



Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

**ADVANCE CARE PLANNING
IN CANADA: A National Framework
and Implementation**

**National Roundtable
Proceedings**

April 30, 2009

Production of *Advance Care Planning in Canada: National Roundtable Proceedings* has been made possible through a financial contribution from Health Canada.

The views expressed herein do not necessarily represent the views of Health Canada.

I. Background

On March 26th and 27th, 2009, Bruyère Continuing Care and the Canadian Hospice Palliative Care Association (CHPCA) held a National Roundtable in Ottawa for *Advance Care Planning in Canada: A National Framework and Implementation*.

Funding for the National Roundtable was provided by the Palliative and End-of-Life Care Unit, Chronic and Continuing Care Division, Health Canada.

The Roundtable was the first national meeting of *Advance Care Planning in Canada: A National Framework and Implementation* — a five-year project of the CHPCA. This five-year project is funded by The GlaxoSmithKline Foundation.

Research, writing and production of an Environmental Scan circulated to Roundtable participants in advance of the meeting was made possible through a financial contribution from the Canadian Partnership Against Cancer. The translation of the Environmental Scan was funded by the Palliative and End-of-Life Care Unit, Chronic and Continuing Care Division, Health Canada.

The goals of the National Roundtable were to:

- Engage a broad group of stakeholders in the development of a draft multi-level national framework on advance care planning.
- Advise on the implementation of the framework – including the development of tools for health care professionals and communication strategies to inform stakeholders, policy makers and the public about the national framework and tools for advance care planning; and
- Identify how stakeholders will be engaged in further development and implementation of the framework.

The National Roundtable was the first step in a five-year project, *Advance Care Planning in Canada: A National Framework and Implementation* (ACP Project), to develop a National Framework through a pan-Canadian consultative process that will facilitate collaboration across sectors, as well as implement the key Framework recommendations relating to education of professionals/health care providers and public awareness education. (See Backgrounder, Appendix 1.) The long-term goal of the ACP Project is to raise awareness among Canadians about the importance of advance care planning and to equip them with the tools they need to effectively engage in the process.

The Roundtable was planned by the Task Group. A list of Task Group members is included in the Backgrounder in Appendix 1.

The participants of the Roundtable included federal/provincial/territorial government representatives; relevant professional groups – e.g., nursing, medicine, law, ethics and social sciences; key national non-governmental organizations; representatives from local health authorities and health agencies; industry and advance care planning experts. The Roundtable participants are found in Appendix 2.

II. Agenda Overview

The Roundtable was planned to enable all participants to come to a common understanding of what is meant by the term “advance care planning” and to recognize the roles and contributions of the variety of stakeholders involved. It began with a series of plenary speakers. The two days then continued with a workshop approach, where participants worked in small groups to contribute to the foundational elements of a National Framework in Advance Care Planning. (The Roundtable Program is found in Appendix 3. See Appendix 4 for the Plenary Speakers’ Bios. See www.chpca.net for the Plenary Speakers’ slides.)

III. Environmental Scan

An Environmental Scan was developed as a foundation document to inform the participants attending the Advance Care Planning National Roundtable and to support the Advance Care Planning Task Group in their work to develop a national framework for advance care planning. The Environmental Scan was presented to the group as a work in progress. It is intended to serve as a starting point – as new information is produced and discovered it will be added to the Environmental Scan. (See www.chpca.net for the Environmental Scan.)

IV. Overview of Proceedings

A. Welcome, Objectives and Background of Project

Jean Bartkowiak, Bruyère Continuing Care’s President and CEO welcomed everyone to Ottawa and expressed his pleasure in having Bruyère host this national event.

Esther Fortin, Health Canada, shared that this two-day event was funded by the Palliative and End-of-Life Care Unit, Chronic and Continuing Care Division of Health Canada and is the first phase in a five-year project of the CHPCA that is being funded by the GlaxoSmithKline Foundation. The objectives of the Roundtable were identified as being:

1. To engage a broad group of stakeholders, which include the non-governmental sector, industry and multi-levels of government, in the development of a multi-level national framework on advance care planning.
2. To advise on the implementation of the framework – this includes the development of tools for health care professionals and communication strategies to inform stakeholders, policy makers and the public about the national framework and tools for ACP.
3. To identify how stakeholders will be engaged in further development and implementation of the framework.

Liliane Locke welcomed everyone and conveyed how exciting it was to have such a diverse group in attendance. She stressed that advance care planning is becoming increasingly important for many reasons, but in particular because of the increased capacity to keep people alive longer. She mentioned that most of us are at different levels of understanding advance care planning. In

particular, in understanding who is/should be responsible for initiating the process of advance care planning, who should be involved, and what instruments should be used to guide the patient/family and professionals in speaking about advance care planning.

Liliane explained to participants the goals of the Roundtable, and provided an overview of the planned proceedings.

Sharon Baxter, Executive Director of the Canadian Hospice Palliative Care Association, explained that the Roundtable was part of a bigger project to develop a national framework for advance care planning in Canada, and that it came from an expressed need from many sectors such as the health care and legal sectors as well as the experiences of the provinces/territories and communities. The groups were looking for an overarching, national framework to guide their work in advance care planning.

Louise Hanvey introduced herself as the Project Manager for the ACP Project. Louise thanked Gwen Barton for having put together the *Environmental Scan on Advance Care Planning in Canada*. As this document is still in a draft format, it was pointed out that any feedback, comments or omitted issues be communicated to Louise.

B. Advance Care Planning: An Introduction

Carolyn Tayler, Director, Hospice Palliative/End of Life Care Division, Fraser Health
See www.chpca.net for Carolyn Tayler's slides.

Carolyn Tayler began the Roundtable with an introduction to advance care planning. She described that Fraser Health is a large and diverse health authority outside of Vancouver. Discussion about advance care planning in that region started in 2003. The definition of advance care planning that they worked with was drawn from the work done by Janet Dunbrack for Health Canada in *The Glossary Project*. Key informants representing the health, legal, social sectors and consumers across Canada were interviewed. As a result, they decided upon the following definition:

Advance care planning is a process of reflection and communication in which a capable person makes decisions with respect to future health and/or personal care in the event that they become incapable of giving informed consent. The process may involve discussions with health care providers and significant others with whom the person has a relationship. Advance care planning may result in the creation of an advance directive.

