former Calgary Health Region (now Alberta Health Services) and Fraser Health Authority, with financial support from Health Canada, led the development of a guide for healthcare authorities implementing advance care planning. A working group established this model in March 2008. They proposed a model with the individuals and families featured at the centre and four basic building blocks⁴² — engagement; education; system infrastructure; and continuous quality improvement.

This Framework is based on this model.

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/palliat/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. The Framework includes key activity areas under each of the blocks:

1. Engagement

- 1.1 Engagement of the healthcare system including policy makers, health authorities, bureaucrats and politicians
- 1.2 Engagement of the legal system
- 1.3 Engagement of healthcare professionals/providers/planners
- 1.4 Engagement of the research community
- 1.5 Engagement of the general public

2. Education

- 2.1 Education and training of professionals/providers
- 2.2 Education and training of policy makers
- 2.3 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

I. 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.

In order for advance care planning to be successfully implemented, engagement of key organizations, communities, and professionals is critical. This engagement is important at the following levels

- Systems/Organizations/Governments
 - Policy and decision makers
 - Federal/provincial/territorial and regional/local health authorities responsible for healthcare
 - Federal/provincial/territorial government departments responsible for seniors' care
 - Provincial/territorial/regional cancer agencies
 - Federal/provincial/territorial government departments responsible for the design and enactment of laws
 - Institutions and agencies providing healthcare, home care and programs/services for patients, and particularly seniors.
- Professionals and Providers
 - Healthcare professionals including physicians, nurses and social workers
 - Spiritual care workers and clergy
 - Lawyers and Notaries in the Province of Québec
- General Public

I.1 Engage the healthcare system

Key Messages

- Advance care planning can be integrated into the continuum of care – primary care; diagnosis of a chronic illness; diagnosis of a serious and progressive illness and when there is a change in function/condition of an individual.
- Leadership and organizational support within the healthcare system are critical to the implementation of advance care planning.
- Advance care planning is best facilitated by a combination of professionals – including physicians – working with individuals and families.
- Advance care planning is best facilitated by having discussions repeatedly along with educational materials.
- While research is developing regarding advance care planning, there remain many unanswered questions.

It is important for advance care planning to be integrated consistently across the continuum of care of the healthcare system.

There are a number of settings and points along the continuum of care where advance care planning can be integrated within the primary care relationship:

- Enrollment with a family health team, family physician or nurse practitioner's office.
- At the time of diagnosis of, and/or hospitalization for, a serious and progressive illness or a life-limiting illness provide opportunities for integration.^{44 45 46 47 48}
- At the time of diagnosis of a chronic illness is another critical time to engage an individual in advance care planning conversations.^{49 50 51 52 53 54}
- At the time of a change in function/condition of an individual.

Primary care is an important setting where advance care planning can be integrated into routine care.^{55 56 57 58} Family physicians and nurse practitioners are in the ideal position to discuss advance care planning with their patients by introducing it into routine visits and following-up at subsequent visits.^{59 60} These visits provide an opportunity to initiate a conversation with healthy capable adults that will create awareness, normalize advance care planning, and start the planning process.

Therefore, advance care planning conversations can be held in a number of settings – of course, always with capable adults: in the offices of family physicians and health clinics; home health settings; acute care; chronic care clinics and residential care.

Experience in Canada has demonstrated that organizational support is critical to the implementation of advance care planning. This involves development and implementation of related policy and procedures, dedicated human and fiscal resources to support program development, and the identification of champions within the organization to take on leadership roles.⁶¹ Senior administrators need to be supportive of advance care planning development and implementation within their organization. There is a need for ongoing investment of time, energy and resources in order for program implementation to be successful.⁶²

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Experience has also confirmed that advance care planning initiatives support many existing organizational policies and priorities in the healthcare system. These include provincial/territorial policy and regulatory frameworks, accreditation, and a variety of health and social service frameworks, for example chronic disease management, interprofessional practice, and patient safety.⁶³ It is important to demonstrate these connections.

Research and experience has demonstrated the following.

- Advance care planning is best facilitated by a combination of professionals initiating and having the discussions, combined with educational materials.^{64 65 66 67 68 69 70}
- The process may unfold over multiple sessions.^{71 72 73 74}
- Physician involvement is key.^{75 76 77}
- As advance care planning is dynamic, healthcare professionals should be routinely reminded to offer advance care planning discussions at an appropriate time to their patients.^{78 79 80 81}

While research is developing regarding advance care planning, addressing the barriers and enablers to its implementation and the impacts and outcomes of engaging in advance care planning, there remain many unanswered questions.⁸²

Recommendations to engage the healthcare system

- 1.1.1 That 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 That advance care planning be integrated into the healthcare delivery system at the local level among local/regional health authorities at all points along the continuum and in all settings.
- 1.1.3 That funding be available to encourage healthcare 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 That a research agenda that identifies the priorities for research in advance care planning be developed in Canada.

I.2 Engage the legal system

Key Messages

- In Canada, capable adults have the right to make oral or written advance directives that set out wishes to provide instructions to their SDM about their healthcare choices during a time of future incapacity.
- 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 healthcare.
- 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 directives.
- Since laws differ across the country, professionals must know what the law says in their own province/territory.
- Increasingly, Canadians are setting out in writing what they want for future care 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.

Background

Canadian common law recognizes the right of capable adults to make oral or written advance directives that provide instructions about their healthcare choices during a time of future incapacity. Such directives may include the adult's preferences regarding the type of treatment he or she wishes to accept or refuse under certain circumstances, and may appoint individuals to speak on the person's behalf during a future period of incapacity.⁸³

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 healthcare.⁸⁴

One of the challenges faced by Canadians is that these laws are not harmonized.⁸⁵ This results in different requirements under the various provincial/territorial statutes.

- 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. Different terms are used to describe that person – e.g., substitute decision maker or proxy.⁸⁶
- Provinces and territories provide legal recognition for different forms of written advance directives. For example, Ontario has *powers of attorney for personal care*, Alberta has *personal directives* and Nova Scotia has *written authorizations*.⁸⁷

Mental capacity to make healthcare decisions is a central issue in advance care planning. Only a capable adult can make an advance directive, or make a wish that is binding on his or her substitute decision maker, and the directive or wish is only in effect if and when the person becomes incapable. Legally, adults are presumed capable to give or refuse consent unless it is established that they are not capable with respect to a particular treatment decision. There are definitions of *capacity* or *competence* in some of the provincial/territorial legislation — and they differ.⁸⁸ Furthermore, healthcare



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professionals must always obtain consent to treatment from a person capable of the particular care or treatment decision. Some provinces/territories have specific consent to treatment legislation.⁸⁹

Since laws differ across the country, professionals must know what the law says in their own province/territory and they need to address such questions as:

What form of advance directive or wish is recognized? Is there a definition of capacity or competence? What is it? Does the law specify an age below which one cannot make an advance directive? What is it? Does the law enable a person to appoint a substitute decision maker? Does it allow the healthcare provider to take instructions from an advance directive or must he/she speak with a substitute decision maker before providing (or not providing) treatment? If there is no substitute decision maker appointed, to whom does the healthcare provider turn? Does the law specify a hierarchy of people who can make treatment decisions for an incapable person?

