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NSW Law Reform Commission
GPO Box 31
SYDNEY NSW 2001

By email: nsw-lrc@justice.nsw.gov.au

Dear Commissioners

Review of the Guardianship Act 1987
Question Paper 5: Medical and dental treatment and restrictive practices

Avant welcomes the opportunity to provide input into the Law Reform Commission's review question 5.

Avant Mutual Group Limited ("Avant") is Australia's largest medical defence organisation, and offers a range of insurance products and expert legal advice and assistance to over 72,000 medical and allied health practitioners and students in Australia.

We provide these comments based on our experience educating and advising our members on a range of issues including the application of the *Guardianship Act* in NSW and similar laws in other jurisdictions around Australia.

General Comments

In general we agree with updating the legislation to ensure that it reflects contemporary practice, both with respect to acceptable clinical practice and as it relates to the rights of people with disabilities and supported decision-making.

Legislation should not be a barrier to appropriate and ethically acceptable clinical practice. Where it does present a barrier, it should be amended so it is in line with acceptable clinical practice.

We believe that consideration should be given to enacting a new statute to cover medical treatment decisions generally, to include withholding and withdrawing life sustaining treatment and advance care directives, rather than having these provisions in the *Guardianship Act*.

We provide the comments below on several of the consultation questions, grouped by category.

Capacity (question 2.1)

As a national organisation we support national consistency of approach in legislation and national consistency of terminology.

Capacity is a legal concept, and doctors and other health care practitioners play an important legal role in applying the legal test in a clinical context. Capacity is decision-specific, and people may have capacity for some decisions and not others. What will differ is the application of the legal test in particular circumstances.

Having different definitions of capacity and incapacity can cause confusion. To ensure consistency and to avoid confusion, we believe that the same legal test for capacity should apply whatever decision is being made by a person.

We believe it would be useful for the legislation to contain a positive test of capacity (similar to the test contained for example in section 4 of the Victorian *Medical Treatment Planning and Decision Act 2016*) that outlines when a patient has capacity, rather than a negative test of incapacity. In our view this would be of more assistance to those who need to apply the test in practice.

Withholding and withdrawing life sustaining treatment (question 3.1)

We agree that the Act lacks clarity about the ability of a substitute decision-maker to make decisions withdrawing or withholding life sustaining treatment, and that conflicting Tribunal decisions cause confusion.

For the sake of clarity, we believe that the legislation should confirm that a substitute decision-maker can decide to withhold or withdraw life-sustaining treatment. This could be done by:

- Including in the definition of "medical treatment decision" a decision to withhold or withdraw life-sustaining treatment including artificial nutrition and hydration (similar to the legislation in Queensland, the ACT and South Australia); and/or
- Confirming that a substitute decision maker can make a decision to withhold or withdraw life-sustaining treatment including artificial nutrition and hydration.

Removing and using human tissue

The interrelationship between the *Human Tissue Act* and the *Guardianship Act* is confusing. In some circumstances the "senior available next of kin" or "next of kin" is the appropriate decision-maker, and in others, such as under section 21Z of the *Human Tissue Act*, the person responsible is referred to. Many doctors believe that in general the next of kin has legal status and is the correct substitute decision-maker.

In our experience the different terminology and different tests for the correct decision-maker can cause confusion for health practitioners, patients and their families. Where-ever the provisions relating to consent to the removal of tissue from a person without decision-capacity are, the legal test and terminology should be the same. Our preference is to use the language of the "person responsible".

It seems to us that part of the problem of the application of the Act in circumstances involving withdrawing and withholding treatment and consent to remove human tissue stems from the objects of part 5, particularly section 32(b). This section

requires that the proposed treatment promote or maintain the patient's health and wellbeing and it has been interpreted in the case law as outlined in the Discussion Paper. Consideration should be given to amending this provision of the Act so that it is does not result in the unintended consequence that it becomes a legal barrier to appropriate and ethically acceptable clinical practice.

Treatment by a registered health practitioner

We agree with the proposal in question 3.3 that the definition of medical and dental treatment in Part 5 of the Act include treatment by a registered health practitioner.

Consent to medical and dental treatment (questions 4.1-4.5; 4.8)

In our experience, the distinction between special, major and minor treatment is confusing and difficult to apply in practice. The distinction is further complicated by exclusions from the Part 5 regime outlined on pages 6-7 of the Discussion Paper.

