



Waterloo Wellington

Advanced Care Planning Education Program

for health care providers and residents

May 2014

Prepared by:

Judy Nairn, Hospice of Waterloo Region, Executive Director

Chris Bigelow RN, BScN, CHPCN(C) Hospice of Waterloo Region, Palliative Pain and Symptom Management Consultant

Arli Klassen, MSW

Tanya Darsi, BA, MA, PhD candidate Research Advisor Capacity Waterloo Region

Waterloo Wellington Advance Care Planning Education Program

The **Waterloo Wellington Advance Care Planning Education Program (ACPEP)** is designed to build system capacity and enhance the quality of palliative care and patient/family experience for residents of Waterloo Wellington. It is a program that reaches community and health care settings as critical sites for engagement and education. Connecting community partners and health care providers is foundational for achieving substantive and meaningful change. As a full system approach, the Waterloo Wellington ACPEP can increase understanding and build skills to ensure correct advance care planning (ACP) practices are delivered across the continuum of care. ACP benefits residents and health care practitioners and once widespread, can contribute to more effective and efficient use of health care resources.

We know there are a number of other stakeholders and committees attending to advance care planning nationally, provincially and locally. However, the various players and initiatives are not well coordinated. Our local region lacks a common protocol for ACP and much needed backbone support for working together better and more effectively. The ACPEP provides for this coordination, along with a common protocol and shared processes for ensuring meaningful and achievable change within complex health care systems.

Themes & Content:

| | |
|---|-----------|
| I. We can honour our shared commitment to high quality, high value palliative care | 4 |
| II. Residents in Waterloo Wellington can benefit from Advance Care Planning..... | 5 |
| Why does Advance Care Planning Matter? | 5 |
| What Is Holding the Health Care System Back? | 8 |
| In Waterloo-Wellington..... | 10 |
| Why an Advance Care Planning Education Program?..... | 11 |
| How Will the Waterloo Wellington ACPEP Make a Difference?..... | 12 |
| III. A Waterloo Wellington ACPEP can create community and systems change | 13 |
| Theory of Change..... | 13 |
| Program Goal | 15 |
| Objectives | 15 |
| Program Structure | 16 |
| Roles | 16 |
| Program Activities | 17 |
| Engagement..... | 17 |
| Capacity Building | 18 |
| Reflective Practice and Evaluation | 19 |
| Program Alignment with ACP National Framework Building Blocks & Outcomes | 19 |
| Implementation Considerations | 20 |
| IV. We can make it happen..... | 21 |
| Work Plan | 21 |
| Phase 1: Ground Work (6 to 9 months) | 21 |
| Phase 2: Activation (Year 1) | 22 |
| Phase 3: Scale the Change (Year 2 to 3) | 23 |
| Timelines | 23 |
| Investment Considerations | 24 |

I. We can honour our shared commitment to high quality, high value palliative care

“We share a common purpose to better support adults and children with life-limiting illness, their families and their caregivers to improve their comfort, dignity and quality of life preceding death. ... Achieving this purpose requires collaboration and commitment with shared ownership of solutions and actions between all partners and across all care settings.”

*From Advancing High Quality, High Value Palliative Care in Ontario:
Declaration of Partnership & Commitment to Action (2011)*

The Declaration of Partnership cited above sets out a shared vision for high quality, high value palliative care. It underscores the rights of Ontarians, which at the end of their lives, include respect and dignity consistent with other phases of life. Furthermore, it positions palliative care not as a unique project for a special population, but as a foundation for broader health care transformation. To achieve transformation, the Declaration sets out a strategy roadmap that speaks to the role of Advance Care Planning (ACP) in improving quality of care and value to Ontarians.

In this strategy roadmap, ACP is positioned to support improved population health outcomes and system performance/sustainability. Specifically, ACP contributes to improving client/family experiences, to greater support for individuals and caregivers, and to Ontarians receiving care at the right time and place based on need and preference. As a core component of quality hospice palliative care, ACP is identified within the Declaration as a priority in building stronger caregiver supports, and as an enabler of client and caregiver empowerment and capacity. An increase in the number of Ontarians who engage in advance care planning is identified as an indicator of success for achieving transformative change.

Beyond the Declaration, there is growing attention and commitment to the role of high quality palliative care in creating compassionate communities. The concept of a “Compassionate Community” is grounded in the World Health Organization’s decades-long practice of promoting a more holistic view of health that includes social, mental and physical wellbeing.¹ The concept has transformed positioning and engagement in public health causes. The compassionate communities movement now includes world-wide momentum around shifting attitudes and garnering support for end-of-life care. The movement connects palliative care to community responsibility. Connecting with schools, workplaces, places of

¹ Kellehear, A. (2013). Compassionate communities: end-of-life care as everyone’s Responsibility *QJM*, 106:1071-1075

worship and local businesses can leverage untapped resources of social and spiritual support, as well as practical resources for end-of-life care.² Education and outreach are key components of successful shifts in community practice.

The Waterloo Wellington Advance Care Planning Education Program is an opportunity to move forward on provincial and local commitments to quality palliative care. It also presents an opportunity to engage the community around end of life experiences, contributing to Compassionate Communities within Waterloo Wellington.

This document presents the program proposal for the Waterloo Wellington ACPEP. It relays the need and challenges within the system and shares the program's theory of change. It then presents the program design and intended outcomes, concluding with the investments needed to ensure successful implementation and positive impact.

*For a detailed discussion of the context, legislation and practice of ACP see the full concept document **Advance Care Planning Education Program Background and Literature Review** in Appendix A.*

II. Residents in Waterloo Wellington can benefit from Advance Care Planning

Why does Advance Care Planning Matter?

Advance Care Planning is a process of reflection and communication to let others know what kind of health and personal care one would want in the future if one were to become incapable of consenting to or refusing treatment or other care. ACP involves having discussions with family and friends, including one's future Substitute Decision Maker(s). A Substitute Decision Maker is the person or people who provides consent or refusal of consent for care and treatments if one is not mentally capable of doing so.³

Advance Care Planning includes choosing a Substitute Decision Maker and expressing one's wishes about future care and treatment. It also can include discussions with health care providers to ensure that one has accurate medical information on which to make decisions. It can also include writing down wishes, and may even involve talking with legal professionals. It is a way to give those who will be required to provide consent for medical treatment and care the confidence to make decisions on a patient's behalf if needed.

² Kellehear, A. (2013). Compassionate communities: end-of-life care as everyone's Responsibility *QJM*, 106:1071-1075.

³ HPCO, Speak Up Advance Care Planning Workbook, Ontario edition 2012 p.3; p. 5

Advance Care Planning is a process, not just a document. In Ontario, an Advance Care Plan can be expressed orally or in written form.

ACP can include reference to one's values, beliefs and goals for care. These values and goals are used to inform the Substitute Decision Maker's consent for treatment on behalf of a patient not capable of communicating their own consent. ACP is a process of reflection and planning, valuable in itself given the possibility of eventual incapacity to make one's own decisions and communicate those wishes to one's family and health care providers. In Ontario, unlike other jurisdiction across the country, an advance care plan is not consent for treatment. In Ontario, consent must be given in the actual situation and context of care.

ACP is based on recognition and respect for patient autonomy in making decisions about one's health care. It reflects the right to self-determination even after one's capacity for informed decision making is gone. No individual can be required to create an ACP; one has the right to not have an ACP.

Demonstrated benefits of ACP for individuals and their families include:⁴

- Comfort in being prepared,
- Ability to die in the place of one's choice,
- Enhanced independence,
- Personal wishes are respected and followed,
- Reduction of stress for decision-makers, and
- Decreased conflict within the family system.

People with complex diseases are living longer and up to 50% of individuals are not able to give their own consent for treatment or make decisions at the end of life.⁵ One Canadian study found that 76% of palliative patients had thought about their ACP wishes, but only 30% had their end-of-life care preferences documented correctly.⁶

⁴ Detering, Hancock, Reade, and Silvester. *The impact of advance care planning on end of life care in elderly patients: randomised controlled trial*. **BMJ**, 2010; Canadian Hospice Palliative Care Association, *Advance Care Planning in Canada: National Framework*, January 2012, <http://www.chpca.net/projects-and-advocacy/projects/advance-care-planning.aspx>; Catalonia WHO Project, 2012; AAN Task Force on End-of-Life, *Advance Care Planning as an Urgent Public Health Concern*, **American Academy of Nursing Policy Brief**, April 2010

⁵ The Canadian Hospice Palliative Care Association (CHPCA) 2009

⁶ CARENET, *What do Canadians think of ACP? Findings from an on-line opinion poll*, **BMJ Supportive and Palliative Care**, 2013

Advance Care Planning matters to the health system because of:

- i) Our core value for informed consent;
- ii) The number of individuals who will experience incapacity to make their own decisions at the end of life; and
- iii) Decisions are becoming more complex and individual wishes are not always obvious.

Health professionals and family members typically decide in favour of treatment when uncertain of patient wishes even though studies have shown that the majority of patients at end of life prefer limited care or comfort care.⁷ Without expression of patient wishes, patients may be cared for in a way they would not have chosen at the end of their life. Engaging in ACP informs a patient's chosen or appointed SDM. ACP also encourages health care providers to engage in and document a discussion about the patient's wishes and values. Engaging in an ACP process can ensure that patients are treated and cared for in ways consistent with their own values and choices.

Greater engagement in ACP can result in more effective and efficient use of health care resources. Respecting patients' rights to self-determination during the terminal stage of life can mean the application of fewer life-sustaining measures when these measures are contrary to patient wishes. Given the changing demographics and the increasing number of seniors, continuing to provide treatment contrary to patient wishes can only contribute further to pressures on the system and unsustainable health care costs.⁸ To have a meaningful and substantive impact on the effectiveness and efficiency of the health care system, ACP **must be integrated and engaged in consistently across all care settings.**⁹

⁷ Silveira, Kim, Langa. *Advance Directives and Outcomes of Surrogate Decision Making before Death*, **New England Journal of Medicine**, April 201

⁸ Ontario's Action Plan for Health Care, 2012 retrieved from http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_healthychange.pdf

⁹ Law Commission of Ontario, *Health Care Consent and Advance Care Planning in Ontario, Legal Capacity, Decision Making and Guardianship* January 2014 retrieved from <http://www.lco-cdo.org/capacity-guardianship-commissioned-paper-ace-ddo.pdf>

What Is Holding the Health Care System Back?