Carolyn identified a recent literature review on advance care planning that was conducted to produce the national advance care planning guidelines of the Royal College of Physicians in Britain (February, 2009). Based on this review, the literature demonstrated that most people did support advance care planning and those patients/families in outpatient and primary settings were happy to have the discussion, as they felt relieved to understand their choices. However, it was reported that approximately eight percent of that population had an advance care plan. In chronic disease management or end-of-life settings, satisfaction in care increased when advance

care planning was introduced. The review concluded that most health care professionals had a positive attitude towards advance care planning; however, doctors were less likely to support it.

Carolyn stressed the fact that advance care planning is often misunderstood. It is not meant to be one conversation about treatment options with a physician or a health care professional – rather it should be ongoing conversations. It is not meant to be strictly for refusal of treatments. It is not meant to be just a document or form (which families or health care professionals are often unaware of or do not have access to). It is also not meant to be a conversation with a family member that is not shared amongst other family members, with the health care professional or a physician.

Carolyn provided a number of reasons why advance care planning is important. Most people will die under the care of health care professionals. Health care professionals typically tend to treat patients when uncertain of treatment wishes. Loved ones have a significant chance of not knowing a person's views without having had a discussion regarding one's wishes at the end of life. Up to 50 per cent of persons cannot make their own decisions when they near death – and health professionals are placed in a precarious position when they are uncertain of a patient's treatment wishes.

Recent studies that looked at the relationship between costs and advance care planning demonstrated that the care in the last week of life of patients with advanced cancer who had had end-of-life discussions with their physicians were 35 per cent less costly. More interventions at end-of-life resulted in increased costs and worse quality of death.

Carolyn stressed that initiation of advance care planning and follow-up should be done by health care professionals, family physicians, nurses, medical specialists, social workers, or case managers. Ideally, these conversations should be initiated with healthy capable adults in order to create awareness and to normalize advance care planning. The conversations become more imperative with capable adults who have chronic diseases before they become acutely ill and become absolutely necessary with capable adults who have a life expectancy of less than 12 months. Advance care planning can be initiated in the primary health care setting (family doctor's offices, health clinics), in the home, in acute care, chronic care, and residential care settings. Carolyn pointed out the importance of system-wide support for advance care planning. She indicated that an advance care planning program is successful if the system created seeks and honours a patient's wishes. She cautioned that advance care planning directives alone do not work.

Carolyn shared that the program in their region has had amazing frontline support and is challenged in order to meet the demands for education and support. One of the barriers to advance care planning that is often cited is physicians' remuneration. In British Columbia, family physicians will be provided a billing code for advance care planning conversations – an important step forward.

Carolyn presented video presentations describing personal stories of patients and families who were involved in advance care planning with the support of a facilitator at Fraser Health. The individuals that spoke in the video talked eloquently about the process of dying rather than dying

itself, and stressed the important role advance care planning plays in enabling people to live more meaningfully at a time when they are not able to make decisions or speak for themselves. They stressed the importance of clear conversations, shared decision-making and the process of translating this into a care plan. The most important component of an advance care plan was identified as being the need to talk openly with family members and friends as this decreases the potential of conflict between family members.

In concluding, she reflected that advance care planning has been identified as a best practice in almost all fields and it is important to explore how it can be embedded into the practice of health care professionals. Advance care planning reflects quality care and respect for patients as partners in care; however, it does challenge the health care system and providers to move from a paternalistic to a partnership model. Decisions made by patients and families need to be respected – and these are some of the barriers that health care providers need to face.

C. Key Note Panel: Advance Care Planning in Canada – Making the Case

See www.chpca.net for the Panel Members' slides.

The key note panel presentation provided an overview of why advance care planning is important from three perspectives – clinical, legal and ethical. The panellists were Melody Isinger (ethicist), Joan Rush (lawyer) and Carolyn Tayler (clinical).

Ethics - Melody Isinger, Ethicist, Canadian Medical Association

From an ethical point of view, Melody Isinger commented that advance care planning is important because it protects both society's and an individual's fundamental values; it helps set parameters on resource allocation and helps families make difficult decisions. She stated that advance care planning protects and promotes a number of values – for example, liberty, the freedom and right to autonomy and privacy, to choose values and beliefs, culture and religion and to determine interests and pursue goals. It also protects and promotes cognitive and bodily integrity. It protects a person's dignity as it respects the person and his or her choices and protects someone when they've lost decisional capacity. Finally, advance care planning protects and promotes justice.

Melody identified a number of barriers associated with implementing advance care planning. For example, it is important to recognize that advance care planning is not the paper it is written on, but rather the conversations one has with their family, their chosen surrogate decision-maker and health care providers. Advance care plans require interpretation as advance care planning cannot address every clinical situation. Advance care planning was originally developed to reduce health care providers' liability risks – however, now it is recognized as valuable for patients, families and caregivers. The language has also changed and now includes both “what I do not want” and “what I want”.

Melody used a case study to illustrate the necessity for a national framework for advance care planning. The case study illustrated the fact that since the legislation differs from province to province, the conditions surrounding the use of advance care planning also differs – and this is confusing and difficult for patients and families when they cross jurisdictions.

Melody concluded with the benefits of a national framework. She concluded that a national framework would determine the process and procedures to enable advance care planning in Canada. It could enable equitable access to the benefits of advance care planning, it would set expectations across the country and it could result in standardized language.

Law – Joan Rush, Consulting Lawyer

From a legal point of view, Joan Rush focussed on three main points – the legality of advance directives, that the provincial legislation must enable and not restrict the process of advance care planning, and the possibility of having federal legislation to move this forward.

Joan pointed out that under the common law of Canada, a competent adult has a right to make an advance directive, (proxy and/or instructional), for health care treatment. This is a fundamental right under the Charter. It does not relate to rationing health care. Only competent adults have this right – not children, with the exception of mature minors.

She stressed that provincial legislation should enable adults to exercise their fundamental right. Restrictions often occur as a result of worries that advance care planning leads to health care rationing or euthanasia. Politicians must understand the benefits of advance care planning and be comfortable about ethics. The planning documents must be easily accessible under the legislation and simple to execute.

