

INQUIRY INTO SUBSTITUTE DECISION-MAKING FOR PEOPLE LACKING CAPACITY

Organisation: Dying With Dignity NSW
Name: Dr Giles Yates and Dr Robert Marr
Telephone: (02) 9212 4782
Date received: 26/08/2009

Submission
from
Dying with Dignity New South Wales
to
An inquiry conducted by the Social Issues Committee of the
Legislative Council
into
Substitute decision-making for people lacking capacity

EXECUTIVE SUMMARY

The Guardianship Act 1987 requires amendment to ensure that it does not discriminate unfairly against persons in NSW to force them to receive unnecessary medical treatment.

This submission recommends a new subsection to be added to Section 32 of the Guardianship Act 1987 to ensure that people are not subjected to any unnecessary medical or dental treatment merely because they lack the capacity to refuse the carrying out of such treatment.

BACKGROUND

Section 32 of the Guardianship Act 1987 sets out the objects of Part 5 of the Act concerning the provision of substitute consent for medical and dental treatment.

32 Objects

The objects of this Part are:

- (a) to ensure that people are not deprived of necessary medical or dental treatment merely because they lack the capacity to consent to the carrying out of such treatment, and*
- (b) to ensure that any medical or dental treatment that is carried out on such people is carried out for the purpose of promoting and maintaining their health and well-being.*

For the vast majority of substitute decisions about medical treatment these objects are entirely appropriate, however we submit there is one exceptional type of substitute decision in which these objects can cause significant harm and unnecessary suffering. The exceptional type of decision occurs at the end of life when the substitute decision-maker decides that further life-prolonging treatment is inappropriate and should be withheld. Section 32(b) can be interpreted as

prohibiting any decision to withhold/withdraw medical treatment that will allow death to take its natural course.

For persons who still have decision-making capacity it is clearly established in common law that we have the right to refuse unwanted medical treatment, even if the refusal of such treatment will cause our death. This has been emphatically upheld in the decision on 14 August 2009 of His Honour Justice Martin, Chief Justice of Western Australia in the case concerning Mr Christian Rossiter.

For persons who wish to anticipate medical decisions that will be required in the future after they have lost decision-making capacity there is an opportunity to write an Advance Care Directive. This is encouraged by the NSW Department of Health in the printed guide, 'Using Advance Care Directives', 2004.

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.

Many members of Dying With Dignity NSW have signed their advance health directives for the specific purpose of giving instructions to withhold unwanted medical treatment at the end of their lives. Moreover many have also appointed an Enduring Guardian pursuant to Part 2 of the Guardianship Act 1987 in order to give their chosen person the authority to refuse unwanted medical treatment.

It is important to understand that the provisions of Part 5 of the Guardianship Act 1987 apply to all substitute medical decisions for anyone who is incapable of making their own medical decisions, even if that incapacity is only very temporary. It applies to all of us, and is not limited to cognitively disabled people who may have a guardian appointed for them. As such Part 5 of the Act applies to a very large proportion of the population in their dying days.

The problem occurs if anyone disputes a substitute decision to withhold life sustaining medical treatment. Such a dispute will generally be resolved with

reference to the Guardianship Act 1987. The problem arises because Section 32(b) of the Act appears to insist that any substitute decision about medical treatment must promote and maintain the health and wellbeing of the person. On the face of it this wording does not permit a decision to withhold life-sustaining treatment.

Thus, we have a situation under the current legislation in which all parties may agree that further life-sustaining treatment is futile and only serves to prolong suffering but everyone's hands are tied by Section 32(b) of the Guardianship Act 1987.

Substitute decision-makers must have the same end-of-life choices available to them that we have for ourselves. Many people rationally choose to refuse life-prolonging medical treatment at the end of their lives because they care more about their quality of life in their last days and less about prolonging the number of days.

RECOMMENDATION

The Guardianship Act 1987 requires an amendment to Section 32 as follows (recommended new text in bold):

Section 32 Objects

The objects of this Part are:

- (a) to ensure that people are not deprived of necessary medical or dental treatment merely because they lack the capacity to consent to the carrying out of such treatment, and
- (b) to ensure that people are not subjected to any unnecessary medical or dental treatment merely because they lack the capacity to refuse the carrying out of such treatment, and**
- (c) to ensure that any medical or dental treatment that is carried out on such people is carried out for the purpose of promoting and maintaining their health and well-being.

Dr Robert Marr MBBS
President
Dying With Dignity NSW

Dr Giles Yates Ph.D
Dying With Dignity NSW

Dying With Dignity NSW (formerly the Voluntary Euthanasia Society of NSW)
T. (02) 9212 4782 E. dwd@dwdnsw.org.au W. www.vesnsw.org.au
PO Box 25, Broadway, NSW, 2007