Increasingly, for practical reasons, Canadians are putting what they want for future care in written, formal signed documents. A written document can be a helpful record of the person's wishes. It is important to note, however, that a person may indicate their wishes or preferences for future care in different ways. While still capable, the person may talk with loved ones and/or with healthcare providers about their values, wishes, and goals of care. They may use alternative forms of communication such as audiotapes. In most provinces, oral advance directives or expressions of wishes govern the manner in which substitute decision makers give or refuse consent, and medical ethics codes direct physicians to record and follow them as much as possible.⁹⁰ Advance care planning encompasses more than written documents.

What are some of the key considerations when engaging the legal sector?

- It is important that the laws enable adults to make treatment preferences known.
- People benefit most from a choice of planning instrument – both *proxy* and instructional advance directives – these are not mutually exclusive planning documents.
- Planning documents must be easily accessible and simple to execute.
- Legislation must incorporate the ideals of patient autonomy and self-determination.
- The patient's goals must be at the heart of every advance care planning discussion.

Source: Joan Rush. Advance Care Planning in Canada: Legal Issues. National Roundtable – Presentation. March 2009.

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 a tool that provides an easy to use summary of the legal requirements for consent, substitute decision-making and advance directives in each province and territory.
- 1.2.3 Develop and maintain provincial/territorial primers for clinicians regarding the laws influencing advance care planning in their jurisdiction.
- 1.2.4 Develop/adapt and disseminate materials that assist legal professionals to recognize their role in advance care planning.
- 1.2.5 The health community should work in tandem with the legal community to view advance care planning as a process and to each participate in the process of ACP – specifically, tools and training should be provided to lawyers regarding discussions with clients about ACP and the drafting of advance directives.

I.3 Engage healthcare professionals/providers

Key Messages

- Most healthcare professionals have a positive attitude towards advanced care planning. However, the majority do not engage in it. While there may be barriers to healthcare professionals engaging in advance care planning, as a profession they recognize the value and need for advance care planning.
- 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
- Healthcare professionals have ethical obligations to honour a person's advance care choices wherever possible.
- They are obliged to know the legal requirements to which they are subject as well as their professional Codes of Ethics.

Background

Healthcare providers have an important role to play in advance care planning. Patients and families look to them for their expertise. Therefore, it is important that healthcare professionals understand the philosophy, process, and resources supporting advance care planning and are committed to integrating it into their practice. The role of an advance care planning facilitator can, and should be, played by people in a variety of healthcare professions including physicians, nurses, social workers, spiritual professionals, case managers and others. Ideally, the approach should be interprofessional with the different members of a healthcare team, each with unique expertise and understanding, involved.

Recent literature reviews have revealed that most health and social care professionals have a positive attitude towards advanced care planning.^{91 92 93 94 95 96 97 98 99 100 101 102} However, the majority do not engage in it.¹⁰³

Research in the U.K. and the U.S. has indicated that physicians, more than other professionals, have significant reservations about the applicability and validity of ACP documents.^{104 105 106 107 108} There are several reasons why physicians are reluctant to engage in the ACP discussion.¹⁰⁹ They include discomfort with end-of-life discussions;¹¹⁰ fear of legal repercussions if the advance directive results in limiting care at the end-of-life and that translates into criminal prosecution or malpractice litigation when honouring an advance directive instructing limiting treatment, time constraints, and limited reimbursement.^{111 112}

While there may be barriers to physicians engaging in advance care planning, as a profession they recognize the value and need for advance care planning. The Canadian Medical Association's policy document, *Achieving Patient-Centred Collaborative Care* states: "First and foremost, medical care delivered by physicians and healthcare delivered by others should be aligned around the values and needs of patients. Collaborative care teams should foster and support patients, and their families, as active participants in their healthcare decision-making".¹¹³

Nurses act as educators and advocates for their patients. They are often more involved in the daily care of patients. Therefore, they can be in position to provide support and information regarding care decisions.^{114 115} Patients are often comfortable discussing advance care planning with nurses.¹¹⁶ Nurses are involved in safeguarding patients' rights and nursing research has found that their presence is an important factor in helping patients to develop advance directives.^{117 118 119}

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Social workers participate in advance care planning. In fact, in many places where ACP takes place, social workers play a very big role.^{120 121 122 123} It appears that social workers have knowledge and a positive attitude about advance care planning.¹²⁴ Social workers' counselling and communication skills bring important expertise to the team.¹²⁵

Healthcare professionals have ethical obligations to honour a person's advance care choices wherever possible and to know the legal requirements.¹²⁶ The Canadian Medical Association, the Canadian Healthcare Association, the Canadian Nurses Association, and the Catholic Healthcare Association of Canada advise members in their *Joint Statement on Preventing and Resolving Ethical Conflicts Involving Healthcare Providers and Persons Receiving Care* that:

“...every effort must be made to ensure that healthcare decisions are consistent with [a patient's] known preferences. These preferences may be found in an advance directive or may have been communicated orally. In jurisdictions where the issue of decision-making concerning care and medical treatment for incompetent persons is specifically addressed in law, the requirements of that legislation should be met.”¹²⁷

The Canadian Medical Association (CMA) in its Code of Ethics (2004) advises its members to:

27. Ascertain wherever possible and recognize your patient's wishes about the initiation, continuation or cessation of life-sustaining treatment.
28. Respect the intentions of an incompetent patient as they were expressed (e.g., through a valid advance directive or proxy designation) before the patient became incompetent.¹²⁸

This statement does not mean that the physician takes direction from the Advance Directive, but must still get an informed consent. Physicians may rely on the Code of Ethics as authority for following Advance Directives in the absence of specific consent. While the law must be followed specific consent is still required.

The Code of Ethics for Registered Nurses (Canadian Nurses Association) states that:

- Nurses must respect a person's advance directives about present and future healthcare choices that have been given or written by a person prior to loss of decisional capacity.
- When a person lacks decisional capacity, nurses must obtain consent for nursing care from a substitute decision maker, subject to the laws in their jurisdiction.¹²⁹

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 Engage relevant professional associations with engaging their members in addressing advance care planning and the barriers related to advance care planning.

I.4 Engage the general public

Key Messages

- 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.
- Community engagement involves reaching out to the public to engage capable adults and their families in advance care planning by raising awareness, initiating dialogue, and connecting people to the resources, mechanisms, and organizations involved in advance care planning.
- Engaging Canadians will involve a number of strategies – dissemination of printed materials and resources through healthcare contacts, non-governmental organizations, community settings, and Web presence.

Background

Community engagement involves outreach to the public that is aimed at engaging capable adults and their families in ACP by raising awareness, initiating dialogue about ACP, and connecting people to the means of engaging in ACP.

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. Often, individuals and families perceive that ACP is irrelevant to them and are of the impression that ACP is only a consideration for individuals who are very sick or terminally ill — not something to be considered for a much broader sector of society.^{130 131 132} In addition, they lack information regarding what advance care planning is.¹³³

Experience in Canada has demonstrated that community engagement involves reaching out to the public to engage capable adults and their families in advance care planning by raising awareness, initiating dialogue, and connecting people to the resources, mechanisms and organizations involved in advance care planning.¹³⁴ An important means of engaging the community is outreach to faith-based groups, seniors' organizations, and cultural communities. Advance care planning provides a process that supports diversity and inquires about values and goals of individuals from all cultural backgrounds. Experience and research show that advance care planning models can be successfully adapted by, and for, diverse cultural communities.¹³⁵

Engaging Canadians will involve a number of strategies. Strategies should be streamlined to address the particular “public” that needs to be engaged — since the Canadian population is diverse.

