

Planning for the end of life

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Quality end-of-life care is recognised as a health-care issue that deserves more attention.^{1,2} People die in severe pain or with other uncontrolled symptoms;³ and two-thirds of health-care professionals feel that the treatments they offer are overly burdensome.⁴

Several important initiatives have been launched to improve end-of-life care. In the UK, Dame Cicely Saunders founded the modern hospice movement and St Christopher's Hospice/King's College London remains a model programme in palliative care; also the British Medical Association has issued a report on withholding and withdrawing medical treatment.⁵ In Canada, the Canadian Senate has updated its 1995 end-of-life care report *Of Life and Death*, and the University of Toronto's *Ian Anderson Program in End of Life Care* aims to train 10 000 physicians on issues surrounding death and dying, and help shape attitudes in health-care institutions, media, and legislatures. In the USA, the *Education for Physicians on End-of-life Care* project is designed to educate all US physicians on the essential clinical competencies required to provide quality end-of-life care, the Open Society Institute's project on death in the USA aims to improve the experience of dying and bereavement through initiatives in research and innovations in the provision of care, public education, professional education, and public policy, and the Robert Wood Johnson Foundation's *Last Acts* initiative is a national effort to raise awareness of the need to improve care of the dying and to share issues and ideas at the national, state, and local levels.

An important element of quality end-of-life care is advance care planning,⁶ a "process of communication among patients, their health-care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make decisions".⁷ Advance care planning may, and generally does, include written advance directive (AD) forms.

Empirical research shows that although patients and providers express positive attitudes towards ADs, they seldom complete such forms;⁸ research interventions have increased the use of AD forms, but only to modest levels.⁹ One large study to assess the effectiveness of ADs in the care of dying patients found that they had no impact on physician-patient communication, incidence, or timing of written do-not-resuscitate (DNR) orders. AD forms also had no physicians' knowledge of patients' preferences, the number of days spent in the intensive care unit receiving

mechanical ventilation or the number of days comatose before death, the level of reported pain, or the use of hospital resources.³ In a review¹⁰ of more than 100 research articles advance care planning and AD forms, Miles and colleagues concluded, "Advance treatment preferences have been shown to be difficult to form, communicate, and implement". The key question is why?

One answer may be that the traditional conceptual framework underlying advance care planning and use of AD forms is not rooted in the needs and experiences of patients. Traditionally, advance care planning was thought to help people prepare for treatment decisions in times of incapacity, to be based on the ethical principle of autonomy, and to focus on completing written AD forms within the context of the physician/patient relationship. However, from the perspective of patients, advance care planning also helps patients prepare for death, is influenced by personal relationships, is a social process, and occurs within the context of family and loved ones.¹¹ Thus, the process of advance care planning and outcome measures used in previous research may not have been the ones of greatest importance to patients and their loved ones.

Accepting the need for revised, patient-centered concepts of advance care planning, this paper aims to address five key questions from within this revised framework about advance care planning and AD forms: what should be the goal of advance care planning? what should be the role of the AD form? which AD form is best for the patient? who should be involved in advance care planning? and how should advance care planning be assessed? Although, this paper is intended primarily for physicians, the content may also be relevant for patients, families, lawyers, bioethicists, and hospital ethics committees.

What should be the goal of advance care planning?

The original goal of the movement for advance care planning—from the perspective of ethicists and legal scholars—was to assist patients to make treatment decisions for the event of incapacity. However, from the patient's perspective, the primary goal of advance care planning is more commonly preparing for death and dying.¹² People struggle to find ways to cope with death.² Once a central ritual of social and religious life, death has been privatised, desacralised, hidden behind institutional walls, and implicitly made taboo. Advance care planning can help people to prepare for death which, from the patient's perspective, tends to mean helping them achieve a sense of control, relieving burdens on loved ones, and strengthening or reaching closure in relationships with loved ones.¹²

Sense of control

Autonomy is central to advance care planning, but not primarily in the sense of controlling each treatment decision, as has generally been assumed. Bereaved family

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members feel that improved communication would improve end-of-life care, but that focusing on specific treatment decisions avoids considerations of death, and “may not satisfy the real needs of dying patients and their families”.¹³ Achieving an overall sense of control in the dying experience is an important psychosocial outcome. Advance care planning can help people achieve a sense of control by thinking beyond an itemised list of concrete objectives to map a personal approach to dying by considering the values and goals that should guide their dying.

Relieving the burden

People who are dying want to attend to the needs of their loved ones.^{11,12} But because the epidemiology of dying has shifted from sudden death caused by communicable disease to slow deterioration, patients fear that loved ones may bear the burdens of a protracted terminal illness. Advance care planning allows people to determine settings for care and limits for life-sustaining treatments which may inappropriately lengthen dying, and facilitates reflective discussion of values, goals, and preferences with loved ones in a non-crisis environment. This may help loved ones who bear the burdens of anxiety and physical care through a protracted dying process. Advance care planning may also help prepare those who serve as substitute decision makers in a crisis, and mitigate the guilt felt by loved ones who must make difficult substitute decisions with respect to life-sustaining treatment. Advance care planning can help the health-care team to be prepared for the patient’s death.

