

sub #13



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**Health and Disabilities Committee**  
**Queensland Law Reform Commission Recommendations**  
**on Guardianship Laws Inquiry**

**Submission**  
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We make this submission as academics with a research interest in the areas of guardianship law and advance directives. Our submission is also informed by ongoing engagement with medical and health professionals in relation to these issues during the course of our research. We note too that both of us have had involvement in law reform in the guardianship context.<sup>1</sup> It is against that background that we make the following comments on the Issues Paper.

We note that we have already participated in this Review in other capacities. Lindy Willmott provided a verbal briefing to the Committee on 14 November, and Ben White presented at the public forum on 30 November. Those presentations afforded the opportunity to comment on issues in some detail. The goal of this submission is more narrow: to respond succinctly to the specific questions raised in the Issues Paper released by the Committee in November.

Further, for the purposes of brevity, in this submission, we will refer to other research we have undertaken where we have engaged in a more detailed discussion of the issues we raise. For the convenience of the Committee, we include a reference list of these articles at the end of this submission.

As a final point, we should mention that unless we indicate to the contrary, we generally support the position taken by the Queensland Law Reform Commission (QLRC) and adopt their reasoning in relation to the various issues dealt with below. Again, for the sake of brevity, the reasoning of the QLRC will not be re-iterated in this submission.

### **General Comments**

#### **An important opportunity for law reform**

At the outset of this submission, we wanted to note that we are pleased to see this area of law receiving such close consideration with a view to its improvement. A great deal of work has been done over a number of years to try and deal with problems in this area of law and this review provides an important opportunity to address them.

The authors of this submission first made a call for reform in this area in 2005 with the publication of an Issues Paper: B White and L Willmott, *Rethinking Life-Sustaining Measures: Questions for Queensland*. This paper identified 14 problems with the law that governs withholding and withdrawing life-sustaining measures (including some issues that arise more generally for advance health directives (AHDs)). Most of the issues being considered by the Committee in this area were ones identified in that paper. That research was supported by an expert advisory group, submissions from interested parties and a number of forums where people had an opportunity to share their views.

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<sup>1</sup> Ben White was a member of the Queensland Law Reform Commission when it completed its Guardianship Report in 2010. However, his views in this submission are those of an academic researching in the area.

Later in 2005, the Attorney-General asked the QLRC to undertake a review of the guardianship legislation and specifically directed the QLRC to consider the issues of withholding and withdrawing life-sustaining measures and AHDs. These issues were part of Stage 2 of the QLRC's review and were reported on in its September 2010 report. The QLRC had a further opportunity to consult widely to inform its ultimate recommendations.

These issues are now being considered by the Health and Disabilities Committee of the Queensland Parliament. We note this history to observe that the Committee's review is an important opportunity to capitalise on the work done to date, and to improve the law in this area. Many of these issues have been identified as problematic for some years and so this review presents an opportunity to address known issues in this area of law.

### **Key values for law reform in this area**

Before turning to the specific questions posed in the Issues Paper, we identify what we consider to be the key values for undertaking law reform in this area. We consider there is merit in expressly identifying the values that should underpin the law in this area to inform decision-making about law reform. We believe that there is general consensus that the below list of values are relevant to decisions in this area. There may, of course, be different views as to the relative importance of these values and how they should be translated or reflected in law.

- **Autonomy or self-determination** – a person should be able to make choices about their life, including whether or not they would accept treatment.
- **Sanctity of life** – human life is important and the State has a role in protecting the lives of its citizens.
- **Dignity** – this can mean a range of things but of significance in this context are questions about a person's dignity if he or she is being kept alive artificially through burdensome treatment.
- **Equality** – decision-making about health care should not be discriminatory. One application of equality is ensuring that people with disabilities have the same rights to health care as anyone else. Assessments of a person's quality of life in making end of life decisions can also give rise to issues of equality.
- **High quality decision-making by the adult, substitute decision-maker and health professionals** – decisions involving advance directives and/or withholding or withdrawing life-sustaining measures are very important. The law should establish a framework that promotes high quality decision-making by all those involved.
- **Clear, accessible, consistent law** – these values are important for this area of law as it is intended to be used by the community without regular recourse to legal advice, QCAT or the Supreme Court. The law should be such so that members of the community are capable of knowing and following their legal rights and responsibilities. Some of the ways in which the current law is inconsistent with these values are discussed in: L Willmott, B White, M Parker, C Cartwright, 'The

legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 2 (Queensland)' (2011) 18 *Journal of Law and Medicine* 522.

