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4 April 2016

Dear Commissioner

Submission to the New South Wales Law Reform Commission *Review of the Guardianship Act 1987 (NSW)*

Executive summary

In this submission, we recommend the NSW Law Reform Commission's *Review of the Guardianship Act 1987* (NSW) include a specific term of reference relating to the law at end of life, including issues such as advance directives, capacity, withholding and withdrawing life-sustaining treatment and powers of substitute decision-makers. Specific areas for reform and recommendations are identified in this submission. Reform of problematic areas of the law at end of life is required to reduce complexity, uncertainty and knowledge gaps for both medical professionals and the community, and to improve their knowledge and understanding of the law at end of life.

Background

We are the Directors of the Australian Centre for Health Law Research (ACHLR), a specialist research Centre within the Queensland University of Technology's Faculty of Law. The Centre undertakes empirical, theoretical and doctrinal research into complex problems and emerging challenges in the field of health law, ethics, technology, governance and public policy.

End of life is one of the Centre's three research programs. Within that program, 10 of our Centre's 20 health law academics undertake research which explores legal, ethical and policy issues in death, dying and decision-making, including: withholding and withdrawing life-sustaining medical treatment; provision of futile treatment at the end of life; advance care planning; palliative care; euthanasia and assisted suicide; and coronial systems and regulation.

Our research has examined issues relating to death, dying and decision-making at the end of life in all Australian jurisdictions, including New South Wales (NSW). Two of our current Australian Research Council funded research projects include collaborative partnerships with the NSW Public Guardian, the NSW Civil and Administrative Tribunal and the Cancer Council New South Wales, and involve specific consideration of end of life law and practice in NSW. We therefore provide this

submission to outline some key areas of legal reform for the law at end of life in NSW which we have identified in our research.

Knowledge of the law at end of life in medical practice

The law in NSW governing decisions to withhold or withdraw life-sustaining treatment from adults who lack capacity is overly complex and unclear, creating unnecessary confusion and impeding legal knowledge of members of the community and medical professionals. While medical professionals play a critical clinical role in the provision of medical treatment at end of life, they also play a significant legal role by assessing a patient's capacity, determining the authorised decision-maker, and knowing whether a patient's previously expressed wishes comprise a valid advance directive.[1] Despite this, our research has identified that there are some critical knowledge gaps among doctors who practise in the end of life field.

Our survey of doctors from seven specialties in New South Wales, Victoria and Queensland (867 responses) found doctors do not possess sufficient legal knowledge in relation to aspects of the law such as the validity and effect of advance directives, and the authority of substitute decision-makers.[2] Significant consequences can flow to patients from a failure by doctors to know and comply with the law, such as life-sustaining treatment being unlawfully withheld or withdrawn.[3] Further, medical professionals could be criminally responsible where treatment is withheld or withdrawn unlawfully, or without consent.[4] Conflict may also arise where doctors and patients' families or friends have little or no legal knowledge, or different understandings of what the law requires.[5]

Our findings indicate that doctors involved in making end of life decisions, as well as the community, should improve their knowledge of the law.[6] Although enhancing medical professional's knowledge of the law is a complex issue, improving the law, through legal reform, is likely to assist. These issues and areas for reform are discussed further in our article Ben White, Lindy Willmott, Colleen Cartwright, Malcolm H Parker and Gail Williams, 'Doctors' knowledge of the law on withholding and withdrawing life-sustaining medical treatment' (2014) 201(4) *Medical Journal of Australia* 229-232, which we enclose for the Commission's consideration.

The law at end of life in NSW: Specific areas for reform

Given the issues identified in our study, we submit that that the Terms of Reference for the *Review of the Guardianship Act 1987* (NSW) should specifically include the law at end of life. Our research has identified significant issues for reform relating to the law at end of life in NSW, particularly in the areas of capacity, advance directives, withholding and withdrawing life-sustaining treatment from adults who lack decision-making capacity, and powers of substitute decision-makers. These issues

[1] Ben White, Lindy Willmott, Colleen Cartwright, Malcolm H. Parker and Gail Williams, 'Doctors' knowledge of the law on withholding and withdrawing life-sustaining medical treatment' (2014) 201(4) *Medical Journal of Australia* 229-232, 229.
[2] Ibid, 232.
[3] Ibid.
[4] Ibid.
[5] Ibid.
[6] Ibid.

are discussed comprehensively in the article Ben White, Lindy Willmott, Pip Trowse, Malcolm Parker and Colleen Cartwright, 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 1 (New South Wales)' (2011) 18(3) *Journal of Law and Medicine* 498-522, (which we attach for the Commission's consideration), however we provide the following overview of the key issues identified in that article:

1. Multiple and uncertain definitions of capacity

The determination of capacity is a threshold issue for medical treatment at end of life, perhaps most significantly when the issue of withholding or withdrawing life-sustaining treatment arises. The NSW law contains three possible definitions for determining whether an adult has capacity. The first is the common law definition of capacity (applied for advance directives) described in *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 at [25]. The other two definitions are contained in the *Guardianship Act 1987* (NSW): in section 14(1), which is relevant in determining whether a person is 'in need of a guardian' and in section 33(2), when determining whether a person is 'incapable of giving consent' for medical and dental treatment. The existence of multiple definitions is undesirable, confusing and creates uncesseary complexity. It is suggested that a single definition for capacity be adopted in the *Guardianship Act 1987* (NSW). We favour the definition giving effect to the functional approach to capacity. This reflects the least restrictive approach favoured by modern guardianship law.

2. Lack of statutory recognition of Advance Directives

New South Wales is one of only two jurisdictions in Australia that does not prescribe a statutory regime for an adult making an advance directive. Instead, the common law relating to advance directives is applied. We consider that a statutory advance directive framework for NSW would reduce uncertainty and improve the clarity of the law, which would assist medical professionals and the broader community to know and understand the law. The enactment of appropriately drafted legislation would also have the desirable effect of enhancing the role and recognition of advance directives as an expression of autonomy.

3. Withholding and withdrawing life-sustaining treatment from adults who lack capacity, and powers of substitute decision-makers

The *Guardianship Act 1987* (NSW) provides for substitute decision-makers to be empowered to make decisions in relation to *health care functions*, and in relation to *consenting to medical and dental treatment*. Whether or not a substitute decision-maker can consent to or refuse life-sustaining treatment depends on the type of decision-maker, and the nature and scope of their appointment.

Following the decision of *FI v Public Guardian* [2008] NSWADT 263, the power to refuse life-sustaining treatment can be exercised only by some substitute decision-makers empowered with **health care functions** (such as a guardian or enduring guardian, depending on the scope of their appointment), and not by those whose power extends only to **consenting (or withholding consent) to medical and dental treatment** (such as a person responsible, or a guardian who is granted more

limited power). This has resulted in an undesirable gap in the law, which may necessitate an application to the NSW Civil and Administrative Tribunal to determine the matter, or for the appointment of a guardian. These distinctions also create problems and further confusion for medical professionals as in practice they will need to know that these differences exist and to distinguish between decision-makers and the scope of their powers. It also broadens the possibility of inappropriate decision-making by someone who has not been specifically entrusted by the Tribunal or the adult with power to refuse life-sustaining treatment.

Further discussion of these issues is contained in our *Journal of Law and Medicine* article enclosed. Given the significance of these issues we consider the Commission's review of the *Guardianship Act 1987* (NSW) an opportune time to examine these and other areas for reform at the law at end of life in NSW.

Thank you for the opportunity to contribute to this review. We would be pleased to assist the Commission further if additional information is required.

Yours sincerely

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The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 1 (New South Wales)

Ben White, Lindy Willmott, Pip Trowse, Malcolm Parker and Colleen Cartwright*

This is the first article in a series of three that examines the legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment from adults who lack capacity. This article considers the position in New South Wales. A review of the law in this State reveals that medical professionals play significant legal roles in these decisions. However, the law is problematic in a number of respects and this is likely to impede medical professionals' legal knowledge in this area. The article examines the level of training medical professionals receive on issues such as advance directives and substitute decision-making, and the available empirical evidence as to the state of medical professionals' knowledge of the law at the end of life. It concludes that there are gaps in legal knowledge and that law reform is needed in New South Wales.

INTRODUCTION

Decisions to withhold or withdraw life-sustaining treatment from adults who lack capacity have complex ethical and clinical dimensions. The various Australian legal frameworks that govern such decisions are also complex and, in places, uncertain. This can make ascertaining the state of the law challenging; yet knowledge of the law in this area matters. Given the significant legal role that medical professionals play in such decisions, it is particularly important for them to know the law in this area. Without such knowledge, there is a risk of unlawful decision-making, the consequences of which can be significant for patients, families and the medical professionals themselves.

A SERIES OF THREE ARTICLES

This article is the first in a series of three on the topic of withholding and withdrawing life-sustaining treatment from adults who lack capacity. The authors make four claims in this series. The first is that, in addition to the involvement of medical professionals in the clinical assessment of the patient and

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her or his treatment options, they play a significant legal role in the decision-making process. At times, the treating medical professional may be the legal decision-maker who determines whether treatment should be provided or not. He or she may also play important legal roles in terms of how the law is applied, eg through an assessment of a patient's capacity or by determining who is entitled to be a substitute decision-maker. Finally, a medical professional's legal roles include a gatekeeping function to ensure appropriate treatment decisions are being made.

The second claim is that it is important that medical professionals know the law in this area. They have important legal roles to play so knowing the law is integral to their being able to fulfil these roles. A lack of knowledge can lead to non-compliance with the law which, as flagged above and explored in more detail below, may have adverse consequences for all involved.

The third claim of the series is that there are significant gaps in what medical professionals know of the law in this area. Only sparse evidence is available but that which exists suggests that medical professionals' legal knowledge is inadequate. As part of this inquiry, the extent to which law in this area is taught in medical schools and other formal training is considered.

The fourth and final claim is that the current state of the law is likely to impede medical professionals' knowledge. The law in this area is complex and sometimes uncertain or inconsistent. Further, the legal position in relation to some issues, although certain, conflicts with good medical practice. Finally, some judicial and other interpretations of the law have led to outcomes that might be regarded as unusual or counterintuitive. These features of the law make it challenging for medical professionals (and others) to ascertain the legal requirements in any given situation. This series of articles examines the law in three jurisdictions (one in each article): New South Wales, Queensland and Victoria. These three jurisdictions have been chosen primarily because they have been the subject of the most judicial and quasi-judicial decision-making in Australia in this field.[1]

This series of articles ultimately reaches two conclusions. The first is that law reform is needed. While the ease with which the law can be stated and known is not the sole criterion for reform, it is relevant when designing a legal framework. This is particularly so if it is expected that a group of legally untrained people such as medical professionals will need to know and apply the law. Although enhancing medical professionals' legal knowledge is a complex issue, improving the state of the law is likely to help.

The second conclusion is that more and better education of medical professionals is needed. These are important decisions and ways need to be found to support medical professionals involved in them to be aware of the legal framework. Consideration should be given to enhancing medical schools' engagement with these issues and also to the ongoing training available to medical professionals after university.

THE FIRST ARTICLE

The first article in this series is comprised of five parts. After the introduction in the first part, the second part sets the scene for the series as a whole and begins by establishing why medical professionals' knowledge of the law in this area matters. Of particular significance is that compliance

[1] In New South Wales, see eg *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88; *Krommydas v Sydney West Area Health Service* [2006] NSWSC 901; *Messiha v South East Health* [2004] NSWSC 1061; *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549; *WK v Public Guardian (No 2)* [2006] NSWADT 121; *BAH* [2007] NSWGT 1 (this decision was previously known as *Re AG* [2007] NSWGT 1); *FI v Public Guardian* [2008] NSWADT 263; *LE and LF v Public Guardian* [2009] NSWADT 78; *QAN* [2008] NSWGT 19.

In Queensland, see eg *Queensland v Astill* (unrep, Sup Ct, Qld, Muir J, 18 January 2006); *Re Bridges* [2001] 1 Qd R 574; *Re SAJ* [2007] QGAAT 62; *Re MHE* [2006] QGAAT 9; *Re HG* [2006] QGAAT 26; *Re MC* [2003] QGAAT 13; *Re TM* [2002] QGAAT 1; *Re RWG* [2000] QGAAT 2; *Re PVM* [2000] QGAAT 1.

