



Complete Summary

GUIDELINE TITLE

Advance care planning with cancer patients: guideline recommendations.

BIBLIOGRAPHIC SOURCE(S)

Harle I, Johnston J, MacKay J, Mayer C, Russell S, Zwaal C. Advance care planning with cancer patients: guideline recommendations. Toronto (ON): Cancer Care Ontario (CCO); 2008 Jan 28. 37 p. (Evidence-based series; no. 19-1). [55 references]

GUIDELINE STATUS

This is the current release of the guideline.

The EVIDENCE-BASED SERIES report, initially the full original Guideline, over time will expand to contain new information emerging from their reviewing and updating activities.

Please visit the [Cancer Care Ontario Web site](#) for details on any new evidence that has emerged and implications to the guidelines.

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SCOPE

DISEASE/CONDITION(S)

Cancer

GUIDELINE CATEGORY

Counseling
Management

CLINICAL SPECIALTY

Oncology

INTENDED USERS

Advanced Practice Nurses
Nurses
Physician Assistants
Physicians

GUIDELINE OBJECTIVE(S)

To evaluate:

- If advance care planning (ACP) has an impact on cancer patient outcomes (e.g., meeting patient or substitute preferences or health care resource use)
- What the key elements of ACP are for cancer patients
- How ACP should be presented to cancer patients
- Who should be involved in ACP for cancer patients
- When ACP should be undertaken with cancer patients
- What the barriers are to engaging in, and following through on, ACP with cancer patients, and how those barriers can be overcome (e.g., educational or training programs or institutional organization)

TARGET POPULATION

Cancer patients are the relevant population; however, where no research on cancer patients is available, research on non-cancer patients with chronic or life-threatening illnesses has been considered.

INTERVENTIONS AND PRACTICES CONSIDERED

Advance care planning

MAJOR OUTCOMES CONSIDERED

- Meeting patient or substitute preferences
- Health care resource use

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Hand-searches of Published Literature (Secondary Sources)

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Literature Search Strategy

The literature search involved two strategies. A search of the following electronic databases was conducted using the relevant database subject headings and text words shown in Appendix B in the original guideline document: MEDLINE (1950 to May, week 4, 2007), EMBASE (1980 to week 21, 2007), PsycINFO (1967 to May, week 4, 2007), CINAHL (1982 to May, week 4, 2007), and the Cochrane Database of Systematic Reviews and Cochrane Central Register of Controlled Trials (Issue 2, 2007). The reference lists of relevant papers and recent reviews were searched for additional citations. In addition, internet searches for current guidelines, standards, policies, and position statement documents related to advance care planning (ACP), advance directives (ADs), living wills, or powers of attorney were conducted in January–February 2007. The websites searched are listed in Appendix C in the original guideline document.

Report Eligibility Criteria

The following were considered within the scope of ACP for the purposes of this review: the development or use of ADs or living wills and the designation of powers of attorney for personal care, proxies, or substitutes for treatment decision making.

Summary reports. Systematic reviews, practice guidelines, and meta-analyses were eligible if they were evidence-based and reported literature search details; included explicit recommendations or conclusions relating to the review questions on the use of ACP; and, for reviews or meta-analyses, were described as systematic or provided explicit literature selection criteria. Given the limited volume of evidence specific to cancer patients in the initial literature searches, research on non-cancer patients was also considered eligible. Consensus guidelines from international, national, provincial, and state organizations were considered if evidence was cited in support of their recommendations.

Standards or policy documents, or position statements from national or provincial professional associations, were also eligible for this review if they addressed ACP beyond simply advocating public and professional education around living wills and ADs or respect for patient autonomy through adherence to ADs.

Primary research. Eligible primary research included randomized controlled trials (RCTs) involving cancer patients in some aspect of ACP and with an outcome relative to the review questions. Where data were limited with cancer patients, trials involving patients with other chronic illness were considered, and where no randomized trials were available, other prospective comparative studies were considered.