While ACP is recognized as a valuable part of quality palliative care, the practice of ACP is variable, and at times, contrary to Ontario law. It is often begun poorly, begun in crisis situation or after life-sustaining treatments have already started.

There exist clear barriers and sources of confusion that prevent effective and appropriate ACP across the health system. These barriers and sources of confusion include:

⇒ Differences in legislation across provinces

Advance Care Planning is regulated by provincial legislation that varies across Canada. In Ontario, ACP is guided by the *Health Care Consent Act* and the *Substitute Decisions Act*, with a mandated role for the *Consent and Capacity Board*, and recognized documentation in the *Power of Attorney for Personal Care (POAPC)*. Ontario legislation is based on principles of autonomy and the right to self-determination in health care, even once capacity is gone.

Ontario legislation differs from other provinces in that:

- Individuals have the right not to have an ACP. There can be no legal coercion or mandate to require individuals to develop an ACP.¹⁰
- The ACP guides the decisions of the SDM. In other provinces, an advance care directive guides health care practitioners. There can be confusion around the difference between an advance care plan and an advance care directive.
- Ontario law requires obtaining informed consent for proposed treatment even when a patient has a formalized advance care plan. Informed consent can only be given by the patient or by their SDM if the patient is not capable with respect to the decision.
- Ontario law favours contextualized decision-making by ensuring that either patients or, if incapable, their SDMs give informed consent before treatment is provided.

These differences in legislation are substantive and must be understood by everyone in Ontario, and including both residents and health care practitioners. **Lack of familiarity with the implication of Ontario legislation and law guiding ACP can lead to inappropriate (and illegal) practice.**

¹⁰ Wahl, Judith, Advocacy Centre for the Elderly, *Health Care Consent, Advance Care Planning, End-of-Life Issues: What You Need to Know*, 2011

⇒ **Limited training for health care practitioners**

Health care practitioners and other professionals can benefit from ACP training, including clarifying the specifics of Ontario law and its implication for practice. This training needs to include how to effectively and appropriately use persuasive means to encourage ACP. As well, training can further clarify the process of ACP, health care consent in the context of ACP, the difference between a directive and a plan as well as the difference between a care plan and an advance care plan.

⇒ **Tools and resources produced in other jurisdictions are not directly transferrable to the Ontario context**

The proliferation of resources and information on the internet contribute to the confusion surrounding ACP. Tools and resources from other jurisdictions can easily be downloaded and used by health care providers, institutions and collaboratives, who may be unaware that the resources do not comply with Ontario law. If tools are used without adaptation, then they can lead to legally incorrect or incomplete practice in Ontario.

⇒ **Inconsistent use of Ontario toolkits and resources**

Toolkits developed for practitioners in the Ontario health care system exist and are available. Appropriate resources for Ontario residents are also available. However, their use is not universal. These tools need to be promoted and made available over out-of-province resources on ACP.

⇒ **Disengaged community stakeholders and lack of education for potential community allies**

Although attention to ACP is growing, there continues to be limited public awareness and engagement in advance care planning. Other potential stakeholders, such as public health, family doctors, faith groups, are also disengaged from the conversation about ACP. Again there are existing resources, such as the Speak Up campaign that can be better leveraged to increase the practice of ACP.

⇒ **Discomfort and reluctance to engage in conversations related to death and dying.**

There also continues to be a general discomfort with the topic and reluctance to talk about or plan for death. The discomfort means that few individuals have engaged in discussions about their wishes and advance care planning. These conversations can be challenging for residents, informal caregivers and professional care providers alike. Existing resources need to be better leveraged to address the discomfort and training needs to be provided within the health care system and to the community not only on the knowledge transfer and legal responsibilities of advance care planning but also on having difficult conversations. Within this is further need to educate and support professional caregivers to enable their efficacy and ability to engage in these difficult conversations allowing them to advocate for an individual's wishes and help families process and honour those wishes.

In Waterloo-Wellington

The barriers and sources of confusion that exist at the provincial level are also present locally. There are significant and widespread gaps and inconsistencies in the practice of ACP in Waterloo Wellington despite legislation, action plans and existing resources. A survey of ACP practices in the region found that:¹¹

- ⇒ There is no common method for engaging in an ACP process
- ⇒ The ACP Toolkit for health care providers in Waterloo Wellington, most recently updated in 2011, is in need of significant review and revision, and had a limited audience
- ⇒ ACP is often left out new staff orientation and in-service training
- ⇒ Family physicians reported that they are not fully informed about ACP processes and regulations
- ⇒ There is a need for ethical decision-making policies and procedures for ACP
- ⇒ There is no coordinated outreach and engagement of potential community partners and allies

To address the widespread challenges and sources of confusion, The Law Commission of Ontario strongly recommended a comprehensive education program for all levels of health

¹¹ WW HPC Network Proposal: Education on Advance Care Planning Across Health Care Sectors in Waterloo Wellington Local Health Integration Network, 2009

care professionals on consent and ACP wishes.¹² The Hospice Palliative Care Ontario ACP Community of Practice also recommends a significant ACP campaign focused on: building public awareness, engaging in public dialogue, developing a consistent and transferable mechanism for sharing ACP content with all care providers, and training for health care providers throughout the system.

At the same time, there is growing attention to ACP locally and interest in ensuring common processes across the Waterloo Wellington Local Health Integration Network (WWLHIN). The Integrated Hospice Palliative Care (IHPC) Program Plan names ACP as one of its deliverables. **What is missing in the community and local health system is a coordinated and concentrated effort to build awareness, clear away confusions, ensure practices are consistent with Ontario law, and better support residents' engagement with ACP.**

Why an Advance Care Planning Education Program?

In Waterloo Wellington, there is the need for:

- ⇒ Appropriate and standardized materials that are in accordance with Ontario laws and reflect the local context.
- ⇒ Greater awareness and more consistent training for local health and social care practitioners and collaborations that connect to end-of-life care
- ⇒ Standardized ACP protocols that are consistent with Ontario legislation
- ⇒ Greater engagement of residents in ACP to increase understanding and awareness of patient rights, as well as reduce anxieties and uncertainties about planning for potential incapacity at the end of life
- ⇒ Greater engagement of other community stakeholders (e.g. lawyers, insurance brokers etc.) to build their knowledge and contribution to promoting ACP.

A coordinated and concentrated education program will meet the need for a broad-based complex change process focused in Waterloo Wellington. The Waterloo Wellington ACPEP will ensure integrated standards of knowledge and behaviour as well as standardized protocols for health care providers and related community sectors. As a unique and strong local strategy, the ACPEP will bring real and sustainable changes in awareness, attitudes, knowledge and behaviours throughout the community. An ACP education strategy for

¹² Law Commission of Ontario, *Health Care Consent and Advance Care Planning in Ontario, Legal Capacity, Decision Making and Guardianship* January 2014 retrieved from <http://www.lco-cdo.org/capacity-guardianship-commissioned-paper-ace-ddo.pdf>

Waterloo Wellington that includes a broad community conversation about values and preferences for end-of-life care is needed and will be welcomed.

How Will the Waterloo Wellington ACPEP Make a Difference?

We have designed a system-wide education program that will:

- ✓ **Build knowledge and capacity of residents, community supports and services, as well as of health and social care practitioners in Waterloo Wellington**
- ✓ **Ensure greater interprofessional collaboration within the health care system and with the broader community**
- ✓ **Increase and improve ACP practice within the Waterloo Wellington health care system. Once widespread, these practices will have a positive impact on system effectiveness and efficiency**

“Great programs need great organizations behind them.” ¹³

Backbone Support: Hospice of Waterloo Region is the lead organization responsible for delivery of palliative care education across WWLHIN, and is the lead on the IHPC deliverable related to ACP. HWR’s mission is to provide the best in hospice/palliative support and education to clients, their families, and the broader community. It is connected to both the community and the broader health system, and has good working relationships with palliative care clinicians. HWR staff is also engaged at a systems level by contributing to national, provincial and regional tables and collaboratives on quality in palliative care and ACP.

Hospice of Waterloo Region works collaboratively with Hospice Wellington to ensure reach and inclusion of the full Waterloo Wellington perspective. This collaboration will continue for the ACPEP. The two hospice organizations will work together to fully leverage their networks and connections across WWHLIN to support broad implementation of the Waterloo Wellington ACPEP.

¹³ McKinsey & Company (2001). Effective Capacity Building in Nonprofit Organizations. Produced for: Venture Philanthropy Partners.