In Victoria, see eg *Qumsieh v Pilgrim* (2000) 21(4) Leg Rep SL 3d (29 October 1999, 11 February 2000); *Qumsieh v Guardianship and Administration Board* [1998] VSCA 45; *Qumsieh v Guardianship and Administration Board* (unrep, Sup Ct, Vic, Beach J, 7 May 1998); *Slaveski v Austin Health* [2010] VSC 493; *Re Herrington* [2007] VSC 151; *Re BWV; Ex parte Gardner* (2003) 7 VR 487; *BK (Guardianship)* [2007] VCAT 332; *Korp (Guardianship)* [2005] VCAT 779; *EK (Guardianship)* [2005] VCAT 2520; *Public Advocate v RCS (Guardianship)* [2004] VCAT 1880.

with the law can be difficult in the absence of knowledge of it, and a failure to know and comply with the law can have serious consequences. The medical and legal factors that affect how these decisions are made are then examined. In the medical context, there are a range of situations where decisions to withhold or withdraw life-sustaining treatment can arise. One is where it is medically appropriate for treatment to be offered, although this category covers a spectrum of situations, as explained in this part. The other two medical situations are where the provision of the treatment is futile and where a decision to withhold or withdraw needs to be made in an emergency. The legal context involves considering how the law will apply in each of these three situations. The authors outline the relevant decision-making framework, which is primarily established by the guardianship legislation and has similar features across all three jurisdictions. The purpose of this part is to establish this wider foundation which will be drawn upon in this article and the two that follow.

The third part of the article then examines the law in New South Wales. It reviews the guardianship legislation and the Supreme Court's parens patriae jurisdiction as they apply to the three medical situations noted above. Of particular significance for this article, with its focus on legal knowledge of medical professionals, is to identify their relevant legal roles within those frameworks. This part also outlines the key problems in the law in this area.

The fourth part considers the limited empirical evidence available in New South Wales as to what medical professionals know of the law in this area. The authors are aware of only one study that has specifically examined this question, and it revealed deficiencies in medical professionals' understanding of the relevant legal decision-making framework. The extent to which medical professionals receive formal training on this topic both at and after medical school is also considered.

The article concludes by calling for law reform in New South Wales. Wider conclusions that span the series of articles, eg in relation to the need for more and better medical education, are considered in the third article.

TERMINOLOGY

One of the unsatisfactory consequences of States having different legislative regimes is the use of different terms for similar concepts. The key terminology in New South Wales, Queensland and Victoria for this series of articles is set out in Table 1, along with the generic term that is used when each concept is referred to generally.

TABLE 1 Key terminology, by State

Generic term	New South Wales	Queensland	Victoria
Adult (who now lacks capacity)	Patient, person under guardianship, person in need of a guardian, or appointor	Adult or principal	Patient, represented person, donor or appointor
Advance directive	Advance directive (recognised at common law only)	Advance health directive	Refusal of treatment certificate
Guardian (namely, a decision-maker appointed by the tribunal)	Guardian	Guardian	Guardian
Agent (namely, a decision-maker appointed by the adult)	Enduring guardian	Attorney	Agent or enduring guardian
Default decision-maker*	Person responsible	Statutory health attorney	Person responsible

*The term "person responsible" in New South Wales and Victoria is broader in scope than just a default decision-maker and this is discussed further in this article and in the third article.

Generally, when the law in a specific State is being examined, the relevant terminology of the jurisdiction is used. The one exception to this is references to the "adult". Given that there are a range

of different terms across the three States, an adult patient who lacks capacity from whom treatment may be withdrawn or withheld is referred to as the "adult".[2] The term "substitute decision-maker" is used as a generic term to cover all individuals who are authorised to make decisions on behalf of an adult.

MEDICAL PROFESSIONALS' LEGAL ROLE AND THE CONTEXT OF DECISIONS TO WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREATMENT

The purpose of this part of the article is to establish the foundation for the series of three articles. Before considering the medical context and the broad legal framework in which decisions to withhold or withdraw life-sustaining treatment from adults who lack capacity occur, the threshold issue of why medical professionals' knowledge of the law matters is considered.

WHY MEDICAL PROFESSIONALS' KNOWLEDGE OF THE LAW MATTERS

Medical professionals play a significant role in end-of-life decisions. They manage the patient's care and treatment and this includes providing information and advice about treatment options, risks and prognosis. But medical professionals also play significant legal roles. These are discussed in more detail over the course of this series of articles but critical legal functions include:

- the assessment of capacity;
- the identification of possible decision-makers (which can include the medical professional herself or himself); and
- determining whether a possible decision-maker possesses the legal power to make the relevant decision.

To fulfil these legal roles adequately, medical professionals need to know the law. Without knowledge of the relevant legal framework, compliance with the law by the medical professional may be difficult. Although it is possible, and often likely, that compliance with good medical practice and ethical obligations will also lead to legal compliance, this cannot be assumed. Indeed, as this series of articles shows, legal compliance will not always follow from adhering to sound medical and ethical practice because, at times, the law departs from such practice.[3]

Broadly speaking, a failure to comply with the law can occur in two ways in this area. Significant consequences for patients can flow from unlawful decisions in relation to both. The first situation is where life-sustaining treatment is unlawfully withheld or withdrawn. This could arise, eg, where the legal criteria for not providing treatment are not satisfied. It could also arise where the legal authority relied upon to not provide treatment is flawed because the purported decision-maker lacks legal authority. For patients, the outcome of such decisions is that, at least as a matter of law, their lives are being ended wrongly.

The second situation is where life-sustaining treatment is provided unlawfully. This can occur where treatment is provided despite a lawful refusal of treatment through an advance directive or by a substitute decision-maker. Again, this has significant implications for patients in that it may infringe their legal rights, including their right to bodily integrity.[4] The provision of such treatment can also cause patients to survive with a poor quality of life, a situation that they had sought to avoid.[5]

The unlawful provision or withholding and withdrawing of life-sustaining treatment also has significant consequences for medical professionals. There is potential for criminal responsibility to be

[2] Despite the use of the term "adult", it is noted that in New South Wales, the *Guardianship Act 1987* (NSW) applies in some respects to persons aged 16 years and older. However, this article only addresses the law so far as it relates to adults.

[3] Non-compliance with the law may also occur where medical practice is shaped by legally inaccurate guidelines or policy: Parker M et al, "Two Steps Forward, One Step Back: Advance Care Planning, Australian Regulatory Frameworks and the AMA" (2007) 37(9) *Internal Medicine Journal* 637 at 637-643.

[4] Parker et al, n 3 at 640.

[5] Gilligan T and Raffin TA, "Whose Death Is It, Anyway?" (1996) 125(2) *Annals of Internal Medicine* 137.

imposed for murder or manslaughter (where treatment is withheld or withdrawn inappropriately)[6] or for assault (where treatment is provided without appropriate consent or authorisation).[7] And a lack of knowledge of the law will not excuse a medical professional from criminal responsibility.[8] Claims of civil liability may also flow from such actions, along with disciplinary or coronial proceedings.[9]

In addition to issues of legal compliance, a lack of knowledge of the law may also lead to conflict at the end of life. This may occur where medical professionals and family or friends have different understandings of the law and what it requires in any given situation. A lack of legal knowledge by medical professionals can also mean that conflicts that do arise are not resolved as expeditiously as possible.[10] A recent New South Wales Health report, *Conflict Resolution in End of Life Settings*, noted the significant adverse consequences that conflict has for patients, family and the health professionals involved, as well as the burden on the health system as a whole.[11]

The foregoing discussion shows why knowledge of the law in this area matters by pointing to a range of adverse consequences that can arise where medical professionals' legal knowledge is lacking. But also contributing to the significance of this issue is that decisions to withhold and withdraw life-sustaining treatment are part of mainstream medical practice.[12] The authors estimate that over 30,000 adult deaths occur each year across New South Wales, Queensland and Victoria (and almost 40,000 deaths nationally) following a medical decision to withhold or withdraw life-sustaining treatment.[13] There would also be many thousands of decisions where this area of law was engaged but death did not occur, eg where a decision to withhold or withdraw treatment was contemplated but ultimately not made. It is important that medical professionals know the law in this area not only because a failure to do so can have adverse consequences, but also because the need for this legal knowledge arises frequently in practice.

The authors acknowledge the argument that, in some cases, an unlawful decision may produce the most desirable outcome (however and by whom this is defined) for the patient. The argument continues that absolute priority should be the care of the patient and that law can sometimes impede best practice. The authors accept that this argument has force, but consider that it is accompanied by serious and unacceptable risks. This view implies selective compliance with law by medical

[6] Willmott L, White B and Then S-N, "Withholding and Withdrawing Life-sustaining Medical Treatment" in White B, McDonald F and Willmott L (eds), *Health Law in Australia* (Thomson Reuters, Sydney, 2010) at [13.20].

[7] *Secretary, Department of Health and Community Services (NT) v JWB and SMB (Marion's Case)* (1992) 175 CLR 218 at 232 (Mason CJ, Dawson, Toohey and Gaudron JJ); *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 at [40]. Note also that the various guardianship and other legislation creates specific offences for providing treatment without appropriate consent or authorisation: *Guardianship Act 1987* (NSW), s 35; *Guardianship and Administration Act 2000* (Qld), s 79; *Medical Treatment Act 1988* (Vic), s 6. See also *Guardianship and Administration Act 1986* (Vic), s 41 and a number of other provisions in Pt 4A, contravention of which are offences pursuant to the general penalty provision in s 80.

[8] Bronitt S and McSherry B, *Principles of Criminal Law* (3rd ed, Thomson Reuters, 2010) at [3.310].

[9] In relation to coronial proceedings, see *Inquest into the Death of Paulo Melo* [2008] NTMC 080 and *Inquest into the Death of June Woo* (unrep, Coroner's Court, Qld, State Coroner Barnes SM, 1 June 2009). In each case, it was concluded that the treating team gave appropriate care, although in the *Woo* decision, Barnes SM noted (p 23) that a failure to initially obtain the relevant consent as required under Queensland's guardianship legislation may have had "significant legal consequences" if Mrs Woo had died before consent was later obtained.. See Parker M, "Futile Choices: Wooing Doctors to Acknowledge the Law in Queensland" in "Bioethical Issues" (2010) 18 JLM 32.

[10] In seeking to reduce conflict at the end of life, it has been recommended that medical professionals' knowledge of the law in this area be enhanced: New South Wales Health, *Conflict Resolution in End of Life Settings (CRELS): Final CRELS Project Working Group Report* (2010) pp 31-32.

[11] New South Wales Health, n 10, p 9.

[12] See White B, Willmott L and Allen J, "Withholding and Withdrawing Life-sustaining Treatment: Criminal Responsibility for Established Medical Practice?" (2010) 17 JLM 849.

[13] Kuhse H et al, "End-of-life Decisions in Australian Medical Practice" (1997) 166 MJA 191; Australian Bureau of Statistics, *Deaths, Australia* (2009). This conclusion is based on the percentage of all Australian deaths that occur following a decision to withhold or withdraw life-sustaining treatment (28.6%) coupled with the number of adult deaths (persons aged 20 and over) each year across New South Wales, Queensland and Victoria (and nationally). It is noted that the above figures include decisions in relation to both adults with and without capacity as it is not possible from these sources to determine how often these decisions are made in relation to adults who lack capacity.

professionals or others based on their own assessment of what the best outcome is for that patient. As noted above, how this is defined and by whom is not uncontested. Such an approach also denies adults lacking capacity, who are a vulnerable cohort of persons, the protection of legal safeguards. It is significant that most of these legal protections are located in the various pieces of State guardianship legislation. That legislation, which is the product of Parliament, is said to reflect our community values through our elected representatives. Excusing non-compliance with the chosen legal framework sits awkwardly with our notions of the rule of law. The authors consider that the appropriate response to these concerns is to reform the law; indeed, how that might be done is an issue grappled with in this series of articles.

CONTEXT OF DECISION-MAKING: MEDICAL CONTEXT AND LEGAL DECISION-MAKING MECHANISMS

Having outlined why medical professionals' knowledge of the law matters, the authors consider now the context in which decisions to withhold or withdraw life-sustaining treatment occur. This context provides a foundation for all three articles and is referred to throughout this series. What the law requires in relation to such decisions depends on two variables:

- the medical context, including the condition of the adult; and
- the relevant legal decision-making mechanism that applies.