- Fair, transparent, efficient dispute resolution – where disputes arise, as they sometimes will, the law needs to establish a framework for resolving those disputes in accordance with these values.

One observation we make at this point is to note the conflict that can sometimes arise between a person's right to self-determination and the State's interest in the sanctity of life. When considering how these conflicting principles should be resolved, the courts have uniformly concluded that the self-determination should prevail over the sanctity of life. In the landmark decision of *Airedale NHS Trust v Bland*, Lord Goff stated the following:<sup>2</sup>

First, it is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so ... To this extent, the principle of the sanctity of human life must yield to the principle of self-determination ... Moreover the same principle applies where the patient's refusal to give his consent has been expressed at an earlier date, before he became unconscious or otherwise incapable of communicating it ...

Recent Australian case law – *Brightwater Care Group (Inc) v Rossiter*<sup>3</sup> and *Hunter and New England Area Health Service v A*<sup>4</sup> – has confirmed this is also the approach taken in this country. We support this approach: see L Willmott, B White, B Mathews, 'Law, Autonomy and Advance Directives' (2010) 18 *Journal of Law and Medicine* 366.

#### **QLRC Recommendations 9.22-9.25**

In chapter 9 of the QLRC Report, the QLRC made recommendations about sections 116 and 117 of the PAA. These provisions give power to the Supreme Court and QCAT to, among other things, change the terms of an AHD and to revoke all or part of an AHD. We note that the QLRC was split over whether the Court or QCAT should retain powers to amend terms or revoke an AHD. We further note that these recommendations did not form part of the terms of reference of this Committee. In the view of the authors, these provisions have implications for the ability of the adult to exercise his or her self-determination in relation to health care and therefore could logically have formed part of the terms of reference of the Committee.

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<sup>2</sup> [1993] AC 789, 864. These comments were referred to in *Re AK (Medical Treatment: Consent)* [2001] FLR 129, 133-134 (Hughes J) and *HE v A Hospital NHS Trust* [2003] 2 FLR 408, 416 (Munby J). See also *Re T (Adult: Refusal of Treatment)* [1993] Fam 95, 112 (Donaldson J).

<sup>3</sup> [2009] WASC 229.

<sup>4</sup> (2009) 74 NSWLR 88.

The authors adopt the minority position taken by the QLRC, namely that the Court or QCAT should not have the power to alter the terms or revoke an AHD in full or in part. This right does not exist at common law, and there is no justification for eroding the autonomy of an adult by allowing previously expressed wishes in an AHD to be overturned through the exercise of this power. Judicial and quasi-judicial bodies should not have the power to override previously expressed views of an adult which may, effectively, have the result that an adult receives treatment that he or she has previously rejected.

The QLRC has made a number of recommendations to alter the POA and GAA which will enhance a competent adult's right to self-determination in relation to medical treatment. The removal of powers under sections 116 and 117 as suggested above is consistent with this approach.

## **Chapter 2 - Advance Health Directives**

### **General comments**

A preliminary observation is to note the critical importance of the perspectives of individuals who complete AHDs. While the views of various interest groups and doctors are readily accessible, it is far more difficult to elicit the views of ordinary members of the public who have decided to complete such a document. Yet we consider that these perspectives are particularly crucial to decisions about what the law in this area should be.

An example is whether a doctor should be able to override an AHD on the basis of good medical practice (Question 6 below). Our experience has been in presenting to a wide range of diverse audiences that people complete AHDs with an expectation that they would be followed and so are generally shocked and unhappy that their AHD can be overridden in this way. But these sorts of perspectives, which we consider are important and valid ones when considering law reform, can only be obtained by engaging with individual members of the community.

As mentioned, accessing these perspectives can be difficult (although we see the Committee is seeking to engage in a wide consultation exercise). To this end, we note that there is some recent research, of which the authors were part, that examined how AHDs were used and perceived by members of the community. Some of the findings of this research may be useful to shed some light on these perspectives: C Tilse, J Wilson, A-L McCawley, L Willmott, B White, *Enduring documents: improving the forms, improving the outcomes* (2011), Part C.

