

Advance care planning

Let's start sooner

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Advance care planning (ACP) is a communication process wherein people plan for a time when they cannot make decisions for themselves. It includes reflection, deliberation, and determination of a person's values and wishes or preferences for treatments at the end of life. Advance care planning should also include communication between an individual and his or her loved ones, future substitute decision makers (SDMs), and health care providers about these values and wishes. Evidence supports the effectiveness of ACP to improve the end-of-life experiences of patients and families.^{1,2} Despite the known benefits of ACP,³ often people with life-limiting illnesses facing an acute health crisis have not spoken up about their preferences.⁴ It is estimated that approximately half of Canadian adults have engaged in some type of end-of-life discussion with family members or friends.⁵ However, it is much less common for people to communicate their preferences to health care providers. In one Canadian survey, only 9% of respondents had discussed their preferences with health care providers.⁵

Research on the extent of engagement in ACP in Canadian health care settings has been done largely from the acute care perspective. One study reported that the documented medical orders for life-sustaining treatments in Canadian hospitals reflected the expressed preferences of patients only one-third of the time.⁴ This finding is surprising, as a study about family practices in Canada found that nearly all patients were familiar with the term *do not resuscitate*, 86% were interested in discussing wishes with their family physicians, and most wanted to have the discussion while they were healthy.⁶ Clearly there is a communication gap between patients and health care providers.

Being prepared

How might inadequate ACP affect people's lives and their experiences with health care? At the end of life, most people prefer less intensive treatment and want to focus on quality of life; yet in Canada and elsewhere in the Western world, the dying experience is largely an in-hospital, technology-laden experience.⁷⁻⁹ Family members of patients who have received

treatment intensification at the end of life are more likely to experience depression, guilt, and reduced quality of life after the death of a loved one.¹⁰ The tendency to default to intensive treatment near the end of life also places strain on health care system costs.¹¹

The goal of ACP is to better prepare the patient and his or her SDM to make "in the moment" medical decisions. Ideally, ACP is an *ongoing* process, not a one-time decision. Patients tend to think they have completed the process of ACP when they have created a written advance directive such as a living will. Advance directives that express preferences cannot be interpreted as treatment choices in the clinical setting and, as such, the SDM must be prepared to make actual medical decisions in the clinical context. The presence of an advance directive does not guarantee that a patient has reflected on a variety of health states that might be experienced in relation to his or her desired quality of life, or that the patient has communicated his or her values and preferences to the SDM. In the moment of crisis, the applicability of decontextualized choices to the patient's unique situation and the extent to which outcomes of such decisions align with the patient's preferences might be unclear. In turn, this situation can cause anxiety around implementing the directive. For these reasons, while ACP might result in a written advance directive, such documents alone have little clinical usefulness. In addition, written directives have no legal standing in many provinces.¹² Advance care planning is better focused on the reflection, value clarification, and communication activities, so that patients and their SDMs are more prepared for decision making when a life-threatening illness occurs.¹³

Initiating ACP in primary care

A family medicine practice is the setting where longitudinal care across the life cycle takes place for most Canadians and where most care for chronic ongoing illness is managed.¹⁴ Implementing ACP with the family doctor and health care team in the patient's primary medical home could capitalize on these pre-existing relationships.

A tenet of patient-centred care is the process of shared decision making that generally consists of 3 steps: informing the patient of options, describing the options in the context of the patient's own situation, and then helping the patient make informed decisions based on his or her preferences.¹⁵ Advance care planning involves similar

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steps of information exchange, deliberation and clarification of values, and decisional responsibility. In primary care, the patient and doctor might engage in the first 2 if not all 3 steps; in some instances the final medical decision might be made between the patient and another physician at a later time. The family physician can take advantage of the continuity of care and the relationship with the patient and his or her family to initiate ACP conversations.¹⁶ In the event that a patient requires admission to another care setting within the health care system, the foundational work done between the family physician and the patient in primary care can provide “informational continuity.”¹⁷ Such continuity could mean that patients and their families at the time of a crisis will be able to either convey the outcomes of previous conversations with family physicians or, at the very least, be better prepared to engage in such conversations anywhere in the health care system. Additionally, “management continuity”¹⁷—for example through information technology solutions to ensure plans move with the patient through the system—is imperative.¹⁸

A number of barriers to discussing ACP have been noted by health care professionals in primary care, including a lack of skill and comfort in handling these

discussions. Specifically, these barriers included not knowing the appropriate timing for discussion, the attitude that patients should initiate the discussion, fear of removing hope, and fear of uncovering needs that cannot be met.¹⁹ In addition, in many jurisdictions physicians are not paid for this activity. Systematic reviews of strategies to increase ACP in health care settings have found that successful interventions used more than one method, involved education materials for both patients and providers, and used deliberate and repeated interactions between patients and providers.^{20,21} It is also important to prepare patients with information resources before their visits,²² use prompts or reminders to initiate discussion in the practice setting, and allow enough time for discussion.²³ In a past issue of *Canadian Family Physician*, Gallagher outlined how family physicians could engage in ACP with patients by incorporating ACP appointments in the office setting, asking questions to start end-of-life discussions, and presenting patients with scenarios in order to understand their values about key issues. She also recommended recording the outcomes of these discussions (ie, values that are critical to the patient) and updating the record as the patient ages.²⁴

There are tools available to help the primary care patient population with ACP. The Speak Up Campaign is an initiative aiming to raise the profile of ACP in Canada. For more information and to find available tool kits²⁵ for provincial and national ACP, visit www.advancecareplanning.ca. For an interactive Web-based ACP tool appropriate for the primary care population, there is the PREPARE program at www.prepareforyourcare.org.²⁶ In 2014, government agencies awarded approximately \$2 million for research and knowledge translation initiatives in support of the i-GAP (Improving General Practice Advance Care Planning) projects to improve ACP in Canadian primary care. To learn more, visit www.thecarenet.ca. The aim of these initiatives is to support the process of ACP in primary care so that patients who have had these conversations can speak up and make better decisions in the moment of crisis.