Exclusion criteria. The following were not considered:

- Publications in a language other than English, because of limited translation resources
- Publications in the form of a letter, editorial, or commentary
- Reports specific to non-cancer patients with mental illness, since the issues for this population were considered of limited generalizability
- Practice guidelines published before 2001, since guidelines more than five years old are generally considered outdated and are removed from guideline indexing services
- Systematic reviews or meta-analyses published before 1996, since these would not include current literature and would provide little information to inform the current review

Where recent high-quality guidelines or systematic reviews were available, only subsequent primary research was considered.

NUMBER OF SOURCE DOCUMENTS

Four existing guidelines, five policy or position statements from health care organizations, 14 systematic reviews, and seven randomized trials were identified.

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Expert Consensus (Committee)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

METHODS USED TO ANALYZE THE EVIDENCE

Review of Published Meta-Analyses
Systematic Review with Evidence Tables

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

The interventions, outcomes, and measures used across studies were variable; therefore, data were not pooled across any of the randomized trials.

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

The Advance Care Planning Report Working Group used the evidence that was available from the published literature, the environmental scan, and their expert opinion, to reach consensus for the recommendations on the organization and delivery of advance care planning in Ontario.

Advance care planning (ACP) is a process that can support individual autonomy with respect to health care choices throughout the course of a life-threatening illness and at the end of life. Advance directives (ADs) or ACP documents are documents enabling capable individuals to plan for care in the case of their own incapacity. Hypothetical benefits of ACP reported in the literature include increased inclusion of patient preferences for health care, more informed decision making, decreased pain and suffering, reduced costs and use of life-sustaining treatments, and improved patient and family satisfaction with care. To date, the existing literature is often conflicting or inconclusive regarding the impact of ACP on health outcomes or resource use. Methodological flaws in study design and lack of homogeneity of study participants and interventions across studies make it difficult to measure the impact of ACP for people with cancer, their family, cancer care practitioners, or the cancer care system.

The majority of studies used the completion of an ACP document as the primary outcome for the study. What appears to be true is that interventions targeted to facilitate discussion about ACP and completion of an ACP document improves the willingness to document individual preferences. Engaging in dialogue with individuals experiencing cancer about their preferences for care is an important first step to improving the meaningfulness of care provided and decreases the costs of care. However, what also appears to be true is that the mere presence of an ACP document does not necessarily translate to those preferences being followed by the professional care team, particularly physicians, and the majority of dialogue for preferences is limited to the use or withholding of cardiopulmonary resuscitation.

When ACP was undertaken, participants overwhelmingly opted for decreased use of life-sustaining treatments, which means that incorporating preferences into plans of care has the potential to decrease costs of care significantly. However, in order for documented preferences to be followed, a multipronged approach is necessary. This approach must include patient and clinician education, systems to support dedicated time for clinicians to introduce and review ACP decisions with patients and their family, and organizational policies to remove the current barriers. The Panel felt that ACP can affect patient outcomes such as the completion of advance directives or powers of attorney for personal care, improvements in the adherence to patient's wishes, patient and substitute decision maker satisfaction, understanding, and comfort, and should be conducted with cancer patients routinely. More rigorous research is required to identify how to support clinicians and systems in the integration of patient preferences into the plan of care throughout the cancer journey.

A review of the literature demonstrated that the process of addressing ACP can vary depending on the setting and the patient's medical status, yet common elements were found in the various approaches. The patient should decide the level of family involvement in developing the ACP, and all relevant parties should be involved in the discussions and communication plan. It is important to be aware and considerate of patient diversity including cultural differences. The provider should review with the patient if there are existing ACP documents. The ACP discussion and documentation should reflect current treatment goals and planning, and the patient's values and preferences. The ACP may include the patient's wishes for specific events such as cardiopulmonary resuscitation, withholding or withdrawing nutrition or hydration and other therapies, and the

preferred location of death. The provider can inform the patient and substitute decision maker about the limitations of ACPs due to the medical uncertainty around the inability to plan for all possible situations. The provider should assess the patient's understanding of the ACP. It should be clearly documented in the ACP who the substitute or proxy decision maker(s) will be when the patient is no longer capable of making decisions for their health care. Although the Panel felt that the minimal elements in ACP should be existing plans, directives, and substitute decision makers documented in the health care record, other common elements found in the literature that were important to enhance the experience with ACP included: (1) education about ACP for patients and health care professionals, (2) providing assistance for patients to complete the necessary documents, and (3) providing support to substitute or proxy decision makers.

