**National Seniors Strategy Evidence Informed Policy Brief**

# Ensuring Older Canadians and their Caregivers are Enabled to Participate in Informed Health Decision-Making & Advance Care Planning

## Setting the Context:

Advances in medical treatments and care practices have meant that more Canadians can expect to live longer in their communities with more complex health conditions. As a result, patients, families, and health care providers will be called on more often to make increasingly challenging, complicated decision as it related to their future care needs.

The scope of these decisions can vary widely, and can include such issues as:

- Whether to take a proposed medication that may not cure a problem but prolong life.
- Whether and when to move into a long-term care home.
- Whether and when to use and/or withdraw a feeding tube.

Often, these questions don't have simple medical answers. Rather, they involve things at the heart of health care: an individual's values and preferences. These are weighty matters.

Yet, often, families and the individuals requiring care and support need to make informed and considered choices in uncomfortable circumstances, aided by busy health and social care professionals who may not have had the chance to get to know them well and are focused on providing medically appropriate care. The experience can be stressful, and individuals and their loved ones may not always have the luxury of long, open discussions.

A basic ethical principle of health care is informed consent: that an individual is entitled to know the risks and benefits of a given treatment or care option, and to decide whether they want to pursue it, free from any form of coercion.

Sometimes, because of illness, an individual may be incapable of making a decision, and their loved ones may have to decide for them as their legally determined designated substitute decision maker. That person's role is to carry out wishes expressed in advance, or, if these are absent, make judgments about what the individual requiring care would have wanted.

Occasionally, despite everyone's best efforts, these choices don't reflect what the individual, with the benefit of full information and sufficient time, would have chosen. In these cases, it's hard to tell whether the principle of informed consent has been fully satisfied.

For this reason, it's important for all Canadians, and especially older Canadians who are most likely to be engaged in making such decisions for themselves and/or loved ones, to inform themselves about their health and care issues and think about and discuss their values, treatment and care options, and preferences well in advance. This includes the management of chronic conditions, what kind of supportive or life-saving care is acceptable in the event of a terminal illness or condition, and where a patient will live and who will look after them if they are no longer able to live independently.

**Advance Care Planning (ACP)** is the process by which a person expresses what they wish to take place should they become incapable of consenting to or refusing treatment or personal care, including deciding who will make decisions on the person's behalf if this happens.[1]


The process should include discussions with family members, friends, and other loved ones, and cover a wide range of scenarios and treatments, including end-of-life care, chronic conditions, and long-term care needs. Other people who may be involved include health care providers, and lawyers who can help to facilitate and document the person's decisions in the form of an advance directive.[2]

The evidence is clear that ACP makes a big difference. Studies show that ACP – especially formal programs involving trained facilitators – improves the quality of end-of-life care.[3]

A review of studies found that patients who had an advance care plan in place were less likely to be admitted to an intensive care unit, and those who were admitted stayed there for less time.[4] Some studies even suggest that just having an advance directive in place reduces risk of hospitalization and the chances of dying in the hospital.[5]

ACP also helps to support loved ones in a difficult time. Formal ACP counseling has been shown to significantly reduce stress, anxiety, and depression in family members, and patients and family members who received the counseling were more satisfied in general.[6] Finally research also suggests that ACP may reduce health care costs by avoiding unwanted treatment.[7]

Clearly, every effort must be made to ensure that as many Canadians as possible, particularly older Canadians, engage in timely, comprehensive ACP, and are supported in doing so.

## What are the Issues?

### 1. Canadians Aren't Sufficiently Informed, Encouraged and Empowered to Initiate and Participate in ACP Discussions

Recent surveys show that many Canadians are either not aware of the need for ACP, or find it difficult to start and sustain the often challenging conversations involved. A 2012 survey found that **86%** of Canadians had not heard of ACP, over **80%** had no form of written plan, and less than **50%** had had a conversation with a family member or friend about what health care treatments they would and wouldn't want if they were ill and unable to communicate.[8]

This problem is not unique to Canada. A survey of experts in Australia concluded that that country's similarly low uptake of ACP was due in large part to "inadequate awareness, societal reluctance to discuss end-of-life issues, and lack of health professionals' involvement in ACP." [9] The Canadian Bar Association similarly observed that "a reluctance to contemplate and speak about [illness and death] often stands in the way of effective ACP." [10]

### 2. Health and Social Care Providers Lack the Education and Training to Effectively Facilitate Advance Care Planning

Health and social care professionals play a critical role in initiating and facilitating ACP in a range of settings. As such, engaging in the necessary sensitive conversations with care recipients and their family members, when appropriate, needs to be part of the core skill set of all clinicians. No one profession can be solely responsible for ACP, and all health and social care team disciplines need to be educated and supported to play their role. In addition to formal instruction, health and social care providers require continuing education and practical training.

