

Advanced Care Planning

The tragic death in April 2005 of Terry Schiavo, a brain-damaged Florida woman, was heart-breaking on a number of levels.

Primarily, for Terry it was the loss of her short life preceded by years of indignity. For her family it was the final, anguished passing of a daughter and wife after years of grief, torment and conflict.

On another level it opened up deep divisions in American society with religious and lobby groups, the media, Courts and Congress weighing in to declare their view on whether Terry Schiavo should live or die.

The one person whose opinion mattered most, but who could not be heard, was Terry herself.

Terry's plight and her family's distressing situation highlight the need to consider planning for one's care in advance.

Advance care planning will take on greater significance over time due to our rapidly aging and longer-living population. In 2001 Australians aged 65 and over accounted for 12.4% of the population. This is expected to rise to 14% by 2011 and to a staggering 21.3% by 2031.¹

Despite medical advances there will be an accompanying increase in the progressive diseases of aging, particularly those which lead to loss of cognitive ability such as dementia.

This year - in which the first of the baby boomer generation turn 60 - there are projected to be 52,000 new cases of dementia in Australia. A quarter of these cases will be in people aged 80-84. By 2050 there are projected to be 175,000 new cases of dementia diagnosed every year, more than the total number of cases in Australia in 2000.²

However, as the Schiavo case demonstrates – Terry was only 27 when she suffered the cardiac arrest that led to her brain damage – it is not just older people who should be turning their attention to these important questions.

Advance care planning is about making informed choices. It refers to the process of preparing for the likely scenarios near the end of life.

It usually includes assessing a person's understanding of their medical history and current medical condition, considering potential future conditions and expressing their

¹ 1 Australian Bureau of Statistics 1998, Population Projections 1997 to 2051, Cat. no. 3222.0, ABS, Canberra.

² *Dementia Estimates and Projections: Australian States and Territories*, Report prepared by Access Economics Pty Ltd for Alzheimers Australia, February 2005.

wishes in relation to treatment options, taking into account their values, religious beliefs and their family's resources.

The three main elements of advance care planning are the making of an Enduring Power of Attorney, an Advanced Care Directive (ACD) and the appointment of an Enduring Guardian.

A power of attorney is a familiar document and is often used outside the advanced care planning context. It authorises a person, the attorney, to act on their principal's behalf to manage the principal's affairs. It will usually be used in relation to financial matters and cannot be used to make personal and lifestyle decisions for the principal.

In NSW there are two types of power of attorney: an ordinary power of attorney and an enduring power of attorney.

An ordinary power of attorney ceases to have effect after the principal has lost mental capacity.

The enduring power of attorney is therefore utilised in advanced care planning. It can operate immediately and provide that the power will continue to operate notwithstanding that in the future the principal loses mental capacity. Alternatively it can provide that the power is only to operate if the principal loses mental capacity.

An ACD is a written statement outlining a person's wishes regarding future medical care in the event that they are unable to make their own decisions through a loss of mental capacity.

It is for this reason that ACDs are sometimes called "Living Wills".

An ACD will usually refer to the types and severity of medical conditions in relation to which the person wishes specified treatment withheld or only palliative care measures administered.

However, it should not be assumed that the content of an ACD must stipulate preferences in relation to limitation of treatment. An ACD may also quite properly indicate an individual's preference that full measures be employed to prolong their life.

Whatever the content of an ACD, it must be clear and specific enough to relate to the person's potential medical circumstances that could exist at that time so that it can guide clinical care.

An ACD may also indicate who should be contacted for advice in relation to treatment decisions.

An ACD cannot however permit the refusal of basic medical care or endorse assisted suicide as both these measures are illegal in NSW.

A properly drafted ACD will be legally binding in NSW based on the common law right to determine one's own medical treatment. It will generally override any contrary

wishes from family members, and a health professional's failure to comply with an ACD may result in civil or criminal liability.

An Enduring Guardian is someone legally-appointed to act as a substitute decision-maker for a person when he or she is no longer able to make personal or lifestyle decisions due to incapacity.

The document appointing the Enduring Guardian may also contain instructions as to future care provision.

If a person has made an ACD and also appointed an Enduring Guardian both documents will need to be examined to determine the person's wishes. Generally a valid, authoritative ACD which is relevant to the circumstances at hand will bind the Guardian.

Anyone interested in taking steps to plan for their future care should in the first instance consult their general practitioner.

Further information can also be obtained from the Office of the Public Guardian, the Department of Ageing, Disability and Home Care and the Benevolent Society of NSW.

A lawyer can assist with the drafting of the relevant documentation once you have an informed opinion about differing medical conditions and associated treatments.

Planning for your future care, while not a pleasant subject, is worthwhile.

Proper communication and preparation will assist in preventing any later conflict between family members and alleviate a potential source of stress and concern during a time of sorrow.

Most importantly it will allow you to retain a sense of control, ensuring your wishes are carried out and your dignity is preserved.

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