The literature focused mainly on the interventions that assisted in completing ACP and components involved in ACP. Most documents stated that discussions should be physician initiated, with multidisciplinary involvement. In addition, the literature focused on ACP being a process, not a single event, during the continuum of the patients' illness path, and the necessity of ensuring that the patient understand where they are any point in time along that path in order to have the opportunity for a re-evaluation of their wishes at the different stages. As well, most documents suggested a combination of tools -pamphlets with information, direct patient counselling, roles presentation, or working booklets- be included in ACP presentation. The Panel concurred with the literature on the presentation of ACP and, in addition, felt that clear explanations of the types of interventions that might or might not be appropriate at specific times, the events that might lead to the implementation of an ACP document, the patient's treatment, the potential patient-related options, and possible outcomes should be addressed in ACP.

The Panel used data from the literature and consensus to establish the range of people involved in ACP, although the literature is inconsistent and limited. Conclusions in the literature were that the patient is the best person to be involved in their own care decisions, if capable, and that substitute decision maker predictions of the patient's wishes were more accurate than physician decisions. Therefore, the Panel felt that, at the patient's discretion, the patient's family and substitute decision maker should be involved. Using the policy statements and expert opinion, the Panel concluded that multiple people should also be involved in ACP, including designated staff, trained facilitators, and an ethics committee member or an advisor for the health care provider, should the patient's preferences not be possible to meet.

The position statements of various agencies suggest that ACP take place before a crisis occurs and be routinely discussed, especially at times when the health status or life circumstances have changed. The Panel concurs with the statements and recommends that ACP take place when the patient requests a review of the ACP document. The Panel recognizes that ACP is an ongoing process depending on the status of the patient.

The Panel and literature identified many barriers to engaging in ACP and following the ACP, including patient barriers (cultural, religious), family barriers (cultural, religious), practitioner barriers (no belief in ACP, lack of time), other health care provider barriers, Institutional barriers, fixation on do not resuscitate (DNR), and

misconceptions about time involvement and efficiency. Although there was some literature on the barriers to ACP, there were only policy statements indicating that education of nursing staff might assist patients in ACP completion. The Panel felt that education on many fronts would be a way to overcome many of the barriers to ACP and created a list of recommended elements that should be involved in educating both patients and health care providers. As well, the panel felt that the ongoing evaluation of ACP programs is necessary to ensure the discussion and completion of documents and that the patient's wishes are met.

Several other factors and barriers can influence advanced care planning and should be taken into account:

- Currently many Canadians complete ACP documents without physician assistance, as part of estate planning and as part of a family decision-making process. Singer suggests that ACP in a broader social context requires an evaluation of the health care provider role.
- The "Personal Coach Program" may be a way of initiating a dialogue with underserved patient groups. This program was piloted by Princess Margaret Hospital to help meet the needs of patients facing significant financial and social barriers.
- Lynn suggests that patients complete a values questionnaire and share the information with their family or substitute decision maker. She states that, given the limitations of advance directives for anticipating all possible situations, this step can help the family understand the values driving the end-of-life decisions.
- The portability of documented ACP decisions is not clear. Some provinces do allow honouring of ACP documents from other jurisdictions. A number of provinces allow reciprocity to some extent (BC, SK, MN, ON, PEI, and in progress for Yukon) as long as the documents meet that province's requirements. Patients should check the legislation if they are planning a move or plan to be out of the province.
- The communication of ACP wishes to professionals at relevant times is an ongoing issue (1). Different strategies include electronic health records, colour-coded medical identification bracelets (although there is some suggestion of stigmatization in the U.S), a colour-coded transparent document holder in the home and in front of the institution medical record, and ACP document enquiry as part of hospital admission process, with a copy and visual reminder placed in the patient's chart.