### **Responses to questions**

1. Should the POA Act be amended to clearly state that an advance health directive can not operate if the directive is uncertain or if circumstances have changed to the extent that, had the patient known of the changed

circumstances they would think the advance health directive was inappropriate?

The authors agree that the POA should be amended to make it clear that an AHD should not operate if it is not sufficiently certain or if circumstances have changed to the extent that, had the patient known of the changed circumstances, they would have considered the terms of the direction are inappropriate.

2. Would the proposed obligation on health and disability services improve health providers' access to and awareness of advance health directives and enduring powers of attorney?

There needs to be an increased emphasis on ensuring directions given in an AHD are brought to the attention of those who are providing health care to the adult. We therefore endorse the proposal of the QLRC to impose obligations on those in charge of hospitals, residential aged care facilities and residential disability services to make inquiries as to whether an adult has an AHD. We also support the recommended obligation in relation to enduring powers of attorney for health matters.

3. What impact would the proposal have on hospitals, residential aged care and residential disability facilities and health providers?

The authors are of the view that it is good practice for the person in charge of a health care facility to make inquiries about whether an adult entering their facility (patient or resident) has an AHD. It is also good practice for a health provider or person working in the facility who becomes aware of the existence of the AHD (or the other matters referred to by the QLRC in its recommendation) to advise the person in charge of the facility of this information. The imposition of the obligations recommended by the QLRC requires such facilities to put systems in place to ensure these two obligations are carried out. Once these systems are in place and staff are familiar with their obligations, this reform should not be resource intensive. The authors note that the QLRC recommends only that 'reasonable steps' need be taken by the health care facility, which again is relevant to an assessment of the impact of these obligations.

4. Should a health provider be required to consult with an attorney appointed under an enduring power of attorney before forming a reasonable belief that a direction in an advance health directive is uncertain (consistent with the current legislation, to consult with an attorney appointed under an advance health directive)?

Yes, the obligation of a health provider to consult with an attorney appointed under an enduring power of attorney for health matters should be the same as the obligation that applies to an attorney appointed under an AHD. This includes whether the attorney is named in the AHD or not.

5. Should the protection for a health provider who does not follow a direction in an advance health directive because of changed circumstances be modified so that it is a valid reason only if the adult would have thought their direction to be inappropriate if they had known of the change in circumstances?

Yes, the protection for a health provider for not following a direction in an AHD should only be available if the adult, rather than the health provider, would have thought that the direction in the AHD was inappropriate because of the changed circumstances. Further discussion of this issue can be found in: L Willmott, B White and M Howard, 'Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment' (2006) 30 *Melbourne University Law Review* 211 at 230.

6. Should the protection for a health provider who does not follow a direction in an advance health directive because he or she believes it is inconsistent with good medical practice be omitted?

Yes, it is critical for this protection to be omitted from the legislative regime as it deprives a competent adult who completes an AHD the right of self-determination. It is further noted that this protection does not exist at common law or in other Australian jurisdictions. See further discussion in: B White and L Willmott, *Rethinking Life-Sustaining Measures: Questions for Queensland* (2005) pp45-47 and L Willmott, B White and M Howard, 'Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment' (2006) 30 *Melbourne University Law Review* 211 at 230.

### **Chapter 3 - Common law right to consent or refuse treatment - impact of the guardianship legislation**

#### **General Comments**

Legislation that facilitates the making of a statutory advance directive was passed in most Australian jurisdictions to address legal uncertainty about whether a competent adult could make an advance directive that refuses life-sustaining treatment that would be binding on health professionals if that adult later lost decision-making capacity. It was also thought to be needed to protect health professionals who followed the advance directive and, as a result, the adult died.

For a detailed account of the Parliamentary debates relevant to the enactment of advance directive legislation in the various Australian jurisdictions, see: L Willmott, 'Advance Directives and the Promotion of Autonomy: a Comparative Australian Statutory Analysis' (2010) 17 *Journal of Law and Medicine* 556.

It would be a preferable outcome for the statutory regimes to co-exist with the common law regime. If, therefore, a directive did not comply with the formal requirements of the legislation, it may still inform or dictate treatment that is provided or not.