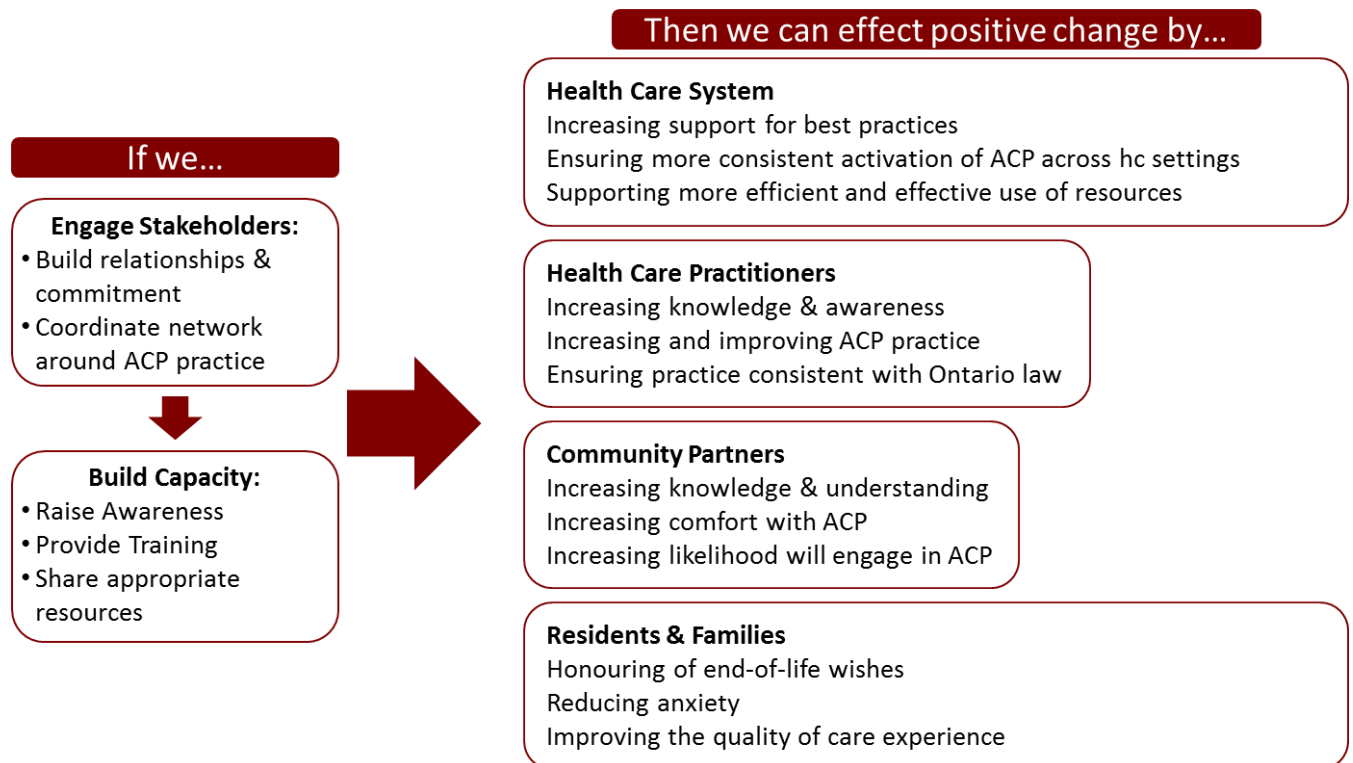
III. A Waterloo Wellington ACPEP can create community and systems change

Theory of Change

The Waterloo Wellington ACPEP is grounded in the practice literature on palliative care and advance care planning. It aligns with the ACP National Framework as well as models for patient-centred care and compassionate communities. The program design is further grounded in a thorough situation analysis of the provincial legislation and legal context, as well as a community survey completed in 2009.

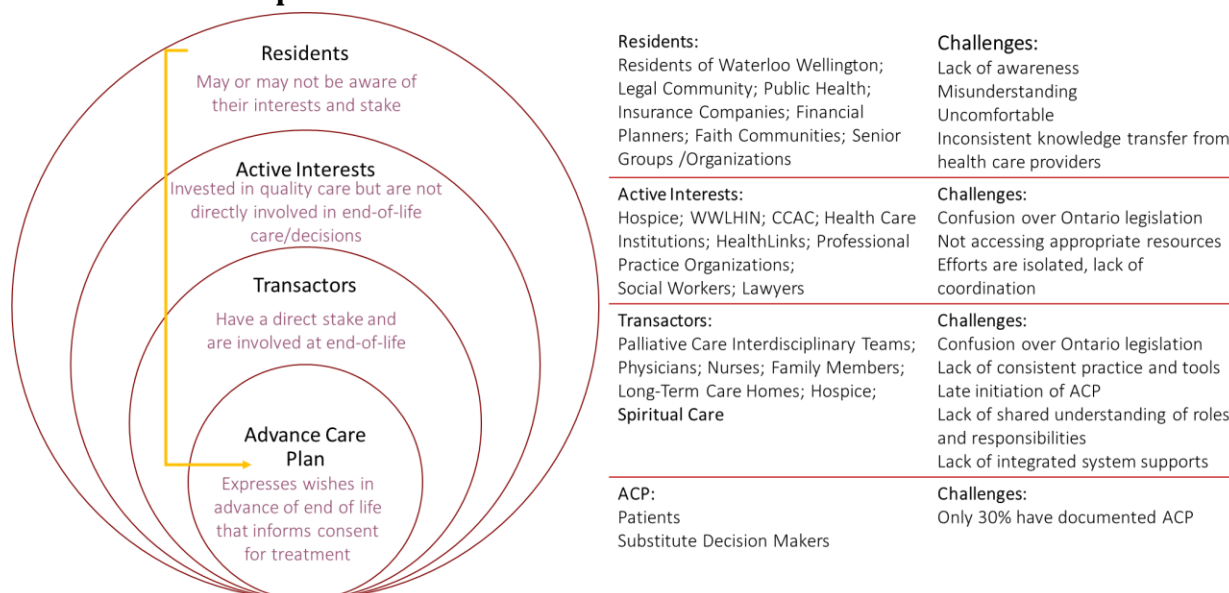
Underlying the ACPEP is a clear theory of change that connects stakeholder engagement with education and capacity building to achieve positive outcomes for residents of Waterloo-Wellington, the community, health care practitioners and the health care system. The ability to impact the attitudes and behaviours of stakeholders is a core component of the program.

Advance Care Planning Education Program: Theory of Change



To be effective, the Education Program needs to be a full-system approach and as such needs to reach a wide range of stakeholders. The following stakeholder map identifies the range of stakeholders and current challenges. **An achievable and measurable outcome is that residents of Waterloo Wellington become residents who engage in discussion about their wishes, values and beliefs for end of life treatment and care.**

ACPEP Stakeholder Map



Advance Care Planning is not a complicated concept to introduce into the community and health care system. At an individual level, the process of engaging in ACP does not need to be time consuming nor does it require significant resources to sustain. The barriers to appropriate and effective ACP are rooted in lack of knowledge, attitudes about death and dying, and the lack of coordination. To address these barriers and effect positive change, all of the partners and key stakeholders within the health care system and the community will need to be engaged. As well, a program that addresses the need for education, awareness and system coordination is a well-suited intervention to achieve significant and meaningful change.

As an education program, its impact will be directly related to its scope. A minor program will achieve minor change. **Because consistent and appropriate ACP practice will require a substantive shift in dominant attitudes and culture, the ACPEP is designed to ensure both reach and sustainability.** The evaluation literature has shown that infusing

resources into a system that cannot absorb them has limited impact.¹⁴ **A comprehensive and full-system program will better realize the opportunity to enhance community and health care capacity as well as the quality of patient/family experiences.**

Program Goal

Full system activation of Advance Care Planning in Waterloo Wellington

Objectives

To realize this goal, the Waterloo Wellington ACPEP leverages **a three to four year scope** to achieve the following objectives:

- To create an internalized knowledge base about ACP among health care practitioners and within health care institutions
- To create internalized knowledge base about ACP among community partners, including the legal community, financial institutions, faith organizations, and seniors groups and organizations
- To establish a common Waterloo Wellington ACP protocol (language, forms, and transitioning information) among active interests and transactors
- To support policy review and revision to ensure health care institutional policies are consistent with Ontario legislation and across the WWLHIN
- To engage residents through a public education campaign, leveraging existing campaign materials (e.g. the Ontario-specific Speak Up resources)
- Establish engaged partnerships with community groups and key influencers, e.g. financial and insurance industries

¹⁴ Caldwell, D.F. et al. (2008). Implementing strategic change in a health care system: The importance of leadership and change readiness. *Health Care Manage Rev*, 33(2), 124-133; Randolph, W. & Viswanath, K. (2004). Lessons learned from public health mass media campaigns: marketing health in a crowded media world, *Annual Review of Public Health* 25, 419-437.

Program Structure

Housed at Hospice of Waterloo Region, the core structure of the ACPEP is shown in the following figure:



Roles

ACPEP Steering Committee:

The role of the steering committee will be to provide program direction and decision-making, confirming and refining the program components, strategies and tactics. Their process will be collaborative and iterative, displaying a commitment to continuous quality improvement and using evaluation findings to develop and innovate to achieve program outcomes. The steering committee will be comprised of decision-makers and influencers from the health care system and the community, as reflected in the stakeholder map (p.14).

Backbone Support:

Administrative and program support will be the role of Hospice of Waterloo Region, working in partnership with Hospice Wellington to ensure coverage and support across WWLHIN.

ACPEP Program Team:

Program Coordinator. The Program Coordinator will report to and support the work of the steering committee. The coordinator will also be responsible for engaging with system leaders, connecting the ACPEP to provincial and national initiatives and

conversations. This role includes reviewing policy and staying current with changes, advocacy and system development. The coordinator will manage the process for developing a common ACP protocol for Waterloo Wellington, working with the steering committee and the program team.

Engagement & Capacity-Building Leads. There will be two engagement and capacity-building leads, one focused on health system stakeholders and institutions, and one focused on community stakeholders and partners. The role of the leads will include building new and deepening existing relationships; establishing and maintaining effective collaborations; engaging stakeholders in program design and evaluation; coordinating and linking efforts within and between the health system and the community. As well, the role will include developing and implementing training opportunities that support the implementation of a common ACP protocol and meets the needs of stakeholders.

Program Activities

This section presents an initial framework for the program concept. Program design details will be developed in collaboration with the steering committee, program coordinator and program stakeholders based on actual need and circumstance.

The Waterloo Wellington ACPEP is comprised of two main activity streams: Engagement and Capacity-Building for both the community and the health care system. Specific activities within each of these streams will be tailored by the engagement and capacity-building leads, with guidance from the steering committee and sector representatives, to suit the particular needs, cultures and circumstances found within the health care system and the community. Relationship building will be critical to ensuring the success of a tailored design. Program components related to each activity stream are identified below.

Engagement

Leadership Engagement:

The ACPEP leverages Hospice of Waterloo Region's existing relationships within the health care system and community to establish a steering committee of leaders and key influencers. The steering committee supports the design of on-the ground program strategies and tactics, providing input and working as champions to engage their networks in the program.

