



ADVANCE CARE PLANNING

RATIONALE

With the advent of technology allowing for the extension of life, and as a result of the increasing importance of personal autonomy, decisional capacity, and informed consent and the growing awareness of issues related to quality of life and dying, Canadians have become increasingly interested in expressing their wishes regarding their health care and having more input into decisions about their care should they become incapable. Advance care planning (ACP) can help patients to achieve these goals.

The CMA supports development of a strategy for ACP¹ in all provinces and territories. ACP leads to better concordance between patients' wishes and treatments provided,^{2,3} decreased anxiety for families,⁴ decreased moral distress for health care providers,⁵ decreased hospitalization rates of nursing home residents³ and fewer unnecessary medical treatments.^{3,6,7}

ACP is at the intersection of the provision of health care, ethical values and legal rights and duties. In particular, it involves the acknowledgement of essential aspects of autonomy, informed consent, and respect of patients' care wishes now and in the future, and their intentions if they become incapable.^{8,9}

The balancing of the need to obtain informed consent for a treatment option in the present with the need to respect health care preferences that were stated in the past has been addressed using various clinical, legal and institutional approaches across Canadian jurisdictions."

Physicians¹⁰ can play a significant role in ACP throughout the course of the patient–physician relationship, including in the pediatric setting. At any time, outcomes of the planning process can be documented and/or the patient can appoint a substitute decision-maker in writing. These documents can be identified as advance directives, personal directives or powers of attorney for personal care¹¹ (hereinafter all will be referred to as advance directives). An advance directive does not remove the need for a physician to obtain consent before providing a treatment to a patient, except in an emergency. As stated in the Canadian Medical Protective Association's consent guide: "[U]nder medical emergency situations, treatments should be limited to those necessary to prevent prolonged suffering or to deal with

imminent threats to life, limb or health. Even when unable to communicate in medical emergency situations, the known wishes of the patient must be respected.”¹²

While much of the focus of ACP is on making care decisions and nominating proxy decision-makers in case the patient becomes incapable of making decisions in the future, ACP has much more utility. ACP conversations¹³ can assist patients in determining treatment trajectories and making decisions about the intensity level of interventions in their current care. Providers can have discussions with patients and their families about proposed treatments in the context of the patient’s communicated goals and wishes. The process of ACP also helps patients and their families to become familiar with the language and processes used to make cooperative health care decisions.

SCOPE OF POLICY

This policy aims to provide guidance on key considerations pertinent to ACP in a way that is consistent with a physician’s ethical, professional and legal obligations. This is a complex subject: physicians should be aware of the legislation in the jurisdiction in which they practise, the standards and expectations specified by their respective regulatory authority, as well as the policies and procedures of the setting(s) in which they practise (e.g., regional health authority, hospital).

GENERAL PRINCIPLES

1. ACP is a process of (a) respecting patients’ wishes through reflection and communication, (b) planning for when the patient cannot make health care decisions and (c) discussion with friends, family and professionals; (d) it may result in a written document.⁵ It informs the substitute decision-maker and provides information for the clinician to consider in the provision of care within the bounds of the law.
2. Although often associated with the end of life, ACP represents the expression of a patient’s wishes for any future health care when the patient is incapable. It expresses the patient’s values and beliefs regarding current care decisions and provides information that can inform any decisions that must be made during an emergency when the patient’s consent cannot be obtained. For these reasons, ACP should occur throughout a person’s lifetime.
3. Respect for patients’ dignity and autonomy is a cornerstone of the therapeutic physician–patient relationship. Patients’ right to autonomous decision-making has become embedded in ethical frameworks, consent legislation and case law.¹⁴ Respect for the wishes of an incapable patient constitutes a preservation of autonomy and promotes trust between the physician and patient.¹⁵
4. The way in which the act of obtaining consent is weighed against the patient’s stated wishes as outlined during the ACP process varies according to the jurisdiction in which the patient and physician are located.

EDUCATION

1. Given the practical, ethical and legal complexities of ACP, physicians, medical learners should be supported in becoming familiar with ACP and comfortable in engaging in the process with their patients. To this end, CMA supports the development of training in ACP and efforts to make it available to all physicians and medical learners.¹⁶ For practising physicians and residents, many resources are available, for example:
 - a. Advance Care Planning in Canada: A National Framework
 - b. Facilitating Advance Care Planning: An Interprofessional Educational Program
 - c. Information from the Health Law Institute of Dalhousie University on the regulatory policies and legislation of individual provinces and territories
 - d. A comprehensive collection of Canadian resources compiled by the Speak Up campaign of the Advance Care Planning in Canada initiative
 - e. Pallium Canada's Learning Essential Approaches to Palliative Care module on ACP

In the case of medical students, the CMA supports the position of the Canadian Federation of Medical Students that end-of-life training is an essential facet of undergraduate medical education.