There was much Panel discussion about legislative and legal issues. Since this area is constantly changing, the Panel decided that it should not be included in the report. However, the Panel also felt that patients and health care providers should be more familiar with the Ontario Healthcare Consent Act as it relates to the patient's wishes. The Panel also included some examples of living wills, advance directives, and ACP programs in Appendix E in the original guideline document.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

External Peer Review
Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Development and Internal Review

This evidence-based series (EBS) was developed by the Program in Evidence-based Care (PEBC) Advance Care Planning Report Working Group.

Report Approval Panel

Prior to the submission of the EBS draft report for external review, the report was reviewed and approved by the PEBC Report Approval Panel, which consists of two members, including an oncologist, with expertise in clinical and methodology issues.

External Review by Ontario Clinicians

Following the review and discussion of Section 1: Recommendations and Section 2: Evidentiary Base of this EBS and the review and approval of the report by the PEBC Report Approval Panel, the Advance Care Planning Report Working Group circulated Sections 1 and 2 to external review participants in Ontario for their review and feedback.

Methods

Feedback was obtained through a mailed survey of 118 external review participants in Ontario (including nurses, palliative care physicians, and administrators). The survey consisted of items evaluating the methods, results, and interpretive summary used to inform the draft recommendations and whether the draft recommendations should be approved as a guideline. Written comments were invited. The survey was mailed out on November 21, 2007. Follow-up reminders were sent at two weeks (post card) and four weeks (complete package mailed again). The Advance Care Planning Report Working Group reviewed the results of the survey.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

1. Advanced care planning (ACP) can affect patient outcomes such as the completion of advance directives (ADs) or powers of attorney for personal care, improvements in adherence to patient's wishes, and patient and

- substitute decision-maker satisfaction, understanding, and comfort and should be conducted with cancer patients routinely.
2. ACP is a dynamic process that includes a range of elements that may vary depending on centre resources and individual patient needs. At a minimum, ACP should include:
 - Existing plans
 - Patient wishes
 - Substitute decision makers
 - Documentation of these in the health care record
 3. ACP should be presented as a staged approach, with education as the first step, and a focus on identifying good overall care for the patient rather than a list of treatments to be administered or withheld. ACP should include:
 - Discussion of anticipated health care decisions, which should focus on decisions relevant to the patient's current health status and anticipate change as the patient's prognosis changes.
 - A clear explanation for the patient of the limits of ACPs and directives, including when they come into effect and situations in which they may not be implemented.
 - Assistance for the patient in the completion of documentation, if desired, and identification of a substitute decision maker.
 - Checking the patient's understanding of their decisions and of the ACP process at all stages of the planning procedure.
 - A clearly defined process to ensure that patient preferences, decisions, and/or values (expressed orally or in writing) are documented in the health care record, communicated across different health care sites, and acted on by health care providers.
 - ACP should involve multiple components (e.g., individual counselling, the use of written or taped material) and should be presented to a patient in an individualized and sensitive manner, taking into account the patient's needs, culture, current health status, and prognosis.
 4. A range of participants should be involved in ACP, including the following:
 - The patient, who is entitled to make their own care decisions as long as they are capable and regardless of previously documented plans or directives.
 - Designated regional cancer program staff who have been identified to act as ACP facilitators and coordinators and have received appropriate training in ACP programming and, if required, facilitation skills. The designated individual should have the ability to champion the ACP program and involve all members of the health care team in the ACP programming at some level.
 - The patient's family and substitute decision maker(s), at the discretion of the patient.
 - An ethics committee or advisor should be available for health care providers to consult with in situations where the patient's preferences cannot be met or family preferences differ.
 5. ACP should be initiated early in the disease process. ACP discussions should occur annually, unless more frequent discussions need to occur, at the patient's request or when the health status of the patient changes.
 6. Education on ACP may address a number of barriers to implementation; therefore, education should be available for all patients and providers working in the cancer system.
 - Education should encompass, but is not limited to, the following:
 - What is ACP