Relationship Building:

Relationships are key to reach and sustainability. The ACPEP requires that new relationships in the health care system community are established to support the

implementation of capacity building activities and support changes in practice. It will be the work of the Engagement Leads to build, deepen and nurture relationships across stakeholder groups.

Public Awareness Campaign:

The ACPEP leverages the resources made available through the provincial campaign Speak Up, and will complement by developing strategies specific for Waterloo Wellington. These strategies are developed with the Steering Committee and in partnership with key stakeholder groups. These can include a media and social media strategies as well as cross-sector and community partnerships to disseminate campaign messages, materials and provide connections to resources. To develop and inform this campaign, the ACPEP team will work with the Hospice Palliative Care Provincial Steering Committee, Communications and Public Awareness Working Group.

Capacity Building

Resources:

The ACPEP will identify one common protocol for use in Waterloo Wellington that can be implemented across health care settings. Working with relevant stakeholders, the ACPEP will also adapt the protocol for use with subset populations (e.g. pediatric, multicultural).

A dissemination strategy will be developed with the Steering Committee and stakeholders groups. Using this dissemination strategy, relevant resources (videos, workbooks, pamphlets, reference cards) will be distributed to health care institutions and practitioners.

Waterloo Wellington resources will be housed online, in a one-stop-shop that includes education and training materials organized by stakeholder group.

Training:

The ACPEP will identify existing trainers and modules for ACP training internally within each institution and profession, and externally within community. Additional training resources (e.g. online modules, workshops, workbooks) will be developed to meet the needs of unique groups. Training will need to be about more than just knowledge transfer. It will also develop communication skills, including efficacy and ability to have difficult conversations. Community training needs will be identified and training resources will be developed in collaboration with community stakeholders, and implemented through the engagement leads.

Policy Review:

The program will also encourage and provide the support for health care institutions and the WWLHIN to complete a comprehensive policy review and encourage the revision of policies, standards and performance appraisals to be consistent with legislation and the common ACP protocol.

Reflective Practice and Evaluation

The ACPEP is designed to be a collaborative program that is developed and implemented in partnership with key stakeholders within the health care system and the community. Reflective practice and continuous improvement will be part of its design and implementation. An evaluation framework will be developed to provide feedback and measure short-term (year 1) and intermediate (years 2 to 3) outcomes. As well, the evaluation will support the development and implementation of a shared measurement strategy to assess system-level contribution and impact.

Program Alignment with ACP National Framework Building Blocks & Outcomes

Theory of change and program design fits with the National ACP Framework, which identified four building blocks. Anything that doesn't do all four has limited value and impact.

| Waterloo Wellington ACPEP | | | | | | |
|--|-----------------------|-----------------------|------------------|-------------------|----------|--------|
| ACP National Framework Building Blocks and 3 to 5 Year Outcomes | Engagement | | | Capacity-Building | | |
| | Leadership Engagement | Relationship Building | Public Awareness | Resources | Training | Review |
| Organizational Engagement ACP is known and visible as an integral part of policies and standards for palliative care in all HC settings, as well as in community-based end-of-life conversations | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Education All target audiences in HC and community partners know and appreciate that ACP is part of a good death experience | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| System Infrastructure Acceptance of one WW-specific ACP protocols across all audience sectors | ✓ | ✓ | | ✓ | ✓ | ✓ |
| Continuous Quality Improvement Use of mechanisms to review and improve ACP policies, standards, protocols, learning modules, and tools | ✓ | ✓ | | | ✓ | ✓ |

Implementation Considerations

The ACPEP builds into its activities and timelines necessary attention to anticipated challenges. Given the complexity of the barriers to full system activation of ACP, including lack of coordination, lack of awareness, and confusion around guidelines and legislation, we anticipate that a significant amount of time and investment will be needed to build the right partnerships in the community and to broaden our existing relationships within the health care system.

We further anticipate that once we have identified and engaged key partners, a significant amount of time and investment will be needed to bring about a common ACP protocol. A common protocol must: i) be locally relevant; ii) be consistent with Ontario legislation and enable appropriate practice; and iii) have the right level of latitude to be useful in a range of situations. Achieving a common protocol implemented across the system is a high leverage, high impact outcome. It will take time, energy and effective working relationships. Our program components and work plan account for these inputs.

We recognize that attitudinal barriers and competing priorities will also challenge the achievement of outcomes. Early on, the Steering Committee and the ACPEP project team will need to promote and engage a range of stakeholders in dialogue about ACP, making the case for change and getting resource commitments from both the health care sector and community partners. The ACPEP is designed with the recognition that it will take time to not only build engagement and buy-in, but also for partners to build ACP into their own strategies, budgets and planning cycles.

The prevailing culture around death and planning for end-of-life itself requires a major attitudinal shift. Stigma, discomfort and anxiety associated with end-of-life planning will be tackled directly through community engagement and education strategies. Emerging conversations on assisted suicide and euthanasia may serve to cloud the effectiveness of the engagement and education strategies, distracting attention from ACP. The ACPEP accounts for this challenge by attending to the need for advocacy at the systems level and by dedicating resources to community outreach and community education.

Lastly, we must remain cognizant of the need to ensure the system can support the outcomes of widespread ACP. When the Waterloo Wellington ACPEP starts to move forward and shift practice, the system will have to be ready to meet ACP plans and the possibility that there may be more individuals planning to die at home or in a hospice residence. Parallel to the ACPEP, there will need to be actions around ensuring the infrastructure is in place to honor advance care plans. This need makes critical the project coordinator's connection to systems-level conversations and leadership.

IV. We Can Make It Happen

The ACPEP will be designed with input from key stakeholder groups and developed collaboratively with the Steering Committee. The specific activities and implementation strategies will need to be tailored to fit with the needs and priorities of the community and the health care system. The following work plan is based on recognition for the kinds of tasks that will move the program forward. A detailed work plan and milestones will be set in collaboration with the Steering Committee.

Work Plan

Phase 1: Ground Work (6 to 9 months)

| Activity | Outcomes | Indicators |
|--|---|---|
| Establish Steering Committee | Program capacity | Composition of Steering Committee Staff hired Strategies and milestones developed |
| Hire Project Coordinator and Outreach & Capacity-Building Leads | | |
| Design communication strategy | | |
| Design detailed engagement strategy | | |
| Initiate preliminary engagement strategy, including making the case for change | New partnerships Stronger presence in local networks | Participation in engagement events Community connections |
| Conduct review of existing ACP resources, tools and protocols | Relevant and practical protocols consistent with Ontario legislation and context of Waterloo Wellington | Recommendations for a common Waterloo Wellington ACP Protocol |
| Present review findings to SC for detailed program design | Effective Program Implementation | Plan for common ACP protocol determination Plan for Training Audit and Development Plan for Engaging Community Partners Plan for Engaging Health Care Providers/Institutions |

Phase 2: Activation (Year 1)

| Activity | Outcomes | Indicators |
|--|--|---|
| Engage health system stakeholders and key influencers | Stronger partnerships Increased commitment | Number of connections Extent of contribution Participation in discussion and in training |
| Engage community stakeholders and key influencers | Stronger partnerships Increased commitment | Extent of contribution by community partners Participation in public awareness campaign New connections to the health system |
| Bring forward recommendations for ACP protocol and engage stakeholders in final content/strategy decisions | Common ACP Protocol for Waterloo Wellington | Final determination of ACP protocol |
| Complete training audit and design training strategy | Relevant and practical training opportunities | Training tools & resources Training Schedule |
| Identify pilot sites for ACP protocol | Improved ACP practice | Engagement of community and health care stakeholders Reported changes in practice Positive patient/family experience with ACP protocol |
| Initiate public awareness campaign | Growing public awareness | Campaign reach Dissemination of campaign materials |
| Initiate policy review | Increased engagement by health care institutions | Participation in the review process |
| Initiate training for health care practitioners based on findings from pilot and common ACP protocol | Increased capacity and Improved ACP practice | Change in practitioner knowledge Increase in efficacy and ability to have difficult conversations More frequent conversations with patients and families Changes in practice |

Phase 3: Scale the Change (Year 2 to 3)

| Activity | Outcome | Indicator |
|--|--|---|
| Initiate dissemination of common ACP protocol | Increased awareness Improved practices | Reach and use of the toolkit Changes in practice Change in practices |
| Complete policy review with health care institutions | Greater consistency in policies and alignment with Ontario legislation | Participation in the process Changes made to policy |
| Continue training within health system and the community | Increased capacity and Improved ACP practice | Change in practitioner and partner knowledge More frequent conversations with patients and families Changes in practice |
| Promote adoption of common ACP Tool Protocol | Increased awareness Improved practices | Reach and use of the toolkit Changes in practice |
| Expand community education and outreach | Greater awareness of ACP Increased practice of ACP | Campaign reach Dissemination of materials % increase in ACP engagement |

Timelines

| | Groundwork | | | | | | | | | Activation (Year 1) | | | | | | | | | | | Scale the Change (Year 2 to 3) | | | | | | |
|--|---------------|---|---|---|---|---|---|---|---|---------------------|----|----|----|----|----|----|----|----|----|----|--------------------------------|----|-------|-------|-------|-------|--|
| | <i>months</i> | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22-27 | 28-33 | 34-39 | 40-45 | |
| GROUNDWORK | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Establish Steering Committee | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Hire Project Staff | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Design Communication Strategy | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Design Detailed Engagement Strategy | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Initiate Preliminary Engagement Strategy | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Conduct ACP resource review | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Present review findings to SC | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| ACTIVATION (YEAR 1) | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Engage health system stakeholders | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Engage community stakeholders | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Bring forward recommendations for ACP protocol | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Complete training audit and design training strategy | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Identify pilot sites for ACP protocol | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Initiate public awareness campaign | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Initiate policy review | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Initiate training strategies | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| SCALE THE CHANGE (YEAR 2 to 3) | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Initiate common ACP protocol | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Complete policy review with heath care institutions | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Continue training | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Promote common ACP Protocol | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Expand community outreach and education | | | | | | | | | | | | | | | | | | | | | | | | | | | |

Investment Considerations

Program Budget

Total Investment required for full program implementation: \$1,380,000.

| | Phase1:Ground Work (6 mths) | Phase2: Activation (Year 1) | Phase 3:Scale the Change (Year 2) | Phase 3:Scale the Change (Year 3) |
|---|------------------------------------|------------------------------------|--|--|
| HR Costs | \$150,000 | \$300,000 | \$300,000 | \$300,00 |
| Office Costs (cell, computer, travel, supplies, etc.) | \$ 30,000 | \$ 50,000 | \$ 50,000 | \$ 50,000 |
| Resource Costs | | \$ 50,000 | \$ 50,000 | \$ 50,000 |
| Total | \$180,000 | \$400,000 | \$400,000 | \$400,000 |

The Case for Change

Quality palliative care has been shown to improve patient and family experience as well as reduce health care costs. A recent review of the literature and economics of end-of-life found that, in Canada, the cost of dying ranges from \$10,000 for a sudden death to \$40,000 for someone with a terminal condition. Given the changing demographics and the increasing number of seniors in Waterloo Wellington, providing costly, life-extending treatment contrary to patient wishes can only contribute further to pressures on the system and unsustainable health care costs. Full-system and community engagement in Advance Care Planning presents the opportunity to help realize improved quality and efficiency as well as ensuring the right care, at the right time, in the right place.

