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# Review of the Guardianship Act 1987
# Question Paper 2
# Decision Making Models

The Royal Australasian College of Physicians
Submission

# Review of the Guardianship Act 1987
# Question Paper 2: Decision Making Models

## 5. A formal supported decision-making framework for NSW?

### Question 5.1: Formal supported decision-making
### 5.1.1 Should NSW have a formal supported decision-making model?

Supported decision-making is relevant to the work of many specialties within the Royal Australasian College of Physicians (RACP), including geriatricians, palliative medicine specialists, rehabilitation medicine specialists, and paediatricians. The RACP is currently developing a position statement in support of the National Disability Insurance Scheme (NDIS), including its person centred approach which supports people living with a disability to exercise choice and control over the services they receive.

The RACP's position statement, End-of-life care: Our roles and responsibilities considers supported decision making in the context of the end of life. The statement sets out five elements that the RACP has identified as essential for the provision of good patient-centred end of-life care, with supported decision making being a key feature of Element 2 and of relevance to each of the other elements:

1. Diagnosing dying or the risk of dying
2. Respecting patient autonomy and ***supported decision making***, and providing personalised care
3. Ensuring that medical treatment decisions respect the patient's best interests
4. Managing symptoms
5. Supporting carers and family/whānau.

The RACP holds that wherever possible, individuals should be involved in decisions about their care at the end of life, including when this involves withholding or withdrawing life-sustaining interventions. Case study 3 in the position statement provides an example of supported decision-making in this context.

The RACP is supportive of the presumption of capacity. Supported decision making pilots in Australia have been small in scale, short term and largely involved people with intellectual disability[iii]. The College recommends expanded pilots and research to provide greater insight into the feasibility of supported decision making models.

The RACP recommends that guardianship legislation reflect both fluctuations in capacity and the requirement for supported or substituted decision making over time, and the domain specificity of decisions. The legislation needs to contain appropriate provisions for review of changes in assessment of decision-making capacity.

The opinion of the medical practitioner in relation to the ability of the patient to understand and make decisions should be considered. Providing appropriate communication supports to patients will assist physicians in determining their opinion of a patient's capacity.

However, with regard to establishing formal models of supported decision making, the RACP would like to raise a number of issues and concerns, as any legislative changes in this area will impact both patients and physicians, in their care of and advocacy for patients:

- If supported decision-making is formalised, people may be less willing to become supporters given the associated administrative processes.
- Whether formal processes would improve clarity regarding doctors' legal liability and patient consent to treatment as compared to informal supported decision-making[iii].
- Whether individuals without family or friends who are available to support their decision making will be at a disadvantage.

- The need for timely decisions relating to the end of life, such as whether to allow a natural death rather than initiate interventions which may provide little or no benefit to the patient and may in fact cause harm and discomfort.
- How a change from supported decision-making to substitute decision-making would be managed in urgent situations.
- The need to have uniformity of purpose and language relating to supporter roles to avoid situations where, for instance, an appointed nominee under the National Disability Insurance Scheme (NDIS) does not have an equivalent under the Guardianship Act.

### 5.1.2 If there were to be a formal supported decision-making model, how can we ensure there was an appropriate balance between formal and informal arrangements?

The RACP cannot make detailed comment in response to this question, but a simplified process is important and a mechanism is needed that protects patient interests. Physicians must have legal clarity to support their decision-making, and that, as above, any changes must take into account the need for timely decisions in areas such as end-of-life care.

### 5.1.3 If there were not to be a formal supported decision-making model, are there any ways we could better recognise or promote informal supported decision-making arrangements in NSW law?

The RACP has no further comment in response to this question.

## Question 5.2: Key features of a formal supported decision-making model

### 5.2.1 Should NSW have formal supporters?

Please see our comments under Question 5.1.

### 5.2.2 If so, should NSW permit personal or tribunal appointments, or both?

### 5.2.3 Should NSW have formal co-decision-makers?

### 5.2.4 If so, should NSW permit personal or tribunal appointments, or both?

### 5.2.5 What arrangements should be made for the registration of appointments?

The registration of appointments (of any type, whether supporters, co-decision makers or substitute decision makers) would assist physicians in the treatment of patients.

## Question 5.3: Retaining substitute decision-making as an option

### 5.3.1 If a formal supported decision-making framework was adopted, should substitute decision-making still be available as an option?

### 5.3.2 If so, in what situations should substitute decision-making be available?

### 5.3.3 Should the legislation specify what factors the court or tribunal should consider before appointing a substitute decision-maker and, if so, what should those factors be?

The RACP is in favour of maintaining substitute decision-making as an option if a formal supported process is introduced. The RACP has a preference for the least restrictive option to allow patient centred, autonomous and dignified care, and we believe that enabling both supported and substitute decision making would support this.

Substitute decision making is a valuable framework used by physicians in situations where a patient lacks capacity. For example, key components to legally recognised Advance Care Planning[iv] are:

- the appointment of a Substitute Decision Maker (SDM)

- the 'default' SDM if no SDM is appointed – this may be the spouse, close relative, carer or friend, and the order of priority varies according to jurisdiction
- the powers of the SDM and the principles which are to guide the decisions of the SDM
- the Advance Care Directive, or documentation of the person's wishes (which may include a legally binding refusal of treatment). Depending on the jurisdiction, this may be a statutory document or a document which may be recognised under common law. In some jurisdictions Advance Care Directives are binding, and in other jurisdictions they only inform decision making. Some jurisdictions may not recognise statutory Advance Care Directives from other jurisdictions.

This is an area of considerable complexity and we understand that currently there is no legislation on Advance Care Planning in NSW. It is vital that healthcare professionals know and understand the law applicable in their jurisdiction and their obligations with regard to caring for patients at the end of life so they are able to make the best decisions for their patients, including withdrawing, withholding or limiting treatment where indicated. The RACP advocates for the harmonisation of Advance Care Planning and other relevant provisions across jurisdictions to provide greater clarity and certainty for health professionals and patients.

When appointing supporters and co-decision makers it would be important to distinguish between an individual who is likely to have further diminution in decision making capacity over time (e.g. dementia) and individuals with either stable levels of functioning or even the potential to improve (e.g. mental illness). The requirement for review of appointments of supporters or substitute decision makers needs to take this into account.

### Question 5.4: Other issues
### Are there any other issues about alternative decision-making models you would like to raise?

Updated guardianship legislation must provide clarity in the areas of:

- Advanced Care Planning (as above)
- The interface with Commonwealth legislation on aged care and the NDIS
- The interface with the Mental Health Act
- Consent to medical treatment

## Supporters and co-decision-makers

No comment on questions 6.1 – 6.10 except to note that the role of a supporter in the hierarchy of decision makers would need to be explicit within the legislation.

[i] Then, Shih-Ning (2013) *Evolution and innovation in guardianship laws: Assisted decision-making*. Sydney Law Review, 35
[ii] Terry Carney (2014) Clarifying, Operationalising, and Evaluating Supported Decision Making Models, Research and Practice in Intellectual and Developmental Disabilities,
1:1, 46-50
[iii] Then, Shih-Ning (2013) *Evolution and innovation in guardianship laws: Assisted decision-making*. Sydney Law Review, 35
[iv] Carter R, Detering KM, Silvester W, Sutton L (2015). Advance care planning in Australia: what does the law say? Australian Health Review. http://dx.doi.org/10.1071/AH15120. [Published online: 16 November 2015].