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Advance Care Directives

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Advance Care Directives

1. What is it, and where did it come from?

Advanced Care Directives originated in the USA in the 1960s and were called 'Living Wills'. At least since the NSWHealth's publication "Using Advanced Care Directives" in 2004, it's been officially (and almost uniformly) called an Advance Care Directive ("ACD"). This is a surprisingly apt name as it succinctly describes the document's function: a Directive, in Advance of the situation occurring, about Care.

2. Is it legally binding?

Yes. In 2009 the NSW Supreme Court confirmed that ACDs are legally binding.

3. Is there a form?

In New South Wales there is no specific form for an ACD. An ACD can take any form. Nevertheless there are some aspects of the process that are important to observe. I suggest that:

3.1 the ACD should be in writing (or some other non-alterable and easily verifiable form). This will remove doubt about the decision that is made.

3.2 the direction should be specific and unequivocal. There are, unfortunately, many examples of vague and unsatisfactory expressions which should be avoided.

3.3 if it is in writing, the maker of the ACD should sign the document to authenticate it as belonging to the maker. Some other ways of making an ACD (such as a video, DVD, CD, tape or cassette) may provide other ways to easily authenticate the maker of the directive.

3.4 if it is in writing, the maker's signature should be witnessed. This will help establish the maker's capacity at the time the document was signed, and the voluntariness of the directive.

4. What should the ACD contain?

There are no parameters on the contents of an ACD. The general concept is that it directs important care, health and welfare issues for the maker. For that reason, the contents that I recommend are:

[1] state the persons or places to whom the direction is addressed (and to whom it should therefore be distributed). This list will often include:

- the enduring guardian,
- members of the maker's family,
- the maker's usual medical practitioner,
- any hospital at which the maker is a patient,
- any care facility where the maker resides, and
- anyone else involved with the person's care, health or welfare.

[2] specify the circumstances where the maker wants the direction(s) to apply. This is referred to at 5 below.

[3] state the direction that the maker wants for his/her care if the specified circumstances exist. This is referred to at 6 below.

5. In what circumstances should an ACD apply?

An ACD is designed to speak for its maker when the maker is unable to communicate his or her wishes directly. As a result, this is usually one of the essential conditions in which an ACD will operate.

The other circumstances in which an ACD will operate will depend on the direction(s) contained in the ACD. For instance, the circumstances in which an ACD operates could be:

- when the maker's death is imminent, and
- 2 medical practitioners independently conclude that the maker's condition is terminal, incurable and irreversible.

6. What type of directions can be given?

There is no limit to the care directions that can be given, but most directions focus on wishes for (or against) medical treatment, such as:

- blood transfusion
- cardio pulmonary resuscitation
- external feeding (of which there are different levels such as oral feeding, supplemental feeding, intravenous feeding or tube feeding)
- antibiotics
- artificial breathing/mechanical ventilation
- hydration
- pain relief medication

or levels of care (including palliative care, limited care, surgical care, intensive care or other specific care).

7. Does an ACD make a difference? (The case of Terri Sciavo)

Terri Sciavo had lived in a 'persistent vegetative state' for 15 years as a result of a heart attack. After 25 court rulings and interventions spread over 10 years Terri's husband was allowed to consent to the removal of her feeding tube.

Terri's husband had insisted that she would have wanted to die; her family had insisted that Terri would have wanted to live. Clearly it would have been less traumatic on all involved if Mrs Sciavo had clearly set out her preferences for treatment prior to her becoming incapacitated.

8. How often should the ACD be reviewed?

A history of regular reviews of the ACD can help resist the argument that an ACD, made some years before it is needed, no longer represents the maker's wishes. The NSWHealth Guidelines recommend an annual review. The former President of the Guardianship Tribunal suggests a review every 3 years.

1to3

It should also be reviewed if there are advances in medical treatment, or development of relevant technology. It may need review with changes in the maker's medical condition or health.

9. To whom should a copy be given?

A copy of the ACD should be given to all persons or organisations to whom the ACD is directed. A suggested list appears at 4 [1] above. I suggest that a certified copy be given. This is a copy bearing a certificate that it is a true copy of the original.

10. What should you do with the original?

The original ACD should be stored safely so that further copies can be easily obtained if the copies are lost or damaged, or further copies are required. It is probably a good idea to store it with your will, enduring guardian appointment and other important documents. *For further information see my paper "Advance Care Directives".*