Recommendation

Our commitment in Ontario is to patient-directed care, with the right care, at the right time, in the right place, even at the end of life when the majority of patients no longer have capacity to make their own health care decisions. It will take a multi-year, multi-faceted concerted effort throughout our Waterloo Wellington community and health care system to create sufficient pathways across all our systems to encourage and support Advance Care Planning as the process and mechanism to protect patient-directed care at the end of life.

Appendix A

Advance Care Planning Education Program Background and Literature Review April 2014

What is Advance Care Planning (ACP)?

“Start the conversation about end-of-life care. It’s about conversations. It’s about decisions. It’s how we care for each other.” (Speak Up)

“People somehow have this superstition that if you talk about it, it might happen”

Posted By Dian Cohen on May 03, 2013 Speak Up website

Dian Cohen has had first hand experience being in intensive care in a hospital – and that has given her a unique insight into the decisions that she would like others to make on her behalf if she could no longer speak for herself.

“I had a fairly traumatic health scare some time ago,” she says. “At the time, I wasn’t thinking about the future – but now, as I get older, I understand that this could happen again. It’s important to be clear about the care that I want – and don’t want.”

Mrs. Cohen is an economist, author and journalist who has counseled Canadians on money management for over 40 years. Now, as she tailors her presentations more towards estate planning, she is also encouraging others to make their Advance Care Plan – not just for themselves, but to give friends and family the confidence to make important decisions on their behalf.

“People somehow have this superstition that if you talk about it, it might happen,” she says. “But if we don’t speak up, how will others know how to help us? That’s an awful burden to leave behind.”

Advance Care Planning is the development and expression of wishes for goals of treatment and continuance or not of treatment and care at end-of-life, including the naming of a Substitute Decision Maker (ACP in Canada National Framework, 2012). Advance Care Planning (ACP) may include reference to one’s values, beliefs and goals of care, all of which will inform the Substitute Decision Maker (SDM) on making treatment decisions at a time when you are no longer able to make them for yourself. ACP is a process of reflection in planning for one’s eventual incapacity to make decisions, and communication of those wishes to one’s family and health care givers.

ACP involves family and friends and professionals. It is not a single event, but a process that begins with conversation, can include documentation of one's wishes, and likely continues to evolve and change as one ages. ACP is not consent for treatment in Ontario.

ACP is based on the principle of autonomy of the individual in making decisions about their health care, and that this right to self-determination continues even after one's capacity for informed decision making is gone. (WW ACP Toolkit, 2009) This right to self-determination extends far enough that no individual can be required to create an ACP; individuals also have the right to not have an ACP. This principle of autonomy implies that there cannot be a legal mandate to create an ACP, but that persuasive means based on conversation and relationship must be used. This requires more training and commitment to ACP by health care and other professionals than a legal requirement.

Some of the benefits to individuals and their families resulting from this principle of self-determination in ACP include:

- Comfort in being prepared,
- Ability to die in the place of one's choice,
- Enhanced independence,
- Personal wishes are respected and followed,
- Reduction of stress for substitute decision-makers, and
- Decreased conflict in the family system.

However there remains much confusion about ACP, for the public and for health care providers. Currently ACP is often begun poorly, begun very late with a crisis event, or begun only after life-sustaining treatments have already started. Few people want to talk about dying or prepare for their death far in advance. In 2012 80% of Canadians had no documentation of their ACP wishes, and only 46% had named a SDM (ACP in Canada, 2012).

ACP is needed because people with complex diseases are living longer, because health care decisions are becoming more complex, because there is a high likelihood that individuals will not be able to give their own consent for treatment right to the end of their life, and because the percentage of the population in their senior years is increasing significantly. The Canadian Hospice Palliative Care Association (CHPCA) 2009 roundtable on ACP found that up to 50% of persons cannot make their own decisions at the end of life, and that health professionals and family members typically decide in favour of treatment when uncertain of treatment wishes. Loved ones will have to make decisions on behalf of others, and that causes increased distress and

anxiety for families unless they have discussed the issues in advance with the individual. ACP results in increased patient and family satisfaction with the palliative process, and also results in decreased moral distress for the health care providers (ACP in Canada, 2012).

One study conducted in Australia found that those having completed the process of ACP were more likely to have their wishes followed, and family members had significantly less stress, anxiety and depression, with higher satisfaction. They believe that without documentation of patient wishes, patients may be cared for in a way they would not have chosen at the end of their life. (Detering et al, 2010)

ACP also offers the potential to result in overall cost savings to the health care system, because fewer life-sustaining measures are begun in the terminal stages of life. A study of elderly Americans found that the majority needed decision-making at the end of life at a time when they lacked the capacity to make those decisions. Patients who had prepared advance directives received care that was strongly associated with their preferences. The majority of these patients preferred limited care or comfort care, whereas only 1.9% wanted all the care possible (Silveira et al, 2010).

A Canadian study led by Dr. Daren Heyland of Carenet (2010) found that 76% of palliative patients had thought about their ACP wishes, but that 70% of their preferences for end-of-life care were not documented at all or were documented incorrectly. They found that 28% of the patients said they wanted only comfort care, but the charts showed only 4% of patients had this wish for comfort care. They also found that there was only 30% agreement between patients' wishes and the documentation in their medical records. Heyland blames this failure on health care professionals.

Ontario's Action Plan for Health Care states that if we don't change anything, keep the age-specific costs what they are today and apply them to the 2030 population, our health care costs will increase by \$24 billion – 50% more than today based on changing demographics alone (Ontario's Action Plan for Health Care, 2012). The current way of managing health care costs, particularly with our aging population, is unsustainable.

ACP is a significant process that can result in higher satisfaction by patients and their families with their palliative care at end-of-life and higher cost-effectiveness in health care (Catalonia WHO Project, 2012). Studies show costly life-extending treatments that are not aligned with patient preferences result in patient and family dissatisfaction with care and higher cost (American Academy of Nursing, 2010). However, ACP does not reliably reduce health care costs except when used

systematically across all health care settings to avoid acute care in the last few weeks of life (Royal College of Physicians, 2009).

Legal Context for ACP

Advance Care Planning is guided by provincial legislation that varies across Canada. This contributes to confusion about ACP, as ACP terminology, tools and practices already developed in other provinces or other countries are not appropriate for Ontario.

In 1996 two different pieces of legislation laid the framework for ACP in Ontario:

- Health Care Consent Act
- Substitute Decisions Act

The basic principles underlying the Ontario legislation are that of autonomy and the right to self-determination in health care, even once capacity is gone. This includes the right for individuals to not have an ACP, and thus in Ontario, there can be no legal coercion or mandate to require individuals to develop an ACP (Wahl, 2011).

Informed consent for treatment is always required in Ontario. Informed consent must be voluntary and must include refusal or consent for specific treatment, at the time the treatment is needed, and for a current condition. Informed consent means the decision-maker is capable because they understand the information and they appreciate the consequences. Informed consent includes information on the nature of the treatment, the expected benefits of the treatment, the material risks and side effects of the treatment, and alternative courses of action or consequences of no treatment. Informed consent can be given by the capable person or by their SDM. ACP, an Advance Directive, or a POAPC do not constitute consent (or refusal) for specific treatment. “Blanket consent”, or a Plan of Care in advance as a condition of admission to a health care facility is not legal in Ontario. Neither a living will nor an Advance Care Directive is a legal document in Ontario, although a POAPC is a legal document. (Wahl, 2011, Law Commission of Ontario, 2013)

In this legal context in Ontario, the purpose of ACP is to guide the SDM when the person is no longer capable. Unlike other provinces, ACP in Ontario does not guide health care practitioners it guides the SDM. This is a substantive difference that must be understood by everyone in Ontario, and especially health care practitioners.