- Raising awareness through the dissemination of printed materials and resources — through healthcare contacts, non-governmental organizations, and community settings.
- A dedicated organization and Web presence are important strategies for providing interested people with answers to questions and additional information.
- The use of social media will engage some segments of the population and include Facebook, YouTube, Twitter and others.
- The media – television, radio and print – can all engage Canadians in thinking about and taking action on advance care planning.
- Community development strategies through local agencies/organizations can engage community members in hands-on activities to facilitate advance care planning.



All awareness initiatives need to demonstrate a clear understanding of the target audience and consider the linguistic and cultural diversity of our society. Consideration also needs to be given to the generational influences of our society such as the growth of individual autonomy, the decrease in religious affiliation, and the impact of social networking systems.¹³⁶

At the local level, it is important to remember that public awareness does not necessarily result in public engagement. As described in the *ACP Implementation Guide for Health Authorities in Canada* (2008), community engagement consists of not only outreach to individuals and groups and raising public awareness, but also fostering community involvement in the planning and implementation of advance care planning initiatives — at the local level.¹³⁷ Additionally, the advance care planning process is more likely to be successful when healthcare systems are in place to ensure that this work is honoured when patients interface with healthcare services.

Public engagement must incorporate the non-traditional sources (legal, health or other) that the public goes to for information/engagement. This would include the growing number of diverse “information grounds” – including places like community centres, public libraries, coffee shops, ethnic grocery stores, hair salons etc.

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, social service, government professionals and the general public about advance care planning.

Professionals are sometimes reluctant to engage in advance care planning because they do not fully understand what it is, when it should apply, or do not feel equipped to undertake it.^{138 139 140} Therefore, successful implementation of advance care planning in Canada will involve professional education and training. In addition, it has been previously stated that the general public lacks sufficient information regarding what advance care planning is and how to accomplish it. Therefore, they also require education.

Experience in Canada has shown that education involves a variety of mechanisms, such as engaging, training, and supporting healthcare providers to facilitate advance care planning conversations and processes as part of their core skill set; providing information resources and tools (workbooks, brochures and web-based resources, etc.) for the public, health care policy makers and administrators and healthcare providers; and providing tools for recording decisions about care wishes. Education, training, and support for the entire care team are essential.¹⁴¹

2.1 Education and training of professionals/providers

Key Messages

- 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, health service providers must have the knowledge and clinical skills required to ensure a consistent application of program elements – including the communication of advance care plans.
- 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 ACP conversations. The ability to facilitate ACP conversations needs to become part of the core skill set for all clinicians.

Background

As noted, 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.^{142 143 144 145 146 147}

In order for an ACP initiative to be successful, health service providers must have the knowledge and clinical skills required to ensure a consistent application of program elements. This begins with the identification of competency areas and the development of education and training programs to support knowledge transfer and skill development. The programs need to have adopted or developed relevant tools to support all aspects of ACP including how to initiate and structure conversations and to record and document conversation outcomes and decisions made. The programs also need to



educate health service providers about the essential components of consent and the difference between advance care planning and consent. The process needs to be promoted through the presence and identification of champions or role models and supported by ensuring continuing education initiatives are in place.¹⁴⁸

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. It includes initiating conversations, asking relevant questions, answering questions that an individual/family may have, providing information resources and workbooks, and calling on the expertise of other team members as required.¹⁴⁹ Anyone on the care team may initiate or continue the conversation with the patient — a physician, nurse, social worker or spiritual care worker, for example.

It is important to remember that although advance care planning is generally seen as a healthcare issue, it goes beyond healthcare to encompass the legal sector, social services, and faith-based groups. Ideally, training in advance care planning should include all of these sectors.

Core competencies for those engaging in advance care planning with clients

All healthcare team members require education and support to facilitate ACP conversations. The ability to facilitate ACP conversations needs to become part of the core skill set for all clinicians.¹⁵⁰

Core competencies for those healthcare professionals engaging in advance care planning have been developed in Canada.¹⁵¹ They are the ability to:

1. Define ACP and its importance.
2. Understand the need to obtain consent and the key elements of consent
3. Understand capacity and understand the legal framework within the relevant jurisdiction.
4. Initiate an ACP conversation and assist in the creation and/or documentation of an advance care plan.
5. Facilitate ongoing ACP conversations across the continuum of care.
6. Identify potential conflicts in ACP and effectively manage conflicts — these could be conflicts between patients and family members; between family members; or involving healthcare professionals.
7. Serve as an ACP resource in an organization.
8. Be familiar with, and effectively use, their organization's work flow process associated with ACP documents.

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 Educate front line staff in advance care planning including a focus on routinely ascertaining if advance care plans have been completed, and if so, bringing them to the attention of the treatment team.
- 2.1.3 Educate staff on how to facilitate discussions of illness and death in an open manner.
- 2.1.4 Develop and support role models and mentors in healthcare settings.
- 2.1.5 Develop online continuing professional education modules for professionals in advance care planning.

- 2.1.6 Invite all professional groups and organizations to post their existing tools on the Web so that they can be easily accessed by others.
- 2.1.7 Provide training for practicing healthcare and legal professionals — both basic education and continuing education.
- 2.1.8 Professional associations and colleges support the professional education efforts surrounding advance care planning and provide professional development credit for this education.

2.2 Education of the general public

Key Messages

- Advance care planning is a relatively new concept to 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 presence of advance directives or living wills.

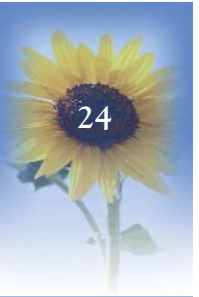
Background

For the general public, ACP is a relatively new concept. Over the last decade, Canadians have become more aware of the meaning of advance directives, but have had limited opportunities to consider and engage advance care planning as a broader process through which their care wishes can be expressed and honoured.

As identified previously, 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 presence of advance directives. Often, individuals and families perceive that ACP is irrelevant to them and are of the impression that ACP is only a consideration for individuals who are very sick or terminally ill — not something to be considered for a much broader sector of society. Another barrier is often the lack of knowledge regarding the complexities related to healthcare decision-making and the misinformation regarding outcomes of various interventions. Finally, individuals and families may not understand the specifics of the requirements and laws relating to advance care planning in their jurisdiction.

There are a number of tools/documents that have been developed for the general public. These include tools developed by specific programs who are implementing advance care planning – in Canada and in other jurisdictions. In addition, educational tools regarding advance care planning are being developed by public legal education organizations in many provinces and territories. Public legal education is guided by adult learning theories rooted in an understanding that the learner accumulates knowledge by accommodating previous knowledge into current experiences – such practices could be put to good use in the education of the general public about ACP.

As in engagement, education strategies for the general public need to be targeted to the particular population that they are intended to reach. It will be useful to have educational strategies and tools that are focused on middle aged and older Canadians, and caregivers/family members – as these Canadians may be already facing chronic and life-limiting illnesses. Different strategies could be utilized to educate younger Canadians – for example introducing the concept of advance care planning with high school students. This kind of education would be geared at ‘normalizing’ the conversations.



Recommendations for education of the general public

- 2.2.1 Identify education initiatives and resources that are already underway and promote their use.
- 2.2.2 Develop/adapt public education materials regarding ACP for the general public and disseminate them in a wide variety of media. Include materials for individuals and their substitute decision makers to support their role.
- 2.2.3 Ensure that resources, tools and materials are innovative and are created in plain language.
- 2.2.4 Develop standard toolkits that can be shared across Canada and adapted locally.
- 2.2.5 Develop, and make available for the general public, on-line and toll-free resources in ACP.
- 2.2.6 Utilize a variety of dissemination strategies for the resources – including web-based; social media based; through the media; and through provincial/territorial/local agencies and organizations.
- 2.2.7 Establish a working group to bring together public health and legal education professionals to create a national education plan.