Patients and families want to talk about ACP with their health care providers. The positive outcomes of meaningful ACP are known and there are tools available to help patients. We must next focus on ways to integrate ACP into routine care in family practice. 

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References

- Canadian Hospice Palliative Care Association. *Advance care planning in Canada: national framework*. Ottawa, ON: Canadian Hospice Palliative Care Association; 2012. Available from: www.advancereplanning.ca/media/40158/acp%20framework%202012%20eng.pdf. Accessed 2014 Dec 23.
- Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* 2010;362(13):1211-8.
- Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010;340:c1345.
- Heyland DK, Barwich D, Pichora D, Dodek P, Lamontagne F, You JJ, et al. Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Intern Med* 2013;173(9):778-87.
- Teixeira AA, Hanvey L, Tayler C, Barwich D, Baxter S, Heyland DK. What do Canadians think of advanced care planning? Findings from an online opinion poll. *BMJ Support Palliat Care* 2015;5(1):40-7. Epub 2013 Oct 4.
- Robinson C, Kolesar S, Boyko M, Berkowitz J, Calam B, Collins M. Awareness of do-not-resuscitate orders. What do patients know and want? *Can Fam Physician* 2012;58:e229-33. Available from: www.cfp.ca/content/58/4/e229.full.pdf+html. Accessed 2015 Jun 15.
- Heyland DK, Lavery JV, Tranmer JE, Shortt SE, Taylor SJ. Dying in Canada: is it an institutionalized, technologically supported experience? *J Palliat Care* 2000;(Suppl 16):S10-6.
- Gruneir A, Mor V, Weitzen S, Truchil R, Teno J, Roy J. Where people die: a multilevel approach to understanding influences on site of death in America. *Med Care Res Rev* 2007;64(4):351-78.
- Heyland DK, Lavery JV, Tranmer J, Shortt SE. The final days: an analysis of the dying experience in Ontario. *Ann R Coll Physicians Surg Can* 2000;33:356-61.
- Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300(14):1665-73.
- Menec V, Lix L, Steinbach C, Ekuma O, Sirski M, Dahl M, et al. *Patterns of health care use and cost at the end of life*. Winnipeg, MB: Manitoba Centre for Health Policy; 2004.
- Unger D. *The Canadian bioethics companion. An online textbook for Canadian ethicists and health care workers*. San Francisco, CA: WordPress; 2011. Available from: <http://canadianbioethicscompanion.ca>. Accessed 2015 Jun 15.
- Sudore RL, Stewart AL, Knight SJ, McMahan RD, Feuz M, Miao Y, et al. Development and validation of a questionnaire to detect behavior change in multiple advance care planning behaviors. *PLoS One* 2013;8(9):e72465.
- College of Family Physicians of Canada. *A vision for Canada. Family practice: the patient's medical home*. Mississauga, ON: College of Family Physicians of Canada; 2011. Available from: www.cfpc.ca/uploadedFiles/Resources/Resource_Items/PMH_A_Vision_for_Canada.pdf. Accessed 2015 Jun 15.
- Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med* 2012;27(10):1361-7. Epub 2012 May 23.
- Tan A, Manca D. Finding common ground to achieve a "good death": family physicians working with substitute decision-makers of dying patients. A qualitative grounded theory study. *BMC Fam Pract* 2013;14:14.
- Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. Continuity of care: a multidisciplinary review. *BMJ* 2003;327(7425):1219-21.
- Chan D, Howard M, Dolovich L, Bartlett G, Price D. Revolutionizing patient control of health information. *Can Fam Physician* 2013;59:823-4 (Eng), e347-9 (Fr).
- De Vleminck A, Houttekier D, Pardon K, Deschepper R, Van Audenhove C, Vander Stichele, et al. Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review. *Scand J Prim Health Care* 2013;31(4):215-26.
- Ramsaroop SD, Reid MC, Adelman RD. Completing an advance directive in the primary care setting: what do we need for success? *J Am Geriatr Soc* 2007;55(2):277-83.
- Tamayo-Velázquez MI, Simón-Lorda P, Villegas-Portero R, Higuera-Callejón C, García-Gutiérrez JF, Martínez-Pecino F, et al. Interventions to promote the use of advance directives: an overview of systematic reviews. *Patient Educ Couns* 2010;80(1):10-20. Epub 2009 Oct 29.
- Tung EE, Vickers KS, Lackore K, Cabanela R, Hathaway J, Chaudhry R. Clinical decision support technology to increase advance care planning in the primary care setting. *Am J Hosp Palliat Care* 2011;28(4):230-5.
- Slort W, Blankenstein AH, Deliens L, van der Horst HE. Facilitators and barriers for GP-patient communication in palliative care: a qualitative study among GPs, patients, and end-of-life consultants. *Br J Gen Pract* 2011;61(585):167-72.
- Gallagher R. An approach to advance care planning in the office. *Can Fam Physician* 2006;52:459-64.
- Advance Care Planning [website]. *Primary care toolkit*. Ottawa, ON: Canadian Hospice Palliative Care Association; 2015. Available from: www.advancereplanning.ca/health-care-professionals/about-advance-care-planning/primary-care-toolkit.aspx. Accessed 2015 Jun 16.
- Sudore RL, Knight SJ, McMahan RD, Fuez M, Farrell D, Miao Y, et al. A novel website to prepare diverse older adults for decision making and advance care planning: a pilot study. *J Pain Symptom Manage* 2014;47(4):674-86. Epub 2013 Aug 21.

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