Strengthening relationships

Current approaches in bioethics may underestimate the importance of social and family ties. Facing death in the context of loved ones may be an important redeeming accomplishment. People live in a web of social ties and generally fear dying in isolation. Advance care planning facilitates communication about death and thus provides an opportunity to strengthen relationships with loved ones. Advance care planning may help people to settle their differences with loved ones, including giving or seeking forgiveness for past disagreements. Reflecting on life and the meaning of death, and sharing those reflections with loved ones may also help to strengthen personal relationships.

Goals are shaped by culture

End-of-life decision making is influenced by culturally shaped values. The principle of autonomy is the dominant ethic of health care in North America and Western Europe. Yet for many other people, autonomy may not be the dominant value. For example, a study of attitudes toward end-of-life decision making among people of Chinese origin found that they were indifferent or negatively disposed to advance care planning. These people reflected a world view that values interdependence, compassion, and protection, by contrast with independence and autonomy. Thus, to be consistent with a patient-centred approach, health-care professionals should discuss patient’s goals about end-of-life decision making.

What should be the role of the AD form?

Advance care planning has commonly been conceptualised as an event, specifically making a set of decision, and AD forms were developed to document these decisions. However, an AD form is not the central or defining feature of advance care planning. Advance care planning is a process of communication, and AD forms are best viewed

AD forms and their categories

AD forms	Categories
California durable power of attorney for health care (www.llorente.com/law/dpahc.htm)	Instruction and proxy; not detailed; generic
New Jersey’s advance directives for health care: planning ahead for important health care decisions	Instruction and proxy; not detailed; generic
Ontario power of attorney for personal care	Instruction and proxy; not detailed; generic
The medical directive (www.medicaldirective.org)	Instruction and proxy; detailed; values, goals, and preferences; generic
The values history (www.euthanasia.org/vh.html)	Instructions and proxy; detailed; values; generic
Five wishes (www.agingwithdignity.org)	Instructions and proxy; detailed; values and preferences; generic
Your life, your choices	Instructions and proxy; detailed; values and preferences; generic
The University of Toronto Joint Centre for Bioethics HIV living will (www.utoronto.ca/jcb)	Instructions and proxy; detailed; preferences; disease specific

as an assisting device embedded in the advance care planning process.^{8,11,12} In an intervention designed to increase completion of AD forms among outpatients, 38% of the experimental group completed an AD form, however, 73% reported having discussions about ADs.⁹ Accuracy of substituted judgments was positively associated with the patient having spoken with the surrogate about end-of-life issues.¹⁴ Many people consider themselves satisfied with their advance care planning without completion of an AD form. They use advance care planning to prepare for dying, and are generally satisfied that advance-care-planning discussions achieve that goal.¹¹

AD forms can facilitate advance care planning as educational tools or worksheets that give structure and clarity to discussions and guidance on how many people think most helpfully about issues concerning death, illness, and end-of-life care. AD forms may help people to articulate their values, goals, and preferences, and can provide a framework to facilitate discussions with others. Thus an AD form is far more than a legal document that merely records an individual’s proxy choice and treatment preferences.

To proceed with advance care planning, individuals should choose an AD form that meets their needs and then work through the AD form, using it as an aid to discussion about their dying and end-of-life care. The focus of these discussions should be on achieving a sense of control, relieving burdens on loved ones, and strengthening relationships. If questions arise about prognosis or treatment, they can be addressed by a physician or other health-care professionals. Finally, the AD form can serve as a vehicle for documenting preferences that will help when substitute decision makers are unsure.

Which AD form is best for the patient?

Numerous AD forms have been developed by organisations, governments, and academics. Many of the forms we refer to in this paper may be accessed full-text on the internet (panel). Each form is different in important ways, but currently no detailed taxonomy of ADs exists. This taxonomy will be developed through the examination of four questions that a physician or other involved party might ask about them. Should it be an instruction or proxy

directive? Should it be a detailed or non-detailed directive? Should it focus on values, goals, or preferences? Should it be a generic or disease-specific directive? The panel shows examples of current forms that use categories based on these questions.

Contrary to a common misperception that only forms published by government are legally valid, any AD that complies with prescriptions mandated by legislation (eg, requirements for signing, witnessing, and dating, or simply providing an authentic representation of the patient's wishes) can be legally authoritative.

Should it be an instruction or proxy directive?