- Why consider ACP
 - Decisions based on values and preference
 - Hierarchy of decision maker under Provincial legislation, naming a substitute-decision maker
 - When ACP takes effect
 - How decisions will be made
 - Role of health care professionals
 - What happens if ACP not initiated
 - Need for ongoing communication
 - How to document and express wishes
 - ACP programs should include ongoing evaluation and improvement as part of a defined quality assurance process. Outcomes that should be considered include whether ACP is being discussed, with the patient's wishes documented, the completion of an advance directive, and adherence to the patient's wishes.
7. Health care providers should be more familiar with the Ontario Health Care Consent Act as it relates to patient's wishes.
 8. It is recommended that the Cancer Care Ontario (CCO) Palliative Care Program Committee look at developing implementation guidelines with a specific ACP model that includes an evaluation component.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

Limited high-quality evidence on the appropriate elements of advance care planning (ACP) was available; therefore, the recommendations in this guideline were developed mainly through the expert opinion and consensus of the Advance Care Planning Report Working Group (see Section 2, Appendix A in the original guideline document), informed by existing practice guidelines, policy or position statements from health care organizations, systematic reviews, and randomized trials.

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

- There is limited evidence from two systematic reviews and five randomized trials for an advance care planning (ACP) impact on patient outcomes, and current evidence from two systematic reviews and one randomized trial does not indicate a benefit for resource use.
- Evidence from four systematic reviews suggests that ACP programs involving provider-patient interaction are more effective than programs that simply provide educational material to patients.
- No trials have compared ACP presentation by different providers, although nurses and social workers have most frequently acted as ACP facilitators in the programs described here.

POTENTIAL HARMS

Not stated

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

- The potential impact of structured advance care planning (ACP) programming on health care system resources is unclear; however, start-up funding may be required to train designated ACP facilitators; provide education resources for staff, patients, and families; and develop an appropriate and effective quality improvement program.
- Care has been taken in the preparation of the information contained in this report. Nonetheless, any person seeking to apply or consult the report is expected to use independent medical judgment in the context of individual clinical circumstances or seek out the supervision of a qualified clinician. Cancer Care Ontario makes no representation or guarantees of any kind whatsoever regarding the report content or use or application and disclaims any responsibility for its application or use in any way.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

An implementation strategy was not provided.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

End of Life Care
Living with Illness

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

Harle I, Johnston J, MacKay J, Mayer C, Russell S, Zwaal C. Advance care planning with cancer patients: guideline recommendations. Toronto (ON): Cancer Care Ontario (CCO); 2008 Jan 28. 37 p. (Evidence-based series; no. 19-1). [55 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2008 Jan 28

GUIDELINE DEVELOPER(S)

Program in Evidence-based Care - State/Local Government Agency [Non-U.S.]

GUIDELINE DEVELOPER COMMENT

The Program in Evidence-based Care (PEBC) is a Province of Ontario initiative sponsored by Cancer Care Ontario and the Ontario Ministry of Health and Long-Term Care.

SOURCE(S) OF FUNDING

Cancer Care Ontario
Ontario Ministry of Health and Long-Term Care

GUIDELINE COMMITTEE

The Advance Care Planning Report Working Group

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FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

The authors were required to disclose potential conflicts of interest relating to the topic of this guideline. No potential conflicts were reported.

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GUIDELINE AVAILABILITY

Electronic copies: Available in Portable Document Format (PDF) from the [Cancer Care Ontario Web site](#).

AVAILABILITY OF COMPANION DOCUMENTS

The following are available:

- Advance care planning with cancer patients: guideline recommendations summary. Toronto (ON): Cancer Care Ontario (CCO), 2008 Jan. 4 p. (Practice guideline; no. 19-1). Electronic copies: Available in Portable Document Format (PDF) from the [Cancer Care Ontario Web site](#).
- Browman GP, Levine MN, Mohide EA, Hayward RSA, Pritchard KI, Gafni A, et al. The practice guidelines development cycle: a conceptual tool for practice guidelines development and implementation. J Clin Oncol 1995;13(2):502-12.

PATIENT RESOURCES

None available

NGC STATUS

This summary was completed by ECRI Institute on July 16, 2008. The information was verified by the guideline developer on August 20, 2008.

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