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**RACP Submission to the NSW Law  
Commission's Review of the Guardianship  
Act 1987 - Question Paper 5 *Medical and  
Dental Treatment and Restrictive Practices***

May 2017

# Review of the Guardianship Act 1987

## Question Paper 5: *Medical and Dental Treatment and Restrictive Practices*

The Royal Australasian College of Physicians (RACP) welcomes this opportunity to provide its feedback to inform the New South Wales Law Commission's Review of the Guardianship Act 1987.

The RACP connects, represents and trains over 15,000 physicians and 7,500 trainee physicians in Australia and New Zealand across a wide range of specialties, including rehabilitation medicine, public health, palliative medicine and geriatric medicine.

We have consulted with relevant expert groups across the RACP to prepare this submission to Question Paper 5 "*Medical and Dental Treatment and Restrictive Practices*". It focuses on the issues most relevant to physicians' practice and complements the two previous submissions we issued in response to the Review's [Question Paper 1 \(\*Preconditions for alternative decision-making arrangements\*\)](#)<sup>1</sup> and [Question Paper 2 \(\*Decision making models\*\)](#).<sup>2</sup>

### **Question 2.1: "Incapable of giving consent"**

#### **2.1.1 Is the definition of a person "incapable of giving consent to the carrying out of medical or dental treatment" in s 33(2) of the Guardianship Act 1987 (NSW) appropriate? If not, what should the definition be?**

The RACP recommends that the Act's definition acknowledges that a person's capacity can vary over time (e.g. some conditions such as mental illnesses can vary in severity from time to time) and depending on the subject matter of the decision (e.g. making a will, making a decision about health care, financial decision, etc.).

The expert members we have consulted to produce this submission have expressed a range of views regarding the Act's current definition of a person "incapable of giving consent to the carrying out of medical or dental treatment". Whilst some consider that the definition is appropriate, others have suggested that the meaning of 'capacity' requires explanation. One definition that could be considered is as follows: "*a person is deemed to have capacity if they are able to understand the information that is relevant to making a decision and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.*" It was suggested that capacity is defined by the ability to understand and appreciate a decision rather than by the ability to communicate that understanding. It may be appropriate for the Act to include provisions for those who are unable to communicate/indicate their preferences to ensure that for the purposes of decision making in their very specific context, they are not presumed to lack capacity.

Clear guidance (not necessarily in the Act itself) should be provided about assessing capacity and incapacity in relation to particular decisions (e.g. making a will, making a decision about health care etc.) as these may differ depending on the subject matter of the decision and may also vary over time as mentioned in our response to question 2.1.1.

#### **2.1.2 Should the definition used to determine if someone is capable of consenting to medical or dental treatment align with the definitions of capacity and incapacity found elsewhere in the Guardianship Act 1987 (NSW)? If so, how could we achieve this?**

There is likely to be benefit in alignment of definitions, but the implications would need to be carefully thought through.

### **Question 3.1: Withholding or stopping life-sustaining treatment**

#### **3.1.1 Should Part 5 of the Guardianship Act 1987 (NSW) state who, if anyone, can consent to withholding or stopping life-sustaining treatment for someone without decision-making capacity?**

The RACP agrees that Part 5 of the Guardianship Act 1987 (NSW) should specify who, if anyone, can consent to withholding or stopping life-sustaining treatment for someone without decision-making capacity.

Physicians have a duty to consider the benefits and harms of any treatments including the provision of medically assisted nutrition and/or hydration before instituting them. Physicians should generally not provide treatments that are not offering benefit to the patient; these treatments should be withheld or withdrawn after

careful consideration of their benefits and harms to the patient. Decisions regarding withholding or stopping life sustaining treatment for someone without decision-making capacity should be made via consensus decision making between the treating team and the patient's substitute decision-maker. The Act should provide guidance around what steps to take when consensus cannot be reached, and either the treating team or the patient's substitute decision maker feel that the patient is being "harmed" by current activities.