3. System infrastructure

GOAL:

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

Canadian experience has demonstrated that system infrastructure in support of advance care planning involves a variety of mechanisms to ensure that healthcare providers are aware of a person's care preferences in the various care settings throughout a health authority. These mechanisms can include the person owning their advance care plan documents; highly visible documents in healthcare charts or in the home; mechanisms for ensuring that care wishes follow people through a variety of healthcare settings; electronic healthcare records; and consistent goals of care designations throughout the healthcare facility or region.¹⁵²

Once an individual has engaged in ACP, it should be clear that the individual, not the facility or organization, is the owner of their advance care planning documents. There is a responsibility of the system to ensure that this information travels with the individual through different care settings and that health service providers consistently inquire regarding their clients' wishes and associated documentation. It is critical that the substitute decision maker be aware of these documents, as these documents will govern their consent to or refusal of treatment on behalf of an incapable person.

3.1 Policy and program development

Key Messages

- 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 include: organizational commitment; guiding principles and value statements; public awareness; healthcare provider education and training; system infrastructure support; sector integration; and evaluation.

Background

An evaluation of the implementation of an advance care planning program in Australia found the following keys to success:¹⁵³

- Integrating the advance care planning program into the existing healthcare culture
- Consultation support for the healthcare facility
- Support from the organization's governing body
- Leadership from the executive, clinical leaders, and nursing managers
- Champions or opinion leaders on the front line

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- System changes to documentation processes
- Education, skill development, and support for staff
- Involvement of the legal system with respect to advance directives

Challenges were related to the following:

- Space, staffing (including staff turnover) and time
- Lack of flexibility in the program in response to local conditions
- Challenges relating to the state legal requirements for advance directives

The Canadian experiences in Alberta Health – Calgary Area and Fraser Health were much the same.

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.¹⁵⁴ They include the following:

- *Organizational commitment* – senior administrators need to be supportive of ACP development and implementation within their organization.
- *Guiding principles and value statements* – describing the beliefs which the organization’s members hold in common and endeavour to put into practice.
- *Public awareness* – not just limited to the distribution of printed materials and resources but also the ability to interact with professionals/organizations.
- *Healthcare provider education and training* – both basic education and continuing education.
- *System infrastructure support* – to ensure that the advance care plan is recorded, communicated recognized and utilized.
- *Sector integration* – so that the different areas involved in ACP implementation are aligned and integrated e.g., the legal and health service sectors.
- *Evaluation* – programs must incorporate evaluation and continuous quality improvement components to evaluate client care preferences and the care received.

Accreditation Canada is the official accrediting body for health service agencies in Canada. They develop standards against which their accreditors measure the organizations. Standard 7.0 in the Canadian Council on Health Services Accreditation for Hospice Palliative and End-of-Life Care states: “The team informs the client and family, verbally and in writing, of their right to establish advance directives and how to do so.” The Long Term Care Guidelines and Oncology Guidelines have a standard that indicates: “When clients are incapable of giving informed consent, the team refers to the client’s advance directives if available or obtains consent using a substitute decision maker”.^{cliv} While they do not use the term advance care planning in the document, they do describe it. (The specific laws in the various jurisdictions must be followed – for example, in Ontario, the team must turn to the substitute decision maker to interpret the advance directive.)

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.
- 3.1.4 Governments set fee codes for physicians and other health care professionals to engage in advance care planning, bearing in mind the need to take appropriate time to do this, and the need to repeat the process periodically to ensure that the ACP remains up to date.
- 3.1.5 Accreditation Canada and relevant funding and regulatory authorities in the provinces and territories be engaged to set requirements for policies and practices for advance care planning.

3.2 Tools to support conversations and documentation

Key Messages

- 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 people 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 conversation and outcomes.
- Tools must include communication systems and system cues that can be built into computerized documentation records that alert for the discussion or process.
- Tools must be innovative and in plain language.

Background

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 a person and their family throughout their experience with the system, tools are required to enable documentation. They 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 conversation and outcomes.

Comprehensive, user-friendly ACP tools benefit professionals in all sectors and clients. The development and implementation of a standard set of tools can contribute significantly to the dissemination of consistent messages, collection of consistent data, and ultimately, a program's successful implementation. In Canada, a number of tools have been identified targeting the implementation needs of clinicians, educational needs of clients and the community at large, as well as tools to support evaluation of ACP initiatives.¹⁵⁶

Tools for professional education include:

- *The Pallium Palliative Pocketbook: A peer-reviewed, referenced resource* (the PPP) where ACP is discussed; *retreat courses targeting primary care professionals* (explicitly covered in Module 5 (Communication) of the *Learning Essential Approaches to Palliative and End-of-Life* (LEAP) courseware package; and the curricular resource package associated with *Developing spiritual care capacity for Hospice Palliative Care* curricular resource package.

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- *Facilitating Advance Care Planning: An Interprofessional Educational Program* – curriculum and trainer’s guide (Educating Future Physicians in Palliative and End-of-Life Care – Canadian Hospice Palliative Care Association).
- Alberta Health Services — Calgary and area — has a well-developed advance care planning initiative entitled *My Voice*. It includes *My Voice – Planning Ahead – Framework for Advance Care Planning Conversations*; *Advance Care Planning Tracking Record*; *Goals of Care Designation Order*; *Greensleeve for patient/client charts* and *Quick Reference Pocket Card/Poster* for all staff that highlights the key interventions associated with each *Goals of Care Designation*. On-line modules including *Goals of Care Designations and Advance Care Planning* are available on the website.
- Fraser Health, British Columbia — has a well-developed advance care planning initiative entitled: *Lets Talk*. They have on-line training modules for providers at two levels, *Level One – Assisting with the Process and Promoting the Concept* and *Level Two – Advance Care Planning Education*; *Advance Care Planning Record Form*; *Greensleeve for patient/client charts*.
- National Initiative for the Care of the Elderly and Advocacy Centre for the Elderly – *Tool on Capacity & Consent: Ontario Edition* – pocket guide to consent and capacity in Ontario.

Several organizations in Canada have put significant effort into the development of brochures and related tools to strengthen the general public’s understanding of advance care planning concepts and implications. For example:

- Alberta Health Services — Calgary and area – *My Voice: A workbook and personal directive for advance care planning*; *My Voice – Planning Ahead* – brochure, wallet card, information for representatives and agents and DVD; *Understanding Goals of Care Designations* brochure.
- Fraser Health – *My Voice* workbook; *My Voice* – brochures and posters; *Making Informed Decisions about CPR* – brochure; DVD
- Ontario Seniors Secretariat – *A Guide to Advance Care Planning*.
- Yukon Health and Social Services – public education brochures and fact sheets – *Abbreviated Advance Directive*, *Planning for your Future Healthcare Choices*, *Making Healthcare Decisions for a Loved One – the Role of the Substitute Decision maker*.

A number of public legal education organizations have developed tools to facilitate advance care planning.