- This means it is the role of the patient:
 - To give consent or refuse consent for each and every health care treatment proposed for as long as the patient is capable;
 - To give consideration to what their wishes for care would be if they became incapable of giving consent, and who they would choose to honour those wishes and give consent on their behalf; and
 - To communicate their ACP wishes and potentially name a SDM in anticipation of a time when they may become incapable of giving consent.
- This means it is the role of the health care practitioners:
 - To provide sufficient information about treatment options and prognosis to the patient so that the patient can make informed decisions about treatment,
 - To encourage the development and communication of ACP wishes,
 - To determine whether a patient is capable or incapable of giving informed consent,
 - To determine if the patient has an ACP that has documented their wishes and to encourage that treatment decisions to be based on this ACP,
 - To ensure that consent is obtained from the patient or the SDM before starting or stopping any treatment.
- This means that the role of the SDM includes:
 - To review and understand ACP wishes for the future with the patient while the patient is capable,
 - To give or refuse consent when the patient is not capable;
 - To follow the last known wishes of the patient and not the SDM's own wishes
 - To make decisions based on the best interests of the patient for current treatment/care plans if the persons wishes are not known;

The Law Commission of Ontario (2013) states that Ontario law is somewhat unique (or at least is near one end of a spectrum) in its emphasis on obtaining consent for proposed treatment from an SDM even where a patient has engaged in formalized advance care planning. “Best practices” and clinical tools cross borders easily and instantly (especially now that they are available on-line), and the proliferation of forms and policies from other jurisdictions appears to have influenced practices in Ontario. The bottom line is that forms, tools, and policies that may work in many other jurisdictions may be legally incorrect (or incomplete) in Ontario when adopted without revision. Ontario law only allows patient wishes, values and beliefs to be implemented through the law of informed consent to treatment. While some jurisdictions allow advance directives to speak directly to health practitioners (for example, Alberta and Nova Scotia allow health practitioners to take direction from a personal advance care directive where an applicable directive does not appoint an

agent), Ontario law favours contextualized decision-making to a greater extent by ensuring that either patients or, if incapable, their SDMs give informed consent before treatment is provided. (Wahl, 2011)

The Law Commission of Ontario (2013) thus recommends that ACP in Ontario be thought of as a three part process involving:

- (1) Identifying the SDM by the capable patient;
- (2) Recording wishes, values, and beliefs expressed by the patient when capable; and,
- (3) Obtaining health care consent from the SDM when the patient becomes incapable.

There is much potential and actual confusion in the Ontario context because of the many different understandings within and beyond Ontario on the role of consent and advance care directives versus advance care wishes. Thus significant resources need to be invested locally in order to address misconceptions and to create appropriate and standardized documentation materials that are suitable for Ontario. The Law Commission of Ontario strongly recommended in 2013 a comprehensive education program for all levels of health care professionals on consent and ACP wishes.

The [Excellent Care for All](#) Act was passed in Ontario in 2010. The Act requires every hospital to publish a Balanced Scorecard. Carenet researchers found that since 2010 palliative care was absent from the Balanced Scorecard in over 84% of hospitals in Ontario, and only indirectly measured and prioritized in the remainder. Their strong recommendation is that palliative care, including ACP, be increased in a variety of ways in these hospitals.

Environmental Context for ACP

Federal Environment:

The Canadian Hospice Palliative Care Association (CHPCA) is working closely with the Quality End-of-Life Care Coalition of Canada on a project called *The Way Forward*, imagining a new reality where hospice palliative care is available to Canadians when and where they need it; where living well until death is the goal of care. This is a bigger project than just ACP, but one of their 4 priorities for 2010 – 2020 is focused on ACP:

Encourage Canadians to discuss and plan for end of life. Hospice palliative end-of-life care will not be a priority in our health care system until it is a priority for Canadians. People must be able to talk about and plan for death,

while still enjoying life. With the aging of our population, more attention must be focused on this issue now.

An Advance Care Planning in Canada Project was initiated in 2008 by the CHPCA. The long term goal of the project 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. There is recognition that the legal context varies across Canada, and that the same tools and processes will not work the same in each province. They created a national “Speak Up” campaign, with ACP tools and education materials available on their website, some of which are generic enough to work in any province along with an Ontario ACP Workbook that speaks to the unique Ontario legal context.

In January 2012 they began a three year process to create an ACP National Framework, which has the patient/family at the centre and four building blocks around the family. This National Framework emphasizes that ACP will take root through work with a variety of target audiences, through much education and training, through system infrastructure development, and through ongoing quality improvement. None of these four building blocks will be sufficient on their own.

1. Engagement of the health care system, the legal system, the health care professionals/planners, the spiritual care providers, the research community, and the general public.
2. Education and training of professionals/providers, of policy makers, and of the general public.
3. System Infrastructure in regards to policies, program development, and tools to support conversations and documentation.
4. Continuous Quality Improvement.

Ontario Environment:

Ontario’s Action Plan for Health Care began in 2012, with a goal of putting patients at the centre of the system. One of its key phrases is to provide the “right care, at the right time, at the right place”. ACP creates the possibility that patients will be able to determine for themselves what kind of care they want and where they want to be cared for at the end-of-life, should they become incapable of deciding for themselves. ACP is the crucial tool for providing patient-directed care with the right care, at the right time and at the right place once the patient has lost capacity to make their own health care decisions. Unless discussions about ACP take place, the SDM will not

know what the patient wishes for their care once they are no longer able to speak for themselves.

The Ontario government recently released a document called “Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action”, dated December 2011. Its primary goal is to enable greater system integration that will put every person and their family at the core of every care decision, and improve their comfort, dignity and quality of life before death. Their three top system goals include:

1. Quality: To improve client/family, caregiver and provider experience by delivering high quality, seamless care and support.
2. Population Health: To improve, maintain and support the quality of life and health of people with progressive life-limiting illnesses.
3. Sustainability: To improve system performance by delivering better care more cost-effectively and creating a continuously self-improving system.

This document on Palliative Care in Ontario recommends a new model of palliative care that is not reactive or disease-focused, but rather one that focuses on a person’s quality of life and managing symptoms.

We envision a system that wraps delivery around the adult or child and their family and informal caregivers and responds in a coordinated way to their goals, needs and personal situation. Care will be delivered by a virtually integrated inter-professional team. Each patient will have a coordinated and continually updated care plan. This plan will encompass all settings in which the patient receives care.”

ACP is a core part of this vision, ensuring the patient’s right to self-determination. Care is client-directed, with decisions about care plans being made by the individuals themselves. Once the patient becomes incapable, decisions about care plans are made by their SDM, based on the patient’s preparatory thinking regarding their end-of-life process, which forms the core of an ACP. An ACP means that patient care remains self-directed even once they become incapable of giving consent.

Thus, this provincial initiative recommends a significant ACP campaign focused on:

- building public awareness,
- engaging in public dialogue,
- developing a consistent and transferable mechanism for sharing ACP content with all care providers, and
- training for health care providers throughout the system.

There is clear recognition in this 2011 document that significant resources will need to be invested to shift the model of hospice palliative care towards one that is patient-directed, team-based, and focused on quality of life and death.

However there remains confusion between a “care plan” and an “advance care plan”. A plan of care is focused on the current treatment plan, and requires consent by the patient (or their SDM) in regards to that care plan. Advance Care Planning is about the conversation and potential documentation of the wishes and values that a patient wants to guide the SDM once the patient becomes incapable of giving consent, so that when the SDM makes decisions about a plan of care, the patient’s wishes will be used as a guide by the SDM for those care decisions. A plan of care is not the same thing as an Advanced Care Plan, and this confusion needs to be addressed. Every patient has a plan of care, but not every patient has an advance care plan.

Waterloo Wellington Environment

A preliminary environmental scan regarding ACP was undertaken in July 2009 to capture a sense of the current practice, needs and directions related to ACP within the WWLHIN (WW HPC Network Proposal: Education on Advance Care Planning Across Health Care Sectors in Waterloo Wellington Local Health Integration Network, 2009). It was found that 62% of respondents indicated while there was a clear expectation to discuss ACP with patients and families, there was no common method of documentation, less than half of respondents included ACP in new staff orientation, and none included ACP in in-service training. The survey included a sampling of all health care institutions in WW, as well as 24 randomly selected physicians. 83% of respondents (all from institutions) indicated that a common process across the LHIN would be useful.

In 2010 a survey was done of senior-friendly care in WW hospitals (Sturdy Smith et al, 2011), with an eye to understanding how to reduce emergency department (ED) wait times and reduce alternative level of care (ALC) days. They found that 17% of WW’s ED visits are seniors, and that 71% of acute ALC days are seniors. They stated that WW’s population growth of seniors (65+) will grow faster than the provincial average. They identify a number of existing or possible senior-friendly priorities that could assist with reducing ED visits and ALC days: collaborative inter-professional care, and enhancing patient and family goals and values. Patient-centred care and policies on ACP already exist in all WW hospitals, but they state more is needed regarding ethical decision-making policies and procedures in order for ACP to have more of an impact.

A WW ACP Toolkit for health care providers was assembled in 2009 and updated in 2011, based on work done in the CW LHIN. The ACP movement has matured since this Toolkit was assembled, and it is in need of significant review and revision.

WW LHIN is working within a three year plan from 2013 – 2016 called “Better Health – Better Futures”, based on the provincial goal of ensuring that WW residents get *the right care, at the right place, at the right time*. The LHIN has identified an Integrated Hospice Palliative Care (IHPC) Program Plan as part of their three year plan. The stated goal of WW IHPC in 2013 is to provide high quality cost-efficient palliative care to individuals with life-threatening illnesses. This aligns well with the WWLHIN strategic priority to reduce ED visits and ALC days in WW while improving access and coordination of palliative care services. ACP is named in the WW IHPC as one of the deliverables to be achieved with a stated goal for “*develop and implement a mechanism and process for individual wishes to be documented and communicated across WW*”. While there can be no legal mandate for documentation of an individual’s ACP, this important commitment to advancement of ACP must be integrated with the other activities in the IHPC plan, and will help to inform the implementation and achievement of ACP throughout the WWLHIN.

Prominence of End-of-Life Issues

Currently the Canada Medical Association (CMA) is conducting a cross-Canada listening tour across Canada (February to May 2014) in regards to end-of-life care, focusing on:

- physician-assisted suicide
- palliative care
- advance care planning

The CMA intends to make a report with recommendations at the end of their listening process sometime later in 2014 or in 2015.

In April 2010 the House of Commons rejected a Bloc Québécois MP’s legislation to permit assisted suicide in Canada under strict conditions. In June 2013 the Quebec legislature introduced an “Act respecting end-of-life care”, a bill that was four years in the making and has all-party support in Quebec. This bill is widely perceived to be a provincial strategy to do an end-run around the federal criminal code that makes euthanasia and assisted suicide illegal in Canada. It allows for medically-assisted death if a patient documents such a wish in writing and two doctors agree that this is

the only way to end the pain and suffering of the patient with a terminal disease and near the end-of-life. Critics of the bill state that there is public interest in this idea only because we are not providing adequate end-of-life care that allows patients to die without pain and with dignity. The bill had been expected to pass the Quebec legislature this spring (2014), but now that a spring 2014 provincial election has been called it is off the table.