2. The issue of the supervision of medical learners practising ACP should be clarified, as considerable ambiguity currently exists.¹⁷ Medical learners would benefit from unified national guidelines concerning the nature of their participation in ACP, especially regarding end-of-life care. In the case of medical students, the CMA agrees with the recommendation of the Canadian Federation of Medical Students that supervision be mandatory during conversations about end-of-life care.
3. The CMA calls for more research on the outcomes associated with the provision of ACP training to physicians and medical learners.
4. The CMA recommends that governments and institutions promote information and education on ACP to patients and their substitute decision-makers.

PROFESSIONAL AND LEGAL RESPONSIBILITY

1. While respecting patients' values, all physicians are expected to encourage their patients to engage in ACP with them. ACP is not a one-time event. The nature of the conversation between the physician and the patient and the regularity with which they discuss the subject will depend on the patient's health status. Family physicians and physicians have ongoing care relationships with chronically ill patients are particularly well placed to have regular discussions with their patients about their beliefs, values and wishes. An effective exchange of information between family physicians (and other physicians who work in the community with outpatients) and acute or tertiary care physicians would assist in ensuring patient's wishes are considered.

2. ACP, in particular advance directives, are at the intersection of medicine and the law. Physicians should recognize this and ask patients whether they have an advance directive or have done any ACP.
3. There is wide variation across jurisdictions in terms of the requirements and procedures for ACP; therefore, physicians should inform themselves about any relevant legislation and the scope of the requirement to obtain consent within that jurisdiction when carrying out ACP.

INSTITUTIONS

1. The CMA supports institutional processes that recognize and support ACP. Support for ACP includes developing a consistent process for the exchange of information about patients' wishes and advance directives among health care providers, as patients traverse sectors and locations of care. Patients with a written advance directive must be identified and the advance directive integrated fully within the patient's records¹⁸ so that it is available across the institution (and ideally the health care system). The CMA advocates for the inclusion of advance care directive functionality as a conformance and usability requirement for electronic medical record vendors.¹⁹ Provinces and territories should be encouraged to establish robust organizational processes and resources for patients in all locations of care and strong province- or territory-wide policy, such as in Alberta.²⁰
2. Institutions and other organizations should encourage health care providers to ask patients to bring their advance directive to appointments at the same time they ask them to bring a list of their medications or other medical information.
3. The CMA supports institutional/organizational audits of structures, processes and outcomes related to ACP as an important step in improving the quality and frequency of ACP activities.

ROLE FOR GOVERNMENTS

1. The CMA supports infrastructures enabling ACP, including funding that will support ACP and other end-of-life discussions.
2. The CMA promotes the incorporation of ACP into future federal and provincial/territorial senior strategies and dementia and/or frailty strategies.
3. The CMA supports the development of ACP metrics and their future inclusion in Accreditation Canada standards.

GLOSSARY

Advance care planning (ACP)

Advance care planning is a term used to describe a process of reflection, communication, conversation and planning by a capable individual with family, friends and professionals about their beliefs, values and wishes for a time when they no longer have the mental capacity to make decisions about their health care. ACP can also involve the naming of a substitute decision-maker.⁸

Advance directive

The legislated term “advance directive” has different names, definitions and legal authority across the country. For example, in British Columbia an advance directive is a written legal document that provides a mechanism for capable patients to give directions about their future health care once they are no longer capable.²¹ As such, in BC an advance directive may, under certain circumstances, be considered “equivalent to consent to treatment and may be acted upon directly by a health care provider without consultation with an SDM [substitute decision-maker].”⁸ In Alberta it is called a personal directive. In Ontario, “advance directive” is a generic non-legal term and refers to communications that may be oral, written or in other forms.⁸

In Quebec, advance care directives are legally binding, as set out in the Act respecting end-of-life care, which recognizes “the primacy of freely and clearly expressed wishes with respect to care. . .”²²

Current legislation does not allow for medical assistance in dying to be requested by an advance directive.²³ The CMA acknowledges that considerable public, expert and legal debate exists around the issue.

Informed consent

To obtain informed consent, physicians must provide adequate information to the patient or capable decision-maker about the proposed procedure or treatment; the anticipated outcome; the potential risks, benefits and complications; and reasonable available alternatives, including not having the treatment; and they must answer questions posed by the patient. Consent is only informed if there is disclosure of matters that a reasonable person in the same circumstances would want to know.²⁴ Consent must be given voluntarily, must not be obtained through misrepresentation or fraud, must relate to the treatment and must be informed.

Substitute decision-maker (SDM or agent or proxy)

A substitute decision-maker is a capable person who will make health care decisions on behalf of an incapable individual. In all jurisdictions the health care provider must take reasonable steps to become aware of whether or not there is a substitute decision-maker before providing health treatment to an incapable patient. Legally there are implementation differences across the country. For example, in BC a substitute decision-maker is appointed

through a representation agreement, in Alberta through a personal directive and in Ontario through a power of attorney for personal care.

