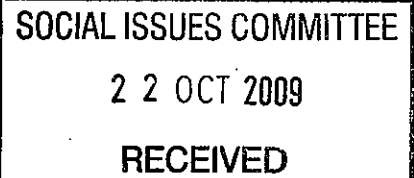


STANDING COMMITTEE ON SOCIAL ISSUES
Inquiry into substitute decision-making for people lacking capacity

QUESTIONS ON NOTICE
(Remaining from questions sent pre-hearing)

Ms Anne-Marie Elias
Council on the Ageing
Submission 14



Advance Medical (Care) Directives

1. NSW has no legislative provisions for advance care directives; however, NSW Health provides advice on how to develop a document that would be valid at common law.

COTA NSW Response: These documents are known by a number of names in the various jurisdictions and may be correctly called "Advance Care Directives or Advance Health Directives"

- The recent case in the NSW Supreme Court (Hunter and New England Area Health Service) confirms that Advance Directives are legally binding in NSW at common law, and also confirms that no specific document is required in order that they are binding – even directions written on a piece of paper can be legally binding, provided there is evidence that they are the patients wishes.

- Could you comment on the status of advance medical directives in NSW?

COTA NSW Response: While they are legally binding and it is understood that the number of people making them is increasing, there is still a great deal of misinformation and misunderstanding in the community and among health care and legal professionals about them.

- Do you believe there is a need for NSW legislation relating to advance medical directives?

COTA NSW Response: Yes. While there is no specific legislation relating to Advance Directives, some doctors and solicitors will argue that they are not legally binding. In addition, specific legislation would allow regulations to be developed regarding their use, as well as penalties for non compliance.

- Are doctors generally willing to comply with the directives?

COTA NSW Response: A recent study in NSW assessed Doctors' knowledge and attitudes to Advance Care Directives and found that the majority of doctors surveyed were strongly in favour of Advance Directives and noted that their use would make doctors' work easier, (Cartwright et al, report currently being written).

- How do advance care directives and guardianship or enduring powers of attorney interact?

COTA NSW Response: The Guardianship Act 1987 states that a guardian (or person responsible) and the treating medical practitioner should, as far as possible, make the decision the person themselves would make if they were competent to communicate their wishes. If the enduring guardian has a copy of the person's advance directive, then "the decision the person would make for themselves" is generally very clear. This greatly assists the enduring guardian.

COTA NSW Response: Advance Care Directives relate to end of life decision making, guardianship relates to personal and health care and enduring power of attorney relates to property and money. As such there is very little interaction between them unless it relates to the cost of care.

Responsible person

4. The *Guardianship Act 1987* provides that the "person responsible" for another person shall ensure that any medical and dental treatment shall be for the purpose of "promoting and maintaining their health and well-being."¹ This effectively prevents the "person responsible" from authorising the withdrawal of life sustaining medical treatment in circumstances where continuing such treatment would not be in the person's best interests.

- Do you think that "persons responsible" under the Act should be able to authorise the withdrawal of life sustaining medical treatment?

COTA NSW Response: Yes. It is promoting the person's well-being to stop their dying being prolonged by technology and such things as artificial nutrition and hydration. The current situation means that the treating medical practitioner either has to contact the tribunal or a court every time they wish to cease futile treatment for a patient or else 'break the law' by conceding to the wishes of the person responsible (often someone very close to the patient) by withholding or withdrawing the technology that is prolonging the patient's dying. (Note: treatment is futile if burden outweighs benefit – but burden and benefit should only be from the perspective of the patient or those closest to them).

COTA NSW Response: If the treating medical practitioner disagrees with the decision of the person responsible, he or she can ask the court for a determination.

- With whom do you think the authority to withdraw life sustaining medical treatment should reside?

COTA NSW Response: An enduring guardian if there is one; if not, with the person responsible; if no person responsible, with the treating medical practitioner then it should be in conjunction

In the original additional questions we were asked, we had prepared for these questions as follows:

- Are there any advantages to having more than one person qualify equally as the "person responsible"?

¹ *Guardianship Act 1987*, s 32 (a)

COTA NSW Response: This usually only applies to the final category of person responsible, i.e. close friend or relative. In most cases it can be determined who has been providing most care for the patient (i.e. who has had "the care of" the patient).

COTA NSW Response: It would be difficult to provide an "order" of friend or relative, particularly for some groups in the community (e.g. the gay and lesbian community, where a friend may, in fact, be closer to the person than a relative and may know better what the person would want)

- What is your comment on any proposal to amend the Act to ensure that only one person can be deemed the "responsible person"?

COTA NSW Response: This may cause more problems than the one it seeks to avoid.

Public Guardian functions

6. The Public Guardian has recommended that section 21A of the *Guardianship Act 1987*, allowing the Public Guardian to authorise members of the NSW Police Force to move a person under a guardianship order from one place of residence to another, be amended to specify that the Police may use "all reasonable force."² Can you comment on this proposal?

COTA NSW Response: In the best interest of the person and least restrictive approach in accordance with what they would have wanted.