- Legal Service Society British Columbia — *When I’m 64: A guide to benefits and services for people aged 60 and over*. Includes Part 3
- “Controlling Your Own Affairs”: http://www.familylaw.lss.bc.ca/resources/publications/pub.aspx?p_id=281
- Legal Resource Centre of Alberta - *Making a Personal Directive in Alberta and Being an Agent*: <http://www.oaknet.ca/node/60>
- Public Legal Education Association of Saskatchewan - *Older Adults and the Law*. Includes a section about “Health Care Directives”: http://www.plea.org/legal_resources/?a=275&searchTxt=&cat=23&pcat=4&searchTxt=&cat=23&pcat=4
- Educaloï in Quebec (available in French and in English) — *Senior Citizens*. Includes information about “The Living Will”: http://www.educaloï.qc.ca/en/loi/senior_citizens/
- Public Legal Education and Information Society of New Brunswick – *Planning Ahead*. http://www.legal-info-legale.nb.ca/en/planning_ahead

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- Legal Information Society of Nova Scotia — Advanced Health Care Directives (including Living Wills). <http://www.legalinfo.org/legal-information/legal-information-content/advance-health-care-directives.html>
- Community Legal Information Association of PEI - Planning Ahead. Includes information about “Health Care Decisions” and “Health Care Directive Form”: http://www.cliapei.ca/content/page/publications_planning
- Public Legal Information Association of Newfoundland - Seniors and the Law: Wills, Enduring Power of Attorney and Advance Health Care Directives: http://www.publiclegalinfo.com/publications.html#Wills_and_Estates_

The Canadian Hospice Palliative Care Association’s Advance Care Planning Project has an online repository of all of the tools available at www.advancecareplanning.ca.

Recommendations for tools to support conversations and documentation

- 3.2.1 Adapt/develop evidence-based tools available and utilized across Canada given that support and enable healthcare providers and legal professionals to engage in effective advance care planning.
- 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 Ensure that tools are innovative and in plain language.
- 3.2.4 Engage appropriate government departments and agencies with responsibility for ACP to assist in developing and disseminating tools and education related to ACP.
- 3.2.5 Encourage the sharing of tools across jurisdictions and agencies.
- 3.2.6 Encourage/support research activities that demonstrate the effectiveness of tools in supporting healthcare providers and legal professionals to engage in advance care planning.
- 3.2.7 Establish a repository of published research findings and current research activities in other jurisdictions relevant to CQI of 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 start. 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. Pilot projects also help to improve and strengthen programs. The two most developed programs in Canada — Alberta Health – Calgary Area and Fraser Health — both used pilot projects to test and improve approaches and to build support within the system and among healthcare providers for integrating advance care planning into their practice.¹⁵⁷ Calgary has used a regional chart audit to establish base-lines and inform them on the uptake on the *Advance Care Planning: Goals of Care Designation* policy implementation work.

As previously noted, 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 the outcomes on individuals and their families. Programs must incorporate evaluation and continuous quality improvement components to evaluate client care preferences and the care received. With sensitivity to the controversy surrounding cost savings associated with advance care planning, evaluation measures must also take into consideration the impact of ACP on resource utilization.

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.

Endnotes

1. Curran, V. Interprofessional Education for Collaborative Patient-Centred Practice: Research Synthesis Paper. Ottawa: Health Canada. No date. <http://www.hc-sc.gc.ca/hcs-sss/hhr-rhs/strateg/interprof/synth-eng.php>
2. Royal College of Physicians. Advance Care Planning: National Guidelines. February, 2009. <http://www.rcplondon.ac.uk/pubs/contents/9c95f6ea-c57e-4db8-bd98-fc12ba31c8fe.pdf>
3. Molloy, DW, et al. Attitudes training issues and barriers for community nurses implementing an advance directive program. *Perspectives* 1997; 21(1):2-8.
4. Tierney, WM., et al. The effect of discussions about advance directives on patients' satisfaction with primary care. *J Gen Intern Med* 2001;16(1):32-40.
5. Finucane, TESJ., RL. Powers, and RM. D'Alessandri. Planning with elderly outpatients for contingencies of severe illness: a survey and clinical trial. *J Gen Intern Med* 1988(3): 322-5.
6. Kass-Bartelmes, BL., and R. Hughes. Advance care planning preferences for care at the end of life. *J Pain Palliat Care Pharmacother* 2004; 18(1):87-109.
7. Heyland, D., et al. Canadian Researchers at the End-of-Life Network (CARENET). Discussing prognosis with patients and their families near the end of life: impact on satisfaction with end-of-life care. *Open Medicine* 2009; 3(2):71-80.
8. Engelhardt, JB., et al. Effects of a program for coordinated care of advanced illness on patients, surrogates, and healthcare costs: a randomized trial. *Am J Manag Care* 2006; 12(2):93-100.
9. Rabow, MW., et al. The comprehensive care team: a controlled trial of outpatient palliative medicine consultation. *Arch Intern Med* 2004; 164(1):83-91.
10. Horne, G., J. Seymour, and K. Shepherd. Advance care planning for patients with inoperable lung cancer. *In J Palliat Nurs* 2006; 12(4):172-8.
11. Royal College of Physicians. Advance Care Planning: National Guidelines. February, 2009. <http://www.rcplondon.ac.uk/pubs/contents/9c95f6ea-c57e-4db8-bd98-fc12ba31c8fe.pdf>
12. Harle, I., et al. Advance Care Planning with Cancer Patients: Evidentiary Base and Guideline Recommendations. Evidence-Based Series #19-1. Toronto: Program in Evidence-Based Care: A Cancer Care Ontario Program. 2008. <http://www.cancercare.on.ca/pdf/pebc19-1f.pdf>
13. Wright, AA., et al. Associations between end-of-life discussions, health care expenditures. *JAMA*. 2008; 300(14):1665-1673.
14. Zhang, B., et al. Health care costs in the last week of life. *Arch Intern Med* 2009; 169(3): 480-488.
15. Zhang, B., et al. Health care costs in the last week of life. *Arch Intern Med* 2009; 169(3): 480-488.
16. Molloy, DW., et al. Systematic implementation of an advance directive program in nursing homes: A randomized controlled trial. *JAMA* 2000;283(11): 1437-44.
17. Finucane, TESJ., RL. Powers, and RM. D'Alessandri. Planning with elderly outpatients for contingencies of severe illness: a survey and clinical trial. *J Gen Intern Med* 1988(3):322-5.
18. Seymour, J., et al. Planning for the end of life: the views of older people about advance care statements. *Soc Sci Med* 2004; 59(1):57-68.
19. Westley C, Briggs LA. Using the stages of change model to improve communication about advance care planning. *Nurs Forum* 2004; 39(3):5-12.
20. Dunbrack, J. Advance care planning: the Glossary project: Final report. Ottawa: Health Canada. 2004. http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2006-proj-glos/2006-proj-gloss_e.pdf
21. Educating Future Physicians in Palliative and End-of-Life Care. Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Materials. Ottawa: CHPCA.2008. p. 7. http://www.afmc.ca/efppe/docs/pdf_2008_advance_care_planning_curriculum_module_final.pdf