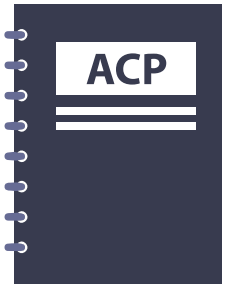
This is especially important because ACP is not solely about documenting an individual's choices at a given point in time so that later discussions are not necessary. Rather, it's an ongoing process that threads through the continuum of care from primary to acute to long-term care settings, and is the responsibility of every health and social care provider the person encounters.

Individuals, including the severely ill and/or cognitively impaired, need to be fully involved in decision-making to the extent possible, and helped to achieve health literacy and formulate the goals of their care. Providers must also recognize that these goals, along with a person's values and preferences, may change over time.

Given the importance and complexity of the ACP process, special formal and experiential education, ideally starting early in providers' professional development, is required. In many cases, however, professionals have inadequate access to this training.[11] For instance, a 2014 survey found that just **24%** of Canadian primary care doctors felt experienced and comfortable talking with their patients about ACP for illness and end of life care. A further 52% felt somewhat uncomfortable, while 24% reported no experience or comfort. The same report found that as few as 18% of primary care nurses felt comfortable discussing ACP with patients, while 50% were having these conversations despite feeling uncomfortable, and 32% were not discussing ACP at all. A 2009 national roundtable convening a wide range of stakeholders revealed that many health care providers were reluctant to engage in ACP discussions, and emphasized 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. [12]

While core ACP competencies for health and social care providers have been identified,[13] there is currently no central resource that provides ACP education materials or standards to which individual providers, health care organizations, or educational institutions can refer.

## 3. Organizations Don't Have Ready Access to Tools, Guidelines, and Best Practices




ACP is most effective when the individual care recipient's decisions are well documented and readily accessible in the full range of health care settings. An ideal health care system would include "a consistent, transferable and seamless mechanism for all care providers to share information about advance care planning and ensure conversations continue throughout an individual's care journey across all care settings."[14]

Hence, every health care organization should have an ACP strategy. Institutions that want to develop or improve an ACP program benefit from knowing what works best based on evidence from other experiences. Institutions' ACP programs should also incorporate quality improvement processes that enhances their ways to support ACP.

At present, while ACP research is constantly progressing, there isn't consensus on the best way to document ACPs, or on how to design medical information systems so the ACP is known to care providers when it's needed most. Nor are there best-in-class evidence-based frameworks that institutions can look to when designing and evaluating an ACP program. These are all significant system-level obstacles to a "consistent, transferable and seamless" ACP regime.

## Evidence-Based Policy Options to Consider

### 1. Raising Awareness and Educating Canadians About ACP:

Existing, well-studied ACP initiatives have emphasized public outreach in order to "engage capable adults and their families, as is appropriate, in ACP through raising awareness, initiating dialogue about ACP and connecting people to the means of engaging in ACP."[15] A number of groups have organized large-scale, nation-wide campaigns to raise awareness and educate the public about ACP.

For example, Advance Care Planning Canada is a campaign organized by a diverse set of stakeholders. One of its main goals is to increase the number of Canadians who engage in ACP with family and friends by 10%. It includes a well-designed, easily navigable website and engages in outreach to community organizations, the general public, patients with acute and/or chronic illness, families/caregivers, health care professionals, and policymakers. Building on such initiatives, the federal government can be a highly effective partner in awareness-raising over the short, medium, and long term.

In the short term, the federal government can encourage Canadians to access the many existing resources developed by provinces and territories, which range from "how to" guides to straightforward, standard ACP forms (see Table 1). For instance, the federal government's services for seniors portal, www.seniors.gc.ca, could include materials promoting the advantages of ACP in simple, accessible terms, and links to key resources.

In the medium term, the many federal organizations involved in the care of could use their portals and communications to direct older Canadians and their caregivers to ACP resources, and make ACP awareness a clear goal at the service delivery level, supported by the necessary training for all client-facing staff.

Over the longer term, ACP engagement could be emphasized as a clear priority in health care discussions between the federal and provincial/territorial governments, and resources dedicated to the development of a joint promotion strategy around an issue of collective national importance.

## 2. Supporting Health and Social Care Professional Education in ACP:

The federal government can lead the way by putting health care provider ACP training on the agenda in all conversations about national health care delivery and education. In particular, it can emphasize the need for professional bodies to set mutually consistent national standards, and for universities and colleges to align their curricula with corresponding training standards, and support these organizations in achieving these objectives in a consistent and coordinated way.