Joan commented that federal legislation could help in moving this forward through a number of different strategies. For example, the federal government could create a draft “uniform act” for provinces to enact; the federal government could advise provinces that suitable advance directive legislation would be required for accreditation; they could withhold transfer payments if advance directive standards were not met; and they could change the *Criminal Code* to alleviate the concerns of health care providers that withholding medical care necessary to preserve life constitutes a crime.

Joan shared a number of thoughts on moving forward. It will be important to ensure that everyone has a common understanding of advance care planning and advance directives. Joan suggested that a committee could be established to draft uniform legislation and she considered the Manitoba Health Care Directives Act as an excellent example. With regard to uniform legislation, it will be important that laws must enable adults to make treatment preferences known; people must have a choice of planning instrument (both proxy and instructional advance directive) and planning documents must be easily accessible and simple to execute.

She also suggested that an approach could be made to Health Canada to discuss including ACP as part of accreditation. And finally, recommendations to amend the *Criminal Code* could be drafted.

On a final note, Ms. Rush added that advance directive legislation must incorporate the ideals of patient autonomy and self-determination. These are at the heart of this fundamental right—and that means the patient’s goals must be at the heart of every advance care planning discussion.

Clinical – Carolyn Tayler, Director, Hospice Palliative/End of Life Care Division, Fraser Health Authority, British Columbia

From a clinical point of view, Carolyn Tayler provided the group with case examples drawn from her professional experience with families who have had to face end-of-life decisions. The case studies illustrated the difficulties that families and health care professionals face when there is not a program in place and things do not go well, as well as situations where the advance care planning conversations were held, and patients are able to die according to their own wishes. She noted that health care professionals often observe that in some instances, medical science cannot meet the patient's requests – however, this should not prevent health care providers from having discussions with their patients. Carolyn stressed that it is important to take care with the language used – describing the outcome of a decision and what it could potentially mean should be part of the conversation.

The comment, question and answer period following the Panel presentation is summarized as follows:

- It is important to remember that ACP is a dynamic process and not a static one – as things change over time, one's wishes will change over time. From a clinical point of view, it was agreed that it is important the conversation be ongoing, and that health care providers need to be aware of what has changed and determine whether the wishes expressed are still the same.
- Sometimes providers fail to recognize and remember that everything in health care is a process and that advance care planning should always be reassessed.
- Since Canada is a multicultural country, it is important to remember that this kind of decision making may be very different depending on the cultures. It was shared that Fraser Health has a very culturally diverse population. A lot of outreach work was done with ethnic community groups on advance care planning. In many situations, community members found that the process of advance care planning was very acceptable to them. Materials were translated for different cultures/languages. It is important that 'culturalism' not be used as an excuse to not talk about advance care planning. Individual circumstances need to be assessed based on one's beliefs, values and objectives instead of stereotyping. Each culture has a way of preparing someone for death and will address this through different means and mechanisms.
- The question was raised regarding children's abilities to make advanced directives. Joan indicated that there are some laws that allow children to make decisions about their own health care. Carolyn indicated that the Canadian Paediatric Society has written guidelines for advance care planning and children.
- One of the major challenges to advance care planning is communication skills – particularly in hospitals. It was highlighted that there is a dearth of programs in hospitals to teach health care practitioners to communicate with their patients about the importance of advance care planning and how to ask the right questions.
- The issue of making decisions about what happens after death was also an important part of advance care planning - e.g., organ donation.

D. Advance Care Planning in Calgary Health – A Case Study

Bert Enns, Project Manager, Alberta Health Services, Calgary Region

See www.chpca.net for Bert Enns' slides.

Bert described advance care planning in the Alberta Health Services (AHS [Calgary and area]) and provided an overview describing why they became engaged; what enabled their engagement; what they did; the outcomes; and their challenges and learnings.

The broad mandate of the AHS (Calgary and area) Project is to enhance the quality of care for individuals at the end of life, their families and their health care providers. There are two key areas: advance care planning and a regional policy addressing goals of care.

AHS (Calgary and area) engaged in this Project because the statistics indicate that at least two-thirds of the population will live for an extended time period with one or more serious chronic illnesses and that available medical interventions provide varying degrees of benefits and burdens. This Project offered opportunities for individuals and families to engage in health care decision making.

The AHS (Calgary and area) serves over a million people. Therefore, their work incorporates many agencies, institutions and providers – three urban and four rural adult acute care sites with over 2,000 beds; 5,000 urban/rural long term care beds; 500 designated assisted living beds; home care services to more than 10,000 clients annually; emergency services personnel; a cancer centre; over 300 outpatient clinics and over 1,100 family physicians.

The project has involved four building blocks: engagement; education; system infrastructure and continuous quality improvement. The work began in the spring of 2005. In order to learn from the experiences of others, they had two visits from 'Respecting Choices' and they visited Fraser Health in British Columbia. They identified five pilot areas for the development of advance care planning and created their resources – "My Voice–Planning Ahead". In January 2006, they secured Charter to develop a regional policy focused on comprehensive Goals of Care. Over the next two years, they developed the content of the regional 'Advance Care Planning: Goals of Care Designation (Adult) Policy' and had the policy approved and implemented. They engaged in all aspects of policy implementation – communication; education; development of clinician/public resources and evaluation. The policy was implemented in November, 2008.

Bert identified a number of enablers of success of the project:

- They had support from senior management and leadership across the continuum of care.
- They had resources for the Project – 4.5 full-time equivalent staff and budget dollars.
- The Project was prioritized within regional initiatives.
- They had a Regional Advisory Committee made up of champions and advocates.

The factors that informed the development and implementation of advance care planning included their partners – Respecting Choices and Fraser Health; the learning opportunities provided through the pilot groups; and the external input from a public task group; a national

symposium and the personal directives legislation. The enablers of the policy work were that they had the mandate from regional senior management; there was a Regional Clinical Policy Framework that identified endorsement bodies; and they had the resources. Furthermore, they had a project plan with implementation activities, education and communication embedded in it. They integrated evaluation into the project and they defined targets for all aspects of implementation.