Instruction directives (also called living wills) describe what type of care a person would or would not want in various situations. Proxy directives (sometimes called durable powers of attorney for health care) indicate who a person would want to make treatment decisions on his or her behalf. Thus, these two types of directives are designed to accomplish different, important, and complementary objectives. In Canada and the USA, jurisdictions have, or are writing, comprehensive statutes covering both instruction and proxy directives. The UK government has introduced legislation to allow adults to appoint substitute decision makers, but has no legislation regarding AD forms. Many health-care institutions have policies regarding the use of ADs.

We recommend that ADs contain both instruction and proxy directives. These are rare exceptions to this recommendation. Some people have no eligible proxy, or desire no proxy, and should complete only the instruction directive. Some cannot handle the cognitive leap of future scenarios even though competent, and should complete only the proxy directive.

Should it be a detailed or non-detailed directive?

Detailed instruction directives systematically lead people through a process that helps them think about the form and articulate values, goals, and preferences relevant to health-care decisions. Most function as a worksheet and then a form for documentation. Non-detailed instruction directives instead provide limited space, usually a few lines, in which people may write instructions. General instructions noted on a non-detailed directive are generally inconsistent with specific treatment preferences.¹⁵ Moreover, compared with a detailed AD, a non-detailed AD results in less uniform interpretation by physicians.¹⁶

Detailed instruction directives are similar to questionnaires and therefore it is important to assess their psychometric properties such as reliability and validity. Some, but not all, have been assessed for reliability and validity. We recommend that AD forms are assessed.

We recommend detailed instruction directives because they provide a systematic process that helps people understand and articulate their values, goals, and preferences, and helps physicians implement them. Whenever possible, these forms should be validated.

Should it focus on values, goals, or preferences

There are three major approaches to the design of detailed directives—values, goals, and preferences. These approaches are generally combined in practice. There are two distinct examples of values-oriented AD forms, both called the values history. One offers a series of statements about personal values with which an individual may choose to agree or not, and a series of statements regarding medical care which an individual may select or reject.¹⁷ The other poses a series of questions about values related to health care that are to be answered in an open-ended

narrative format.¹⁸ Preference-oriented instruction directives can be illustrated by the middle section of the *Medical Directive*. This provides descriptions of health states and treatments, a grid where individuals can indicate their preferences for treatments in specific health states, and a blank section for open-ended comments. The *Medical Directive* also elicits goals for care in this section depending on the specified health state. In addition, some AD forms elicit preferences regarding “states worse than death”.¹⁹

Values-based instruction directives can help clarify values that underly health-care preferences and address the concern that one cannot anticipate all situations that may be encountered. Values-based AD forms can thus assist proxy decision makers who must make specific decisions in situation that were not anticipated. However, studies show poor correlation between statements of values and specific preferences.²⁰

Similarly, goals based instruction directives can help individuals to articulate goals regarding their health and health care (for example, “treat everything” or “comfort”), which may help resolve problems regarding more concrete decisions. Goal choices have a logical relationship to treatment choices in specific situations. Goals may provide a bridge between general values and specific wishes and may be helpful to patients and families as they make their decisions.

Preference-based instruction directives provide the proxy with specific guidance in specific situations. They can account for most but not all situations of incapacity (eg, current health with a sudden, potentially reversible illness; mild, moderate, and severe stroke; mild, moderate, and severe dementia; terminal illness; and permanent coma). Given an opportunity to express preferences over a range of health states and treatment options, people are greatly influenced by health states and illness severity.^{8,21,22} In a study of dialysis patients, about 90% of people wanted life-sustaining treatment in their current health state, but only about 10% in permanent coma. 80% wanted treatment in mild dementia, 60% in moderate dementia, and 20% in severe dementia. By contrast, there was little variation in preferences (10–20% across treatments).²² Extrapolation from one preference to another can be strongly predictive within a scenario and quite predictive between scenarios.¹⁷

We recommend a combination of values, goals, and preference-based approaches. For situations of incapacity that can be anticipated, specific preferences can relieve a proxy of the burden of decision making in specific particular circumstances. However, to account for those situations that cannot be anticipated, the AD form should also contain values or goals. Moreover, goals and values can give coherence and meaning to specific treatment preferences. These types of information are complementary, and by asking a person to think systematically about values, goals, and preferences, the AD form can help the person develop and articulate both flexible and specific derivatives.

Should it be a generic or disease-specific directive?

Generic, preference-oriented, detailed instruction directives offer choices covering a number of treatment options and a range of potential health states, and are intended for anyone. Disease-specific, preference-oriented, detailed instruction directives offer patients a narrower range of choices that are more likely to be encountered by people who have a particular disease.²³

Generic AD forms help an individual prepare for events that are possible for anyone—eg, anyone may be hit by a

motor car and end up in a coma, and many people face chronic disability and some degree of dementia. Generic forms can be useful in laying the groundwork for personal comfort with mortality and for a quality therapeutic relationship in which value-guided decisions can be made by the patient and care team on a wide range of scenarios. They may also be of use for patients with specific diagnoses where the dying context may not be predictable, the likely scenarios are covered in the generic form, or disease-specific forms do not exist.