As it has done with respect to many other critical health policy issues, the government can convene and facilitate discussions between stakeholders involved in health care education. It can sponsor research, e.g., through targeted Canadian Institutes of Health Research grants, to identify effective ACP education strategies and further support ACP education initiatives. In 2002-2003, the Canadian Institutes of Health Research deployed over $19 million in funding for palliative care research studies and capacity building. And as part of the development of the 2007 Canadian Strategy on Palliative and End-of-Life Care, the federal government sponsored and contributed to the creation of an interprofessional ACP education module. [16]

## 3. Promoting ACP Best Practices:

The federal government is actively involved in promoting and disseminating end-of-life care and palliative care best practices.[17] For instance, the Palliative and End-of-Life Care Unit at Health Canada ensures that these issues are taken into consideration in relevant federal health policy initiatives. The Public Health Agency of Canada (PHAC), through the Division of Aging and Seniors, provides federal leadership and serves as a focal point for information on public health issues related to aging and older Canadians.

As it does in the area of palliative care generally, the federal government can play a critical leadership role in ensuring that the findings from ACP research and experiences are distilled and shared among health care institutions and practitioners. For instance, in 2008, Health Canada collaborated with two health authorities that had successfully implemented regional ACP strategies to create an implementation guide to help other authorities "develop or enhance their own advance care planning initiatives." [18] Health Canada also helped fund production of a 2009 report on a national roundtable on advance care planning.[19] Expanding the scope and scale of these collaborative activities would be worthwhile, especially with federal leadership, given that recent surveys show there is still much to be done to make sure all Canadian and care providers can become more routinely familiar and active with ACP principles and practices.

**Table 1: Selected Provincial/Territorial ACP Resources Available to the Public**

| Jurisdiction | Resource | Description |
|---|---|---|
| **British Columbia** | Making Future Health Care Decisions | Includes "My Voice: Expressing My Wishes for Future Health Care Treatment," the B.C. Government's user-friendly guide to advance care planning. |
| | Comox Valley, "Advance Care Planning" | Dedicated website explaining need to ACP and linking to helpful resources. |
| **Alberta** | Alberta Health Services, "Conversations Matter" | Interactive online guide to advance care planning, organized around helping patients to clarify their values and wishes. |
| **Saskatchewan** | Regina Qu'Appelle Health Region, "Advance Care Planning" | Contains forms and brochures, as well as details about the Region's ACP information sessions. |
| | Ministry of Justice & Attorney General, "Planning Ahead" | Detailed memorandum about how to ensure an ACP is effectively documented, with emphasis on legal considerations. |
| **Manitoba** | Manitoba Health, "Health Care Directive" | Brief overview of health directives, together with a directive template and accompanying guide. |
| | Winnipeg Regional Health Authority, "Advance Care Planning" | ACP workbook and educational materials. Also includes resources for health care professionals, including forms, policies, and videos of simulated ACP scenarios. |
| **Ontario** | Advance Care Planning, "ACP Workbook – Ontario Version" | Detailed, comprehensive ACP workbook for patients and families, accompanied by easy-to-follow forms. |
| | Ontario Seniors' Secretariat, "A Guide to Advance Care Planning" | Comprehensive guide to ACP. Also includes a printable wallet card to identify the patient's substitute decision-maker. |

| Jurisdiction | Resource | Description |
|---|---|---|
| **Quebec** | Curateur Public Québec, "My Mandate in Case of Incapacity | Background and forms to complete a provincial "Mandate in Case of Incapacity." |
| | Éducaloi, "Mandates in Anticipation of Incapacity" | Overview of provincial Mandates of Incapacity. |
| **Nova Scotia** | Nova Scotia Department of Justice, "Personal Directives in Nova Scotia" | Booklet explaining personal directives, including a simple checklist. |
| **New Brunswick** | Public Legal Education Information Service of New Brunswick, "Powers of Attorney" | Overview of powers of attorney and testamentary planning in general. |
| **Prince Edward Island** | Health PEI, "Health Care Directives" | Short summary of health care directives, accompanied by a form with explanatory notes. |
| | Health PEI, "Advance Care Planning" | Advance care planning workbook, including reflective writing exercise on values and beliefs. Also has links to a number of educational resources. |
| | Community Legal Information Association of PEI, "Health Care Directives" | Plain language overview of health directives and the legal process for obtaining one. |
| **Northwest Territories** | Northwest Territories Health & Social Services, "Personal Directives: Choosing for the Future" | Brief guide to personal directives, as well as sample directives. |
| Yukon | Yukon Health & Social Services, "Advance Directives" | Booklet explaining advance directives, as well as simple checklist for required steps. |
| Nunavut | Nunavut Department of Family Services, "Guardianship" | Explains services available to protect adults who are unable to make care decisions for themselves. |

# Supporting Documents


[1] College of Physicians & Surgeons of Ontario, Policy No 1-06, "Decision-making for the End of Life" (2006).

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