### **3.1.2 If so, who should be able to consent and in what circumstances?**

If the patient lacks decision-making capacity, the health professional should ask the family/carer and/or GP whether the patient has an Advance Care Plan and review, in discussion with the family/carer, whether it is intended to apply to the current circumstances. In the absence of an applicable Advance Care Plan setting out the patient's wishes, the health professional should enquire of the patient's substitute decision maker or Enduring Guardian, if they have one, to ascertain the patient's previously expressed wishes. If there is no substitute decision maker, the health professional should take into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise (cf right 7(4) of NZ Code of Consumers' Rights).<sup>3</sup>

In cases where the previously expressed wishes of a patient lacking decision-making capacity are unknown, the RACP is of the view that the patient's substitute decision maker should be able to consent to withholding or stopping life sustaining treatment if these treatments have been assessed by the health professionals caring for the patient as not offering benefit to the patient. In some cases, this may require obtaining a second professional opinion. In addition, as outlined in our response to question 3.1.1., decisions regarding withholding or stopping life sustaining treatment for someone without decision-making capacity should be made via consensus decision making between the treating team and the patient's substitute decision-maker. The Act should provide guidance around what steps to take when consensus cannot be reached, and either the treating team or the patient's substitute decision maker feel that the patient is being "harmed" by current activities.

### **Question 3.3: Treatment by a registered health practitioner**

#### **Should the definition of medical and dental treatment in Part 5 of the Guardianship Act 1987 (NSW) include treatment by a registered health practitioner?**

The RACP agrees that expanding the definition of 'medical and dental treatment' to include treatment provided by a registered health practitioner would benefit patients who lack capacity as it would clarify their eligibility to access a wider range of health treatments which they may require. As with any health treatments careful considerations need to be given to the potential harms and benefits of these treatments by a registered health practitioner for the patient and only those with clear benefits and of high quality should be undertaken.

### **Question 3.4: Types of treatment covered by Part 5**

#### **3.4.1 Are there any other types of treatment excluded from Part 5 of the Guardianship Act 1987 (NSW) (or whose inclusion is uncertain) that should be included?**

The RACP has not identified any additional types of treatment to be included in Part 5 of the *Guardianship Act 1987*.

### **Question 4.1: Special treatment**

#### **4.1.1 Is the definition of special treatment appropriate? Should anything be added? Should anything be taken out?**

Please refer to our response to question 4.5.

### **Question 4.2: Major treatment**

#### **4.2.1 Is the definition of major treatment appropriate? Should anything be added? Should anything be taken out?**

#### **4.2.2 Who should be able to consent to major treatment and in what circumstances?**

#### **4.2.3 How should a patient's objection be taken into account?**

#### **4.2.4 In what circumstances could major treatment be carried out without consent?**

Please refer to our response to question 4.5.

### **Question 4.3: Minor treatment**

**4.3.1 Is the definition of minor treatment appropriate? Should anything be added? Should anything be taken out?**

**4.3.2 Who should be able to consent to minor treatment and in what circumstances?**

**4.3.3 How should a patient's objection be taken into account?**

**4.3.4 In what circumstances could minor treatment be carried out without consent?**

Please refer to our response to question 4.5.

#### **Question 4.5: Categories of treatment as a whole**

**4.5.1 Does the legislation make clear what consent requirements apply in any particular circumstance? If not, how could it be clearer?**

The expert members we have consulted to produce this submission have expressed a range of views on the categories of treatment and consent requirements outlined in the Act. Whilst some consider that these categories and associated requirements are appropriate, others have outlined that they find the distinction between different levels of treatment unnecessary and potentially confusing given that ethically, consent is required for all medical interventions.

#### **Question 4.6: Person responsible**

**4.6.1 Is the "person responsible" hierarchy appropriate and clear? If not, what changes should be made?**

The RACP is of the view that the "person responsible" hierarchy is appropriate and clear.

**4.6.2 Does the hierarchy operate effectively? If not, how could its operation be improved?**

The RACP is of the view that the "person responsible" hierarchy operates effectively. However, it would be useful for the Tribunal to develop some guidelines around points c) "a person who has care of the patient" and d) "a close friend or relative of the patient" of the hierarchy.

#### **Question 4.7: Factors that should be considered before consent**

**Are the factors a decision-maker must consider before consenting to treatment appropriate? If not, what could be added or removed?**

The RACP finds the factors a decision-maker must consider before consenting to treatment appropriate overall.

#### **Question 4.8: Requirement that consent be given in writing**

**Is the requirement that consent requests and consents must be in writing appropriate? If not, what arrangements should be in place?**

The RACP find the requirement that consent requests and consents must be in writing appropriate.

#### **Question 4.9: Supported decision-making for medical and dental treatment decisions**

**4.9.1 Should NSW have a formal supported decision-making scheme for medical and dental treatment decisions?**

Supported decision-making is relevant to the work of many specialist physicians 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 *Improving Care at the End-of-life care: Our roles and responsibilities*<sup>4</sup> 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 the view 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.<sup>5</sup> We recommend 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 practitioners 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.
- 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.