Disease-specific AD forms have three advantages. First, people completing a disease-specific form need only consider primarily decisions they are likely to confront. Second, the people completing a disease-specific AD form are more homogeneous therefore, more specific prognostic information can be presented. Third, because an individual already has experience with their illness, the choices in a disease-specific form are less hypothetical. In studies, 77% of people living with HIV and 64% of cancer patients preferred an HIV-specific and cancer-specific forms, respectively, saying it was more relevant to their situation than in similarly designed but generic AD forms.²³

In practice, the disease-specific concept can be superimposed on generic ADs and advance-care-planning discussions. Patient-specific scenarios can be added to generic forms, and some leave space specifically for this purpose. Physicians and others should not limit their discussions with patients who have foreseeable problems to only the standardised scenarios from pre-printed AD forms. For instance, if a patient has chronic obstructive pulmonary disease, the main intervention and scenario she needs to consider is intubation and ventilation with the physician's estimated chances for successful weaning.

We recommend a disease-specific AD form, or the addition of specific situations to a generic form, for people who have a disease that follows a predictable course and for which specific treatment options can be anticipated. We recommend a generic AD form for people who have a disease for which the potential treatment options cannot be predicted, for healthy people who may become incapable through accidents or other unpredictable events, and for those for whom a validated disease-specific form is not available. In the last case, we recommend that the physician consider one or more likely scenarios for that patient and add these to the generic form.

Who should be involved in advance care planning?

Advance care planning has commonly been considered within the context of the patient/physician relationship. However, advance care planning is also, and in a sense primarily, a process of communication between people and their loved ones. Studies show that patients are much more likely to have advance-care-planning discussions with loved ones than with their physician.^{11,24} In one study,¹¹ the main reason people reported for not completing written AD forms was because their family already knew their wishes.

However, patients do not always understand the medical implications of their documented preferences and physicians have an important role in fostering understanding and implementing care.²⁵ In some specific situations, preferences may be difficult for health-care providers or proxies to interpret, especially if they were not part of the advance-care-planning discussions at all.⁸ Therefore, it is helpful for clinicians to answer questions, clarify issues, review completed AD forms, and ensure that their patients have understood the relevant medical information. Unfortunately, many patients consider their physician to be too busy for lengthy discussions about end-

of-life issues; other patients consider these issues as private.¹¹ Physician-identified barriers to communication also exist, including discomfort talking about death and dying, lack of knowledge, difficulty determining appropriateness, and time constraints.²⁶ Open, unhurried, and warm communication—initiated by a trusted physician who is able to speak comfortably and competently—may help overcome barriers and facilitate communication. However, AD forms are generally intended to “speak” primarily to the substitute decision maker, and some AD forms have not enhanced patient-physician communication.²⁷ Although some physicians do accomplish the goal of introducing patients to ADs, they infrequently deal with all the components of advance care planning, in particular they infrequently deal with the patient's values.²⁸

The physician's role in advance care planning should be supportive and sufficiently participatory that preferences can be well understood and translated into clinical care. Physicians may raise issues, direct patients and families to appropriate resources, provide information about diagnoses and treatments tailored to their patients' individual health situations, address information needs as they arise, to help ensure that the proxy is involved in the process, and review the results of the process. Advance care planning is just like most quality clinical encounters in medicine; the physician has a key but not an all-encompassing role. The key participants are patients and their loved ones (including their proxy decision maker).

How should advance care planning be assessed?

Advance care planning should be assessed against its patient-centred goals. Current findings indicate that these should include: how successfully patients and loved ones prepare for the patient's death, including helping patients achieve a sense of control, relieve burdens on loved ones and strengthen relationships with loved ones. These psychosocial outcomes cannot be adequately measured without asking patients and their loved ones about their experiences.^{29,30}

Advance care planning should not be assessed primarily or simply by the number of AD forms completed or improvements in clinical measurements such as length of stay, health-care costs, or use of life-sustaining treatments.³ AD form completion is the wrong end point because patients do not usually consider the forms either necessary or sufficient. Length of stay, cost, and uptake rates alone do not measure patients' goals with respect to advance care planning. Lastly, advance care planning is related to subsequent treatment decisions, and data suggesting that patient wishes are not always followed signal an important area for further research and improvement. However, advance care planning cannot completely ensure that patients' wishes are ultimately honoured, nor is that its goal, and therefore it should not be assessed by this outcome. Focusing on whether a patient's wishes are followed in specific treatment decisions sidesteps and may detract from important psychosocial needs of patients or families.

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