## Responses to questions

7. Should the guardianship legislation be amended to ensure that common law rights to consent to or refuse health care are not affected by the legislation?

Yes, the guardianship legislation should be amended to ensure that common law rights to consent to or refuse health care are not affected by the legislation. This would reflect the proposal of the QLRC when it originally recommended the enactment of legislation, and the intention of Queensland Parliament when the POA was originally enacted.

See the further discussion in: B White and L Willmott, 'Will you do as I ask? Compliance with instructions about health care in Queensland' (2004) 4 *Queensland University of Technology Law and Justice Journal* 77.

## **Chapter 4 - Decisions to withhold or withdraw a life-sustaining measure**

### Responses to questions

8. Should any limitations on the effect of decisions about health care be more clearly stated in the body of the Act, rather than in a definition?

The authors consider that the definition of health care should be amended in the manner suggested by the QLRC. We note that the current definition leads to a range of problematic outcomes. Some of these are mentioned in the QLRC report but there are also others outlined earlier in: B White and L Willmott, *Rethinking Life-Sustaining Measures: Questions for Queensland* (2005) 73-76.

We note also the implications that this definition has for QCAT when making decisions about such matters: L Willmott and B White, 'Charting a course through difficult legislative waters: Tribunal decisions on life-sustaining measures' (2005) 12 *Journal of Law and Medicine* 441 at 446-7, 450.

9. Should it be an offence to withhold or withdraw a life-sustaining measure without consent or authorisation when continuation or commencement of the life-sustaining measure would not be inconsistent with good medical practice?

The authors comment below on whether health providers should be required to obtain consent to withhold or withdraw treatment when to provide such treatment is inconsistent with good medical practice.

10. Should the limitations on when a direction in an advance health directive to withhold or withdraw a life-sustaining measure can operate be omitted?

Yes, the limits set out in section 36(2) PAA should be omitted. For a detailed examination of the limitations set out in section 36(2) and the implications of those



limitations on an individual's right to self-determination, see: L Willmott, 'Advance Directives to Withhold Life-Sustaining Medical Treatment: Eroding autonomy through statutory reform' (2007) 10 *Flinders Journal of Law Reform* 287, and see also B White and L Willmott, *Rethinking Life-Sustaining Measures: Questions for Queensland* (2005) 30-34.

11. Should the limitations on a direction to withhold or withdraw artificial nutrition or hydration be treated differently to other life-sustaining measures?

No, the limitations on a direction to withhold or withdraw artificial nutrition and hydration should be treated in the same way as other life-sustaining measures. We discuss concerns about treating artificial nutrition and hydration differently from other forms of life-sustaining medical treatment in: B White and L Willmott, *Rethinking Life-Sustaining Measures: Questions for Queensland* (2005) 30-34.

12. Should the limitations on operation of a substitute decision maker's consent to withhold or withdraw a life-sustaining measure be omitted?
13. Alternatively, if a substitute decision maker's consent cannot operate under s.66A of the GAA Act, should the legislation allow the health provider to refer the decision to the adult guardian to make a decision (if the adult guardian is the guardian for the adult, for the Tribunal to make a decision)?

We believe that the current limitation in section 66A should be removed. Our concerns about a health provider effectively having a 'right of veto' when a substitute decision-maker consents to the withholding or withdrawal of a life-sustaining measure are outlined in: B White and L Willmott, *Rethinking Life-Sustaining Measures: Questions for Queensland* (2005) 61-64.

We agree with the majority view of the QLRC that the Adult Guardian's existing powers are a sufficient safeguard against bad decision-making, and agree with the proposed addition of the specific provision alerting health providers and others to the existence of this power.

We note also the implications that section 66A has for QCAT when making decisions about such matters: L Willmott and B White, 'Charting a course through difficult legislative waters: Tribunal decisions on life-sustaining measures' (2005) 12 *Journal of Law and Medicine* 441 at 450.

14. Should consent be required to withhold (not commence) a medically futile life-sustaining measure?
15. Should consent be required to withdraw a medically futile life-sustaining measure that has been commenced?

The issue of whether there should be a legislative requirement to obtain consent before withholding or withdrawing treatment that a doctor regards as futile raises a

number of complex issues. We flag those issues that we feel require thorough consideration.

