Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

Advance Care Planning in Canada:

Synthesis of Tools

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Advance Care Planning Tools

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

Tools for the Public

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

Several organizations in Canada have put significant effort into the development of brochures and related tools to strengthen clients understanding of ACP concepts and implications.

Here are some examples of tools. *(N.B. This is not meant to be an exhaustive list.)*

Alberta Health Services (Calgary Zone) has a well developed ACP program entitled *"My Voice – Planning Ahead"* that includes tools for clients when considering ACP options such as: • "My Voice" Workbook – Standard Form and Short Form • "My Voice – Planning Ahead" Advance Care Planning for Future Medical Decisions brochure • "My Voice – Planning Ahead" Wallet Card • "My Voice – Planning Ahead" Information for Representatives and Agents brochure • "My Voice – Planning Ahead" Advance Care Planning DVD • "Understanding Goals of Care Designations" brochure	http://www.calgaryhealthregion.ca/programs/advancecareplanning/index.htm
Fraser Health has a well developed advance care planning initiative entitled: *Lets Talk*. The program involves health service provider training, as well as client-focused information resources such as: • My Voice Workbook© in English, Punjabi and Cantonese	http://www.fraserhealth.ca/your_care/planning_for_your_care/

• Information Booklet for Advance Care Planning in English, Punjabi and Cantonese • Making Informed Decisions about CPR brochure in English, Punjabi and Cantonese • Advance Care Planning Wallet Card • Posters in 7 languages • E-book "Planning in Advance for your Future Health Care Choices" • Toll free number • Educational DVDs in English, Punjabi and Cantonese	
Vancouver Island Health Authority has developed *My Wishes for Future Health Care: Information Package*. This package of information is a resource to patients and families as a way to engage in a conversation about future health care decisions. It includes background information about advance care planning; explains terminology; things to consider – such as life support with medical intervention, CPR. It also includes a "My Wishes for Future Health Care Planning Document" where people can provide information to guide substitute decision-makers.	http://www.viha.ca/advance_directives/
HealthLink BC provides access through their website to information on advance directives and advance care planning services in BC. For example, they have information on Writing and advance directive; Should I receive artificial hydration and nutrition? Should I receive CPR and mechanical ventilation? Should I stop life-prolonging treatment?	www.HealthLinkBC.ca
Yukon Health and Social Services has developed a series of tools to support *Care Consent Act* – dealing with making advance directives. These include: • Card to complete once you have done an advance directive • Making Health Care Decisions for a Loved One – The Role of a Substitute Decision-Maker • Planning for your Future Healthcare Choices – Advance Directives Notes and Form for Completing an Advance Directive • Planning for your Future Healthcare Choices – Advance Directives in the Yukon - Booklet • Planning for your Future Healthcare Choices – Advance Directives in the Yukon - Brochure	www.hss.gov.yk.ca
The **Government of Ontario** has produced *A Guide to*	http://www.culture.go

Advance Care Planning as part of Ontario's Strategy for Alzheimer Disease and Related Dementias. It provides information for seniors on making choices about personal care including health care (treatment and services), food, living arrangements and housing, clothing, hygiene and safety. It also provides sources of further information. The Secretariat has also produced a wallet card which can be downloaded, completed – and people can carry it with them. . It contains substitute decision-maker contact and other information.	v.on.ca/seniors/english/programs/advancedcare/
The **Provincial Health Ethics Network of Alberta** has developed *Comfort, Hopes and Wishes: Making Difficult Health Care Decisions*. It is a booklet meant to help guide decision-making by giving clear information about medical treatments and ethical issues that may arise. It may be used during a crisis or in advance of one, to help start discussions with loved ones about future health care planning.	www.phen.ab.ca/hopesandwishes
The Prince Edward Family Health Team (PEFHT) provides a single point of access to health care services for all County residents. An interdisciplinary care teams offer comprehensive patient-centred, primary health care. They have developed: *My Voice: Advance Care Plan*. This booklet provides background information regarding advance care planning and a workbook to prepare an advance car plan.	http://pefht.ca/site/images/stories/PDF/advance%20care%20plan%20my%20voice.pdf
Parkinson Society British Columbia has developed *Health Care Decision Making and Parkinson's'* – a brochure to help people living with Parkinson's/their families/caregivers to become more informed about health care planning as it relates to Parkinson's. It includes information about advance care planning, representation agreements; and advance directives.	http://www.parkinson.bc.ca/Information-Resources

Tools for Professionals

There are some tools developed that support the efforts of the health service provider. Tools identified as part of this environmental scan focus on quick reference guides, tools that support ACP conversations and tools that support the documentation of ACP outcomes. This allows for a consistent approach to engaging clients and consistent reporting of conversation and outcomes.