It is not clear whether the inclusions within the definitions have kept up (or will continue to keep up) with clinical practice and we recommend that clinical input be obtained in amending the definitions to ensure they are current.

Other confusing aspects of the regime are:

- The definition of "special treatment" includes treatment that "has not yet gained the support of a substantial number of specialists in the relevant practice area". It is not clear whether this is intended to refer to experimental treatment. There are treatments that doctors use (for example off label use of medication) that may be accepted as competent practice by a group of practitioners that falls short of "substantial". This could also overlap with medical research and clinical trials.
- The Discussion Paper notes that for most special treatments, under section 45(3) the Tribunal must be satisfied that the treatment is necessary to save the patient's life or to prevent serious damage to the patient's health. Yet section 37(1)(a)-(b) permits a doctor to carry out special treatment without consent in these circumstances.

Question 4.8 asks about written consent. There may be situations where a patient cannot provide written consent, so at a minimum there should be a requirement that consent be documented.

Person responsible (question 4.6)

In our experience, the person responsible hierarchy within the legislation is reasonably clear. However, in our view there are two main issues that reduce the effective operation of the hierarchy:

1. A lack of knowledge among medical practitioners of the existence of the hierarchy and how it applies in practice. As noted above, in our experience many doctors believe that the "next of kin" is the appropriate substitute decision-maker for medical treatment decisions.

2. There is no guidance within the section to determine who has decision-making authority where there are two or more people at the same level of the hierarchy.

Advance care directives (questions 4.13-4.17)

One of the advantages of the current system for the regulation of advance care directives in NSW (common law supported by comprehensive guidelines) is its flexibility. The guidelines approach allows practitioners the scope to consider the patient's individual circumstances and exercise clinical judgment, and is more easily able to adapt to changing standards of medical practice.

While we believe that the NSW Health Guidelines are very helpful in assisting practitioners in navigating this area, in our experience, practitioners are uncertain about their obligations. Doctors are often challenged ethically by the implications of an advance care directive. In general doctors feel very uncomfortable about proceeding on the basis of a document that indicates the patient is refusing treatment. Practitioners express concern about providing increasing pain relief and sedation in the terminal phases of illnesses because of the concern that they may be subject to prosecution.

On balance our view is that there should be legislative recognition of advance care directives in NSW.

The legislation needs to provide a clear framework within which patients and doctors can operate, and provide an appropriate balance between prescription and flexibility.

Avant supports a nationally consistent approach to end of life decision-making. Each state and territory in Australia has a different legal framework for end of life decision-making. As a result there are different terms for similar concepts. For example, in the context of advance care planning, although advance care directives (ACD) are used in all states and territories, the terminology, format, documentation requirements, how the ACD applies and even the hierarchy of substitute decision-makers differ markedly from state to state.

In 2012, the Senate Community Affairs References Committee's report, Palliative Care in Australia, found that differences in state and territory legislation and complexities with advance care planning were hampering greater take-up. The Senate Committee recommended that "national model legislation for advanced care planning be developed, and that all governments pursue harmonisation of legislation as a high priority".

We support the development and use of consistent terminology across Australia as a matter of priority. The legislative framework should be clear in its application and should facilitate appropriate end of life decision-making. We believe that the legislation around Australia that impacts on end of life choices should be harmonised.

The National Framework for Advance Care Directives (National Framework) released in 2011 and the Australian Commission on Safety and Quality in Health Care's National Consensus Statement: Essential elements for safe and high-quality end of life care are a useful start towards a nationally consistent approach to end of life care.

Clinical trials

Clinical trials are one type of medical research, which rests on a spectrum from minor clinical innovations to phase two and three clinical trials. Thus the definition of "clinical trial" in the Act is much narrower than the broad types of medical research in which a person with limited decision-making capacity might be involved.

We query the need for the Tribunal to have oversight of clinical trials for people without decision-making capacity, given the comprehensive ethical framework and processes for human research under the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* referred to in the Discussion Paper.

Please contact me on the details below if you require any further information or clarification of the matters raised in our submission.

Yours sincerely

Georgie Haysom
Head of Advocacy

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