Advance Care Planning in Canada: National Framework

Endnotes

22. Educating Future Physicians in Palliative and End-of-Life Care. Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Materials. Ottawa: CHPCA. 2008. p. 7.
http://www.afmc.ca/efppecc/docs/pdf_2008_advance_care_planning_curriculum_module_final.pdf
23. Subcommittee to update "Of Life and Death", & Standing Senate Committee on Social Affairs, Science and Technology. 2000, Part 1, B5 - Advance Directives section, para. 2.
24. Ipsos, Reid. Hospice Palliative Care Study. Study commissioned by GlaxoSmithKline and the Canadian Hospice Palliative Care Association. 2004.
25. Royal College of Physicians. Advance Care Planning: National Guidelines. February 2009. <http://www.rcplondon.ac.uk/pubs/contents/9c95f6ea-c57e-4db8-bd98-fc12ba31c8fe.pdf>
26. Schiff, R., C. Rajkumar, and C. Bulpitt. Views of elderly people on living wills: interview study. *BMJ* 2000; 320(7250):1640-1.
27. Blondeau, D., et al. Comparison of patients' and health care professionals' attitudes towards advance directives. *J Med Ethics* 1998; 24(5): 328-35.
28. Sam, M., and PA. Singer. Canadian outpatients and advance directives: poor knowledge and little experience but positive attitudes. *CMAJ* 1993; 148(9):1497-502.
29. Morrison, RS., and DE. Meier. High rates of advance care planning in New York City's elderly population. *Arch Intern Med* 2004; 164(22):2421-6.
30. Sahm, S., R. Will, and G. Hommel. What are cancer patients; preferences about treatment at the end of life, and who should start talking about it? A comparison with healthy people and medical staff. *Support Care Cancer* 2005; 13(4):206-14.
31. Sahm, S., R. Will, and G. Hommel. Attitudes towards and barriers to writing advance directives amongst cancer patients, healthy controls, and medical staff. *J Med Ethics* 2005; 31(8):437-40.
32. Thorevska, N., et al. Patients' understanding of advance directives and cardiopulmonary resuscitation. *J Crit Care* 2005; 20(1):26-34.
33. Ashby, M., and M. Wakefield. Attitudes to some aspects of death and dying, living wills and substituted health care decision-making in South Australia: public opinion survey for a parliamentary select committee. *Palliat Med* 1993;7(4):273-82.
34. Singer, PA., et al. Life-sustaining treatment preferences of hemodialysis patients: implications for advance directives. *J Am Soc Nephrol* 1995; 6(5):1410-7.
35. Voltz R., et al. End-of-life decisions and advance directives in palliative care: a cross-cultural survey of patients and health-care professionals *J Pain Symptom Manage* 1998; 16(3):153-62.
36. Ontario Health Quality Council (2007). 2007 Report. Toronto. <http://www.ohqc.ca>.
37. Deaths, 2003. Statistics Canada, 2005. Catalogue no. 84F0211XIE.
38. Alzheimer's Society of Canada. Rising Tide: The Impact of Dementia on Canadian Society. Toronto: Alzheimer's Society of Canada. 2010.
39. Canadian Hospice Palliative Care Association. Advance Care Planning in Canada: Environmental Scan. Ottawa: CHPCA. 2009.
http://www.chpca.net/projects/advance_care_planning/acp_environmental_scan_sept_9_09.pdf
40. Dunbrack, J. Advance care planning: the Glossary project: Final report. Ottawa: Health Canada. 2004.
http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2006-proj-glos/2006-proj-gloss_e.pdf
41. There are various definitions of an advance directive across the country. Commonly it is understood as an expression of the patient's wishes for care when he/she is unable to communicate in any form or not capable of giving informed consent to treatment. The wishes can be in writing or expressed verbally, as long as they have been understood by the family and health care providers, and as long as the patient trusts that his/her wishes will be respected to the extent that this is possible. It is also understood as a document prepared by a lawyer which names proxy; a document prepared by the patient which names a proxy and has the same legal status as a document prepared by a lawyer. (Dunbrack, 2004)

Endnotes

42. Kass-Bartlmes, BL., and R. Hughes.
43. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
44. Heyland, DK., et al. for the Canadian Researchers, End-of-Life Network (CARENET). What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ* 2006; 174(5). DOI:10.1503/cmaj.050626
45. Kass-Bartlmes, BL., R. Hughes, and MK. Rutherford. *Advance Care Planning: Preferences for Care at the End-of-Life*. Rockville (MD): Agency for Healthcare Research and Quality. 2003. Research in Action Issue #12. AHRQ Pub No. 03-0018.
46. Quill, TE. Initiating end-of-life discussions with seriously ill patients. Addressing the “elephant in the room”. *JAMA* 2000; 284(19):2502-7.
47. Bravo, G., FM. Dubois, and B. Wagneur. Assessing the effectiveness of interventions to promote advance directives among older adults: A systematic review and multi-level analysis. *Social Science and Medicine* 2008; 67:1122-1132.
48. Patel, RV., T. Sinuff, and DJ. Cook. Influencing advance directive completion rates in non-terminally ill patients: a systematic review. *Journal of Critical Care* 2004; 19:1-9.
49. Royal College of Physicians. *Advance Care Planning: National Guidelines*. February, 2009. <http://www.rcplondon.ac.uk/pubs/contents/9c95f6ea-c57e-4db8-bd98-fc12ba31c8fe.pdf>
50. Kass-Bartlmes, BL., R. Hughes, and MK. Rutherford. *Advance Care Planning: Preferences for Care at the End-of-Life*. Rockville (MD): Agency for Healthcare Research and Quality. 2003. Research in Action Issue #12. AHRQ Pub No. 03-0018.
51. Harle, I., et al. *Advance Care Planning with Cancer Patients: Evidentiary Base and Guideline Recommendations*. Evidence-Based Series #19-1. Toronto: Program in Evidence-Based Care: A Cancer Care Ontario Program. 2008. <http://www.cancercare.on.ca/pdf/pebc19-1f.pdf>
52. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
53. Bravo, G., FM. Dubois, and B. Wagneur. Assessing the effectiveness of interventions to promote advance directives among older adults: A systematic review and multi-level analysis. *Social Science and Medicine* 2008; 67:1122-1132.
54. Patel, RV., T. Sinuff, and DJ. Cook. Influencing advance directive completion rates in non-terminally ill patients: a systematic review. *Journal of Critical Care* 2004; 19:1-9.
55. Kass-Bartlmes, BL., R. Hughes, and MK. Rutherford. *Advance Care Planning: Preferences for Care at the End-of-Life*. Rockville (MD): Agency for Healthcare Research and Quality. 2003. Research in Action Issue #12. AHRQ Pub No. 03-0018.
56. Royal College of Physicians. *Advance Care Planning: National Guidelines*. February 2009. <http://www.rcplondon.ac.uk/pubs/contents/9c95f6ea-c57e-4db8-bd98-fc12ba31c8fe.pdf>
57. Emanuel, LL., et al. Advance directives for medical care – a case for greater use. *N Engl J Med* 1991; 324(13):889-95.
58. Searight, HR., and J. Gafford. Cultural diversity at the end of life: issues and guidelines for family physicians. *American Family Physician* 2005; 71(3):515-22.
59. Aitken, PV. Incorporating advance care planning into family practice. *American Family Physician* 1999; 59(3):605-14.
60. Gallagher, R. An approach to advance care planning in the office. *Canadian Family Physician* 2006; 52:459-64.