Bert described their outcomes. They have a number of key resources for individuals and families – “My Voice – Planning Ahead”. They have developed Advance Care Planning: Goals of Care Designation (Adult) Policy that involves a decision-making framework focused on the broader goals of care; provides one framework across all care settings to support portability of documents; is patient-focused; integrates the process of advance care planning into collaborative decision making; and includes decision support resources and a dispute resolution process.

Finally, Bert outlined the key challenges and learning. They included:

- The importance of defining the interplay between advance care planning and goals of care designations.
- It is possible to create systems that support advance care planning and recognize the dynamic nature of goals of care;
- From a systems/workflow perspective, the consistency of transmission of documents within and between sectors is critical.
- Conversations take time – there is need to clarify “who does it?” and “which sector is responsible?” It is important to consider how to influence the quality of the conversation/decision-making.
- There needs to be clarity with regards to how all of the pieces fit together.
- It is important to assess patient and family readiness and to recognize different cultural approaches.

The comment, question and answer period following Bert’s presentation is summarized as follows:

- The observation was made that British Columbia has a billing code for physicians to engage in advance care planning discussions and the question raised as to whether or not other provinces/territories had a similar code. It was also observed that discussions are underway in Alberta to implement a billing code for physicians doing advance care planning. The observation was also made that Ontario has three codes that could be used for these conversations – whether they are used or not is unknown.
- The issue was raised regarding the importance of examining patient outcomes to see if there is a change. Bert reported that they are looking at a number of outcomes – for example, are patients’ wishes honoured at end of life? They will be conducting satisfaction surveys regarding patient and family engagement. They are also looking at the transfer of documents and communication – to determine if, once patients and professionals have had advance care planning conversations and a commitment has been made to the individual around a goal of care, the system honouring that commitment as the patient transitions.
- When looking at outcomes, there can be a fear of rationing – and that can preclude people from becoming involved in advance care planning. It is important to look at the

difference between rationing and making a personal choice – rationing is when someone else makes the choice for a patient – a system choice or hospital choice based on policy – choice is when the person makes the choice for themselves.

- The observation was made that sometimes these discussions can be quite difficult. The quality will really depend on the relationship that happens in the team – and it is known that teams are not functioning in a collaborative way in some settings. The example was given that if it is the spiritual care provider that has the best relationship with the patient and has the discussion, does the physician then re-have the conversation before writing the order? Bert reflected that they have had positive experiences where residents from continuing care centres come into the emergency department and the emergency physicians find it very valuable that the resident has come in with the document – the goals of care designation already framed. They can then build on it rather than starting from square one.
- The question was asked: “Is there a legal requirement to have a physician order? If this is a patient’s choice – why do we need a medical order?” Participants commented that they were not sure that it had to be a physician’s order. In some jurisdictions, in hospital environments it is a hospital policy – for example, when the DNR policy was developed for Ontario, it could be a nurse, physician, or other health care provider having that conversation and recording it. In Regina they are implementing advance care planning without a physician order – they are creating a ‘person order’. The person determines what they want and informs their physician and other health care providers.
- Gunderson Lutheran developed POLST – Physician’s Orders for Life Sustaining Treatment. There are now seven or eight states that use POLST. A nurse, nurse practitioner or physician takes the advance care plan and translates it into a physician order that can be quickly acted on – the patient carries the order with them and can be reassured that it will be accepted. A couple of states have gone to MOLST – Medical Orders for Life Sustaining Treatment. It was stressed that the validity is the process that happened before the orders were written.
- The participants commented on the difficulty of having physicians engage in training around advance care planning. The suggestion was made that an online course or modules could be put in place for physicians. A caution was voiced about over-reliance on education – just educating people does not change practice. It is important to have standards and champions in order to change the system. The observation was made that the change literature says that if you can change 20 per cent of the system, the whole system will change.

E. Small Group Discussion 1:

Values/Guiding Principles

Implementing Advance Care Planning: Barriers and Strategies to Overcome Them

The participants worked in five small groups centered on the Values/Guiding Principles and the Core Elements for the Advance Care Planning Framework that was circulated (See Appendix 5). Their discussions were based on two identified themes:

- Values/guiding principles
- Barriers to advance care planning within professional groups at a system level, as well as for patients and families – and strategies to overcome them

The groups then shared their discussions in plenary.

Values/Guiding Principles

The groups generally agreed with the intent of the Values and Guiding Principles, but all agreed that they needed more work. This included:

- Clarification of language.
- Consistency of language.
- Making them more focussed.
- Clear definition of advance care planning.
- Focus on making the values/guiding principles patient-centred.
- Importance of distinguishing between values, principles and operating standards.

Barriers to Advance Care Planning and Strategies to Overcome Them

A number of common themes emerged from the five groups relating to barriers and strategies.

- There is reluctance on the part of many health care providers and many patients/families to engage in advance care planning conversations. Therefore, there is a need for a culture shift – that should be focused on re-educating the public and health care providers and providing them with the tools they need to do this.
- Advance care planning is values-based. There may be many values held by health care professionals and patients/families that are contrary to advance care planning. For example, a value system that results in a paternalistic approach by health care providers will not facilitate the development of an advance care plan. Therefore, implementation will have to include attention to and work with values of providers and patients.
- Time and resources were a major theme. Many groups indicated that there is a lack of these precious commodities. For example, health care providers do not have time; there are no resources specifically allocated to advance care planning; not everyone has a family doctor or has continuity of care. Since advance care planning is based on relationships and conversations, this makes it difficult.
- Taking responsibility for one's health (and life) is a major component of advance care planning. The groups identified that some people do not easily do this. Therefore, it

will be important to integrate strategies to enable them to learn the skills needed to take this kind of responsibility when implementing advance care planning. Furthermore, patients and families need access to information regarding advance care planning and the tools to engage in it. Lack of information was often cited as a barrier.