### 4.9.2 If so, what should the features of such a scheme be?

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 any changes must take into account the need for timely decisions in areas such as end-of-life care.

## Question 4.10: Consent for sterilisation

### 4.10.1 Who, if anyone, should have the power to consent to a sterilisation procedure?

The RACP's view is that clinical decision making with respect to fertility control for people without decision-making capacity must be made as though treating a person with decision-making capacity.

People without decision-making capacity have the same right to the full range of options to manage their fertility as people with decision-making capacity. Recommended treatment options must always be the least restrictive and in the person's best interests. The most appropriate treatments are reversible ones and these will always be preferred to surgical procedures that are not reversible, such as sterilisation (i.e. vasectomy and tubal ligation). As such, reversible treatments including subdermal progestogen implants and progestogen intrauterine system should always be considered preferential treatments. It is worth noting that these two options may not be appropriate for all patients and that consideration should be given to the person's capacity

to provide information about their experience of the treatment (e.g. side effects). In addition, the administration of treatment to a person without decision-making capacity must be in accordance with the current law and guardianship provisions of the relevant jurisdictions.

Please also refer back to our detailed comments in relation to question 4.9.1.

#### **Question 4.11: Preconditions for consent to sterilisation**

##### **What matters should the NSW Civil and Administrative Tribunal be satisfied of before making a decision about sterilisation?**

The RACP is of the view that the factors the NSW Civil and Administrative Tribunal must consider to be satisfied prior to sterilisation (i.e. that it is the most appropriate form of treatment for promoting and maintaining the patient's health and wellbeing and that it is necessary to save the patient's life or prevent serious damage to the patient's health) are appropriate.

Please also refer back to our detailed comments in relation to question 4.9.1.

#### **Question 4.13: Legislative recognition of advance care directives**

##### **4.13.1 Should legislation explicitly recognise advance care directives?**

The RACP is of the view that NSW legislation should explicitly recognise advance care directives as is done in most other Australian states and territories. One of the recommendations the RACP made in its position statement, End-of-life care: Our roles and responsibilities,<sup>6</sup> is that the legislations on advance care directives should be harmonised across jurisdictions.

#### **Question 4.14: Who can make an advance care directive**

##### **Who should be able to make an advance care directive?**

The RACP agrees with the common law principles that an individual needs to have decision making capacity in order to make a valid advance care directive; that it needs to be made voluntarily and in the absence of any factors that could invalidate it such as misrepresentation or undue influence.

On a broader level, the RACP is of the view that advance care planning is an important process for all patients with life-limiting illnesses including children and young people. In this respect, we support the Australian and New Zealand Intensive Care Society (ANZICS)'s view on advance care directives in paediatric practice which is outlined in Chapter 9 of the *ANZICS statement on care and decision-making at the end of life for the critically ill*.<sup>7</sup>

*“Advanced Care Directives have less relevance in paediatric practice compared with adult practice as:*

- *children do not usually have the capacity to communicate their future treatment choices*
- *their substitute decision-makers are usually the parents and they are almost always present when treatment decisions need to be made.*

*On the other hand, many children do suffer from chronic, life-limiting illnesses and for these children a reasoned discussion in the cold light of day with the child's regular physician to explore what the parents/guardians and child might consider reasonable future treatment options is helpful. Documentation of the outcome of such discussions will also provide helpful information to an ambulance crew or emergency department staff if a child has agreed treatment limitations or even palliative care at home needs urgent transfer to hospital.”*

#### **Question 4.15: Form of an advance care directive**

##### **What form should an advance care directive take?**

The main purpose of an advance care directive is to help ensure that an individual's choices are respected for future medical treatment. Its primary role is in making the individual's beliefs, values and preferences known in order to guide future care in the event that the person is unable to make decisions or communicate.

This process can be done formally in writing but it can also be done informally through discussions with family members, carers and health professionals.

Although having a written advance care directive is generally preferable, the RACP is of the view that all individuals should have the opportunity to make their care and treatment preferences known. Thus, more

informal ways of making these care and treatment preferences known (e.g. orally, in informal discussions) are also valuable and should be taken into account as long as the criteria outlined in question 4.14 are upheld.

#### **Question 4.16: Matters an advance care directive can cover**

##### **What matters should an advance care directive be able to cover?**

The purpose of an advance care directive is to document an individual's expression of wishes and preferences for treatment. The RACP is of the view that the range of matters that can be covered by an advance care directive should not be prescriptive as such a directive needs to enable individuals to include all the issues which they feel may impact on their future care in the event that they become unable to make decisions or communicate. Nonetheless, it may be useful for the Act to include some guidance about the matters an advance care directive can cover for those not familiar with the field and the legal implications.