Approved by the CMA Board of Directors May 2017

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- ¹ Canadian Medical Association. *Policy resolution GC14-25 – strategy for advance care planning, palliative and end-of-life care*. Ottawa (ON): The Association; 2014. Available: policybase.cma.ca/dbtw-wpd/CMAPolicy/PublicB.htm (accessed 2016 Oct 17)
- ² Houben CHM, Spruit MA, Groenen MTJ, et al. Efficacy of advance care planning: a systematic review and meta-analysis. *J Am Med Dir Assoc* 2014;15:477–89.
- ³ Martin RS, Hayes B, Gregorevic K, et al. The effects of advance care planning interventions on nursing home residents: a systematic review. *J Am Med Dir Assoc* 2016;7:284–93.
- ⁴ Mack JW, Weeks JC, Wright AA, et al. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol* 2010;28(7):1203–8.
- ⁵ Canadian Hospice Palliative Care Association. *Advance care planning in Canada: national framework*. Ottawa; The Association; 2010.
- ⁶ Teo WSK, Raj AG, Tan WS, et al. Economic impact analysis of an end-of-life programme for nursing home residents. *Palliat Med* 2014;28(5):430–7.
- ⁷ Zhang B, Wright AA, Huskamp HA, et al. Health care costs in the last week of life: associations with end-of-life conversations. *Arch Intern Med* 2009;169(5):480–8.
- ⁸ Wahl J, Dykeman MJ, Gray B. *Health care consent and advance care planning in Ontario*. Toronto (ON): Law Commission of Ontario; 2014.
- ⁹ Canadian Medical Association. *CMA Code of Ethics (update 2004)*. Ottawa: The Association; 2004.
- ¹⁰ Physician involvement is not mandatory in the process. However, it is important for physicians to engage with their patients in ACP as this can facilitate change in patients' ACP behaviour and understanding.
- ¹¹ Wahl JA, Dykeman MJ, Walton T. *Health care consent, advance care planning, and goals of care practice tools: the challenge to get it right. Improving the last stages of life*. Toronto (ON): Law Commission of Ontario; 2016.
- ¹² www.med.uottawa.ca/sim/data/Images/CMAPA_Consent_guide_e.pdf
- ¹³ Frank C, Puxty J. Facilitating effective end-of-life communication – helping people decide. *CJS Journal of CME* 2016;6(2). Available: <http://canadiangeriatrics.ca/wp-content/uploads/2017/02/Facilitating-Effective-End-of-Life-Communication---Helping-People-Decide.pdf> (accessed 2017 April 25).
- ¹⁴ *Fleming v Reid* (1991) 82 DLR (4th) 298 (CA ON); *Cuthbertson v Rasouli*, 2013 SCC 53; *Malette v Shulman* (1990), 72 OR (2d) 417; *Starson v Swayze* (2003) 1 SCR 722.
- ¹⁵ Harmon SHE. Consent and conflict in medico-legal decision-making at the end of life: a critical issue in the Canadian context. *University of New Brunswick Law Journal* 2010;60(1):208–29.
- ¹⁶ Canadian Medical Association. *Policy resolution GC13-69 – training in advance care planning*. Ottawa (ON): The Association; 2013. Available: policybase.cma.ca/dbtw-wpd/CMAPolicy/PublicB.htm (accessed 2016 May 26).
- ¹⁷ Touchie C, De Champlain A, Pugh D, et al. Supervising incoming first-year residents: faculty expectations versus residents' experiences. *Med Educ* 2014;48(9):921–9.
- ¹⁸ Canadian Medical Association. *Policy resolution GC14-19 – advance care plans*. Ottawa (ON): The Association; 2014. Available: policybase.cma.ca/dbtw-wpd/CMAPolicy/PublicB.htm (accessed 2016 May 26).
- ¹⁹ Canadian Medical Association. *BD14-05-163 Advance care directive functionality*. Ottawa (ON): The Association; 2014. Available: policybase.cma.ca/dbtw-wpd/CMAPolicy/PublicB.htm (accessed 2016 May 26).
- ²⁰ *Conversations matter*. Edmonton (AB): Alberta Health Services. Available: <http://goals.conversationsmatter.ca.s3-website-us-east-1.amazonaws.com/> (accessed 2017 May 19).
- ²¹ Health Care (Consent) and Care Facility (Admission) Act, RSBC 1996, c 181, s.3
- ²² Act respecting end-of-life care, S-32.0001. Government of Quebec. Available : <http://legisquebec.gouv.qc.ca/en/ShowDoc/cs/S-32.0001>
- ²³ An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying) S.C. 2016, c.3. Ottawa: Government of Canada; 2016. Available: <http://canlii.ca/t/52rs0> (accessed 2016 Oct 17)
- ²⁴ *Riebl v Hughes*, [1980] 2 SCR 880; *Hopp v Lepp*, [1980] 2 SCR 192.