- The core values of the health care system can sometimes be at odds with advance care planning. For example, the health care system values cure more than it values care. Added to that was the observation that health care professionals are often short-sighted, and have difficulty looking past what is being done now. Furthermore, it was observed that the culture of medicine and nursing, and the way people have practiced, is very slow to change. Finally, some participants noted that there is a lack of trust in the health care system – therefore, documents that are sent from agency to agency are not always accepted. As a result, implementing advance care planning will have to focus on areas such as organizational values and organizational/system structures. It will be important to choose champions who can be leaders in implementation.
- A lack of skills and knowledge on the part of health care professionals was also seen as a barrier. Education and training would have to consist of building both knowledge and skills. It will be important to build on the successes and responsibilities that will result in improving skills. It is particularly important to make the benefits of advance care planning very clear to the providers.
- A lack of clear definitions is still seen as a barrier. For example, there is a general lack of understanding of the difference between advance care planning and advance directives.
- Advance care planning is seemingly only associated with dying. There is a need to move away from this image to focus on things such as end-of-life decisions. It will be important to engage primary care providers in advance care planning implementation.
- Communication skills were seen as critical – and many groups saw this as an area of particular need. They felt that health care professionals lacked adequate training in the communications skills needed to do advance care planning effectively.
- Working in teams is essential to successfully implement advance care planning. Currently, parts of the system are fragmented and people work in silos. Therefore, there will have to be organizational support, to allow people to work together. Sharing information is often a problem – so again, organizational structures and supports will have to enable sharing. In order for advance care planning to be successful, a system-wide approach will be necessary.
- Legislation is seen as a barrier, rather than an enabler. It will be important to make efforts to enact enabling legislation – and ideally to harmonize legislation. Furthermore, lack of knowledge regarding the law was seen as a barrier. Teaching health care providers about the law, and teaching legal students about the health care system is imperative.

- Cultural competence was seen as a barrier. Since the process of advance care planning is very culturally based, it is critical for health care professionals to develop cultural competences.

**F. Small Group Discussion 2:
A Model for Advance Care Planning in Canada**

During this small group discussion, participants were asked to consider the following three potential models for implementing advance care planning.

- Opt-in – for example, in organ procurement, the opt-in model involves signing a donor card to indicate that you want to donate organs. This would require the individual to proactively engage in advance care planning.
- Opt-out – for example, in organ procurement, the opt-out model means everyone is an organ donor unless they say they do not want to be. Therefore, everyone would be engaged in advance care planning unless they stated they did not wish to do so.
- Mandated choice – in this model, every time a health care provider has an interaction with a patient, they are asked about advance care planning, e.g. “Have you thought about it?” or “Do you want to do it?” This gives the health care provider the responsibility to initiate the conversation

Participants were asked to identify the pros and cons of each of these models of implementing advance care planning and indicate which model they found to be most suitable. The groups reported back in plenary.

The groups had varying responses to these models. For example, two preferred the opt-in model, one the opt-out model; and two preferred a blended model. In their discussions of a model of advance care planning, a number of common themes emerged.

- Advance care planning would always be a choice in any of the models presented and it would remain a patient’s choice to engage in advance care planning. By definition, advance care planning can never be ‘forced’. The model should focus on how to approach patients about the issue, i.e., would the health care provider initiate the conversation or would patients come to health care providers. As such, it will always be up to the individual; the goal for this Project is to give them an opportunity to do it.
- The groups felt that the opt-in model better reflected choice and respected autonomy – whereas the opt-out model was more legislatively driven. The health care system would need to put in place a system for people to have the option to opt-out (in the opt-out model) – the cost would be high, and there would be a need for education and training. There may be a risk that people who do not want to be included may be included by default.

- However, with the opt-in model, there is a larger responsibility placed with the public. The strategy to drive that would be a highly informed public – and this would be dependent on readiness. In the opt-out model, there is some responsibility of the health care team or health care service providers.
- Communication and engagement were seen as the critical elements of any model chosen/implemented. This is at the societal and health care system/professional level.
- The identification of leaders and role models are essential for any model chosen.
- There needs to be a system to support advance care planning with any model chosen. Therefore, there is a need for legislation, accreditation, policies, education and consistent tools along with the resources to support the model. This will involve looking at the justice, health care and social systems.
- A staged approach to implementing any model is critical – it would not be wise to make system-wide changes all at once, due to challenges associated with getting all of the jurisdictions on board and all of the resources together.
- If the onus is placed on the health care providers, then the question needs to be asked: ‘Are we ready?’ ‘Do the health care providers have the tools to inform their patients if they ask about advance care planning?’ All groups believed that all models required a significant amount of education for health care providers.
- With any model, there is a need for an enabling legislation that is similar across the health jurisdictions in order to allow advance care planning to be widely implemented.
- In order to build a strong model, there is a need to engage and secure the input of both members of the community as well as different health care professionals.

G. Where Do We Go from Here?

Louise Hanvey and Sharon Baxter thanked everyone for the very rich discussions and the important issues that will need to be explored and synthesized. The next steps were outlined as follows:

1. Feedback will be requested on the Draft Environmental Scan by April 10th.
2. The final report of this meeting will be submitted to Health Canada by the end of April 2009 and then to participants.
3. Throughout the months of April and May, the project staff will be working on the next version of the Draft Framework by integrating the discussions held today. In May/June, today's participants as well as other stakeholders will be surveyed for comments on the Draft Framework.
4. Work will be done with the CPHCA to look at a communication strategy for the framework as we move forward in order to ensure that everyone is engaged.

Everyone in attendance was thanked for having participated in this national roundtable. Thanks also went out to the members of the Task Group for the work done around today's event. Nicoda Foster and Johanne Sabourin were also thanked for taking notes. Liliane Locke provided the final thanks – she recognized Louise Hanvey for her work done and Bruyère Continuing Care for the excellent meeting facilities. She thanked all of the participants for their hard work wished them bon voyage.

Appendix 1: Backgrounder ***Advance Care Planning in Canada: A National Framework and Implementation***

The long term goal of *Advance Care Planning in Canada: A National Framework and Implementation* is to raise the awareness of Canadians about the importance of advance care planning and to equip them with the tools they need to effectively engage in the process. The secondary goal is to prepare professionals/health care providers with the tools they need so they can facilitate and engage in the process of advance care planning with their clients.

What is Advance Care Planning?