7. The Public Guardian has recommended that the *Guardianship Act 1987* be amended to allow the Public Guardian to pro-actively investigate matters where it becomes aware a vulnerable person may be in need of a guardian.³ Can you comment on this proposal?

COTA NSW Response: Yes this is important to enable the Public Guardian to proactively investigate matters where it becomes aware a vulnerable person may be in need of a guardian.

COTA NSW Response: However a public campaign is required to make people aware of who they need to notify if they identify someone is vulnerable.

8. The Public Guardian has recommended the *Guardianship Act 1987* be amended to allow the Public Guardian to assist people with decision-making disabilities without the need for a guardianship order.⁴ Can you please comment on this proposal?

COTA NSW Response: Yes but we need very clear guidelines and definitions.

Tribunal processes

9. Section 14 (2) of the *Guardianship Act 1987* (NSW) lists the factors the Guardianship Tribunal shall have regard to when deciding whether or not a person is in need of a guardian. Do you feel these factors give sufficient assistance to the Tribunal in reaching this decision?

² Submission 7, Office of the Public Guardian, p 19

³ Submission 7, Office of the Public Guardian, p 14

⁴ Submission 7, Office of the Public Guardian, p 13

COTA NSW Response: As long as the rights of the affected person are paramount, as outlined in 25G of the Act, as long as it is based on the best interests and least restrictive approach to the affected person.

10. Section 25G of the Guardianship Act 1987 (NSW) lists the factors the Tribunal must be satisfied of before making a financial management order in respect of a person. Do you think this section provides sufficient assistance to the Tribunal in deciding whether a person requires a financial management order?

COTA NSW Response: Yes it is based on the best interests and least restrictive approach to the person affected.

From questions to all witnesses:

Capacity

2. It has been suggested to the Committee that decision-making capacity should be regarded as a spectrum with complete autonomy at one end and substitute decision-making at the other.⁵

COTA NSW Response: It is important that we need to be flexible with the spectrum – and consider the approach taken by the Intellectual Disability Sector where people are encouraged and supported to decide for themselves as far as practicable.

- Who do you believe is qualified to assess where on this spectrum a person may be and what information is required in order to make this assessment?

COTA NSW Response: There is a view that Trained Professionals can follow a standardised assessment Tool – such as the Capacity Toolkit⁶. This can then be used by government and community workers, professionals, families and carers.

COTA NSW Response: If in doubt, Capacity Assessment should be undertaken by a Professional Assessor as outlined in Alzheimer's Online⁷. This document outlines professional assessors as psychiatrists, psychologists, gerontologists, neurologist, geriatrician, psycho geriatrician, and members of the Aged Care Assessment Team (ACAT).

- In practice, how could substitute decision-making arrangements be constructed to accommodate the fact that a person's capacity may vary from time to time and situation to situation?

COTA NSW Response: Application of due diligence checks and of professional assessments as outlined above.

⁵ Submission 3, Intellectual Disability and Rights Service, p 3

⁶ New South Wales Attorney General's Department *Capacity Toolkit: Information for government and community workers, professionals, families and carers in New South Wales*, (Sydney, 2008) at http://www.lawlink.nsw.gov.au/lawlink/diversityservices/LL_DiversityServices.nsf/pages/diversity_services_capacity_toolkit.

⁷ <http://www.alzheimeronline.org/facts/faq.php>.

Additional questions on notice

The Hon. MICHAEL VEITCH: Is it better to define "capacity" as opposed to spending a lot of time defining the disability?

COTA NSW Response: Defining capacity is critical – that is the issue – many people with a disability are able to function and make decisions for themselves – and are encouraged to do so. The point at which a disability impedes a person's capacity is the issue in question.

The Hon. MICHAEL VEITCH: Earlier in your evidence you spoke about the Queensland as opposed to Victorian public advocate role, almost an adult ombudsman type role. We heard evidence yesterday that another organisation preferred the Victorian model above the Queensland model. Could you explain in more detail why the Queensland model is more meritorious than the Victorian model?

COTA NSW Response: COTA NSW is not able to comment on this, suffice to say we believe that both models have their merits. The Victorian model combines the function of systemic and individual advocacy, while the Queensland Model separates the systemic advocacy - the role of the Public Advocate; from the individual advocacy which is taken on by the Adult Guardian. We have consulted with COTAs nationally and it seems the two models most discussed were the QLD and Victorian. It seems that other jurisdictions (NT, SA) are reviewing their legislation in this arena so it may be worthwhile to make this request through COAG.

The Hon. MICHAEL VEITCH: We also heard yesterday that there is almost a need for—and I think this was the phrase used—a vulnerable person's ombudsman. I cannot remember who said that, but it was mentioned yesterday. I wonder whether the Queensland model that you are talking about fits that perspective where you have an adult ombudsman and a public advocate?

COTA NSW Response:

Ms ELIAS: I think so, and the role of the adult guardian, if I can read it out, is to protect the rights and interests of adults who are unable to make decisions for themselves. This lack of decision-making ability, known as impaired capacity, may be caused by intellectual or psychiatric disability, acquired brain injury, dementia or temporary illness such as delirium. So that is the role of the adult guardian.