Medical context

The authors have identified three categories of situations that arise at the end of life where the medical context has implications for how the law will apply:

- where the medical professional considers offering life-sustaining treatment to be medically appropriate;
- where the medical professional considers life-sustaining treatment to be futile; and
- where an urgent decision about whether or not to provide life-sustaining treatment is required.

Category 1: Medical professional considers offering life-sustaining treatment to be medically appropriate

Category 1 applies to cases where a medical professional will offer life-sustaining treatment to an adult because he or she considers it to be medically appropriate. This category covers a wide spectrum of situations. At one end of the spectrum, a medical professional might not only offer treatment but strongly recommend that the treatment be given. At the other end of the spectrum, although of the view that offering the treatment may still be medically appropriate, a medical professional may nevertheless recommend that it *not* be accepted perhaps because of wider non-medical considerations. Cases will also arise that fall somewhere in the middle. For example, an adult's condition may be such that a medical professional considers accepting the offered life-sustaining treatment as a reasonable course of action, but also regards as reasonable a decision not to accept that treatment. Depending on a medical professional's values, an illustration of this situation may be Example A.

Example A

Mrs V is 83 and lives in an aged care facility. She has had diabetes for many years, which has been well controlled. The nursing staff detect evidence of gangrene developing in the toes of one foot. After examining Mrs V, the medical professional who visits advises Mrs V that this is an eventually life-threatening condition, which will progress without treatment. At this early stage, treatment would consist of a minimal amputation procedure. Failure to act now would necessitate a larger and more risky procedure in the future. Mrs V must decide between going to hospital for the procedure, or remaining in the nursing home with regular nursing attention to the gangrenous foot. She elects to remain where she feels safe and cared for, in spite of being aware of the risks of this choice. The gangrene inevitably spreads, until her entire leg to the mid-thigh is black and has an offensive odour. At this point, Mrs V develops a fever, and becomes somewhat delirious, certainly past the point of having decision-making capacity. The medical professional is not certain, but suspects that the gangrenous tissue is the likely source of infection. Another decision must be made.

The treatment decision that needs to be made now that Mrs V has lost capacity is whether potentially life-sustaining treatment (namely the amputation) should be provided, or that treatment be withheld and Mrs V receive palliative care.

Category 2: Medical professional considers life-sustaining treatment to be futile

In some cases, a medical professional may believe, on a considered clinical basis, that life-sustaining treatment is not medically appropriate and so should be regarded as futile.

Example B

Mr J is in the final stages of terminal cancer and is being given palliative care in a hospital. The effects of his illness and some of his medications are such that he is no longer able to make health care decisions for himself. The treating team meets to decide if Mr J should be resuscitated if he suffers a cardiac arrest, a distinct possibility given his medical condition. Attempts to resuscitate him may be successful in that his heart may start beating again. However, it is more likely that Mr J will not respond to the treatment and, even if he does, he is unlikely to retain consciousness and will be in a compromised medical condition until death, which is likely to occur within days. Further, there are likely to be burdens associated with this kind of treatment. Mr J, already emaciated, may suffer extensive soft tissue bruising or broken ribs, with the associated discomfort or pain, from the vigorous efforts to restart his heart.

If the treating team regards this treatment as futile, they may consider that it should not be provided. It is noted that the meaning of "futile" or "futility" is contested (the same could be said of the term "medically appropriate" used above) and there have been calls for greater clarification as to what is meant by these terms.[14] Nevertheless, for the purposes of this series of articles, treatment will be regarded as futile when there is a medical consensus to this effect.

Category 3: Urgent decision about life-sustaining treatment is required

In some cases, a decision about whether to provide life-sustaining treatment must be made as a matter of urgency.

Example C

Mrs F is an elderly woman who is seriously ill and is being cared for at home. She collapses at home and her daughter calls the local medical practice. Mrs F's regular medical professional is unavailable and a new medical professional attends the emergency. "I'm sorry, I shouldn't have called you, but I panicked," says the daughter, as the medical professional rushes through the front door. "Mum said that if anything like this happened, not to do anything." Unless the medical professional mechanically supports Mrs F's breathing and circulation, she will die.

There is not sufficient time for the medical professional to establish whether the views expressed by the daughter actually reflect her mother's wishes, whether an advance directive exists, or an order appointing a decision-maker or dictating treatment has been made by a guardianship tribunal or any other body. An immediate treatment decision needs to be made. Expressly excluded from this category are those decisions that are urgent but where legal decision-making arrangements are in place, known about and capable of being utilised.

Relevant legal decision-making mechanism

The second factor that affects how the law applies to a particular situation is which of the seven possible decision-making mechanisms discussed below are relevant. Who the decision-maker is, or what the decision-making mechanism is, in a given situation will depend on the particular circumstances of the case.

The adult has completed an advance directive

At common law and pursuant to legislation in Queensland and Victoria, an adult is able to give a direction about treatment in the future which operates after he or she loses capacity to make the relevant decision. At common law, such a direction will generally be binding on a medical professional and will act as consent to receive treatment or as a lawful refusal of life-sustaining

[14] See eg Kerridge I et al, "Defining Medical Futility in Ethics, Law and Clinical Practice: An Exercise in Futility?" (1997) 4 JLM 235; Rapoport J et al, "Can Futility be Defined Numerically?" (1998) 26(11) *Critical Care Medicine* 1781 at 1782; Nevins MA, "It's Time to Get Serious About Defining Futility" (1994) 9(1) *Trends Health Care Law Ethics* 31 at 32, 36; Schneiderman LJ et al, "Medical Futility: Its Meaning and Ethical Implications" (1990) 112(12) *Annals of Internal Medicine* 949.

treatment. The extent to which such a direction will be binding under the statutory frameworks in Queensland and Victoria depends on compliance with the various legislative conditions.

A person has been appointed by the tribunal to make health care decisions on the adult's behalf

The guardianship legislation in all three jurisdictions provides for the appointment by a tribunal of a person to make health decisions on behalf of the adult. That tribunal will be the Guardianship Tribunal (in New South Wales), the Queensland Civil and Administrative Tribunal or the Victorian Civil and Administrative Tribunal. Depending on the nature of that appointment (and the relevant jurisdiction), that authority can extend to making a decision about whether treatment should be withheld or withdrawn. Indeed, sometimes such appointments are made in specific contemplation of a forthcoming end-of-life decision. The criteria upon which such a decision is made and the safeguards that operate will generally be different from those that exist where the adult's decision is incorporated in an advance directive.

The adult has appointed an agent to make health care decisions on the adult's behalf

New South Wales, Queensland and Victoria allow an adult who has capacity to appoint a person to make health care decisions, if the adult later loses capacity. Depending on the jurisdiction, this person will be an "enduring guardian", "attorney", or "agent". Whether or not that authority will extend to decisions about withholding or withdrawing life-sustaining treatment depends on the powers that are conferred on the agent. Again, the legislation prescribes the criteria which should govern such a decision and any safeguards that apply.

A person is nominated by the legislation as health care decision-maker ("default decision-maker")

The completion of an advance directive or the appointment by an adult of someone to make health care decisions on her or his behalf is not commonplace.[15] It is also comparatively rare that a tribunal appoints a person to make health care decisions on behalf of an adult. In response to that, the legislation in all three jurisdictions establishes a default position under which a person who is close to the adult is nominated by the legislation to make decisions about health care. The extent of such a person's power differs between the three jurisdictions so this "default decision-maker" does not always have the power to refuse life-sustaining treatment.

Decision by a statutory official

A statutory official may, depending on the jurisdiction, be appointed or nominated in some or all of the above roles to make decisions about health care. The relevant statutory officials are the Public Guardian, the Adult Guardian and the Public Advocate in New South Wales, Queensland and Victoria respectively.

In addition, the Queensland legislation provides for the Adult Guardian to resolve difficult situations that might occur within the decision-making framework. For example, in some cases where the substitute decision-maker is not complying with the relevant criteria, the Adult Guardian may have power to become the decision-maker, even in relation to a decision about withholding or withdrawing life-sustaining treatment.

Order of the tribunal

In some cases, often where there is some conflict about the decision to be made, the relevant tribunal may be called upon either to make a decision about whether treatment should be withheld or withdrawn, or to appoint a person to make such a decision.

[15] Prendergast TJ, "Advance Care Planning: Pitfalls, Progress, Promise" (2001) 29(2) *Critical Care Medicine* N34; Bezzina AJ, "Prevalence of Advance Care Directives in Aged Care Facilities of the Northern Illawarra" (2009) 21(5) *Emergency Medicine Australasia* 379; Nair B et al, "Advance Care Planning in Residential Care" (2000) 30(3) *Australian and New Zealand Journal of Medicine* 339.

Order of the Supreme Court exercising its parens patriae jurisdiction

The Supreme Court, pursuant to its parens patriae jurisdiction, may decide whether life-sustaining treatment should be withdrawn or withheld from an adult who lacks capacity. In these cases, the court must determine the best interests or welfare of the adult involved.

THE LAW IN NEW SOUTH WALES

The authors consider now how the foundation established above applies to the law in New South Wales. Particular consideration is given to the role that is played by the medical professional in each decision-making situation.

GUARDIANSHIP LAW IN NEW SOUTH WALES

The legal framework: An overview

The relevant legislation in New South Wales is the *Guardianship Act 1987* (NSW).[16] It facilitates the appointment of a guardian and an enduring guardian to make decisions about health care or to consent to medical or dental treatment. Whether such a decision-maker is able to refuse life-sustaining treatment will depend on the scope of her or his appointment. The legislation also facilitates a "person responsible" consenting to "medical treatment" for an adult who lacks capacity. "Medical treatment" is defined to mean:[17]

> medical treatment (including any medical or surgical procedure, operation or examination and any prophylactic, palliative or rehabilitative care) normally carried out by or under the supervision of a medical practitioner …

The *Guardianship Act 1987* (NSW) does not prescribe a statutory regime for an adult making an advance directive and the common law will continue to apply in this regard.[18] An adult who still has capacity, therefore, can make decisions about withholding or withdrawing life-sustaining treatment in an advance directive that will operate if he or she later loses capacity.

The law governing substitute decision-making in New South Wales has been reviewed recently in the Legislative Council's Standing Committee on Social Issues report *Substitute Decision-making for People Lacking Capacity*. The report considered a range of issues relevant to this article, including how capacity is defined, medical consent and end-of-life decision-making.[19] Of significance is that the Committee recommended that the law that governs advance directives and end-of-life decision-making generally be referred to the New South Wales Law Reform Commission for its consideration.[20]

Capacity

As this article deals with withholding and withdrawing life-sustaining treatment from adults who lack capacity, determining that capacity is a threshold issue. The starting point is to note that there is a presumption at common law that an adult has capacity[21] and that this presumption has not been disturbed by the guardianship legislation.[22]

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[16] Note that although advance directives at common law (as opposed to those recognised by statute) might be regarded as falling outside "guardianship law", they are discussed below under this heading for ease of reference.

[17] *Guardianship Act 1987* (NSW), s 33(1)(a).

[18] *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88.

[19] New South Wales Parliament, Legislative Council, Standing Committee on Social Issues, *Substitute Decision-making for People Lacking Capacity* (2010) Chs 4, 12.

[20] New South Wales Parliament, Legislative Council, Standing Committee on Social Issues, n 19 at [12.82]-[12.83].

[21] *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 at [23].

[22] *Re TAC* [2010] NSWGT 23 at [11].

Part 5 of the *Guardianship Act 1987* (NSW), which deals with substituted consent to medical and dental treatment, applies when an adult is "incapable of giving consent".[23] This occurs if the adult:[24]

(a) is incapable of understanding the general nature and effect of the proposed treatment; or
(b) is incapable of indicating whether or not he or she consents or does not consent to the treatment being carried out.