Much of the current public conversation in Canada in 2014 is focused on assisted suicide, but the starting point for this conversation might be better served by focusing on the larger picture of one's values and ethics in regards to how and where one would prefer to die, instead of focusing on assisted suicide as one possible answer to that question. ACP provides the ethical framework and foundation in order to have informed conversation about assisted suicide. Adequate education, support and compliance with ACP wishes could transform this whole conversation about end-of-life care.

At the same time as assisted suicide has become a popular topic for public debate, ACP has become a popular concept in health policy and health care organizations, even as it remains poorly understood by the public. Every level of government and many related community-based organizations are paying attention to ACP, and most are creating tools and resources for ACP use and training.

Many health care institutions are quickly creating or choosing their ACP tools and training resources from the plethora that have appeared on the Internet in just the last five years. However, all this frenzy of activity and multiplicity of tools seem to be resulting in ever more confusion about ACP, as there is little consistency in knowledge or tools across health care systems and community-based organizations and even less understanding in the general public. A listing of these resources is available from the Canadian Virtual Hospice, with new resources continually being generated and added to this list.

An ACP strategy for Waterloo Wellington will not just add more tools to the plethora that already exists – that will simply add to the confusion. What is needed at this point is not more tools, but a broad-based change process focused in Waterloo Wellington that will create widely accepted and integrated standards of knowledge and behaviour as well as standardized tools in relation to ACP across all health care providers and related community sectors. An ACP strategy for Waterloo Wellington that includes a broad community conversation about values and preferences for end-of-life care is needed and will be welcomed. A unique and strong local strategy that is built by consensus of all partners will bring real and sustainable changes in awareness, attitudes, knowledge and behaviours throughout the community.

Healthy Cities/Compassionate Communities Approach

The World Health Organization (WHO) Healthy Cities approach to health care is based on commitments to prevention, harm reduction and early intervention instead of focusing on addressing illness. Healthy cities promote comprehensive local strategies for health protection and sustainable development. Basic features include community participation and empowerment, intersectoral partnerships, and participant equity. The target is the community itself, with strategies focused on population-based and public sector interventions, instead of the individual patient or family.

The discipline of palliative care, with its understanding of the relationships between the physical, spiritual, emotional and practical domains of human existence and suffering, fits comfortably into an approach to population health that recognizes multiple determinants of health and enduring health problems. (O'Neil and Wolf, 2006)

The WHO is investing in palliative care models around the world based on this community development model for end-of-life care, where services are population-based, available earlier, become more sustainable, and are less reliant on episodic care. The WHO's three priorities for palliative care including impacting government policy, educating the public, the media, policy makers, business leaders and community leaders as well as health care professionals, and providing adequate access to pain medication. (O'Neil and Wolf, 2006)

Dr. Allan Kellehear from the United Kingdom has long been promoting a "Compassionate Communities" approach to palliative care, where community partnerships and community engagement are the crucial components of success, with health care professionals providing services within the much broader context of compassionate community-based care (Kellehear, 2005, 2013). This Compassionate Communities approach has its origin in the WHO Healthy Cities model of community involvement in health care.

Last October Dr Kellehear spoke in St Catharines , (**St Catharines Standard**, 2013), summarizing that becoming a Compassionate Community means:

- death education for everybody,
- community development initiatives,
- community and service partnerships,

- empowerment of volunteers to be networkers, movers and shakers,
- public health workers as partners,
- health promotion starting at home, and
- providing leadership and role models in the community.

British palliative care policy and practices are now building on this model of Compassionate Communities, and in 2013 the United Kingdom Palliative Care Best Practices prioritized community engagement through the compassionate communities approach (Kellehear, 2013). This entails embracing public health ideas such as health promotion, community development and death education.

In a similar approach, Denise Marshall from McMaster University in Hamilton, Ontario is promoting end-of-life care as a new public health approach (Marshall, 2013). She documents the international movement towards health promotion, community partnership and social ecology as moving Hospice Palliative Care to be truly integrated and sustainable in public health.

Earlier studies also document the value of a population health, public health, and community health based approach for palliative care. Higgins and Koffman (2005) documents that palliative care offered outside of health care institutions is the most effective solution, as shown by studies in Italy, Spain, and the United States. Stjernsward, Foley and Ferris (2007) state that in 1990 the WHO pioneered a Public Health Strategy to integrate palliative care into public health, as public health is the best approach for translating new knowledge and skills into evidence-based cost-effective interventions. They state that palliative care must be incorporated into all levels of health care systems and be owned by the local community, requiring the engagement of local opinion leaders, a situational analysis, a steering committee and an action plan that includes policy development, drug availability, and education of multiple community-based target audiences.

Other Jurisdictions Experiences with ACP Education Plans

The First Two in Canada: Calgary Health and Fraser Health

Health Canada created an Implementation Guide to ACP in Canada (2008) with a case study of the Calgary Health and Fraser Health experiences. This Implementation Guide eventually formed the foundation for the ACP National Framework (2012).

The Calgary Health Region of Alberta Health Services developed its ACP strategy and resources from 2005-2008, and then in 2008 launched the ACP: Goals of Care Designation with a primary focus on culture change within health care institutions to

enhance informed, collaborative health care decision-making, especially at end-of-life.

In Alberta, ACP is defined similarly to Ontario, as a process that involves thinking about values and wishes regarding future health care choices, choosing an agent (SDM), and documenting ones choices, wishes and values for the agent (and for health care providers in Alberta). The difference from Ontario is that Alberta mandated in 2008 that patients upon entry to a health care institution (eg hospital, LTC) complete a Goals of Care Designation order that specifies their goals of care within three areas of focus.

- R – Resuscitative Care
- M – Medical Care
- C – Comfort Care

This type of Medical Order has been deemed to not meet the legal standards in Ontario of consent for treatment, and unlike Alberta, it cannot be used in Ontario to give direction to health care practitioners in Ontario.

The Calgary Health Region did a chart audit at baseline (2008) and 18 months after implementation (in 2010). They found that in 18 months documentation of ACP discussions rose from 33% to 41% in acute care, from 38% to 69% in home care, and from 77% to 88% in LTC. They found that in 18 months a Goals of Care Designation (GCD) Order increased from 84% to 94% in acute care, from 36% to 55% in home care, and from 95% to 97% in LTC. They found that resource utilization differed for those who died with a GCD Order versus those that died without a documented GCD Order, with fewer patients with a GCD Order receiving resuscitation or being transferred to acute care.

The Calgary Health Region invested heavily in resources for rolling out ACP – they dedicated 7 Full Time Equivalent positions for the first 3 years to ACP. They invested in training and tools for patients, families and health care practitioners. They specifically developed a Goals of Care Designation order that is valid across the continuum of health care services and is informed through the process of engaging patients in advance care planning discussion. Significant investment was made in establishing health records and transfer processes (“green sleeve”) that capture and transfer information among health care sites and health care practitioners related to advance care planning and a Goals of Care Designation medical order. They continue to work at education, training and evaluation to ensure that ACP is well integrated into the Calgary Health Region, and see it as a model for other regions in Canada. As of March 1, 2014, this will be the approach used by all of Alberta.

The Fraser Health Authority (British Columbia) ACP process started in 2004 with a 20-member steering committee, laying the groundwork for two years before implementation began. They worked with 2 FTE in staffing, and developed formal education modules for health care providers, and developed tools and resources including a phone line and a website for the public and for health care providers. They found that health care providers needed to engage in an average of 2.5 conversations with patients and their families before there was any documentation of an ACP, showing that ACP is a multidisciplinary skill that takes time and crosses all health care providers. They also developed a “green sleeve” with fridge magnets as the consistent documentation tool to be used by everyone, including health care professionals, community professionals, and individuals.

In summary, Health Canada outlined these critical factors for success experienced by these case studies:

- Secure support from organizational leaders
- ACP is about culture change
- Be flexible, as ACP is not a linear implementation process
- Engage passionate champions, who will be agents of change
- Gather and tell stories
- Plan for small changes, and hook ACP to other initiatives
- Embed quality improvement into the process
- Engage all HC disciplines, and engage the broader community
- Ensure that both the public and the health care providers have easy access to resources
- Provide consistent leadership
- Engage physicians, as this is essential for success, including dealing with billing concerns

They also outlined potential challenges, largely focused around attitudes that require a culture shift:

- Discomfort with the topic of preparing for end-of-life
- Lack of time for ACP conversations by HC professionals and providers
- Lack of adequate billing codes for physicians
- Difficulty making the culture shift to patient-directed care decisions
- Lack of collaborative processes and communication across health care streams
- Lack of consistent terminology and tools across multiple systems
- Lack of clear documentation regarding wishes that pass legal standards.

It is from these two case studies that the four ACP National Framework building blocks were developed, with the understanding that investing in changing structures and changing attitudes are just as important as providing information and training for the successful implementation of ACP.

Central West LHIN ACP

The Central West LHIN created a strategic plan to enhance ACP within their regional organizations in 2008. Their aims were to create a common ACP teaching tool to use across all continuums of care, to augment and disseminate ACP resources, to promote the appropriate use of Emergency Department resources, and to enhance the communication and co-ordination of care amongst care providers.

They advise that previous ACP initiatives have fallen short in capacity-building, integration, and sustainability, and that a successful strategy will need to address:

- Compliance with laws and professional standards/ ethics
- Safe, effective, consistent and culturally sensitive conversations
- Alignment with other strategies
- Collaboration with key stakeholders
- Clear attractive advertising that reaches all community partners and the public
- Attitudes of SDMs and doctors who don't follow ACP wishes because they believe they know best.

The Central West LHIN emphatically states that inadequate ACP training results in the misuse of scarce resources and causes undue harm and suffering, because patients are treated without the dignity and respect of following their wishes. They recommend that education is insufficient on its own to make change, but that there also be change in ongoing organizational processes, policies and procedures to ensure that ACP is done well across the system.