It is also important to note that advance care directives are only to guide patients' preferences regarding consent or refusal for specific treatments and that they cannot bind or obligate a physician to offer treatments that they do not believe will be of benefit to the patient.

#### **Question 4.17: When an advance care directive should be invalid**

##### **In what circumstances should an advance care directive be invalid?**

The RACP is of the view that the examples outlined in Question Paper 5 regarding the specific circumstances under which an advance care directive would be invalid are useful. In addition to these, we would add that in order to be considered valid, it needs to "have been made voluntarily and in the absence of any factors that could invalidate it such as misrepresentation or undue influence" as outlined in our response to Question 4.14.

#### **Question 5.6: Requirements after consent**

##### **What should researchers be required to do after consent is obtained?**

The RACP supports National Health and Medical Research Council, *National Statement on Ethical Conduct in Human Research* (2007) (updated May 2015) which states that even when a substitute decision-maker has consented, a researcher should still explain to the patient what the research is and what their participation will involve, to the extent this is possible.

#### **Question 7.4: Defining restrictive practices**

##### **How should restrictive practices be defined?**

The RACP supports the definition outlined in the Australian Department of Social Services' *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* (2013) 4: "any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with disability, with the primary purpose of protecting the person or others from harm".<sup>1</sup>

#### **Question 7.5: When restrictive practices should be permitted**

##### **In what circumstances, if any, should restrictive practices be permitted?**

The RACP is of the view that restrictive practices should only ever be used as a last resort with the primary purpose of protecting the person or others from harm as outlined in the Australian Department of Social Services' *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* (2013).

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## References

- <sup>1</sup> The Royal Australasian College of Physicians (2016), Submission to the NSW Law Reform Commission Question Paper 1 *Preconditions for alternative decision-making arrangements*. <https://www.racp.edu.au/docs/default-source/advocacy-library/racp-submission-to-the-review-of-the-guardianship-act-1987---question-1-preconditions-for-alternative-decision-making-arrangements.pdf> [Retrieved 27 April 2017]
- <sup>2</sup> The Royal Australasian College of Physicians (2017), Submission to the NSW Law Reform Commission Question Paper 2 *Decision making models*. <http://www.lawreform.justice.nsw.gov.au/Documents/Current-projects/Guardianship/Submissions/GA66.pdf> [Retrieved 27 April 2017]
- <sup>3</sup> Right 7 – Right to Make an Informed Choice and Give Informed Consent 4) “Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where:
- a) It is in the best interests of the consumer; and
  - b) Reasonable steps have been taken to ascertain the views of the consumer; and
  - c) Either:
    - i. If the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or
    - ii. If the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.”
- [http://www.hdc.org.nz/the-act--code/the-code-of-rights/the-code-\(full\)](http://www.hdc.org.nz/the-act--code/the-code-of-rights/the-code-(full)) [Retrieved 27 April 2017]
- <sup>4</sup> The Royal Australasian College of Physicians (2016), Improving Care at the End of Life: Our Roles and Responsibilities. <https://www.racp.edu.au/docs/default-source/advocacy-library/pa-pos-end-of-life-position-statement.pdf> [Retrieved 27 April 2017]
- <sup>5</sup> Then, Shih-Ning (2013) Evolution and innovation in guardianship laws: Assisted decision-making. Sydney Law Review, 35
- <sup>6</sup> The Royal Australasian College of Physicians (2016), Improving Care at the End of Life: Our Roles and Responsibilities. <https://www.racp.edu.au/docs/default-source/advocacy-library/pa-pos-end-of-life-position-statement.pdf> [Retrieved 27 April 2017]
- <sup>7</sup> The Australian and New Zealand Intensive Care Society (ANZICS) (2014), ANZICS statement on care and decision-making at the end of life for the critically ill. Edition 1.0. See Chapter 9 ‘Infants and Children’, p.116-117. [www.anzics.com.au/Downloads/ANZICS%20Statement%20on%20Care%20and%20Decision-Making%20at%20the%20End%20of%20Life%20for%20the%20Critically%20Ill.pdf](http://www.anzics.com.au/Downloads/ANZICS%20Statement%20on%20Care%20and%20Decision-Making%20at%20the%20End%20of%20Life%20for%20the%20Critically%20Ill.pdf) [Retrieved 6 April 2017]