Advance Care Planning in Canada: National Framework

Endnotes

61. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
62. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
63. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
64. Royal College of Physicians. Advance Care Planning: National Guidelines. February 2009. <http://www.rcplondon.ac.uk/pubs/contents/9c95f6ea-c57e-4db8-bd98-fc12ba31c8fe.pdf>
65. Bravo, G., FM. Dubois, and B. Wagneur. Assessing the effectiveness of interventions to promote advance directives among older adults: A systematic review and multi-level analysis. *Social Science and Medicine* 2008; 67: 1122-1132.
66. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
67. Hanson, LCRK, M. Henderson, and GG. Pickard. A quality improvement intervention to increase palliative care in nursing homes. *J Palliat Med* 2005; 8(30):576-84.
68. Dexter, PR., et al. Effectiveness of computer-generated reminders for increasing discussions about advance directives and completion of advance directive forms. A randomized, controlled trial. *Ann Intern Med* 1998; 128(2):102-10.
69. Heffner, JE. Outcomes of advance directive education of pulmonary rehabilitation patients. *Am J Respir Crit Care Med* 1997; 153(3):1055-9.
70. Morrison, RS., et al. The effect of a social work intervention to enhance advance care planning documentation in the nursing home. *J Am Geriatr Soc* 2005; 53(2):290-4.
71. Bravo, G., FM. Dubois, and B. Wagneur. Assessing the effectiveness of interventions to promote advance directives among older adults: A systematic review and multi-level analysis. *Social Science and Medicine* 2008; 67: 1122-1132.
72. Patel, RV., T. Sinuff, and DJ. Cook. Influencing advance directive completion rates in non-terminally ill patients: a systematic review. *Journal of Critical Care* 2004; 19:1-9.
73. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
74. Ramsaroop, SD., MC. Reid, and RD. Adelman. Completing an advance directive in the primary care setting: what do we need for success? *Journal of the American Geriatrics Society* 2007; 55:277-83.
75. Royal College of Physicians. Advance Care Planning: National Guidelines. February, 2009. <http://www.rcplondon.ac.uk/pubs/contents/9c95f6ea-c57e-4db8-bd98-fc12ba31c8fe.pdf>
76. Keay, TJ., et al. Nursing home physician educational intervention improves end-of-life outcomes. *J Palliat Med* 2003; 6(2):205-13.
77. Hanson, LCRK., M. Henderson, and GG. Pickard. A quality improvement intervention to increase palliative care in nursing homes. *J Palliat Med* 2005;8(30):576-84.
78. Tierney, WM., et al. The effect of discussions about advance directives on patients' satisfaction with primary care. *J Gen Intern Med* 2001;16(1):32-40.
79. Dexter, PR., et al. Effectiveness of computer-generated reminders for increasing discussions about advance directives and completion of advance directive forms. A randomized, controlled trial. *Ann Intern Med* 1998; 128(2)102-10.

Endnotes

80. Heiman, H. Improving completion of advance directives in the primary care setting: a randomized controlled trial. *Am J Med* 2004; 117(5):318-24.
81. Smucker, WD. Elderly outpatients respond favorably to a physician-initiated advance directive discussion. *J AM Board Fam Pract* 1993; 6(5):473-82.
82. Canadian Hospice Palliative Care Association and CARENET. Developing a Research Agenda for Advance Care Planning in Canada: Report of a Meeting of Decision Makers and Researchers. Ottawa: Canadian Hospice Palliative Care Association. 2009.
83. Educating Future Physicians in Palliative and End-of-Life Care. Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Materials. Ottawa: CHPCA. 2008.
84. Educating Future Physicians in Palliative and End-of-Life Care. Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Materials. Ottawa: CHPCA. 2008.
85. Rush, JL. Advance Care Planning in Canada National Roundtable: Legal Issues. Presentation.
86. Educating Future Physicians in Palliative and End-of-Life Care. Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Materials. Ottawa: CHPCA. 2008.
87. Educating Future Physicians in Palliative and End-of-Life Care. Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Materials. Ottawa: CHPCA. 2008.
88. Educating Future Physicians in Palliative and End-of-Life Care. Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Materials. Ottawa: CHPCA. 2008.
89. Educating Future Physicians in Palliative and End-of-Life Care. Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Materials. Ottawa: CHPCA. 2008.
90. Educating Future Physicians in Palliative and End-of-Life Care. Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Materials. Ottawa: CHPCA. 2008.
91. Royal College of Physicians. Advance Care Planning: National Guidelines. February, 2009. <http://www.rcplondon.ac.uk/pubs/contents/9c95f6ea-c57e-4db8-bd98-fc12ba31c8fe.pdf>
92. Voltz, R., et al. End-of-life decisions and advance directives in palliative care: a cross-cultural survey of patients and health-care professionals *J Pain Symptom Manage* 1998; 16(3):153-62.
93. Thompson, TDB., RS. Barbour, and L. Schwartz. Health professionals' views on advance directives: a qualitative interdisciplinary study. *Palliat Med* 2003; 17(5):403-9.
94. Hughes, DL, Singer, PA. Family physicians' attitudes toward advance directives. *CMAJ* 1992; 146(11):1937-44.
95. Kelner M., et al. Advance directives: the views of health care professionals. *CMAJ* 1993; 148(8):1331-8.
96. Downe-Wamboldt, B., L. Butler, and S. Coughlan,. Nurses' knowledge, experiences and attitudes concerning living wills. *Can J Nurs Res* 1998; 30(2):161-75.
97. Sahm, S., R. Will, and G. Hommel. Attitudes towards and barriers to writing advance directives amongst cancer patients, healthy controls and medical staff. *J Med Ethics* 2005; 31(8):437-40.
98. Black, K. Social workers' personal death attitudes, experiences, and advance directive communication behavior. *J Soc Work End Life Palliat Care* 2005; 1(3):21-35.
99. Badzek, LA., et al. Advanced care planning: a study on home health nurses. *Appl Nurs Res* 2006; 19(2):56-62.
100. Solomon, MZ., AL. Romer, and KS. Heller. (Eds.). *Innovations in End-of-Life Care: Practical Strategies and International Perspectives*. Larchmont, NY: Mary Ann Liebert, Inc. 2000.
101. Davidson, KW., et al. Physicians' attitudes on advance directives. *JAMA* 1989; 262(17):2415-19.
102. Shmerling, RH., et al. Discussing cardiopulmonary resuscitation: A study of elderly outpatients. *Journal of General Internal Medicine* 1988; 3(4):317-21.
103. Ipsos, Reid. Hospice Palliative Care Study. Study commissioned by GlaxoSmithKline and the Canadian Hospice Palliative Care Association. 2004.