However, as will be seen below, Pt 5 applies only to *consent to* treatment and so does not extend to withholding and withdrawing life-sustaining treatment.[25] Perhaps the more important definition in this context is, therefore, whether an adult is "in need of a guardian". This is the threshold for the tribunal to appoint a guardian[26] and the point at which the appointment of an enduring guardian can have effect[27] and both of these decision-makers, if appointed with the relevant functions, can have power to withhold or withdraw treatment. A person is in need of a guardian when he or she, "because of a disability, is totally or partially incapable of managing his or her person".[28] A person will have a "disability" for the purposes of this Act when he or she is "restricted in one or more major life activities to such an extent that he or she requires supervision or social habilitation" and this arises by virtue of one of the listed impairments which include being intellectually, physically, psychologically or sensorily disabled, or being of advanced age.[29] The possible tensions between these different statutory conceptions of capacity have been noted.[30]

Finally, because advance directives are dealt with under the common law in New South Wales, presumably the common law definition of capacity will apply as to when the adult cannot make her or his own decisions and so the directive becomes operative. In *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 at [25], McDougall J described the test at common law for when an adult will be found to lack capacity as where the adult:

(1) is unable to comprehend and retain the information which is material to the decision, in particular as to the consequences of the decision; or
(2) is unable to use and weigh the information as part of the process of making the decision.

Role of medical professional

A medical professional will need to assess whether an adult has capacity to make her or his own decisions about health care, and in this context, whether that capacity extends to decisions to withhold or withdraw life-sustaining treatment. If not, then the guardianship legislation applies, and the medical professional will need to know the relevant statutory definition of capacity and determine whether it is met (except where the tribunal has appointed a guardian, and therefore a determination of incapacity has already been made). The medical professional will also need to be aware of the common law definition of capacity if there is an advance directive which is purporting to refuse life-sustaining treatment.

Category 1: Medical professional considers offering life-sustaining treatment to be medically appropriate

The remainder of this Part revisits, from the perspective of the law in New South Wales, the three categories of medical context which were outlined above. Each category is considered in turn along with the applicable legal decision-making mechanisms.

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[23] *Guardianship Act 1987* (NSW), s 34(1)(b).

[24] *Guardianship Act 1987* (NSW), s 33(2).

[25] Note, however, that the power to consent carries with it the power to *withhold* that consent. This is discussed further below at 512-513.

[26] *Guardianship Act 1987* (NSW), s 14(1).

[27] *Guardianship Act 1987* (NSW), s 6A(1)(a).

[28] *Guardianship Act 1987* (NSW), s 3. As to what this phrase means and some of its problems, see New South Wales Parliament, Legislative Council, Standing Committee on Social Issues, n 19, Ch 4.

[29] *Guardianship Act 1987* (NSW), s 3(2).

[30] *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 at [39].

The adult has completed an advance directive

Statutory advance directives are not provided for by the *Guardianship Act 1987* (NSW).[31] This means that recognition of advance directives falls to the common law. Given the state of authority in other common law jurisdictions,[32] it was assumed that advance directives would be recognised by the Australian common law and this was confirmed by the recent decision of the New South Wales Supreme Court in *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88. This case involved a Jehovah's Witness, Mr A, being kept alive by mechanical ventilation and kidney dialysis. In the course of his treatment, the New England Area Health Service became aware of a document prepared (but not signed) by Mr A which indicated that he wished to refuse kidney dialysis. Proceedings were commenced by the Area Health Service seeking declarations, including one that the document was a valid advance directive. McDougall J concluded (at [40]) that it was such a directive and that the dialysis could therefore not be provided.

The common law will recognise an advance directive as binding if it is valid and applicable to the relevant circumstances.[33] An advance directive will be *valid* if two conditions are met. First, the adult must have been competent at the time the directive was given, and there is a presumption that he or she was.[34] Secondly, the adult must have been free of undue influence at the time the directive was made.[35] Suggestions that there is a third requirement for validity,[36] namely that a person has to receive sufficient information before completing the advance directive, were rejected in *Hunter and New England Area Health Service v A* (at [28]-[30], [40] (McDougall J)).[37]

An advance directive will be *applicable* if it was intended by the adult to operate in the circumstances that have later arisen.[38] Commentators have identified four categories of situation from the limited case law where a directive may not reveal such an intention, and they include where circumstances have changed or where the directive is uncertain or ambiguous.[39]

Role of medical professional

Where an adult has completed an advance directive, the medical professional needs to assess its validity and applicability. He or she will need to consider whether the completion of the directive was subject to undue influence or occurred when the adult lacked capacity (but noting the presumption that he or she did have capacity). The medical professional will also need to consider whether the terms of the directive were intended to apply to the current circumstances. This would include consideration of the terms of the directive and whether there is anything that should prevent it from being followed, such as a change in the adult's circumstances since the directive was completed. If the advance

[31] Although note the suggestion that the Act provides for some limited recognition of advance directives by way of the "objection" provisions: *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 at [39].

[32] See eg *Malette v Shulman* (1990) 67 DLR (4th) 321; *Re T (Adult: Refusal of Treatment)* [1993] Fam 95; *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 WLR 290; *HE v A Hospital NHS Trust* [2003] 2 FLR 408; *W Healthcare NHS Trust v H* [2005] 1 WLR 834.

[33] See eg *Malette v Shulman* (1990) 67 DLR (4th) 321; *Airedale NHS Trust v Bland* [1993] AC 789 at 864 (Lord Goff); *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 at 103 (Lord Donaldson MR); *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 WLR 290 at 294-295 (Thorpe J); *HE v A Hospital NHS Trust* [2003] 2 FLR 408 at 414-415 (Munby J); *W Healthcare NHS Trust v H* [2005] 1 WLR 834 at [15] (Brooke LJ); *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 at [40] (McDougall J). For a more detailed discussion of when an advance directive will be valid and applicable, see Willmott L, White B and Mathews B, "Law, Autonomy and Advance Directives" (2010) 18 JLM 366.

[34] *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 at [26], [40] (McDougall J).

[35] *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 at [26], [40] (McDougall J); *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 at 121 (Staughton LJ).

[36] See eg Kennedy I and Grubb A, *Medical Law* (3rd ed, 2000) pp 2037-2038.

[37] Compare *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84; [2009] WASC 229 at [49] (Martin CJ). Note also *H Ltd v J* (2010) 240 FLR 402; [2010] SASC 176 at [37]-[44] (Kourakis J).

[38] *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 at [26], [40] (McDougall J); *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 at 114 (Lord Donaldson MR).

[39] These categories are discussed in greater detail in Willmott L, White B and Howard M, "Refusing Advance Refusals: Advance Directives and Life-sustaining Medical Treatment" (2006) 30 MULR 211 at 222-224.

directive is valid and applicable, the medical professional will need to accept that refusal of treatment. If there is "genuine and reasonable doubt" as to these matters, then the medical professional may need to apply to the courts for a determination.[40]

A person has been appointed by the Guardianship Tribunal to make health care decisions on the adult's behalf

The Guardianship Tribunal may appoint a plenary or limited guardian for an adult who lacks capacity.[41] The tribunal must not make a plenary order if a limited guardianship order would be sufficient.[42] If the tribunal does make a plenary order, the guardian will be conferred with "all the functions of a guardian of that person that a guardian has at law or in equity".[43] This power is broad enough to include a power to refuse life-sustaining treatment.[44]

If a limited order is made, the guardian will be given specified functions. Such functions can include deciding the health care that the adult is to receive, or giving consent to the carrying out of medical or dental treatment for the adult. An important issue for the purpose of this article is whether a person who is given a limited appointment with the functions of "health care" or "medical and dental consent" will have power to refuse life-sustaining treatment. As will be seen below, of relevance to this issue is Pt 5 of the *Guardianship Act 1987* (NSW), which facilitates consent being given by a person responsible for medical and dental treatment to be provided to the adult. "Person responsible" is defined to include the adult's guardian if the order appointing the guardian provides for her or him to exercise the function of giving consent to the carrying out of medical or dental treatment for the adult.[45]

The powers of a guardian conferred with functions in relation to health care and medical and dental consent have been considered in a series of three important decisions. It is beyond the scope of this article to consider these decisions in any detail. However, it is important to outline the different approach taken in each case. The first was a decision of the New South Wales Administrative Decisions Tribunal, *WK v Public Guardian (No 2)* [2006] NSWADT 121. The tribunal held that the functions conferred on the guardian to make decisions about health care and to consent to medical and dental treatment were insufficient to allow the guardian, in this case the Public Guardian, to agree to the withdrawal of dialysis as part of a broader treatment plan for a 73-year-old man who had end-stage kidney disease and was suffering from dementia. This decision was criticised and concerns were expressed about the decision-making gap that would follow from this decision if the best medical practice in a particular case is to withdraw or withhold active treatment measures and to provide appropriate palliative care.[46]

In a subsequent case (*BAH* [2007] NSWGT 1),[47] and notwithstanding the above decision of the Administrative Decisions Tribunal, the Guardianship Tribunal took a different view and held that the medical consent function allowed a guardian to refuse medical treatment. The tribunal decided that the guardian in this case was able to consent to a palliative care plan which included a decision to withhold cardio-pulmonary resuscitation and to withdraw dialysis.

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[40] *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 at [40].

[41] *Guardianship Act 1987* (NSW), ss 14, 16.

[42] *Guardianship Act 1987* (NSW), s 15(4).

[43] *Guardianship Act 1987* (NSW), s 21(1)(b).

[44] See the wide interpretation given to this term in *FI v Public Guardian* [2008] NSWADT 263 at [47].

[45] *Guardianship Act 1987* (NSW), s 33A(a). "Person responsible" also includes an enduring guardian appointed by the adult. This appointment is considered in more detail below at 511-513.

[46] For concerns about the implications of this decision, see Stewart C, "Problems with Substitute Medical Decision-making in NSW" (2006) 3 *Journal of Bioethical Inquiry* 127; Bowen T and Saxton A, "The NSW Guardianship Act – How Far Can It Go?" (2006) 15(1) *Australian Health Law Bulletin* 1; Giles D and Townsend R, "End-of-life Decisions and the NSW Guardianship Act: A Square Peg in a Round Hole? The Law and Clinical Practice" (2006) 15(1) *Australian Health Law Bulletin* 4.

[47] This decision was previously known as *Re AG* [2007] NSWGT 1.

The third in this series of cases is the decision of the New South Wales Administrative Decisions Tribunal in *FI v Public Guardian* [2008] NSWADT 263. This decision also considered the powers conferred on the Public Guardian who had functions in relation to health care and to consent to medical and dental treatment. A different approach was taken by the tribunal in this case. It held that the power *to consent to medical and dental treatment* that is conferred by Pt 5 of the Act did *not* extend to authorising the withholding or withdrawing of treatment from an adult. Part 5 contemplated only the giving of consent to "proactive medical interventions" (at [40]). The tribunal held, however, that the power of a guardian *to make health decisions* was sufficient to allow decisions to be made to withdraw or withhold life-sustaining treatment.

The approach taken in *FI v Public Guardian* has been adopted by both the Guardianship Tribunal and the Administrative Decisions Tribunal in subsequent cases.[48] As a result, it appears now established that a limited guardian with a function in relation to health care, as well as a plenary guardian, will have power to refuse life-sustaining treatment. By contrast, a guardian with a function only in relation to consent to medical or dental treatment will not have such power. Such a guardian will, however, be able to withhold her or his consent to treatment and this may result in the treatment not being given. This distinction between *withholding consent* to treatment and *refusing that treatment* is discussed further below in the context of the person responsible as a default decision-maker.[49]

Criteria applicable to the decision

The Administrative Decisions Tribunal in *FI v Public Guardian* gave some guidance as to what factors a guardian should consider in exercising a function in relation to health care. The tribunal expressed the view that a specified function in a limited guardianship order "should be interpreted in accordance with what is permitted by law or in equity in relation to the kind of conduct that is the subject of the specified function" (at [47]). In the context of a decision about health care, it was observed that the duties imposed on medical professionals under the general law to provide treatment "rest on consideration of what is in the patient's best interests for the purpose of preservation of life" (at [46]). The tribunal further observed, however, that the duty does not require treatments that are "therapeutically ineffective, or are extraordinary, excessively burdensome, intrusive or futile" (at [46]).

As well as these factors under the general law that were regarded as relevant by the tribunal, the guardianship legislation also requires those exercising functions to observe the general principles listed in the Act, including giving paramount consideration to the welfare and interests of the adult.[50]

Role of medical professional

The role of the medical professional is to identify the relevant decision-maker. In this context, that decision-maker is a guardian. The medical professional will then need to ascertain what functions have been conferred upon the guardian and know that the requisite function needed to refuse life-sustaining treatment is one in relation to health care.