The following list provides some examples of tools for professionals. *(N.B. This is not meant to be an exhaustive list.)*

Canadian Tools	
The **Alberta Health Services (Calgary Zone)** ACP program, *"My Voice – Planning Ahead"* that includes training and tools for health care providers, (physicians and other clinicians) and Goals of Care reference and chart forms such as: • My Voice – Planning Ahead – Framework for Advance Care Planning Conversations • Quick Reference Pocket Card • Quick Reference Poster • Green Sleeve – a green plastic holder for ACP documents • Advance Care Planning Tracking Record • Goals of Care Designation Order	http://www.calgaryhealthregion.ca/programs/advancecareplanning/index.htm
Fraser Health's *Lets Talk* program involves health care provider training, as well as professional/chart resources such as: • Two-30 minute Level One and Two on-line modules for health care providers • Greensleeve for client/patient charts • Community greensleeve for home use • Advance Care Planning Record • Guidelines for Greensleeve • Advance Care Planning Referral Card • Educational DVDs in English, Punjabi and Cantonese • Acute Care DNR Policy • Instructor Guides for classroom teaching • PowerPoint Presentations and scenarios for classroom teaching • Health care provider conversation tip cards (laminated)	http://www.fraserhealth.ca/your_care/planning_for_your_care/
Vancouver Island Health Authority's (VIHA) website provides information for professionals (and the public) regarding advance directives. It includes frequently asked questions for physicians, nurses and the public.	www.viha.ca/advance_directives

The Pallium Project has supported the adoption and incorporation of advance care planning within professional practice using a workplace learning module approach. ACP is embedded within many of The Pallium Project's activities and initiatives. Examples include: • *The Pallium palliative pocketbook: A peer-reviewed, referenced resource* (the PPP) where ACP is discussed as a generic cross-jurisdictional, pan-Canadian term in the *Language/construct conventions* section (p. xiv). • *Retreat courses targeting primary care professionals* (explicitly covered in Module 5 (Communication) of the *Learning Essential Approaches to Palliative and End-of-Life (LEAP)* courseware package • Curricular resource package associated with *Developing spiritual care capacity for Hospice Palliative Care* curricular resource package (2006). • *Advance care planning: Policy, legal and practical implications*	http://www.palliativeinsight.net/
The **Ian Anderson Program: A Continuing Education Program for End of Life Care** (University of Toronto) has developed a series of modules including one related to *End of Life Decision Making* (the Program is no longer offered, but resources continue to be available on-line).	http://www.cmetoronto.ca/endoflife/Modules.htm
The **National Initiative for the Care of the Elderly** (NICE) and **Advocacy Centre for the Elderly** (ACE) have developed *Tool on Capacity and Consent: Ontario Edition.* This is a pocket card format that addresses issues regarding what is valid consent, informed consent; how it is obtained; along with issues relating to substitute decision-makers. It also provides information on decisional mental capacity	http://www.nicenet.ca/files/NICE_Capacity_and_Consent_tool.pdf
Educating Future Physicians in Palliative and End-of-Life Care – co-sponsored by the Canadian Hospice Palliative Care Association and the Association of Faculties of Medicine of Canada developed *Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum.* It is an educational program/module on ACP targeting interprofessional health care providers at all levels (undergraduate, postgraduate and continuing professional development). The module details the steps in the ACP process from the importance of determining capacity to initiating the conversations and building organizational capacity for ACP (including guidelines for policy development).	http://www.afmc.ca/efppec/docs/pdf_2008_advance_care_planning_curriculum_module_final.pdf

International Examples

There are a number of examples of advance care planning tools for the public and professionals that have been developed in other countries.