Advance care planning (ACP) is the process by which a person considers options about future health care decisions and identifies what his or her wishes are. An advance care plan is a verbal or written instruction describing what kind of care he or she would want (or not want) if he or she is no longer able to speak for his or her self. It describes a person's wishes regarding: who will speak on their behalf; the type of treatment they would want considered; the type of treatment they would not want considered; their wishes for their end of life experience; and the values that guide them in making significant decisions.

Background

As health care technologies improve and people with many complex diseases live longer, advance care planning is becoming increasingly important. There is considerable evidence showing that advance care planning is poorly done, often happening only at the very end of life when crises occur and people are incapable of making decisions about the care they want. The ACP Project aims to implement a number of changes to the current practices.

Presently there are many Canadian health care organizations that would like to provide tools to their clients, residents, or patients to assist them in making appropriate decisions regarding their care. Tools have been developed by different organizations within the country, including Health Canada, but no clear implementation or communication plan has been developed. Bringing advance care planning to Canadians requires coordination of many players including the non-governmental sector, health care providers, regional health authorities, provincial/territorial/federal government(s) and industry (employers).

The Project

Advance Care Planning in Canada: A National Framework and Implementation is a five-year project that will:

- Complete a needs assessment/environmental scan identifying the basic components of a National Framework.
- Through a national consultative process, develop a National Framework that remains flexible and facilitates collaboration across sectors.
- Implement the key recommendations in the Framework relating to education of professionals/health care providers and public awareness/education. This will include:
 - Engaging professionals/health care providers in advance care planning.
 - The development and dissemination of tools for professional/health care provider education.
 - Educating/raising the awareness of consumers/the public.
 - Engaging consumers/the public in the process of advance care planning.

The project will result in collaboration across Canada to engage professionals and citizens in advance care planning. This is a project of the CHPCA, but is being undertaken under the guidance of a Task Group which brings together a number of partners. (A list of members of the Task Group follows).

The National Roundtable

The National Expert Roundtable was held with the goals of:

- Engaging a broad group of stakeholders in the development of a draft multi-level national framework on advance care planning – including the non-governmental sector, industry and multi-levels of government.
- Advising on the implementation of the Framework, including the development of tools for health care professionals and communication strategies to inform stakeholders, policy makers and the public about the National Framework and tools for advance care planning; and
- Identifying how stakeholders will be engaged in further development and implementation of the Framework.

The Roundtable was organized by a Coordinating Committee which included staff of Bruyère Continuing Care, two representatives from Health Canada's (HC) Palliative and End-of-Life Care Unit, as well as members of the CHPCA's national task group. This committee worked with the Project Manager on the development of the multi-level national framework as well as the necessary logistics for the roundtable.

Funders:

Advance Care Planning in Canada: A National Framework and Implementation (overall Project): GlaxoSmithKline Foundation

National Roundtable: Palliative and End-of-Life Care Unit, Chronic & Continuing Care Division, Health Canada

Environmental Scan: Canadian Partnership Against Cancer

Project Task Group

Michael Aherne (Quality End-of-Life Care Coalition)
Sharon Baxter (Canadian Hospice Palliative Care Association)
Karen Chow (GlaxoSmithKline Foundation)
Bert Enns (Calgary Health)
Esther Fortin (Health Canada)
Debbie Gravelle (Bruyère Continuing Care)
Melody Isinger (Canadian Medical Association)
Leanne Kitchen Clarke (Canadian Partnership Against Cancer)
Julie Lachance (Health Canada)
Larry Librach (Canadian Hospice Palliative Care Association/Academic)
Liliane Locke (Bruyère Continuing Care)
Carolyn Tayler (Fraser Health)

Staff:

Louise Hanvey (Project Manager)
Nicoda Foster (Project Assistant)

Appendix 2 ACP Roundtable 2009 – Participant List

Michael Aherne

Chair, Education Committee, QELCCC
Pallium Project, Co-founder

Brian Banks

Advance Directives Coordinator
Health and Social Services Yukon Government

Gwen Barton

Health Services Consultant

Sharon Baxter

Executive Director
Canadian Hospice Palliative Care Association
(CHPCA)

Jean Bustard

Director, Extra-Mural Program and
Rehabilitation Services
NB Department of Health

Caitlin Brydges

Public Education Coordinator
Alzheimer Society of Ottawa and Renfrew
County

Karen Chow

Vice President
The GlaxoSmithKline Foundation

Jennifer Colepaugh

Territorial Home and Continuing Care
Coordinator
Government of Nunavut

Bert Enns

Project Manager
Alberta Health Services – Calgary Area

Esther Fortin

Manager, Palliative and End-of-Life care Unit,
Strategic Policy Branch
Health Canada

Nicoda Foster

Project Assistant, Advance Care Planning in
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Canadian Hospice Palliative Care Association

Debbie Gravelle

Manager, Regional Palliative Care Community
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Bruyère Continuing Care

Leslie Greenberg

Director Strategy
Canadian Partnership Against Cancer

Pippa Hall

Associate Professor, Palliative Care Physician
University of Ottawa, Bruyère Continuing Care

Louise Hanvey

Project Manager
Advance Care Planning in Canada (ACP)
Project

Melody Isinger

Ethicist
Canadian Medical Association

Nancy Kidd

Continuing Care Manager of Quality Risk and
Clinical Resource
Health and Social Services Yukon Government

Judy Knight

Director, Continuing Care
Manitoba Health

Jennifer Kryworuchko

OTC Health Services Policy Student/ PhD
Candidate
PEOLCU Health Canada/University of Ottawa
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Julie Lachance

Senior Policy Analyst
Palliative and end-of-Life Care Division, Health
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Dr. S. Lawrence Librach

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Denise Page
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Catherine Peters
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Regina Qu'Appelle Health

Dr. José Pereira
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University of Ottawa and Bruyère Continuing
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Lonny Rosen
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Joan Rush
Lawyer and Health Law Consultant

Johanne Sabourin
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Mary Sullivan
Provincial Home Care Coordinator
Prince Edward Island Department of Health

Carolyn Tayler
Director, Hospice Palliative/End of Life Care
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Fraser Health Authority

Anne Van Dam
Acting Director, National Lung Health
Framework
The Lung Association, National Office

Linda Wright
Director, Toronto General Hospital
University Health Network

Kirsten Wurmamn
Librarian
Legal Resource Centre of Alberta Ltd.