If a guardian refuses the provision of life-sustaining treatment to the adult in circumstances where the medical professional considers such treatment should be provided, the medical professional may apply to the Guardianship Tribunal for consent to provide the treatment.[51] He or she may also seek a review by the tribunal of the guardian's appointment.[52]

[48] *QAN* [2008] NSWGT 19; *LE and LF v Public Guardian* [2009] NSWADT 78.

[49] See below at 512-513.

[50] *Guardianship Act 1987* (NSW), s 4.

[51] *Guardianship Act 1987* (NSW), s 42(1).

[52] *Guardianship Act 1987* (NSW), ss 25, 25B, 25C.

The adult has appointed an enduring guardian to make health care decisions on the adult's behalf

The *Guardianship Act 1987* (NSW) allows an adult to appoint a person as her or his guardian pursuant to a written instrument.[53] The appointee is known as an "enduring guardian" and the appointment only operates during the time that the adult is in need of a guardian.[54] The enduring guardian will have the functions that are conferred by the instrument. Such functions will include "deciding the health care that the adult is to receive",[55] or giving consent under Pt 5 to the carrying out of medical or dental treatment on the adult[56] unless the instrument limits or excludes these functions.[57]

Applying the reasoning of the Administrative Decisions Tribunal in *FI v Public Guardian*, it appears that a function in relation to making decisions about health care is required to withhold or withdraw life-sustaining treatment. A function merely to consent to medical treatment would not authorise an enduring guardian to make such a decision.[58]

Criteria applicable to the decision

The criteria that must be taken into account by an enduring guardian when making a decision about withholding or withdrawing life-sustaining treatment are the same as for a guardian appointed by the Guardianship Tribunal as set out above, and include consideration of the adult's best interests for the purpose of preservation of life, and the general principles listed in the *Guardianship Act 1987* (NSW).[59]

Role of medical professional

Again, the medical professional's role is the same as considered earlier where the decision-maker is a guardian appointed by the Guardianship Tribunal. The medical professional will need to identify the enduring guardian as the relevant decision-maker, determine the functions conferred by the adult and understand the difference between a function in relation to health care and one in relation to consent. The medical professional will also need to know that he or she may apply to the Guardianship Tribunal for consent to provide the treatment if concerned that an inappropriate decision is being made.[60] The enduring guardian's appointment may also be reviewed by the tribunal[61] or the Supreme Court.[62]

A person is nominated by the legislation as person responsible ("default decision-maker")

The *Guardianship Act 1987* (NSW) empowers a "person responsible" to give consent for certain medical treatment under Pt 5 of the Act.[63] A "person responsible" is defined to include a guardian or enduring guardian with consent functions but in the absence of such appointees, the default decision-maker will be the first of the following:[64]

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[53] *Guardianship Act 1987* (NSW), s 6.

[54] *Guardianship Act 1987* (NSW), s 6A.

[55] *Guardianship Act 1987* (NSW), s 6E(1)(b).

[56] *Guardianship Act 1987* (NSW), s 6E(1)(d).

[57] *Guardianship Act 1987* (NSW), s 6E(2).

[58] An enduring guardian may, however, withhold that consent, the effect of which is considered below when examining the powers of a person responsible.

[59] See above at 510.

[60] *Guardianship Act 1987* (NSW), s 42(1).

[61] *Guardianship Act 1987* (NSW), ss 6J, 6K.

[62] *Guardianship Act 1987* (NSW), s 6L.

[63] *Guardianship Act 1987* (NSW), s 36(1)(a). See also *Guardianship Act 1987* (NSW), s 37(2)-(3) in relation to the provision of "minor treatment" where there is no person responsible or the person responsible is not contactable, able or willing to make a decision in response to a request for consent.

[64] *Guardianship Act 1987* (NSW), s 33A.

- the spouse of the adult, including same-sex or de facto spouse (if the relationship is close and continuing and the spouse is not under a guardianship order);
- a person who has the care of the adult; and
- a close friend or relative of the adult.

Although a default decision-maker, as a person responsible, may consent to medical treatment, applying the reasoning of *FI v Public Guardian*, such a decision-maker does not have a function in relation to health care and so could not refuse life-sustaining treatment. A person responsible could, however, withhold consent to that treatment.

Criteria applicable to the decision

In making a decision about whether to consent to treatment or withhold that consent, the person responsible must have regard to information about the proposed treatment provided by the medical professional, any views of the adult, the need to ensure the adult is not deprived of necessary medical treatment but that any treatment carried out is done so for the purpose of promoting and maintaining the adult's health and wellbeing, and the general principles.[65]

Role of medical professional

The distinction drawn in *FI v Public Guardian* between being able to make decisions about health care and being able to consent to medical treatment was discussed above. Although this distinction has been settled only relatively recently, it appears that a power to consent to medical treatment, although falling short of allowing a substitute decision-maker to refuse treatment, would carry with it the ability to *withhold* consent to treatment.[66] The discussion below considers the implications of withholding consent. Because "person responsible" is defined to include guardians and enduring guardians (both of whom may be appointed without the wider health care function), this section applies to all substitute decision-makers whose power is limited to consent or the withholding of that consent.

The medical professional's role begins by identifying the person responsible in the hierarchy from whom they may request consent.[67] He or she will have to be aware that a person responsible is not able to refuse life-sustaining treatment, but that the person responsible may withhold consent to the adult receiving treatment. The medical professional's response to such a withholding of consent may depend on her or his view of how desirable or necessary the provision of treatment is. The wide spectrum of medical situations that fall within the ambit of the Category 1 medical contexts was explained earlier.[68] If the medical professional believes that treatment should be provided to the adult, he or she will need to obtain consent or authorisation elsewhere, most likely from the tribunal as discussed below.[69] On the other hand, if the situation fell towards the other end of the spectrum where the medical professional thought it preferable, or at least acceptable, that treatment *not* be given, he or she may accept the person responsible's decision to withhold consent to treatment and so not treat. A medical professional will need to be aware of these two options when confronted with a withholding of consent and be aware that he or she exercises some discretion in how to respond.

A medical professional will also need to know that the power to withhold consent to treatment can impact upon withdrawing treatment and withholding treatment differently. To provide treatment, a medical professional requires consent or some other authorisation. This means that if consent is withheld, and other consent or authorisation is not obtained, a person responsible can prevent treatment from being started. However, once consent or authorisation is obtained for the provision of ongoing treatment, further consent or authorisation is not necessary. This means that a person

[65] *Guardianship Act 1987* (NSW), ss 4, 32, 40(3).

[66] This is consistent with the approach taken in Victoria which differentiates between the power to withhold consent to treatment and the power to refuse that treatment: see Willmott L, White B, Parker M and Cartwright C, "The Legal Role of Medical Professionals in Decisions to Withhold or Withdraw Life-sustaining Treatment: Part 3 (Victoria)" (2011) 18 JLM (to be published in the June 2011 part of the *Journal of Law and Medicine*).

[67] *Guardianship Act 1987* (NSW), s 40(1).

[68] See above at 503.

[69] See *Guardianship Act 1987* (NSW), ss 42(1), 44; and at 513-514 below.

responsible cannot prevent treatment from continuing simply by withholding consent if there is already justification for providing the treatment. To require that treatment be withdrawn, a substitute decision-maker needs the power to refuse treatment. Accordingly, a medical professional will need to be aware of how a power to withhold consent may operate differently where the question is whether treatment should be withheld as opposed to withdrawn.

Decision by the Public Guardian

The *Guardianship Act 1987* (NSW) creates the statutory office of the Public Guardian.[70] The Public Guardian may be appointed by the Guardianship Tribunal as a guardian for an adult and the functions that may be conferred were considered above.

Unlike in Queensland, the Public Guardian does not have power to intervene and make the decision herself or himself to resolve a disagreement within a family or between family and the treating team as to the appropriate course, or where decisions are being made inappropriately.[71] The Public Guardian does, however, have a limited ability to make a decision as guardian if the appointed guardian dies and there are no surviving or alternative guardians.[72] This power will subsist until the guardianship order is reviewed.

Criteria applicable to the decision

The criteria that the Public Guardian must consider in exercising her or his functions are the same as apply to other guardians, and were considered above.[73] These include consideration of the adult's best interests for the purpose of preservation of life and the general principles listed in the Act.

Role of medical professional

The role of the medical professional where a decision to withhold or withdraw treatment is made by the Public Guardian is the same as described earlier in that the medical professional must identify the decision-maker and the relevant functions conferred.[74] However, in addition to being able to approach the Guardianship Tribunal as discussed above, review of a decision by the Public Guardian may be undertaken by the Administrative Decisions Tribunal.[75]

Order of the Guardianship Tribunal

The Guardianship Tribunal is conferred with power to consent to the carrying out of medical treatment on an adult who lacks capacity.[76] Prior to *FI v Public Guardian*, it was possible to argue that this power was sufficiently wide to include a power to withhold or withdraw life-sustaining treatment. Such an interpretation does not now seem tenable, and it appears unlikely that the tribunal has power to withhold or withdraw such treatment. However, as with the person responsible, the tribunal may withhold consent to treatment. It is suggested that a decision by the tribunal to withhold its consent will *in effect* operate as a refusal of treatment.

It is also noted that a guardian or enduring guardian may apply to the tribunal for directions as to how functions are to be exercised.[77]

Criteria applicable to the decision

In considering an application for consent to medical treatment, the tribunal must have regard to:

- the views of the adult, the medical professional and any persons responsible;
- information about the nature of the proposed treatment;

[70] *Guardianship Act 1987* (NSW), s 77.

[71] See Willmott L, White B, Parker M and Cartwright C, "The Legal Role of Medical Professionals in Decisions to Withhold or Withdraw Life-sustaining Treatment: Part 2 (Queensland)" (2011) 18 JLM 523 (below).

[72] *Guardianship Act 1987* (NSW), s 22A(1)(c).

[73] See above at 510.

[74] See above at 510.

[75] *Guardianship Act 1987* (NSW), s 80A; *Guardianship Regulation 2010* (NSW), reg 17.

[76] *Guardianship Act 1987* (NSW), ss 36(1)(b), 44.

[77] *Guardianship Act 1987* (NSW), s 28.

- the need to ensure the adult is not deprived of necessary medical treatment and that any treatment carried out is done so for the purpose of promoting and maintaining the adult's health and wellbeing; and
- the general principles.[78]

Further, the tribunal must not consent to the treatment unless satisfied it is the most appropriate form of treatment for promoting and maintaining the adult's health and wellbeing.[79]

Role of medical professional

The medical professional will need to know about the jurisdiction and powers of the tribunal, and that it is possible to bring a matter before it where there is a dispute or disagreement about a proposed treatment decision.

Category 2: Medical professional considers life-sustaining treatment to be futile

At common law, a medical professional is under no duty to treat an adult where "no benefit at all would be conferred".[80] Treatment that is futile is not in a person's best interests and so need not be provided. The statutory regime in New South Wales does not alter the common law regarding the provision of futile treatment. There is no obligation on medical professionals to provide futile treatment, even where it is requested by a substitute decision-maker or by an advance directive. Accordingly, there is no obligation to obtain consent to the withholding or withdrawing of such treatment, though, as a matter of practice, consent may be obtained.

However, disputes can, and have,[81] arisen as to assessments of futility and they are open to challenge by those close to the adult who believe that the continuation of treatment is in the adult's best interests. Such a challenge could be brought before the Guardianship Tribunal, which has power to consent to the treatment, or the Supreme Court in its parens patriae jurisdiction (discussed below).

Role of medical professional

The medical professional is the initial decision-maker in this context, and must therefore be aware that the law does not require provision of futile treatment. However, as noted above, this decision can be challenged. Medical professionals need to be aware of avenues for legal review to the Guardianship Tribunal and the Supreme Court.

Category 3: Urgent decision about life-sustaining treatment is required

In New South Wales, medical treatment may be provided without consent under the *Guardianship Act 1987* (NSW) if the medical professional considers the treatment is necessary, as a matter of urgency, to save the adult's life, or to prevent serious damage to the adult's health, or to prevent the adult from suffering or continuing to suffer significant pain or distress.[82] No provision is made for withdrawing or withholding treatment on an urgent basis. However, as discussed above, if treatment is considered to be futile, at common law, the medical professional is under no obligation to provide it, so it can be withdrawn or withheld without obtaining consent.[83]

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[78] *Guardianship Act 1987* (NSW), ss 4, 32, 42(2), 44(2). For an illustration of how the Guardianship Tribunal applies these criteria, see *NKQ* [2008] NSWGT 21.