- a) Defining what is meant by 'futile treatment' is problematic.
  - i. This term can refer to treatment that is physiologically incapable of producing a particular outcome.
  - ii. More commonly, defining treatment as 'futile' requires a quality of life assessment. For example, because the quality of life of the adult will be so compromised even if this treatment is given, the treatment is regarded as futile. The authors also note that where quality of life assessments are made, doctors themselves may not be in agreement about whether treatment is futile. This can arise, for example, where a patient is admitted to hospital with a range of co-morbidities and a range of specialists are involved in the treatment of that one patient.
- b) Who should be the decision-maker where treatment is 'futile'?
  - i. Whether a patient is capable of benefitting from medical treatment in a purely physiological sense is a medical determination that would fall within the realm of expertise of a doctor only. For that reason, the authors believe that doctors are the appropriate decision-makers about such treatment, and should generally be able to withhold or withdraw this kind of treatment without obtaining consent of a substitute decision-maker. We note, of course, that good medical practice in such cases would still involve appropriate discussions with family members and others.
  - ii. Where futility assessment is made based on quality of life determinations, doctors do not have sole expertise. Indeed, the substitute decision-makers will generally have more insight into the views of the adult about what quality of life would be acceptable, and such insight would inform whether the adult would regard the treatment as futile. For these reasons, we think that decisions about futility (defined as above) should be made by substitute decision-makers.
- c) 'Futility' is an assessment unrelated to 'resourcing'
  - i. Whether particular treatment is futile for a particular patient requires an individual assessment of the circumstances of that patient. The factors that must be assessed are the patient's diagnosis, prognosis, as well as factors personal to that patient including their characteristics and views and wishes.
  - ii. This assessment is and must be unrelated to issues of resourcing. However, resourcing of health care is a critical issue that needs to be addressed as part of a broader discussion, as there are limits to the health care that can be provided. This point is addressed next.
- d) Broader context in which medical treatment is provided
  - i. Decisions about whether a patient should receive treatment are made in a context of limited resources. For example, there are a limited number of intensive care unit beds, there are a restricted number of human organs that are available for transplantation purposes and

- certain treatments are simply not available in some regional and rural areas.
    - ii. It is critical that there be transparent policies and guidance developed about the best use of health resources, agreement being reached after appropriate and extensive community and stakeholder engagement, including with medical and health professionals. These are important decisions for society as a whole to make.
    - iii. If this occurs, decisions about the provision of medical treatment for a patient will be determined by considering factors relevant to that patient alone, but within the broader regulatory framework which may operate to limit the options that are available for that particular patient.
- e) Conclusion – the authors have strayed outside the narrow question raised in the Issues Paper. However, we have done so because our suggestion regarding what the law should be – generally that substitute decision-makers must consent to the withholding or withdrawal of treatment – provides challenges for doctors if there is not a broader regulatory context in which systemic policies are developed about the use of health resources. If the Queensland law remains as is currently drafted (which is largely our recommendation), then the government in consultation with stakeholders (including the community) must develop such policies and guidance.

A paper which might be of interest that canvasses some of these issues is: J Downie and K McEwen, 'The Manitoba College of Physicians and Surgeons Position Statement on Withholding and Withdrawal of Life-Sustaining Treatment (2008): Three Problems and a Solution' (2009) 17 *Health Law Journal* 115-138.

16. Should 'withholding or withdrawing a life-sustaining measure' be omitted from the definition of health care for the purpose of s.67 of the GAA Act?

Yes, 'withholding or withdrawing a life-sustaining measure' should be omitted from the definition of health care for the purpose of section 67 GAA Act for the reasons articulated by the QLRC in its report.

17. Should the proposed new s.67A (above) be added to the GAA Act?

Yes, the new section 67A should be added to the GAA Act.

18. Should the Criminal Code be amended to remove any doubt that a health provider who withholds or withdraws a life-sustaining measure in accordance with the guardianship legislation is not criminally responsible?

Yes, the Criminal Code should be amended to remove this doubt. For more detail about why this issue needs to be clarified, see: B White, L Willmott and J Allen, 'Withholding and withdrawing life-sustaining treatment: criminal responsibility for established medical practice?' (2010) 17 *Journal of Law and Medicine* 849.

## Reference list

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