Appendix 3
Advance Care Planning In Canada
National Roundtable Program
March 25th – 26th 2009

Élisabeth Bruyère Hospital
Gilbert Paquette Room – 6th Floor
43 Bruyère Street, Ottawa, Ontario

Roundtable Objectives

1. Engage a broad group of stakeholders in the development of a draft multi-level national framework on advance care planning – including the non-governmental sector, industry and multi-levels of government.
2. Advise on implementation of the framework – including the developing of tools for health care professionals and communication strategies to inform stakeholders, policy makers and the public about the national framework and tools for ACP; and
3. Identify how stakeholders will be engaged in further development and implementation of the framework.

Acknowledgements

This National Roundtable was funded by the Palliative and End-of-Life Care Unit, Chronic and Continuing Care Division, Health Canada. It is the first national meeting of *Advance Care Planning in Canada: A National Framework and Implementation*—a five-year project of the Canadian Hospice Palliative Care Association that is funded by The GlaxoSmithKline Foundation. The research, writing and production of the Environmental Scan circulated to Roundtable participants was made possible through a financial contribution from Health Canada, through the Canadian Partnership Against Cancer. Translation of the Environmental Scan was funded by the Palliative and End-of-Life Care Unit, Chronic and Continuing Care Division, Health Canada.

Day One

Wednesday, March 25, 2009

1400-1415 Welcome, Objectives and Background of Project

Sharon Baxter, Canadian Hospice Palliative Care Association

Liliane Locke, Bruyère Continuing Care

Esther Fortin, Palliative and End-of-Life Care Unit, Chronic and Continuing Care Division, Health Canada

1415-1445 Advance Care Planning: An Introduction

Carolyn Tayler, Fraser Health

- 1445-1615 Key Note Panel: Advance Care Planning in Canada – Making the case**
Melody Isinger, Canadian Medical Association
Carolyn Tayler, Fraser Health
Joan Rush, Barrister and Solicitor
- 1615-1645 Break**
- 1645-1730 Key Note Address: Advance Care Planning in Calgary Health – A Case Study**
Bert Enns, Calgary Health
- 1730-1815 Why do we need a National Framework?**
Sharon Baxter and Louise Hanvey, Canadian Hospice Palliative Care Association
- 1815 Dinner/networking**

Day Two

Thursday, March 26th 2009

- 0730-0800 Continental Breakfast**
- 0800-0815 Welcome and Objectives**
Karen Chow, The GlaxoSmithKline Foundation
Sharon Baxter and Louise Hanvey, Canadian Hospice Palliative Care Association
- 0815-0945 Small Group Discussion**
Values/Guiding Principles
Implementing Advance Care Planning: Barriers and Strategies to overcome them
- 945-1015 Break**
- 1015-1100 Plenary Discussion**
Report Back
- 1100-1215 Small Group Discussion**
A model for advance care planning in Canada
- 1230-1330 Lunch**
- 1330-1430 Plenary Discussion**
Report Back
- 1430-1500 Where do we go from here?**

Appendix 4: Speakers' Bio

Bert Enns B.A., MTS

Bert Enns has provided project leadership in the not-for-profit sector both in Canada and internationally. In the late 90's, she trained as a hospital chaplain, providing spiritual support for individuals facing the end of life, their families and their health care providers.

In spring of 2005, Bert began to lead a new regional initiative focused on enhancing the quality of care at the end of life. Two key accomplishments include the development and implementation of an advance care planning program, "My Voice—Planning Ahead" and the development of a policy that addresses goals of care across the continuum of care.

Melody Isinger, DHCE

Melody Isinger has worked as an Ethicist for the Canadian Medical Association (CMA) for the past five years. She came to the CMA from the Royal Alexandra Hospital in Edmonton, where she was the Clinical Ethics Resident in 2003-2004. As the Clinical Ethics Resident Ms. Isinger attended medical and clinical rounds, conducted ethics consults, was a member of the hospital's Ethics Committee and served on the Policy Review Sub-committee.

Ms. Isinger recently received her Doctor of Health Care Ethics (DHCE) from Duquesne University, Pittsburgh, PA. To fulfill the requirements for the DHCE, Ms. Isinger did ethics internships and residencies at St. Francis Hospital and The University of Pittsburgh Medical Center: Shadyside Hospital, both which entailed conducting ethics consults and membership on the hospitals' Ethics Committees. Ms. Isinger also served as the Ethicist in Residence at a long-term care facility. Ms. Isinger received a Certificate in Conflict Resolution and Peace Studies from Duquesne University; a Master of Arts (Philosophy) and Bachelor of Arts (History and Political Theory) from the University of Saskatchewan.

Ms. Isinger is the CMA representative on the Quality End-of-Life Care Coalition of Canada and The Pharmaceutical Advertising Advisory Board of Canada. Ms. Isinger is the Bioethicist on the Bruyère Continuing Care Health Service Research Ethics Board and serves as the Community Representative on the University of Ottawa Animal Care Committee and is the Ethicist for the Carleton Place Hospital.

Joan L. Rush, B.Comm., LL.B., LL.M.

Joan Rush is a lawyer consulting in the areas of health law, corporate governance, and legal issues relevant to health care providers and the financial services industry. Before establishing her consulting practice, Joan was Vice President and General Counsel to a Canadian life insurance company. She has been an Adjunct Professor at the Faculty of Law, U.B.C., teaching life and disability insurance law. She has written articles and spoken widely on the topic of advance care planning.

Carolyn Tayler, RN, BN, MSA, CON(C)

Carolyn is the Director, Hospice Palliative and End of Life Care and is responsible for Advance Care Planning in Fraser Health BC.

Carolyn is a Past President of the Canadian Association of Nurses in Oncology, Past President of the BC Hospice Palliative Care Association and was Chair of a Pallium Initiative to develop western Canadian palliative care telenursing protocols. She is a member of the End of Life Standing Committee in BC and Co Chair of the Canadian Strategy for Cancer Control BC/Yukon Quality End of Life and Palliative Care Action Group. She is also a member of the CHPCA Advance Care Planning Task Group.