[79] *Guardianship Act 1987* (NSW), s 45(1).

[80] *Airedale NHS Trust v Bland* [1993] AC 789 at 858-859 (Lord Keith), at 869 (Lord Goff), at 884-885 (Lord Browne-Wilkinson), at 898 (Lord Mustill). See also *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235 at 251; and *Messiha v South East Health* [2004] NSWSC 1061.

[81] See eg in New South Wales, *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549; *Messiha v South East Health* [2004] NSWSC 1061.

[82] *Guardianship Act 1987* (NSW), s 37(1). McDougall J noted the existence at common law of the "emergency principle" or the "principle of necessity" and that this could justify treatment without consent: *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 at [31]-[34], [40]. His Honour did not, however, consider how this principle or principles might operate in light of s 37(1) of the *Guardianship Act 1987* (NSW).

[83] See above.

Role of medical professional

The medical professional in the urgent situation is the sole legal decision-maker because there is not time to consider other legal decision-making mechanisms.

If the treatment is not assessed as futile, the medical professional has authority under the legislation to provide treatment without consent, but not to withhold or withdraw it. However, if the medical professional assesses the treatment as being futile, he or she is under no obligation to provide such treatment (even if it is an emergency situation) and it can be lawfully withheld at common law.[84]

ORDER OF THE SUPREME COURT EXERCISING ITS PARENS PATRIAE JURISDICTION

In addition to the guardianship legislation discussed above, decisions for adults who lack capacity can also be made by the Supreme Court in its parens patriae jurisdiction. This jurisdiction is capable of applying to all three categories of medical context discussed above. In practice, however, given how situations requiring an urgent decision are defined, it is unlikely that the court's involvement would be sought in the Category 3 context.

The scope and nature of this jurisdiction is discussed in more depth in the second article in this series. For the purpose of this article, it is sufficient to note that the jurisdiction continues to exist despite enactment of the guardianship legislation[85] and that the test applied by the Supreme Court is "the protection of the best interest of the health and welfare of the person the subject of its exercise".[86]

Role of medical professional

The role of the medical professional is that he or she (or the relevant hospital) may engage the legal system by bringing an application before the Supreme Court.

CONCLUSIONS ON THE LAW

Some problems with the law in New South Wales

From the foregoing analysis of the law that governs withholding and withdrawing life-sustaining treatment from adults who lack capacity, it is clear that there are some problems with the law as it currently stands. This section draws together some of the key problems identified from the above discussion that are likely to be impediments to medical professionals knowing the law. It is noted that this section does not seek to review comprehensively all of the problems with New South Wales law in this area, only those relevant to the focus of this article (medical professionals' knowledge of the law). This section also does not consider the issue of the complexity of the law generally as this is examined in the third article in the series.

Distinction between health care functions and consent to treatment functions

Following the decision of *FI v Public Guardian* [2008] NSWADT 263, the power to refuse life-sustaining treatment arises only for decision-makers empowered with health care functions and not for those whose power extends only to consenting to treatment.

One result of this is that a default decision-maker can never have power to refuse life-sustaining treatment. A default decision-maker, as a person responsible, only has power to consent or to withhold consent. It is suggested that not granting this power to this cohort of decision-makers leaves an undesirable gap in the law. This means that where such a decision might be required, it may be

[84] See above at 514.

[85] *Guardianship Act 1987* (NSW), ss 8, 31, 31G; *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549 at 553.

[86] *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549 at 554 and *Slaveski v Austin Health* [2010] VSC 493 at [34] referring to the criterion as discussed by the High Court in *Secretary, Department of Health and Community Services (NT) v JWB and SMB (Marion's Case)* (1992) 175 CLR 218 at 240, 249, 252, 270-273, 295, 300, 316. There are many other formulations of this criterion. See eg *Re Herrington* [2007] VSC 151 at [22]; *Melo v Superintendent of Royal Darwin Hospital* (2007) 21 NTLR 197 at [25]; *Messiha v South East Health* [2004] NSWSC 1061 at [25].

necessary to engage the formal guardianship system (which is inconsistent with the least restrictive approach), and apply to the tribunal either for its consent (or withholding of that consent) or for the appointment of a guardian.

This is also problematic in terms of medical professionals' knowledge of the law in that they will need to know that the person responsible, who is normally relied upon to give consent, does not have the wider power to refuse treatment. The *Conflict Resolution in End of Life Settings* report suggested there is confusion among medical professionals as to the scope of the person responsible's power.[87]

A further problem is that the interpretation adopted by *FI v Public Guardian* means that some guardians and enduring guardians will have power to refuse life-sustaining treatment, but others will not. Again, the scope of that power will depend on whether they have been appointed with a health care function or only a consent function. This distinction presents problems in that, again, medical professionals are required to know that this difference exists and to check the scope of power for these decision-makers.[88]

Finally, another problem is that medical professionals will need to know that the power to withhold consent operates differently in practice depending on whether treatment has already been instituted or not. As discussed above, merely withholding consent cannot stop ongoing treatment for which there is already lawful justification but it may be effective in preventing treatment from being commenced in the first place. This requires a nuanced understanding of the law and how it works in practice which is unlikely to be known by medical professionals.

Multiple and uncertain definitions of capacity

Another problem identified in terms of knowing the law is the multiple definitions that can be relevant to assessing the adult's capacity. As noted above, there is the definition used in Pt 5 of the legislation, a definition that applies to guardians and enduring guardians (that a person is "in need of a guardian") and a third definition of capacity that is applied at common law (for advance directives). The term "in need of a guardian" (which is perhaps the most significant definition in the end-of-life context) has also been critiqued as being uncertain.[89] The state of the law regarding capacity is likely to present challenges for medical professionals seeking to know and comply with the law.

No statutory recognition of advance directives

New South Wales is one of only two States in Australia that has not given advance directives legislative recognition.[90] It has been suggested that continued reliance on the common law could lead to some uncertainty.[91] The current authors consider that, at least so far as medical professionals' knowledge of the law is concerned, relying on common law is undesirable. Recognition of advance directives and when they will be binding in statute is likely to make ascertaining the law easier. Indeed, one of the stated rationales for legislative action in other Australian jurisdictions has been to try to achieve greater certainty and clarity.[92] Further, although the *Hunter* decision has made clear that advance directives will be recognised at common law in Australia, it is unclear how such recognition fits with the provisions of the *Guardianship Act 1987* (NSW). Although not purporting to address this

[87] New South Wales Health, n 10, pp 20, 24-25. See also New South Wales Parliament, Legislative Council, Standing Committee on Social Issues, n 19 at [12.74].

[88] This distinction is also likely to be confusing for others involved in these decisions, including eg, adults seeking to appoint enduring guardians. It is unlikely that an adult would be aware of this distinction in making such an appointment, absent competent legal advice.

[89] New South Wales Parliament, Legislative Council, Standing Committee on Social Issues, n 19 at [4.8]-[4.20].

[90] Tasmania is the other Australian jurisdiction which has not recognised advance directives in statute.

[91] New South Wales Parliament, Legislative Council, Standing Committee on Social Issues, n 19 at [12.65]-[12.68].

[92] See Willmott L, "Advance Directives and the Promotion of Autonomy: A Comparative Australian Statutory Analysis" (2010) 17 JLM 556. It may also be that the enactment of legislation will avoid some of the problems that have been identified with the application of common law principles: see eg Willmott L, "Advance Directives Refusing Treatment as an Expression of Autonomy: Do the Courts Practise What They Preach?" (2009) 38(4) *Common Law World Review* 295.

issue comprehensively, McDougall J in *Hunter* observed in relation to Pt 5 of the Act that "to some extent and for some purposes, the *Guardianship Act* may give recognition to advance care directives".[93]

Legal role of medical professionals

In addition to the conclusion that the law is problematic, the analysis of the law in New South Wales also supports the conclusion that medical professionals play a significant legal role in these decisions. The specific roles were discussed above but the significant legal roles played by medical professionals can be characterised in the following three ways.

Medical professional as legal decision-maker

The first of these roles is where the medical professional is the legal decision-maker. This will occur where the medical professional has assessed that life-sustaining treatment is futile. In such cases, there is no obligation to treat and a medical professional can therefore legally decide to withhold or withdraw life-sustaining treatment. Likewise, a medical professional in an emergency setting is empowered to make decisions in certain circumstances.

Medical professional making decisions about how to apply the law

The second role arises where the medical professional is not the legal decision-maker but has a formal legal role as to how the relevant law is applied to the situation at hand. In this context, there are three aspects of the decision-making process that are legally significant for medical professionals, and about which an understanding of sometimes complex legal issues is essential.

The first aspect is that the medical professional must be aware that he or she needs to assess whether the adult has the capacity to make the treatment decision. This assessment can be made competently only if the medical professional has an understanding of the legal meaning of "capacity".[94]

The second aspect arises only if the medical professional has made an assessment that the adult lacks capacity. If this is the case, the medical professional must then determine the appropriate decision-making mechanism (if he or she is not the decision-maker). This determination requires an understanding of advance directives and possible substitute decision-makers.

The final (and related) legally significant aspect of the decision-making process is whether a substitute decision-maker in fact has power to make the decision to withhold or withdraw life-sustaining treatment. Concerns about whether certain categories of decision-makers have this power were discussed above. There is also, as part of determining the legal power to make a decision, the question of whether an advance directive is capable of being relied upon. In this case, the role of a medical professional includes the need to determine whether the directive is valid and applicable.

Medical professional as legal gatekeeper

The third legal role played by a medical professional is that of gatekeeper. Various legal avenues for review are enlivened if there are concerns about a health care decision made under an advance directive or by a substitute decision-maker. For example, a medical professional who is concerned about a treatment decision that has been made by a person responsible may make an application to the Guardianship Tribunal to obtain consent to the treatment or, where relevant, to review the appointment of a guardian or enduring guardian. If the treatment decision is made by the Public Guardian, the medical professional may be able to seek a review of that decision by the Administrative Decisions Tribunal. Being able to take such steps assumes knowledge that these avenues to obtain consent or for review are available. Indeed, it has been suggested that the treating team (or their hospital), rather than the adult's family or friends, should take responsibility for bringing any disputes to the courts (or

[93] *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 at [39]. The uncertainty raised by this comment is also noted by New South Wales Parliament, Legislative Council, Standing Committee on Social Issues, n 19 at [12.79].

[94] For comment on the extent to which medical professionals are familiar with this legal test, or have in place the appropriate procedures and protocols for making this assessment, see Appelbaum P, "Assessment of Patients' Competence to Consent to Treatment" (2007) 357(18) NEJM 1834.

relevant tribunal). In *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449 at [98]-[99], Butler-Sloss LJ was critical of the relevant health service trust for its failure to initiate legal proceedings to resolve an entrenched dispute, and that it fell instead to the adult herself to seek legal redress. A final gatekeeping role arises when a substitute decision-maker withholds consent to treatment (rather than refusing treatment). Here a medical professional may choose to accept that withholding of consent and not treat, or choose to seek consent or authorisation to treat elsewhere.

MEDICAL PROFESSIONALS' KNOWLEDGE OF THEIR LEGAL ROLE

The preceding section established that medical professionals play significant legal roles in decisions to withhold and withdraw life-sustaining treatment. The authors also identified above the grave adverse consequences that can flow where there is a lack of knowledge of the law in this area. Having demonstrated the importance of this knowledge, the following question is addressed: what do medical professionals know of the law that governs these decisions? In doing so, the authors examine what formal training medical professionals receive on this topic and any available empirical evidence in New South Wales as to the state of their knowledge of the law.

WHAT ARE MEDICAL PROFESSIONALS TAUGHT ABOUT THIS AREA OF LAW?

Although medical professionals may acquire knowledge about the law from a range of sources (including, eg, professional guidelines),[95] the focus of this section is on what formal teaching is provided in medical school as this represents a minimum level of training that all medical professionals will receive. There is also some discussion of training opportunities that might arise after medical school.