Challenges/Barriers

There remain a number of challenges to ACP acceptance that are outside the influence of any ACP project within Waterloo Wellington:

1. OHIP billing practices that do not provide physician billing codes for time spent on ACP,
2. Patient health records that could capture ACP wishes but do not electronically move with the patient and are not available to all providers,
3. No legal mandate for ACP wishes to be documented on entry to acute care or long term care,
4. Lack of clarity in wording or intent in ACP documentation of patient wishes,

5. Attitudes by family members and doctors that they “know best” and don’t want to follow patient wishes, and
6. Societal and cultural attitudes that encourage individuals and their families to avoid facing death.

Some of these challenges are named and can be addressed to some extent in the activities listed above, but these are all issues that extend far beyond Waterloo Wellington. These will need care and sensitivity to address within Waterloo Wellington, and beyond.

"The conversations we had and the confidence that we as a family felt in knowing her wishes for her final days are a gift"

Posted By Chandra Vig on May 10, 2013 Speak Up website

When my husband's step mother was diagnosed with Primary CNS Lymphoma (brain cancer) in February 2012 we were all in crisis mode. She was confused and disoriented and experiencing a lot of pain. Thankfully we had engaged in conversations about end of life prior to this and my father in law felt as though he knew what her wishes were in a general sense.

As steroids and chemotherapy shrunk the tumors my mother in law regained her capacity to engage in meaningful conversation. We had many. We talked about treatment options and the potential outcomes of those treatments. We talked about what was important to her in terms of the goals she would hope to achieve in her life and what her hopes were for her healthcare. Some days we talked about the coming months. Some days we talked about what the final days would look like. Many of these conversations were just between her and I in quiet moments while chemotherapy drugs were dripping into her veins. Many others included her children and her husband. A few included her health care team – she was abundantly clear about certain aspects of her care and had specific wishes around intervention she would and would not be accepting of. We revisited these specific wishes with each change in her health circumstances. And when her goals for her care changed we were sure to communicate those goals to her health care team.

Eleven months after diagnosis we were near those final days. She was more confused and it became hard to know for sure what she did and did not understand. Yet we continued to talk.

This journey has been a difficult one. There is nothing easy about watching someone you love experience pain and distress. But the conversations we had and the confidence that we as a family felt in knowing her wishes for her final days are a gift. A gift that she gave to us by being so open and courageous in speaking about her life and her death with us. We are sad. But we are not in distress. We faced those days with her advocating for her and supporting her health care team in honoring her wishes. Now that she's gone we miss her tremendously. As sad as we are we continue to take comfort in knowing that the end of her life was the way she wanted it to be. Conversations matter.

References

Acclaim Health, *Advance Care Planning Resources*,
<http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/advance-care-planning/>

Alberta Health Services, *Advance Care Planning: Goals of Care – Calgary Zone, Looking Back and Moving Forward*, 2012

AAN Task Force on End-of-Life, *Advance Care Planning as an Urgent Public Health Concern*, **American Academy of Nursing Policy Brief**, April 2010

Canadian Hospice Palliative Care Association, *Advance Care Planning in Canada: National Framework*, January 2012, <http://www.chpca.net/projects-and-advocacy/projects/advance-care-planning.aspx>

Canadian Hospice Palliative Care Association, *The Way Forward*,
<http://www.hpcintegration.ca/about-us.aspx>

Canadian Medical Association, *CMA End of Life Care: A National Dialogue*, Feb-May 2014, www.cma.ca/advocacy/end-of-life-care

Canadian Press, *Urgency to pass Quebec's right to die bill as provincial election looms*, **CTV News**, February 20, 2014, www.ctvnews.ca/politics

Canadian Virtual Hospice, *Tools for Practice*,
http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/For+Professionals/For+Professionals/Tools+for+Practice/Advanced+care+planning+ +Decision+making.aspx?page=7#id_357bb8eb26753c8037c723f34d1a834e

Cancer Care Ontario, *ACP with Cancer Patients*, Evidence-based Series 19-1, April 2012

Cancer Quality Council of Ontario, *End of Life Care Measures*, www.csqi.on.ca/cms

CAPCE, *Comprehensive Advance Palliative Care Education for RN and RPN in Waterloo Region and Wellington County*, 2013 Information Booklet

CARENET, *What do Canadians think of ACP? Findings from an on-line opinion poll*, **BMJ Supportive and Palliative Care**, 2013

CBC, *Palliative chemo patients' end-of-life wishes overlooked*, March 4, 2014, www.cbc.ca/news

Central West LHIN, *Strategic Plan to Enhance ACP at Regional Organizations*, 2008

Detering, Hancock, Reade, and Silvester. *The impact of advance care planning on end of life care in elderly patients: randomised controlled trial*. **BMJ**, 2010

Downar, CARENET, *Ontario hospitals are not using palliative performance indicators in their balanced scorecards*, http://www.thecarenet.ca/index.php?option=com_content&view=section&layout=blog&id=5&Itemid=54

Dykeman Dewhirst O'Brien LLP, Advocacy Centre for the Elderly, *Health Care Consent and Advance Care Planning: Standards and Supports*, commissioned by the **Law Commission of Ontario**, 2013

Engage with Grace, *The One Slide Project*, <http://www.engagewithgrace.org/>

Evans, Michael, *Plan for a good death – talk about your wishes*, **Globe and Mail**, May 19, 2009

Givetash, Linda, *Discussing end-of-life care with family invaluable experts say*, **Waterloo Region Record**, Sept 21, 2013

Globe and Mail Editorial, *Quebec gets it right on the right to die*, **Globe and Mail**, February 19, 2014

Gomez-Batiste, Caja, Espinosa, Bullich, Martinez-Munoz, Porta-Sales, Trelis, Esperalda, Stjernsward, *The Catalonia WHO Demonstration Project for Palliative Care Implementation: Quantitative and Qualitative Results at 20 Years*, **Journal of Pain and Symptom Management**, April 2012

Gomez-Batiste, Martinez-Munoz, Blayun, Lipponcott, Williams, Wilkins, *Identifying Needs and Improving Palliative Care of Chronically Ill Patients: A community-oriented, population-based, public health approach*, 2012. www.supportiveandpalliativecare.com

Health Canada, *Implementation Guide to ACP in Canada: A Case Study of Two Health Authorities*, March 2008

Heyland, Daren, ACCEPT, CARENET, *Failure to engage hospitalized elderly patients and their families in ACP*, **JAMA Intern Med**, May 2013

Higgins and Koffman, *Public Health and Palliative Care*, **Clinics in Geriatric Medicine**, Vol 21, 2005

Institute for Healthcare Improvement, *The Conversation Project*, www.theconversationproject.org

Kellehear, *Compassionate Communities: End of Life Care as Everyone's Responsibility*, **QJM**, Sept 30, 2013

Kellehear, **Compassionate Cities: Public Health and End-of-Life Care**, 2005

Marshall, Denise. *End-of-Life: New Public Health Approach*, CHPC Conference, 2013

Martin, Andrea. *WW Integrated Hospice Palliative Care Program*, January 2013

Mulholland, Angela, *Quebec euthanasia bill puts spotlight back on right-to-die debate*, **CTV News**, June 13, 2013, www.ctvnews.ca/canada/quebec

Mullock, Martin and Sallrow, *An Introduction to ACP in Practice*, **BMJ**, 2013

NHS End of Life Care Programme, *The Differences Between General Care Planning and Decisions Made in Advance*, 2010

National Institute for the Care of the Elderly (NICE), *Tool on Consent and Capacity*, [www.nicenet.ca/files/NICE Capacity and Consent tool.pdf](http://www.nicenet.ca/files/NICE_Capacity_and_Consent_tool.pdf)

O'Neil, Joseph and R Cameron Wolf, *Palliative care as a public health issue*, **Textbook of Palliative Medicine**, Florida: CRC Press, 2006

Ontario, *Advancing High Quality, High Value Palliative Care in Ontario: Declaration of Partnership and Commitment to Action*, December 2011

Ontario Medical Association, *End of Life Care Must be a Priority*, May 5, 2013, www.oma.org/mediaroom/pressreleases/pages/endoflifecaremustbeapriority.aspx

Royal College of Physicians, *ACP National Guidelines, Concise Guide to Good Practice Series No 12*, 2009

Silveira, Kim, Langa. *Advance Directives and Outcomes of Surrogate Decision Making before Death*, **New England Journal of Medicine**, April 2010

Stall, Doig and Tepper, *Planning for care at the end of life: our collective responsibility*, May 30, 2013 <http://healthydebate.ca/2013/05/topic/community-long-term-care/advanced-care-planning>

Stjernsward, Foley and Ferris, *The Public Health Strategy for Palliative Care*, **Journal of Pain and Symptom Management**, Vol 33, #5, May 2007

Sturdy Smith, Noor, and Sertoria, *A Summary of Senior Friendly Care in WW LHIN Hospitals*, <http://www.google.ca/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CCkQFjAA&url=http%3A%2F%2Fwww.waterloowellingtonlhin.on.ca%2FuploadedFiles%2FHome%20Page%2FWWLHIN%2520SFH%2520-%2520Summary%2520Report-Final.pdf&ei=BZkOU4uTC8rQyAHThIGgDA&usg=AFQjCNGe6MKeLoL76lj7Iaq-uVpXPYMOwQ&sig2=ObuXg0WkIN5OCBneMPZp4Q&bvm=bv.61965928,d.aWc&cad=rja>

Wahl, Judith, Advocacy Centre for the Elderly, *Health Care Consent, Advance Care Planning, End-of-Life Issues: What You Need to Know*, 2011

Wahl, Judith, Advocacy Centre for the Elderly, *25 Common Misconceptions about the Substitute Decisions Act and Health Care Consent Act*, 2009

Walter, *Palliative care is everyone's business expert says*, **St Catharines Standard**, October 28, 2013

WW Hospice Palliative Care Network and Palliative Pain and Symptom Management Consultation Services, *WW Advance Care Planning Toolkit*, 2009, updated 2011