Appendix 5
Advance Care Planning in Canada: National Framework
Draft Outline for Discussion: March 18, 2009

Executive Summary

Preamble and Assumptions

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

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. There are, however, common values and principles that underlie advance care planning – no matter what the system or jurisdiction. Therefore, these values and principles are articulated in the Framework.

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

I. Background

Advance care planning or ACP is a process whereby a capable (mentally competent) adult engages in a plan for making personal health care decisions in the event that this person becomes incapable (legally incompetent to personally direct) his or her own health care. ACP describes what kind of care the person would want (or not want) if he or she were unable to make health care decisions. It is the process of exploring questions that often go unasked, such as: What gives life meaning? Are there circumstances (loss of physical functioning or loss of mental awareness, for example) in which the person would not want their life prolonged by certain treatments, but rather would want nature to be allowed to take its course and they be allowed to die?

As health care technologies improve and people with many complex diseases live longer, advance care planning is becoming increasingly important. There is considerable evidence that advance care planning is poorly done, often happening only at the very end of life when crises occur, when life-sustaining treatments have been instituted despite issues of poor prognosis, and when people are not capable of making decisions about the care they want. Furthermore, Canada is a large country – where health is a provincial jurisdiction; there are a number of models of health care organization, with many different health regions/authorities/departments. In addition, advance care planning is not only a health care issue, but a much broader issue. The legal context for ACP across the country varies and can be confusing.

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 and other areas with little knowledge. Information sharing is important across all of those jurisdictions. Raising the subject of advance care planning with people can be difficult for professionals/health care providers and fearful for patients. Nevertheless, there is evidence to suggest that many consumers are eager to discuss advance care planning if they are given the opportunity in a supportive environment. Education, user-friendly tools and resources are needed by professionals in all sectors and by consumers. There is a need to foster ongoing dialogue about advance care planning among the legal sector (including those who develop legislation), policy makers, health care providers and consumers so that legislation, law and policy can be both legally and medically sound and socially responsive.

The goal of a national framework for advance care planning is to provide a model that can be used to guide all related activity, program development and standards of practice. Implementing key recommendations in the framework will result in raising the awareness of Canadians about the importance of advance care planning and to equip them with the tools they need to effectively engage in the process; and to prepare professionals/health care providers with the tools they need so they can facilitate and engage in the process of advance care planning with their clients.

The national framework will be developed through a national consultative process – that remains flexible and facilitates collaboration across sectors.

II. The Framework Overview: Graphic Presentation

To be developed

III. The definition of advance care planning/an understanding of advance care planning

Advance Care Planning (ACP) is the process by which a person considers options about future health care decisions and identifies what his or her wishes are. An advance care plan is a verbal or written instruction describing what kind of care he or she would want (or not want) if he or she is no longer able to speak for him or herself. It describes a person's wishes regarding: who will speak on their behalf; the type of treatment they would want considered; the type of treatment they would not want considered; their wishes for their end of life experience; and the values that guide them in making significant decisions.

IV. Values underlying advance care planning

1. Each person is intrinsically valuable, unique and has the moral right to autonomous decision-making.
2. Life and the natural process of death provide opportunities for personal growth and self-actualization.
3. Caregivers enter into a therapeutic relationship with patients and families based on mutual respect for one's inherent dignity and integrity.
4. It is important to address individuals' (patients') and families' suffering, expectations, needs, hopes and fears.
5. Advance care planning is only facilitated when the patient and family is prepared to accept it.
6. Advance care planning is guided by quality of life as assessed by individuals for themselves.

V. Guiding principles related to advance care planning

The following principles guide all aspects of advance care planning:

Individual respect

1. Advance care planning must occur with in 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.

Benefits

2. There are benefits from advance care planning for the person involved, their family and the health care team/system.

Access

3. All individuals (patients) and families should have equal access to engage in advance care planning.
4. All individuals (patients) and families should have equal access to accurate and relevant information regarding health care and advance care planning, and informed consent.

Need for support and collaboration

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

Ethical and legal responsibilities

7. Whenever possible, care providers should engage in conversations regarding advance care planning with individuals (patients) and families, according to the ethical framework of their profession and the laws of their jurisdictions.
8. Care 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

9. The ability for care 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

10. All advance care planning activities are guided by: the ethical principles of autonomy, beneficence, nonmaleficence, justice, truth-telling and confidentiality; standards of practice that are based on nationally-accepted principles and norms of practice, 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

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

VI. Advance Care Planning in Canada: Key Elements of a National Framework

To be further developed

- a. Engagement:
 - i. Engagement of professionals/providers – across all relevant sectors
 - ii. Awareness raising and engagement of the general public
 - iii. Engagement of systems/organizations/governments
 - iv. Challenges and enablers to engagement
 - v. Risks/consequences of not engaging professionals/providers; the general public and systems/organizations/governments
- b. Education
 - i. Education and training of professionals/providers
 - ii. Education of the general public
 - iii. Core competencies for those engaging in advance care planning with clients
 - iv. Challenges and enablers to education
- c. System infrastructure
 - i. Policy development
 - ii. Program development
 - iii. Accreditation standards
 - iv. Tools to support conversations
 - v. Tools to support documentation
 - vi. Legislation to support advance care planning
 - vii. Challenges and enablers within the system
 - viii. Risks/consequences of not having supportive system infrastructure
- d. Continuous quality improvement

Sources:

Advance Care Planning in Canada: Environmental Scan – Interim Report, February 13, 2009

Advance care planning: the Glossary project, Final report (unpublished), by Janet Dunbrack for Health Canada, August, 2006.

Advance care planning: An implementation guide for health authorities in Canada. March 31, 2008.

A Model to Guide Hospice Palliative Care. Canadian Hospice Palliative Care Association, 2002.

Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Material. 2007. Educating Future Physicians in Palliative and End-of-Life Care.

Health Care Consent and Advance Care Planning Community of Practice. Guiding Principles and Processes for the CoP Working Group.

<http://www.calgaryhealthregion.ca/programs/advancecareplanning/>

<http://www.fraserhealth.ca/Services/HomeandCommunityCare/AdvanceCarePlanning/Pages/default.aspx>