International Examples	
Australia – Respecting Patient Choices The government of Australia has a national advance care planning program: *Respecting Patient Choices.* They have developed a national document – Respecting Patient Choices: Advance Care Planning Guide. This general (4-page) guide provides questions for reflection on past health experiences; current health; future health; general decision-making; substitute decision-makers. It is to be used with Respecting Patient Choices Advance Care Planning Information Booklet for their particular state which is more specific. In addition, there are state specific information sheets; contact sheets for details of those who have a copy of the plan; forms for nominating a substitute decision maker; and a Statement of Choices for healthcare decisions. They have also outlined a 9-step process (nationally) – on How to make an Advance Care Plan. (In step 6 they refer to their specific state.) They also provide frequently asked questions. This is all on their website. They also provide e-learning programs for professionals.	http://www.respectingpatientchoices.org.au/
United Kingdom – The National Gold Standard Framework (GSF) – National Health Service The National Gold Standard Framework (GSF) Central Team develops frameworks and training programs to enable generic care providers deliver a gold standard of care for all people nearing the end of life. GSF is a systematic evidence based approach to optimising the care for patients nearing the end of life delivered by generalist providers. GSF is extensively used in the UK, by thousands of primary care teams and care homes. GSF is recommended as best practice by the Department of Health End of Life Care Strategy, NICE, Royal College of General Practitioners, Royal College of Nurses and other major policy groups. The Gold Standards Framework Toolkit includes templates and tools to enable care providers to deliver GSF in various settings – advance care planning is part of the GSF program/toolkit. They have developed an 'ACP Thinking	http://www.goldstandardsframework.nhs.uk/AdvanceCarePlanning

Ahead' template to be used in advance care planning. They have also developed 'Tips on Using Communication Skills in the Advance Care Plan in the Gold Standard Framework in Care Homes.'	
United Kingdom – Advance Care Planning: National Guidelines The Clinical Standards Department of the Royal College of Physicians has facliltated the development of National Guidelines for Advance Care Planning. They have done this in partnership with: The British Geriatrics Society; The National Council for Palliative Care; The British Society of ; The Alzheimer's Society; the Royal College of Nurseing; the Royal College of Psychiatrists; Help the Aged; and the Royal College of General Pracitioners. The guidelines are evidence-based. They have 'Tips for a Successful ACP Discussion'; and 'Suggested Content for an ACP Document'. They have specific recommendations for when and with whom professionals should consider ACP discussions and the elements of the discussion.	http://www.rcplondon.ac.uk/pubs/contents/9c95f6ea-c57e-4db8-bd98-fc12ba31c8fe.pdf
United States – Respecting Choices® The Gundersen Lutheran Respecting Choices® program takes a comprehensive, systematic approach to advance care planning. In this program, the focus is on developing a system of training, practices, and policies so that effective advance care planning and end-of-life decision making becomes the routine - the expected care - throughout a health organization or a community. It uses an integrated systems approach that not only depends on printed material and videos to educate the community, but also provides the personal assistance of trained staff. This approach is then integrated as the routine standard of care through consistently applied policies and practices. Originally based on experiences in La Crosse, Wisconsin, the lessons and skills learned have been developed into a comprehensive curriculum that has become known as Gundersen Lutheran's Respecting Choices® Organization and Community Advance Care Planning Course. Respecting Choices® is being implemented statewide in a number of states and provides the basis of the Australia program. Respecting Choices® has a number of resources (for sale) for patients and families including a Wallet Card, Planning Guide, Information Booklet, Healthcare Agent Information Card, an Information Card; posters and DVDs. They also	http://respectingchoices.org/

provide professional training – in person and on line.	

Disease Specific Tools

Here are two examples of advance care planning tools designed for patients and families with specific illnesses or health situations.

United States – Respecting Choices® The Respecting Choices® program (cited above) has developed the Disease Specific-Patient Centered Advance Care Planning (DS-PCACP) Intervention. They have defined "special patient populations" – who need extra assistance and more skilled facilitation in making future health care decisions. They include individuals with end-stage chronic illness such as congestive heart failure, renal disease or AIDS and individuals who, because of the timing of their illness or injury, have not been considered appropriate for ACP, such as those facing emergent and high risk surgery or those who experience a sudden event, such as a trans ischemic attack and are at risk of repeated episodes. They have developed a scheduled interview process with a consenting patient and a chosen substitute decision-maker. They have also developed an "Advance Care Planning Questionnaire" to be completed by patients to "better inform [their] health care team in knowing and understanding your values and goals". They have also developed a competency-based educational approach to train qualified professionals (e.g., nurses, social workers with clinical experience within the designated patient population) who are selected to implement the DS-PCACP interview.	http://respectingchoices.org/
Parkinson Society British Columbia has developed *Health Care Decision Making and Parkinson's'* – a brochure to help people living with Parkinson's/their families/caregivers to become more informed about health care planning as it relates to Parkinson's. It includes information about advance care planning, representation agreements; and advance directives.	http://www.parkinson.bc.ca/Information-Resources