During the last 20 years, medical programs in Australia have undergone dramatic changes in numbers of programs and students, entry processes, structure, content and pedagogy. One significant curriculum development has been the integration of teaching in medical ethics, law and professional issues in all programs. The Australian Medical Council expects Australasian medical graduates to have knowledge and understanding of the principles of ethics related to health care and the legal responsibilities of the medical profession, and to demonstrate an appreciation of the complexity of ethical issues related to human life and death.[96]

In 2001, a working group of the Association of Teachers of Ethics and Law in Australian and New Zealand Medical Schools published "An Ethics Core Curriculum for Australasian Medical Schools" in the *Medical Journal of Australia*.[97] Although they were not specified as legal topics but were included under the title "Ethics in Practice", the following areas of relevance to this series of articles were included as core knowledge areas:

- determining capacity;
- consent to and refusal of treatment;
- informed decision-making;
- legal aspects of the duty of care;
- surrogate decision-making;
- futility/limiting treatment;
- withdrawing treatment; and
- end-of-life decisions and causation of death.

Despite these expectations and proposals, it is not easy to gauge the extent to which the areas of medical law pertinent to withholding and withdrawing life-sustaining treatment from adults who lack capacity are taught in both medical programs and junior medical professional training. An informal

[95] For example, New South Wales Health, *Guidelines for End-of-Life Care and Decision-making* (2005); New South Wales Health, *Using Advance Care Directives* (2004).

[96] Australian Medical Council, *Assessment and Accreditation of Medical Schools: Standards and Procedures* (2009), http://www.amc.org.au/images/Medschool/standards.pdf viewed 1 November 2010.

[97] A Working Group, on Behalf of the Association of Teachers of Ethics and Law in Australian and New Zealand Medical Schools (ATEAM), "An Ethics Core Curriculum for Australasian Medical Schools" (2001) 175(4) MJA 205.

survey conducted by the authors via personal communication with colleagues in 2010 yielded three responses from the seven medical schools in New South Wales. The authors asked about coverage of decision-making capacity and capacity determination, ethical and legal aspects of withdrawing and withholding treatment (patients with and without capacity), substitute decision-making and guardianship, and advance care planning. Of the three responding schools, one covered the areas "over the course", but in some detail in three sessions in Year 3; the second taught all areas by lectures and student group presentations, with a particular focus on relevant legislation in the Australian Capital Territory and New South Wales, and assessed them via multiple-choice questions, short answers and mini-case exams; and the third provided lectures linked to a case on dementia/delirium in Year 2 (capacity, substitute decision-making, guardianship), and teaching in the oncology-palliative care rotation in Year 4 (ethical and legal aspects of withdrawing and withholding treatment from patients with and without capacity, advance care planning). The authors believe that it is likely that the non-respondent schools have at least some teaching in the same areas.

State postgraduate medical councils accredit training institutions (mainly hospitals) for junior medical professionals, and the Confederation of Postgraduate Medical Councils has developed the Australian Curriculum Framework for Junior Doctors.[98] The framework includes the topics end-of-life care, medicine and the law, and ethical practice, but these have not been populated with resources or references, despite the fact that the framework was launched in 2006. It should be noted that many other sections of the framework also remain relatively unpopulated with resources, and that the framework is not a training program per se, but more a list of aspirational curricular statements. These statements are somewhat vague and general, such as "Liaises with legal & statutory authorities"; "Ensures relevant family/carers are included appropriately in meetings and decision-making"; and "Arranges appropriate support for dying patients". There is no evidence the authors are aware of that any systematic teaching occurs in New South Wales (or in Queensland or Victoria), and there are few, if any, required core units in any areas of medical law, let alone the areas of interest here, at the specialist college stages of training.

Continuing medical education programs for medical professionals in private practice sometimes include medico-legal matters, but since the majority of these programs are supported by pharmaceutical companies, most content pertains to clinical management. Setting aside the critiques of how pharmaceutical companies utilise continuing education to persuade medical professionals to use their products, education sessions on clinical management are undoubtedly valuable for medical professionals in maintaining their knowledge and skills. But clinical management clearly involves considerable knowledge of and guidance by the law in an increasing number of areas, including those under discussion here. Medical defence organisations and professional medical associations likewise provide sporadic medico-legal education for members. It can be fairly said, on the basis of one of the authors' long experience with these organisations, that these programs often focus on risk management issues and legal changes that threaten the profession, rather than the legal aspects of routine clinical management.

The above discussion reveals that current Australian medical students will receive some training on the law and medical professionals' role in end-of-life decision-making, and that qualified medical professionals may undertake some continuing medical education programs from professional medical associations and/or medical defence organisations. However, such postgraduate training is neither mandatory nor systematic and so relies on the interest of the medical professional to participate. These observations support a broad generational difference in relevant education.[99] Medical professionals older than say, 40, are likely to have received little, if any, formal education concerning the focal issues of this series of articles at the postgraduate level, or during their undergraduate medical

[98] Confederation of Postgraduate Medical Councils, *Australia Curriculum Framework for Junior Doctors* (2009), http://www.curriculum.cpmec.org.au viewed 1 November 2010.

[99] Miles SH et al, "Medical Ethics Education: Coming of Age" (1989) 64 *Academic Medicine* 705; Mattick K and Bligh J, "Teaching and Assessing Medical Ethics: Where Are We Now?" (2006) 32(3) *Journal of Medical Ethics* 181; Musick DW, "Teaching Medical Ethics: A Review of the Literature from North American Medical Schools with Emphasis on Education" (1999) 2(3) *Medicine, Health Care and Philosophy* 239; Goldie J, "Review of Ethics Curricula in Undergraduate Medical Education" (2000) 34(2) *Medical Education* 108. This is also consistent with the finding of Darvall and others that accurate

training. The position is different, however, for junior medical professionals, specialty trainees and junior consultants who have graduated over the past decade or so, as they will have had some exposure to the field of ethics and law generally, and end-of-life decision-making more specifically, in their undergraduate training.

WHAT DO MEDICAL PROFESSIONALS KNOW OF THIS AREA OF LAW?

Given the state of formal training on the law in this area and the complexity of the law, it might be expected that medical professionals' legal knowledge will be inadequate. There is strong anecdotal evidence to this effect. For example, the *Conflict Resolution in End of Life Settings* report found that "there is persistently inadequate understanding amongst health professionals about the role of 'Person Responsible' in so far as who decides, and what is permissible in [end of life] substitute decision-making".[100]

In terms of empirical evidence, the authors are aware of only one study that has specifically sought to determine what medical professionals know of this area of law.[101] In 2009, one of the authors conducted a survey of New South Wales medical professionals to assess their level of knowledge and understanding of advance care planning (including in relation to enduring guardians, persons responsible, and advance directives).[102] Only 30% of the 260 respondents had ever received educational material about advance directives; of these, 25% had received the material through their local Divisions of General Practice, 19% from New South Wales Health, 8% from their workplace and 31% from a combination of the above.

Prior to receiving the questionnaire, a majority of respondents had heard of advance directives, enduring guardians and persons responsible and approximately half of the respondents reported having experience with at least one of these decision-making mechanisms. However, experience and knowledge did not necessarily equate. When asked: "If one of your patients has given someone Enduring Power of Attorney, do you think that the person appointed has authority to make health care decisions?", 23% of respondents thought that it did and 30% were unsure. Less than half (47%) understood that an enduring power of attorney appointment in New South Wales does not allow the appointee to make health care decisions, only financial decisions.

In order to ground the theoretical questions, respondents were presented with a scenario which involved an 87-year-old non-competent woman, Georgina, in a residential aged care facility. She had two children, Theo, the elder, and a daughter, Maria, who had been caring for her mother at home and who had been appointed attorney by her mother under an enduring power of attorney. The patient never completed an advance directive and her children disagreed about her treatment. Respondents were told:

> Theo says that he should have the right to make decisions about what treatment Georgina does or does not receive because he is the eldest and therefore her next-of-kin. Maria says that she has been managing all her mother's affairs, paying bills and doing her banking and that because her mother gave her enduring power of attorney to do that, she should have the right to make the decisions.

Respondents were then asked: "Who do you think has the legal right to make health care decisions for Georgina?" and "Why?"

knowledge of the Victorian law in this area decreased with the medical professional's age: see Darvall L, McMahon M and Piterman L, "Medico-legal Knowledge of General Practitioners: Disjunctions, Errors and Uncertainties" (2001) 9 JLM 167 at 181, which is discussed further in the third article in this series: see Willmott, White, Parker and Cartwright, n 66.

[100] New South Wales Health, n 10, p 25.

[101] There have been other studies that looked at related issues. For example, Corke et al surveyed Australian intensive care doctors to evaluate how potential end-of-life treatment decisions might be influenced by a substitute decision-maker or an advance directive: Corke C et al, "The Influence of Medical Enduring Power of Attorney and Advance Directives on Decision-making by Australian Intensive Care Medical Professionals" (2009) 11(2) *Critical Care and Resuscitation* 122. The results of this study reveal non-compliance with the law although whether this is due to a lack of knowledge is not specifically addressed.

[102] Cartwright C et al, *NSW Medical Practitioners' Knowledge of and Attitudes to Advance Care Planning: Report to NSW Health* (November 2009).

While 54% of respondents correctly nominated Maria as the person with authority to make Georgina's decisions, when asked why this was so, 50% of those who nominated Maria said it was because she held Georgina's enduring power of attorney. Only 35% (or 19% of the whole sample) correctly recognised that Maria would be the person responsible under the *Guardianship Act 1987* (NSW) because she had been Georgina's carer (and Georgina no longer had a spouse). The study concluded that there is a "significant gap" in the legal knowledge of medical professionals in this area and that further education is required.[103]

CONCLUSION

This is the first in a series of three articles looking at medical professionals' knowledge of the law governing withholding and withdrawing life-sustaining treatment in New South Wales, Queensland and Victoria. One of the goals of the present article was to establish the foundation for the series as a whole and this was the focus of the second part of the article. It was devoted to arguing why medical professionals' knowledge of the law in this area matters and to outlining the general context of decision-making. The matters considered in this part are drawn upon by the two articles that follow.

The remainder of this article considered the position in New South Wales. It examined the law in this State and concluded that it has problems that will impede medical professionals' legal knowledge. It also concluded that the law in New South Wales provides for medical professionals to play significant legal roles in these decisions. It then considered what medical professionals know of this law. Formal training appears to be delivered primarily through medical school, although it has been only relatively recently that this issue seems to have been given greater weight. Training after medical school is more sporadic. The authors also considered an empirical study which specifically examined, and found deficits in, medical professionals' knowledge of this area of law.

This article, at least in relation to New South Wales, has therefore demonstrated the four claims outlined in the introduction, namely:

- medical professionals play significant legal roles in decisions to withhold and withdraw life-sustaining treatment;
- so it is important that medical professionals know the law in this area;
- but there are significant deficits in relevant legal knowledge by medical professionals; and
- the state of the law is such that it is likely to impede medical professionals knowing the law.

In relation to the last two points, particular evidence linking the state of the law to the level of medical professionals' knowledge is found in the *Conflict Resolution in End of Life Settings* report.[104] It indicates that a lack of clarity in the law is having an adverse impact upon the legal knowledge of medical professionals in this area.

This series of articles also reaches two conclusions, namely that law reform is needed and that medical professionals need more and better education on this topic. Conclusions in relation to medical training apply to all three jurisdictions and so are considered in the final article. There are also general claims that can be made about law reform, such as those in relation to complexity of the law, which will also be made at that time. At this point, however, it is possible to make some observations about law reform in relation to the three problems identified above that are specific to New South Wales law. In doing so, it is stressed that the focus of this article is on addressing medical professionals' knowledge of the law and not on advocating for desirable law reform on a broader, systematic basis.

In relation to the distinction made between substitute decision-makers having the health care function and having only the consent function, the range of problems this causes were noted above. Of particular relevance is that this distinction is likely to be confusing for medical professionals and the anecdotal evidence discussed above supports this conclusion. Perhaps the most persuasive argument in favour of a distinction which confers more limited power on a default decision-maker relates to the possibility of inappropriate decision-making by someone who has not been specifically entrusted by

[103] Cartwright et al, n 102, pp 23-26.

