

Advance Care Directives (NSW) - Using

Document Number GL2005_056

Publication date 22-Mar-2005

Functional Sub group Clinical/ Patient Services - Aged Care
Clinical/ Patient Services - Medical Treatment
Clinical/ Patient Services - Nursing and Midwifery
Clinical/ Patient Services - Nursing homes

Summary There is a growing expectation that one's wishes for medical care at the end of life will be respected even if progressive disease takes away decision-making capacity. There is also a need for improved mechanisms whereby an incompetent person's prior wishes about end of life care can be known and considered at the time that treatment decisions need to be made. This guide aims to assist health professionals in discussing advance care planning with patients, and to clarify how to use an advance care directive as part of that process.

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Applies to Area Health Services/Chief Executive Governed Statutory Health Corporation, Board Governed Statutory Health Corporations, Affiliated Health Organisations, Affiliated Health Organisations - Declared, Divisions of General Practice, NSW Ambulance Service, Private Hospitals and Day Procedure Centres, Public Hospitals

Distributed to Public Health System, Ministry of Health

Review date 30-Nov-2012

Policy Manual Patient Matters

File No. 03/76-2

Previous reference N/A

Status Active

Using Advance Care Directives

New South Wales



Acknowledgements

The NSW Department of Health wishes to acknowledge the contributions of the members of the Advance Care Directive Working Party.

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SHPN (HEB) 040109
ISBN 0 7347 3675 4

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June 2004

Purpose

To provide advice to health professionals on the best practice use of advance care directives within an advance care planning process.

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Introduction

Advance care planning refers to the process of preparing for likely scenarios near the end of life and usually includes assessment of, and dialogue about, a person's understanding of their medical history and condition, values, preferences, and personal and family resources. An advance care directive (ACD), sometimes called a 'living will', is a document that describes one's future preferences for medical treatment in anticipation of a time when one is unable to express those preferences because of illness or injury. Completion of an ACD ideally should be one component of the broader advance care planning process. This document was guided by a literature search conducted in March 2003 (see *Search strategy*).

1 Why is advance care planning important?

Improving advance care planning for end of life care is likely to become an increasingly important quality of care issue. There is a growing societal expectation that one's wishes for medical treatment will be respected at the end of life if progressive disease has taken away decision-making capacity. At the same time there is a need for improved mechanisms whereby an incompetent person's prior wishes about end of life care can be known and considered at the time that critical treatment decisions need to be made. This is likely to become even more urgent in the next decade as a large predicted increase in the number of people with dementia and cognitive disability results in greater numbers with loss of capacity to determine their own medical treatment.

In addition, there appears to be significant variation in the ways that health care professionals currently approach situations where the use of life-sustaining treatment is being considered. There are concerns that such treatments are being used in terminally ill patients resulting in over-zealous treatment or, less frequently, inappropriate under-treatment. Advance care planning may allow for use of life-sustaining treatments in ways that are more consistent with the individual's choice and priorities at the end of life.

Although family or others close to the person who becomes incompetent usually become involved in making treatment decisions, they are often not able to easily judge the person's wishes without prior discussions taking place with that person. Families and others often shoulder significant burdens in such situations. Reflective discussion in a non-crisis situation can prepare all involved and may diminish any guilt or concerns over later decisions to limit treatment.

Aims of advance care planning

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Effective and thorough advance care planning aims to achieve the following:

- 1 Encouraging conversation about what are the most important things for someone as they approach death, and specifically the place of life-sustaining treatment in relation to that.
- 2 Achieving a sense of control for the person as their death approaches, and a means of mapping a personal approach to their care during the terminal phase by explicitly considering the person's values and goals. It is nonetheless important not to focus solely on medical treatment preferences as this may result in avoiding thinking about the person's goals, values, priorities and expectations during the final phase of their life.
- 3 Engaging others in decision-making according to the person's wishes. An ACD can be a private, individual process, and does not have to involve family members or close friends. However, evidence suggests that many people would like selected members of their family or friends to be involved, in which case the ACD is not only an instruction to health care workers but also a document guiding family and friends who may be called upon to help make decisions. The process of advance care planning may provide opportunity for talking about dying wishes, settling interpersonal differences, may prevent later conflict over substitute decisions about treatment, and improve communication amongst family members. The autonomy of the patient is enhanced whether the locus of control is with the individual alone, or the individual plus their family.
- 4 Providing flexibility in how treatment decisions are made. Advance care planning is a continuum of treatment choices that may be reviewed as the person's condition, and possibly preferences, change. The person may defer at any time to family or others close to them to decide on their behalf. In some cultural groups, such as some Aboriginal or Torres Strait Islander communities, the latter is the preferred way of making decisions about care during the dying phase.

Advance care planning and the use of advance care directives are always optional and some individuals will prefer not to make decisions for the future, but rather make decisions about their medical treatment at the time the need arises.

3 Barriers to advance care planning

A number of barriers or impediments to effective advance care planning may exist in the health care sector and wider community. These include:

- 1 Time constraints – advance care planning is perceived as onerous with necessarily lengthy discussions with patients and their families.
- 2 Discomfort in talking about death on the part of the patient, family, or health professionals.
- 3 Patient perceptions about who should or does control medical decision-making. Where people prefer their doctors to lead decision-making, they may be less inclined or willing to engage in this process.
- 4 Fears about being unable to change one's mind once treatment preferences are documented.
- 5 Patients and families may not know about the availability of advance care directives, or the medical implications of their documented preferences.
- 6 Health professionals may not appreciate the legal standing of advance directives, or the legal implications of acting on treatment limitation decisions generally.

How an advanced care directive (ACD) functions as one component within the process 4

Advance care planning may or may not involve the completion of an ACD. Where an ACD is used the following comments are applicable:

- 1 *Different contexts* – An ACD may be made in a wide variety of circumstances. These may include the person who is healthy but wants to plan their future medical care, the chronically ill person who anticipates deterioration in their condition, or someone who is terminally ill and faces more immediate treatment choices.
- 2 *Authority* – An advance care directive that complies with the requirements set out in this document is legally binding in NSW, and functions as an extension of the common law right to determine one's own medical treatment. A failure to comply with such an advance care directive refusing a particular treatment may result in the health professional incurring criminal or civil liability for providing that treatment. See 5.3 and 5.4 for discussion of documentation standards for ACDs.
- 3 *A tool for discussion* – Although the ACD has legal authority, its use in practice should be thought of as an assisting device: an education tool, a 'worksheet', a framework for discussion, or a way of documenting preferences when substitute decision-makers may later be unsure or disagree. Its completion is not the only goal, and effective advance care planning does not necessarily require the completion of a directive. The person may instead choose to verbally communicate specific wishes to the doctor and family, or formally appoint a substitute decision-maker (enduring guardian) to make treatment decisions on their behalf in the event of their incompetence.
- 4 *Scope* – An ACD can usefully document:
 - Medical treatment preferences, including those influenced by religious or other values and beliefs.
 - Particular conditions or states that the person would find unacceptable should these be the likely result of applying life-sustaining treatment, for example severe brain injury with no capacity to communicate or self-care.
 - How far treatment should go when the patient's condition is 'terminal', 'incurable' or 'irreversible' (depending on terminology used in specific forms).
 - The wishes of someone without relatives to act as their 'person responsible' in the event they became incompetent, or where there is no-one that person would want to make such decisions on their behalf.
 - A nominated substitute decision-maker that the treating clinician may seek out to discuss treatment decisions.
 - Other non-medical aspects of care that are important to the person during their dying phase.
 - Although the content of an ACD usually stipulates treatment *limitation* preferences, this should never be assumed as some individuals may indicate they want full measures to prolong their life.
- 5 *Enduring guardianship and ACDs* – Two main elements to advance care planning are recognised: the written directive and the appointment of a substitute decision-maker. In NSW, the *Guardianship Act* provides for a person to make their wishes known about medical treatment through appointment of an 'enduring guardian' who acts as their substitute decision-maker. A person may choose to prepare written instructions as to their future care in the enduring guardianship appointment document. Where a person has made both a separate ACD and appointed an enduring guardian, an examination of both documents is required. See 6.6 and 6.7 for further discussion.

5 Best practice recommendations

5.1 Starting the discussion process

- A key factor in effective advance care planning is starting up and continuing discussions about what the person finds important at the end of life. These wishes usually focus on medical treatment preferences but may also include other matters, such as spiritual or interpersonal issues. The patient, their family and health professionals should expect *ongoing* consultation in order to allow the person to make their choices known over time as death approaches.
- Suggest that the person involve family members, such as the ‘person responsible’ or others close to them, so as to minimise the decision-making burden and thoroughly understand their wishes. The question is ‘How can you guide those closest to you to make the best decisions for you if you are no longer able to do so yourself?’ The family’s role may initially involve only listening, taking notes or asking questions for clarification. The person should at least inform them of their wishes and the existence of an advance directive (where one exists). It is likely that the family will be involved in some way in the decision-making process if the person becomes incompetent, whether they have an ACD or not.
- Some people will not have an eligible substitute decision-maker or ‘person responsible’ (see Glossary), or may prefer that no-one makes particular medical decisions on their behalf. Encouraging the person to consider making a more detailed directive in these circumstances may be appropriate.
- Where a health professional conducts discussions about end of life care, it is best if they are someone who is identified as significantly involved in active care of the person and can discuss prognostic information in clear terms. It is recognised that pastoral care workers or clergy also frequently conduct these discussions but, in order for it to be useful, such information needs to be communicated to the treatment team; therefore a multidisciplinary approach to advance care planning is recommended.
- Many individuals welcome the opportunity to discuss end of life care in advance, when raised by doctors or other health professionals. Some people will raise these issues themselves, but many will usually expect health professionals to initiate these discussions. Not all, however, will choose to complete an ACD.
- Opportunities for opening these discussions may include when the person or their family enquires about whether palliative care is appropriate, when a person has recently been hospitalised for severe progressive illness or with repeat recent admissions, when a person says they want to forego recommended life-sustaining treatment, or when they express a wish to die.
- Advance care planning is most easily accomplished during stable health or after adjustment to a new illness has occurred. A non-threatening environment like an outpatient or GP’s clinic may be preferable.
- Begin by enquiring how familiar the person is with advance care planning and explain the goals: that is, to plan for the potential loss of their capacity to make decisions, either temporarily or permanently, and to ensure they are protected from either unwanted or under-treatment.
- An understanding of the person’s goals and values may be elicited through asking about past experiences with illness, either their own or others, describing possible scenarios, or potentially by asking them if they would like to write down in a letter how such scenarios should be handled. Such a letter may be a tool for developing a formal ACD, if the person subsequently chooses to prepare one.
- The person usually needs information to understand the meaning of the types of clinical scenarios that may arise in their situation, and the benefits and burdens of various treatment options. Key medical terms should be explained in words they can understand. Time for reflection and discussion is usually needed after this information has been given.

5.2 Multicultural perspective

Different cultural groups in NSW may have different perceptions of how end of life decisions are to be made, and by whom. Different views of autonomy and how this is to be respected exist, and any advance care planning process should be sensitive to this.

5.3 Documentation standards

The following should be satisfied before an ACD is considered to have sufficient authority to act on:

- *Specificity* – It must be clear that an advance directive applies to the clinical circumstances arising. This can include treatment preferences in relation to both conditions existing at the time the ACD is made, as well as future anticipated conditions (including catastrophic injury). The advance care directive should be clear and specific enough to guide clinical care. The specificity of the ACD may be improved if the person discusses it with their doctor.
- *Currency* – An advance care directive prepared a long time before it is referred to may not reflect the current intentions of the patient. Nonetheless, if the person was competent at the time the ACD was made then it should still be treated as legally binding. People should be encouraged to review their directives periodically, for example once a year, after an illness, or with a change in health as treatment preferences may change accordingly.
- *Competence* – The person must have been competent to make their own health care decisions when the advance directive was drafted. A person should be considered competent to make a health care decision if they appear able to comprehend, retain, and weigh up the relevant information and then make a choice. Some situations may pose particular difficulties in assessing competence to make an ACD, such as early dementia or intermittent mental health problems. A second opinion from a suitably qualified health professional is advisable.
- *Witnessing* – It is not essential to have an ACD witnessed. However, there are a number of reasons to encourage a person to do this. It may allow for later follow-up if doubts are raised about the person's competence at the time of drafting.

It offers some protection against forgery. It may also allay concerns about undue influence in the expressed treatment choices. If an ACD is completed in conjunction with the appointment of an enduring guardian, then the witness may only be a solicitor, barrister or registrar of the Local Court. If a 'stand alone' ACD is prepared, the person may select whom they wish to witness the document.

See also 6: *Questions about interpreting and acting on advance care directive instructions* for further information on legality of advance care directives in NSW.

5.4 Ways of documenting an ACD

Someone wanting to prepare an ACD may or may not choose to initially discuss this with a health or legal professional, although such discussion is encouraged (see 5.1 and 5.6).

A person may simply write their wishes down, as if writing a letter and with no 'form' used.

Alternatively, and more commonly, a specifically designed form is used. Several forms are available in NSW from a number of organisations but forms obtained from other states or overseas may also be used. As there is no legislation in NSW pertaining to ACDs, there is no mandated form. The NSW Department of Health does not endorse the use of one particular form over another but does endorse forms that satisfy the recommendations in Parts 5.1 and 5.3 of this document.

There is no requirement to lodge the form with any agency or office in NSW. There is also currently no register of people who have appointed an enduring guardian.

Advance care directives are designed in different ways. One size does not fit all and different forms are more or less appropriate in different contexts. For example they may contain:

- *Statement of general values* (a 'values history' – this will often ask the person to rank certain states as 'worse than death'). The values expressed can be referred to, and inform later treatment decisions made by substitute decision-makers.

Best practice recommendations

This approach may be good for situations that were not anticipated – perhaps if the person was healthy when they prepared the ACD.

- *Statement of goals* – may provide a bridge between general values and specific wishes (eg comfort measures only).
- *Statement of specific treatment preferences* relevant to an existing illness (eg use of invasive or non-invasive ventilation techniques in a patient with chronic respiratory failure).

Often these approaches are combined within one form.

5.5 Role of health professionals

A person is not required to involve a health professional in preparing an ACD. There are however a number of advantages in having a doctor or other health professional involved with the person in preparing an ACD. These include:

- Raising the issue of end of life care options at the outset.
- Providing information about prognosis or treatments that may specifically relate to the person's condition.
- Clarifying terminology.
- Encouraging the person to involve other appropriate substitute decision-maker/s in discussions about treatment preferences.
- Witnessing the ACD as a means of vouching for the person's competence at the time of discussion/writing.

5.6 More information

More information about ACDs and/or forms can be obtained from the following organisations:

- 1 Advance Care Directive Association
 - Print an order form from the Benevolent Society's website at www.bensoc.org.au/ageing/myhealth_acda.html
 - Write to the Advance Care Directive Association Inc. at 18/113 Johnston Street, Annandale NSW 2038, asking for a form
 - Leave a message with your name and address on 0423 157 003.
- 2 Department of Disability, Health and Aged Care 'Planning Ahead Kit'
 - www.dadhc.nsw.gov.au/dadhc/Publications+and+policies
 - Tel. (02) 8270 2000
- 3 Law Consumers Association
 - www.lawconsumers.org/contactus.asp
 - Tel. 1300 668 001
- 4 Guardianship Tribunal
 - www.gt.nsw.gov.au/
- 5 Voluntary Euthanasia Society
 - www.vesv.org.au/
 - www.saves.asn.au/

Questions about interpreting and acting on advance care directive instructions

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1. Can a person use an ACD to instruct a doctor or other health professional to help them die?

No. An ACD may not contain instructions for illegal activities, such as euthanasia or assisted suicide.

2. What are the legal implications of acting contrary to an advance directive?

A failure to comply with an advance care directive that meets the standards discussed in this document and refuses treatment may be considered an assault and battery under common law. Civil liability may also ensue.

3. Who else should be consulted if there are concerns about the details or the legality of an ACD?

Where concerns about legality or applicability arise in an emergency, then the medical practitioner can treat the person in accordance with the person's perceived best interests, regardless of what is said in an advance care directive. Legal advice should be sought as a matter of urgency so that timely treatment decisions can subsequently be made.

Where there is more time to resolve concerns and the person is not competent, the family or those close to the person should be consulted to see if those concerns could be resolved. For example, if an ACD was made some years ago and there are concerns about its currency, those close to the person may be able to confirm that the person's wishes remained the same. When there are concerns about the person's competence at the time of making the ACD, those close to the person may be able to provide information on this issue.

4. What should be done if undue influence on the person preparing the ACD is suspected?

A directive must be free from the 'undue' influence of others. The person must not have been forced or pressured by others to such an extent that they could not exercise free choice when the ACD was made. Factors to consider are the person's level of maturity, the effect of their condition, the influence of treatment and the relationship between the persuader(s) and the person. If it is suspected that a person was unduly influenced into making an ACD and they are now incompetent, the health professional should seek legal advice and, in the interim, make treatment choices consistent with what is perceived to be in the patient's best interests.

5. What should be done when the prior documented wishes of the patient conflict with those of substitute decision-makers?

If the person's prior expressed wishes regarding treatment or its limitation are known, and the documentary evidence is authoritative, then these wishes take priority over those of the family. Disagreement by the family or other legitimate substitute decision-maker with the person's prior wishes is usually resolved by further discussion and the provision of ancillary support through social workers, pastoral care workers or others aimed at the family's acceptance of the person's wishes.

While some cultural groups believe that the locus of control appropriately lies with collective or family decisions when a person is dying, there may be wide variation in beliefs within a population and the dying person may not adhere to the dominant cultural norm. The overriding legal and ethical responsibility of the health care professional is to the patient and thus to his or her desire for direct communication and information. Family involvement in treatment discussions is only permissible on the fact or presumption that the person would permit their involvement.

6. What if the person has appointed an enduring guardian and made an ACD?

A person may choose to prepare written instructions as to their future care in the enduring guardianship appointment document. If an ACD has been drafted independent of the enduring guardianship appointment, and this ACD is authoritative, then an enduring guardian is bound by these directions. If such a directive is not sufficiently authoritative to act on (for example it does not apply to the clinical circumstances at hand), then the enduring guardian consents or refuses consent to treatment according to the perceived best interests of the patient. Where a person has not appointed an enduring guardian and an ACD is not sufficiently authoritative to act on, the 'person responsible' (see Glossary) takes on this role.

7. What if an appointed enduring guardian disagrees with the ACD?

They are bound like everyone else. An ACD is the author's decision. The enduring guardian has no power to disagree.

8. What is the status of an oral directive, for example if a person tells the family or a nurse what they do or do not want regarding life sustaining treatments?

Advance care directives are usually written and signed by the person himself or herself. However, anyone can make an oral directive by making their wishes known through discussion with their family or health care team. This may arise where physical disability, illness or illiteracy means that writing is not possible but may also be the person's preferred approach. These wishes should be clearly documented in the person's medical history, even if a specific advance care directive 'form' is not used, and made known through liaison between treating health professionals.

9. Is a NSW ACD valid interstate and is an interstate ACD valid in NSW?

Yes, in both circumstances. Most states preserve the right to make an ACD at common law in addition to prescribed forms where they exist, such as in Queensland or South Australia. In some states, like Queensland, there is express recognition of interstate ACDs.

10. What should a person do with an ACD after they have completed it?

In order for an advance care directive to be acted upon, it must be available and its contents known at the time decisions need to be made, including time-pressured situations such as resuscitation decisions. A simple approach is for the likely 'person responsible' to be given a copy of the directive and any revisions it receives, along with the GP, any other doctors involved, and other key family members. An ACD should be brought to the attention of new treating clinicians as soon as possible. The ACD should be included in a prominent position in the medical history.

Glossary

Advance care directive – An ‘advance care directive’ contains instructions that consent to, or refuse, specified medical treatments in the future. They become effective in situations where the person is no longer able to make decisions. For this reason advance care directives are also, though less frequently, referred to as ‘living wills’.

Advance care planning – The process of preparing for likely scenarios near the end of life that usually includes assessment of, and dialogue about, a person’s understanding of their medical history and condition, values, preferences, and personal and family resources.

Enduring guardian – A formally appointed substitute decision-maker of an individual’s choice to make lifestyle and/or health care decisions should the individual lose the capacity to make their own decisions at some time in the future. The terms of all guardianship appointments must be carefully checked to ensure they cover the situation at hand, as some appointments are limited to handling only property and financial affairs and do not apply to health care decisions.

Person responsible – The role of the ‘person responsible’ is to make substitute decisions that consent to, or refuse consent to medical treatment. This person is required to have regard to the views of the patient but they are not bound to follow them. The ‘person responsible’ replaces the old term ‘next of kin’ as the person from whom consent for active treatment in the incompetent patient must be sought. The ‘person responsible’ is determined according to the hierarchy within the *Guardianship Act 1987* (NSW) and in the following order:

- An appointed guardian (enduring guardian) with the function of consenting to medical and dental treatment. If there is no-one in this category:
- A spouse or de facto spouse who has a close and continuing relationship with the person. If there is no-one in this category:
- The carer or person who arranges care on a regular basis and is unpaid (the carer pension does not count as payment). If there is no-one in this category:
- The carer of the person before they went into residential care. If there is no-one in this category:
- A close friend or relative.

Search strategy

Preparation of this best practice advice included a search of literature from the five years up to March 2003. Medline, Embase, PsychInfo, Science Direct, Synergy, Expanded Academic Index and Ingenta were searched using terms including 'advance directives', 'advance care planning', 'living will', 'end of life decision making', 'substitute decision making', 'CPR', 'guardianship', 'palliative medicine', 'resuscitation', 'enduring power of attorney' and 'values history'.

Websites of the e-journals MJA, BMJ, CMAJ, NZJM and Internal Medicine Journal were also searched with these strategies, and Google was used to search for material not available in these databases.

The bibliographies of key articles were hand-searched for further articles relevant to the Australian experience of advance care planning. Preference was given to papers including empirical data as well as expert opinion, those from Australian jurisdictions and those in peer-reviewed journals.

Three hundred articles were selected on the basis that they provided insight into the following themes: 'efficacy', 'reliability and validity', 'accessibility', 'durability', 'consumer view', 'portability', 'principles, processes and forms'. Forms from various jurisdictions were collated to provide examples of legally mandated forms, disease- or treatment-specific forms and goals, values or outcome-based forms.

Some of these citations are included in the reference section.

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