Advance Care Planning in Canada: National Framework

Endnotes

104. Royal College of Physicians. Advance Care Planning: National Guidelines. February 2009. <http://www.rcplondon.ac.uk/pubs/contents/9c95f6ea-c57e-4db8-bd98-fc12ba31c8fe.pdf>
105. Shore, AD., et al. Health care providers' and cancer patients' preferences regarding disclosure of information about advance directives. *J Psychosoc Oncol* 1993; 11(4):39-53.
106. Haisfield, ME., et al. Patients' and healthcare providers' opinions regarding advance directives. *Oncol Nurs Forum* 1994; 21(7):1179-87.
107. Neuman, K, and, L. Wade. Advance directives: the experience of health care professionals across the continuum of care. *Soc Work Health Care* 1999; 28(3):39-54.
108. Fried, TR, RR. Rosenberg, and LA. Lipsitz. Older community-dwelling adults' attitudes toward and practices of health promotion and advance planning activities. *J AM Geriatr Soc* 1995; 43(6):645-9.
109. Con, A. Cross-Cultural Considerations in Promoting Advance Care Planning in Canada. CIHR Cross-Cultural Palliative NET. BC Cancer Agency. 2008. http://www.bccancer.bc.ca/NR/rdonlyres/E17D408A-C0DB-40FA-9682-9DD914BB771F/28582/COLOUR030408_Con.pdf
110. Hudson, T. Advance directives: still problematic for providers. *Hospitals & Health Networks* 1994; 68(6):46-50.
111. Hudson, T. Advance directives: still problematic for providers. *Hospitals & Health Networks* 1994; 68(6):46-50.
112. Murphy, DJ. Improving advance directives for healthy older people. *Journal of the American Geriatrics Society* 1990; 38(11):1251-6.
113. Canadian Medical Association. Achieving Patient-Centred Collaborative Care. CMA Policy Document PD08-02. 2008. p 2. <http://policybase.cma.ca/dbtw-wpd%5CPolicypdf%5CPD08-02.pdf>
114. Con, A. Cross-Cultural Considerations in Promoting Advance Care Planning in Canada. CIHR Cross-Cultural Palliative NET. BC Cancer Agency. 2008. http://www.bccancer.bc.ca/NR/rdonlyres/E17D408A-C0DB-40FA-9682-9DD914BB771F/28582/COLOUR030408_Con.pdf
115. Werner, P, and S. Carmel. Life-sustaining treatment decisions: Health care social workers' attitudes and their correlates. *Journal of Gerontological Social Work* 2001; 34(4): 83-97.
116. Emanuel, L. Advance directives: What have we learned so far? *Journal of Clinical Ethics* 1993;4(1):8-16. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
117. Con, A. Cross-Cultural Considerations in Promoting Advance Care Planning in Canada. CIHR Cross-Cultural Palliative NET. BC Cancer Agency. 2008. http://www.bccancer.bc.ca/NR/rdonlyres/E17D408A-C0DB-40FA-9682-9DD914BB771F/28582/COLOUR030408_Con.pdf
118. Brown, M. The law and practice associated with advance directives in Canada and Australia: Similarities, differences and debates. *Journal of Law & Medicine* 2003; 11(1):59-76.
119. Schirm, V, and L. Stachel. The values history as a nursing intervention to encourage use of advance directives among older adults. *Applied Nursing Research* 1996; 9(2):93-96.
120. Con, A. Cross-Cultural Considerations in Promoting Advance Care Planning in Canada. CIHR Cross-Cultural Palliative NET. BC Cancer Agency. 2008. http://www.bccancer.bc.ca/NR/rdonlyres/E17D408A-C0DB-40FA-9682-9DD914BB771F/28582/COLOUR030408_Con.pdf
121. Black, K. Advance directive communication with hospitalized elderly patients: Social workers' roles and practices. *Journal of Gerontological Social Work* 2004; 43(2/3):131-45.

122. Werner, P, S. Carmel, and H. Ziedenberg. Nurses' and social workers' attitudes and beliefs about and involvement in life-sustaining treatment decisions. *Health and Social Work* 2004; 29(1):27-35.
123. Baker, ME. Knowledge and attitudes of health care social workers regarding advance directives. *Social Work in Health Care* 2000; 32(2):61-74.
124. Baker, ME. Knowledge and attitudes of health care social workers regarding advance directives. *Social Work in Health Care* 2000; 32(2):61-74.
125. Black, K. Advance directive communication practices: Social workers' contributions to the interdisciplinary health care team. *Social Work in Health Care* 2005; 40(3):39-55.
126. Educating Future Physicians in Palliative and End-of-Life Care. Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Materials. Ottawa: CHPCA. 2008.
127. Canadian Medical Association, the Canadian Healthcare Association, the Canadian Nurses Association, and the Catholic Healthcare Association of Canada. Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care.
http://www.cna-aiic.ca/CNA/documents/pdf/publications/prevent_resolv_ethical_conflict_e.pdf
128. Canadian Medical Association. Code of Ethics. 2004. <http://policybase.cma.ca/PolicyPDF/PD04-06.pdf>
129. Canadian Nurses Association. Code of Ethics for Registered Nurses. 2008. http://www.cna-aiic.ca/CNA/documents/pdf/publications/Code_of_Ethics_2008_e.pdf
130. Adam, D., et al. A Clinical Framework for Improving the Advance Care Planning Process: Start with Patients' Self-Identified Barriers. *J Am Ger Soc* 2009; 57:31-9.
131. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
132. Kass-Bartlmes, BL, R. Hughes, and MK. Rutherford. Advance Care Planning: Preferences for Care at the End-of-Life. Rockville (MD): Agency for Healthcare Research and Quality. 2003. Research in Action Issue #12. AHRQ Pub No. 03-0018.
133. Adam, D., et al. A Clinical Framework for Improving the Advance Care Planning Process: Start with Patients' Self-Identified Barriers. *J Am Ger Soc* 2009; 57:31-9.
134. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
135. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
136. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
137. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
138. Kass-Bartlmes, BL, R. Hughes, and MK. Rutherford. Advance Care Planning: Preferences for Care at the End-of-Life. Rockville (MD): Agency for Healthcare Research and Quality. 2003. Research in Action Issue #12. AHRQ Pub No. 03-0018.
139. Educating Future Physicians in Palliative and End-of-Life Care. Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Materials. Ottawa: CHPCA. 2008.
140. Royal College of Physicians. Advance Care Planning: National Guidelines. February 2009. <http://www.rcplondon.ac.uk/pubs/contents/9c95f6ea-c57e-4db8-bd98-fc12ba31c8fe.pdf>



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141. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
142. Royal College of Physicians. Advance Care Planning: National Guidelines. February 2009. <http://www.rcplondon.ac.uk/pubs/contents/9c95f6ea-c57e-4db8-bd98-fc12ba31c8fe.pdf>
143. Educating Future Physicians in Palliative and End-of-Life Care. Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Materials. Ottawa: CHPCA. 2008.
144. Harle, I., et al. Advance Care Planning with Cancer Patients: Evidentiary Base and Guideline Recommendations. Evidence-Based Series #19-1. Toronto: Program in Evidence-Based Care: A Cancer Care Ontario Program. 2008. <http://www.cancercare.on.ca/pdf/pebc19-1f.pdf>
145. Con, A. Cross-Cultural Considerations in Promoting Advance Care Planning in Canada. CIHR Cross-Cultural Palliative NET. BC Cancer Agency. 2008.
http://www.bccancer.bc.ca/NR/rdonlyres/E17D408A-C0DB-40FA-9682-9DD914BB771F/28582/COLOUR030408_Con.pdf
146. Briggs, L, and E. Colvin. The nurse's role in end-of-life decision-making for patients and families. *Geriatric Nursing* 2002; 23(6):302-10.
147. Sam, M, and P.A. Singer. Canadian outpatients and advance directives: Poor knowledge and little experience but positive attitudes. *CMAJ* 1993; 148(9):1497-502.
148. Canadian Hospice Palliative Care Association. Advance Care Planning in Canada: Environmental Scan. Ottawa: CHPCA. 2009.
http://www.chpca.net/projects/advance_care_planning/acp_environmental_scan_sept_9_09.pdf
149. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
150. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
151. Educating Future Physicians in Palliative and End-of-Life Care. Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Materials. Ottawa: CHPCA. 2008.
152. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
153. Austin Health. Respecting Patient Choices: Final Evaluation of the Community Implementation of the Respecting Patient Choices Program. 2006.
154. Canadian Hospice Palliative Care Association. Advance Care Planning in Canada: Environmental Scan. Ottawa: CHPCA. 2009.
http://www.chpca.net/projects/advance_care_planning/acp_environmental_scan_sept_9_09.pdf
155. Accreditation Canada. Standards: Hospice, Palliative and End of Life Services. Ottawa: Accreditation Canada. 2010.
156. Canadian Hospice Palliative Care Association. Advance Care Planning in Canada: Environmental Scan. Ottawa: CHPCA. 2009.
http://www.chpca.net/projects/advance_care_planning/acp_environmental_scan_sept_9_09.pdf
157. 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/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf