

Advance Care Planning for Health Professionals

FREQUENTLY ASKED QUESTIONS

1. How is Advance Care Planning different to an Advance Care Directive?

Advance Care Planning refers to the process of planning in advance based on a person's wishes before treatment decisions must be made. This process will involve exploration and identification of values and concerns relating to a person's health care and management at end of life.

Advance care planning may, or may not involve the writing of an advance care directive. An **advance care directive is a document** that records a person's wishes in advance of when treatment decisions must be made. .

Where a person is competent, they will be involved in their treatment decisions and any advance care planning or advance care directives that may have been generated. Where a person is no longer competent to make treatment decisions, end of life care must still be planned with appropriate substitute decision-makers.

2. What is the legal principle on which both advance care planning & advance care directives are based?

Advance care planning & advance care directives are based on the principle of autonomy - i.e the 'right to self determination'. This principle allows competent adults to refuse any medical intervention, on any ground. Advance care planning & advance care directives seek to sustain the status of a person's autonomy into the future, and to ensure that future decisions are informed by their wishes to the greatest degree possible.

3. Is there legislation for advance care planning or advance care directives in NSW?

NSW does not have specific legislation pertaining to advance care planning or advance care directives. However an advance care directive is enforceable under common (judge made) law. Although there is little case law on advance care planning or advance care directives in NSW, NSW follows the common law of other jurisdictions where courts have enforced advance care directives and a person's right to refuse medical treatment.

4. Are advance care plans and advance care directives legally binding in NSW?

Yes.

An advance care directive that was made by a person with legal capacity at the time of writing, after being provided with relevant information on their future treatment needs and options and which was made freely without coercion and is specific (i.e. sufficiently applicable to the clinical circumstance at hand to guide decisions) should be considered binding. However, people who wish to engage in advance care planning or make an advance care directive can be reassured that an advance care directive would always be interpreted using professional clinical judgement, according to the specifics of the clinical case.

5. If a health professional follows the wishes expressed in documentation about advance care planning or an advance care directive are they acting lawfully?

Yes. A health care professional who complies with a valid advance care directive that was:

- Made by a person with legal capacity at the time of writing, after being provided with relevant information on their future treatment needs and options
- Made freely without coercion and
- Specific (i.e. sufficiently applicable to the clinical circumstance at hand to guide decisions)

is acting lawfully. The health professional will have cared for the patient in accordance with their consent or refusal.

Careful documentation of conversations with person responsible, Enduring Guardian, spouse, carer, close friend or relative will be essential to demonstrate that the health care professional has taken into consideration the above criteria and that there has been no change in circumstances.

6. What might happen if the instructions within an advance care directive are ignored?

If an advance care directive is ignored despite meeting the above criteria for being 'authoritative' (i.e. specific to the clinical situation at hand, and a competent and non-coerced choice), a Court may consider any medical treatment provided in contradiction to the advance care directive to be treatment provided without consent. This may result in the health professional incurring criminal or civil liability and or/ disciplinary action.

7. It is difficult to predict and plan for every future health scenario so does this raise too many questions to enable an advance care directive to be a valid basis for decision-making?

It is true that, when a person is fit and well, delineating end of life treatment preferences can be hard to contemplate. Even in individuals with severe and chronic illness, it can be difficult to imagine treatment preferences in future, often undefined scenarios. However, the process of advance care planning and the development of an advance care directive may provide useful stimulus for exploring and documenting preferences where a person's medical situation is plain, where their preferences are strong, clear and delineable and where they may have special reasons to prescribe their care.

8. How is it possible to be sure that the advance care directive covers the situation at hand?

Ideally an advance care directive will document the kind of 'functional state' that the person would find intolerable, for example if the outcome was that they could no longer recognise or communicate with family and friends, or if they could no longer be self-caring, as determined by that person. This is where advance care planning is so valuable as it enables people to explore these ideas in detail with their Person responsible, Enduring Guardian, spouse, carer, close friend or relative. In such situations it will be possible to ensure the applicability of the advance care directive to the situation because these conversations have occurred and are remembered and documented.

Interpreting an advance care directive in isolation from other sources of information about the person's wishes regarding use of life-sustaining treatment can be difficult, especially where the

treating clinicians are not familiar with the patient. In a situation where the advance care directive may be ambiguous Fisher (2007) has suggested a hierarchy of evidence for decision making with level 1 being optimal.

Level 1 Well patient opinion with appropriate documentation and a written directive.

Level 2. Sick patient opinion.

Level 3. Person responsible, Enduring Guardian, spouse, carer, close friend or relative discussion involving patient.

Level 4. Person responsible, Enduring Guardian, spouse, carer, close friend or relative hearsay or supposition.

9. What if the advance care directive was drawn up years ago? Is it probable the person has changed their mind?

Not necessarily.

Those wishes, where clear and specific, may still be as relevant now as when the person initially documented them. However, it is possible that where a person has experienced significant, unanticipated illness, especially over an extended time period without revisiting their stated wishes, this *may* indicate a potential for change in their preference regarding the use of life-sustaining treatment. The value of advance care planning is that it is seen as an iterative decision making process and therefore the process would recur with life changing experiences. A person who has prepared an advance care directive should be encouraged to review their directives periodically, for example once a year, or when their medical condition or personal circumstances change significantly. The potential for any change to the person's wishes should be explored, where possible at the time treatment decisions must be made, using a hierarchy of evidence such as the one set out above.

10. Does an advance care directive need witnessing, and if so, by whom?

No, the advance care directive does not need to be witnessed in NSW.

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 allows some protection against forgery. It may also allay concerns about undue influence in the expressed treatment choices. If the advance care directive is made as a result of an ongoing advance care planning process then it will be important to witness and date the advance care directive to ensure that it is the most current and relevant.

If an advance care directive 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' advance care directive is prepared, the person may select whom they wish to witness the document.

11. What if the patient has refused a certain intervention in an advance care directive but the treating doctor believes it should be provided as part of 'good medical practice' or recognising advances in medical science?

This is not sufficient grounds alone for overriding an advance care directive, unless the advances in medical science are so significant as to render the advance care directive invalid because it is

no longer specific enough to apply to the clinical circumstances which have arisen. For example where the conditions described in Q.4 are met.

12. If a person has an advance care directive, do they need an Enduring Guardian?

No, but appointing an Enduring Guardian is a more flexible way of having the person's wishes interpreted and conveyed to treating clinicians during decision-making. An Enduring Guardian must still decide as that person would and, in nearly all circumstances, may not override that person's (documented or undocumented) wishes.

However, some individuals will not have anyone appropriate or that they want to act as a guardian. In those situations the hierarchy of evidence will apply.

13. Can an enduring guardian override the patient's instructions in an advance care directive?

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

14. What if the family disagrees with the instructions in an advance care directive after the patient is no longer able to make their own decisions?

A person's family may not override the explicit wishes expressed in an advance care directive simply because they disagree.

15. Does a person always need to use an advance care directive 'form' when developing an advance care plan in NSW?

No. NSW, by not having legislation which mandates the use of one type of form for advance care planning, enables individuals to record their preferences for end of life care in a number of ways.

16. What ways can the person's wishes about end of life care be made known, and recorded?

A person should discuss these with person responsible, Enduring Guardian, spouse, carer, close friend or relative and treating health professionals. These can be documented:

- In an advance care directive. Any form available in NSW, from other states, or from overseas can be used in NSW. This is because a prescribed form is not legally required in NSW where there is no statute governing use of advance care directives.
- As an entry in the person's medical notes.
- In a letter written by the person addressed to their person responsible or treating doctors.