[104] New South Wales Health, n 10, pp 20, 24-25.

the Guardianship Tribunal or the adult with power to refuse life-sustaining treatment. However, in Queensland, default decision-makers automatically have this power and the authors are unaware of these concerns being problematic under that regime. It is also pertinent to note that there are a number of safeguards that protect adults from inappropriate decision-making. A significant safeguard considered in this article is the gatekeeping role played by medical professionals. A medical professional has a range of avenues to challenge a decision if he or she is concerned about it. Accordingly, the authors favour removing the distinction between the health care function and the consent function so that all substitute decision-makers have power to withhold or withdraw life-sustaining treatment.[105] In support of this, the authors note the observation by the Office of the Public Guardian that it was never intended that such a distinction be made.[106]

The article also pointed to the three possible definitions for determining whether an adult has capacity (with two of them being contained in the same piece of legislation). This is obviously undesirable and confusing. It is suggested that a single definition for capacity be adopted in the *Guardianship Act 1987* (NSW). The authors favour that definition giving effect to the functional approach to capacity. This reflects the least restrictive approach favoured by modern guardianship law and is a position that one of the authors has argued for elsewhere.[107]

Another problem identified in this article is the failure to recognise advance directives in statute. New South Wales is one of only two jurisdictions in Australia that relies on the common law in this regard. The authors consider that a statutory advance directive framework would improve the clarity of the law, which would assist medical professionals and others seeking to know the law.[108] One of the authors has argued elsewhere that the enactment of appropriately drafted legislation would also have the desirable effect of enhancing the role and recognition of advance directives as an expression of autonomy.[109]

This concludes the review of the law that governs withholding and withdrawing life-sustaining treatment from adults who lack capacity, and medical professionals' knowledge of that law, in New South Wales. The position in Queensland is considered in the second article of this series.[110]

[105] This is also the outcome favoured by Office of Public Guardian, *Submission to Inquiry into Substitute Decision-making for People Lacking Capacity* (2009) p 20. The Standing Committee on Social Issues recommended that this issue be clarified but declined to make a specific recommendation as to how this should be done: New South Wales Parliament, Legislative Council, Standing Committee on Social Issues, n 19 at [12.77]. Instead, it recommended that the wider issue of end-of-life decision-making be referred to the New South Wales Law Reform Commission for its consideration (at [12.83]).

[106] Office of Public Guardian, n 105, p 20.

[107] Devereux J and Parker M, "Competency Issues for Young Persons and Older Persons" in Freckelton I and Petersen K (eds), *Disputes and Dilemmas in Health Law* (Federation Press, Sydney, 2006) pp 54, 57-58. This is also the position adopted in New South Wales Parliament, Legislative Council, Standing Committee on Social Issues, n 19 at [4.52]-[4.57], Recommendation 1.

[108] The Standing Committee on Social Issues noted some uncertainty as to the current status of advance directives at common law and recommended that this issue (along with the wider issue of end-of-life decision-making generally) be referred to the New South Wales Law Reform Commission for its consideration: New South Wales Parliament, Legislative Council, Standing Committee on Social Issues, n 19 at [12.79]-[12.83].

[109] See Willmott, n 92.

[110] Willmott, White, Parker and Cartwright, n 71.

Research

Doctors' knowledge of the law on withholding and withdrawing life-sustaining medical treatment

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Abstract

Objectives: To examine doctors' level of knowledge of the law on withholding and withdrawing life-sustaining treatment from adults who lack decision-making capacity, and factors associated with a higher level of knowledge.

Design, setting and participants: Postal survey of all specialists in emergency medicine, geriatric medicine, intensive care, medical oncology, palliative medicine, renal medicine and respiratory medicine on the AMPCo Direct database in New South Wales, Victoria and Queensland. Survey initially posted to participants on 18 July 2012 and closed on 31 January 2013.

Main outcome measures: Medical specialists' levels of knowledge about the law, based on their responses to two survey questions.

Results: Overall response rate was 32%. For the seven statements contained in the two questions about the law, the mean knowledge score was 3.26 out of 7. State and specialty were the strongest predictors of legal knowledge.

Conclusions: Among doctors who practise in the end-of-life field, there are some significant knowledge gaps about the law on withholding and withdrawing life-sustaining treatment from adults who lack decision-making capacity. Significant consequences for both patients and doctors can flow from a failure to comply with the law. Steps should be taken to improve doctors' legal knowledge in this area and to harmonise the law across Australia.

Decisions to withhold or withdraw life-sustaining treatment are part of mainstream medical practice.[1] Almost 40 000 adult deaths occur each year across Australia following a medical decision to withhold or withdraw life-sustaining treatment.[2]

Doctors play a critical clinical role in the provision of medical treatment at the end of life. What is less recognised is that doctors also play a significant legal role in that process.[2-4] For example, a doctor must assess whether a patient has the capacity to make a treatment decision, determine who the authorised decisionmaker is if the patient does not have that capacity, and know whether a person's previously expressed wishes comprise a valid advance directive that must be followed.

Further, the law in this field is complex and differs between states and territories. For example, in some situations a doctor may be obliged to follow an advance directive in one state but will be in breach of the law if he or she does so in the same situation in another.

Doctors currently receive some training about the law in this and other areas in medical school, during specialist training, and/or as part of continuing medical education.[3] However, it is unclear whether this training equips doctors sufficiently with adequate practical knowledge. One aim of this research was to establish the level of doctors' legal knowledge about withholding or withdrawing life-sustaining treatment from adults who lack decision-making capacity.

Methods

This study explored doctors' knowledge of the law relevant to end-of-life care in New South Wales, Victoria and Queensland. These states have both similarities and differences between legal regimes, which allowed us to explore whether the different regimes affected levels of knowledge.

Data were collected through a survey instrument, developed over 18 months, informed by a detailed review of the law in each state, focus groups, pretesting, and piloting of the instrument with specialists. The accuracy of the legal questions and responses were confirmed by independent legal experts in each state.

The sample cohort comprised all specialists in emergency medicine, geriatric medicine, intensive care, medical oncology, palliative medicine, renal medicine and respiratory medicine who were on the AMPCo Direct (a subsidiary of the Australian Medical Association) database in the three states at the time the instrument was distributed ($n = 2858$). These specialties were chosen as these specialists are likely to be involved in making decisions about whether to withhold or withdraw life-sustaining treatment. This was determined by a review of relevant literature, interviews and an analysis of pilot results. Although general practitioners are commonly involved in end-of-life decision making, they were excluded from our study, which focused on the acute care setting.

AMPCo Direct administered the survey mailout, which began on 18 July 2012. Recruitment strategies included having the survey instrument professionally designed, providing incentives (continuing professional development [CPD] points, educational material and a chance to win one of six prestige bottles of wine), engaging with all the colleges and specialist societies of the target specialties (except the emergency medicine society given the overlap with the college) and publishing editorials in relevant professional journals to request participation in the study.[5,6] Two follow-up requests were sent to non-responders and the survey was closed on 31 January 2013.

The project was approved by the human research ethics committees at the

1 Mean correct responses to seven statements relating to knowledge of the law regarding end-of-life care, and number of respondents scoring ⩾ 4, by doctor characteristics

Characteristic	No. of respondents	Mean correct score (SD)	Adjusted mean score*	No. of respondents scoring ⩾ 4 (%)
Total	867	3.26 (1.32)		365 (42.1%)
State				
New South Wales	335	3.65 (1.24)		185 (55.2%)
Victoria	314	3.17 (1.38)		124 (39.5%)
Queensland	218	2.79 (1.18)		56 (25.7%)
Specialty†				
Geriatric medicine	107	3.89 (1.28)	3.77	61 (57.0%)
Palliative medicine	52	3.71 (1.49)	3.69	27 (51.9%)
Intensive care	125	3.48 (1.35)	3.44	63 (50.4%)
Renal medicine	80	3.37 (1.13)	3.28	37 (46.3%)
Emergency medicine	270	3.09 (1.27)	3.04	103 (38.1%)
Medical oncology	80	3.07 (1.23)	3.00	29 (36.3%)
Respiratory medicine	98	2.72 (1.34)	2.68	25 (25.5%)
Sex†				
Male	567	3.18 (1.30)	3.08	232 (40.9%)
Female	298	3.43 (1.35)	3.26	132 (44.3%)
Country of birth†				
Australia	517	3.35 (1.32)	3.41	231 (44.7%)
Other English-speaking	151	3.23 (1.42)	3.23	65 (43.0%)
Asia	120	3.12 (1.18)	3.08	45 (37.5%)
Europe	31	2.87 (1.31)	3.01	7 (22.6%)
Other	43	3.12 (1.35)	3.14	15 (34.9%)

* Adjusted mean scores for specialty were adjusted for state; for each of sex and country of birth, they were adjusted for state and specialty and each other. † 55, 2 and 5 respondents did not state main specialty, sex and country of birth, respectively. ◆

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Measures

The survey instrument had six sections: perspectives about the law; education and training; knowledge of the law; practice of and compliance with the law; experience in making end-of-life decisions; and demographics. The knowledge section contained two questions. The first comprised six items: three concerning the validity of an advance directive, two concerning consent from and the authority of substitute decisionmakers, and one dealing with both issues. All questions were to be answered True, False or Don't Know in relation to the relevant state law. The second question asked which of four plausible decisionmakers had legal authority to make medical decisions for a patient without capacity. Participants could score correct responses on a scale of 0 to 7 (Don't Know was scored as an incorrect response).

Doctors were asked how much knowledge of the relevant law they felt that they currently had: very little; some; moderate; or considerable.

To determine any correlation between decision making and knowledge, doctors were asked how many decisions to withhold or withdraw life-sustaining treatment they were directly involved in as a member of the treating team in the previous 12-month period, including situations where such decisions were considered but treatment was ultimately provided or continued.

To determine any correlation between the extent of CPD training received in this area and knowledge, doctors were asked whether they had received such training and, if so, when.

Statistical analysis

Questionnaires were coded and double-entered into an Access database and transferred to SPSS Statistics 20 (IBM) and SAS 9.3 (SAS Institute Inc) for analyses.

Preliminary analyses examined descriptive statistics and bivariate associations by χ^2 tests. Mean scores were calculated to assess differences in knowledge among subgroups and linear trends associated with ordinal variables. Formal comparison of mean scores was performed using a general linear model, assuming a normal distribution for scores. Variables examined as predictors of knowledge were state, age, sex, main specialty, religion, years of practice, country of birth, country of degree, self-perceived knowledge of the law, number of decisions made in relation to withholding and withdrawing life-sustaining treatment, and CPD training. Mean scores for subgroups were compared with the sample average using the Nelson–Hsu method within the SAS Statistics GLM procedure, which also adjusts for multiplicity of comparisons. Linear trends associated with ordinal variables, such as self-perceived knowledge, were assessed by modelling these as continuous. Likelihood ratio tests (LRTs) were used to assess each variable overall. Adjusted means were obtained from a linear model that included selected covariates, and similarly compared.

Results

The final overall response rate was 32% (867/2702): 29% (335/1147) from NSW, 33% (314/957) from Victoria and 36% (218/598) from Queensland. Response rates by specialty by state ranged from 75% for palliative medicine specialists in Victoria to 22% for oncologists in NSW.

The mean correct response for the knowledge of law questions overall was 3.26 (out of a possible score of 7), with a standard deviation of 1.32.

State and specialty were the strongest predictors of knowledge (Box 1), with LRTs giving $P_{LRT} < 0.001$ for both variables. NSW showed the highest scores and Queensland the lowest. All pairwise differences were statistically significant at $P < 0.001$. After adjustment for state, specialists in geriatric medicine ($P < 0.001$) and in palliative medicine ($P = 0.033$) had significantly higher scores than average, and specialists in emergency medicine ($P = 0.035$) and respiratory medicine ($P < 0.001$) had significantly lower scores than average. Medical

oncologists had a lower mean score than average but this was not significant ($P = 0.53$), because of the small number of medical oncologists.

Sex and country of birth were weaker predictors of knowledge. Women and Australian-born doctors scored somewhat higher than other groups. The sex effect is reduced when adjusted as described in Box 1, but remains significant ($P_{LRT} = 0.05$). Country of birth was also a significant predictor after adjustment ($P_{LRT} = 0.042$). The difference between Australian-born doctors and others was significant after adjustment for state, specialty and sex ($P = 0.017$).

Years of practice, age, country of degree and religion did not predict knowledge (data not shown).

The results demonstrated a highly significant and linear association between doctors' perception of and actual knowledge of the law in this area (Box 2; $P < 0.001$). This effect remained after adjusting for state, specialty, sex and country of birth ($P < 0.001$).

The results also demonstrated a highly significant and linear association between the number of decisions doctors made and their knowledge of the law (Box 2; $P < 0.001$), an effect which remained after adjustment for state, specialty, sex and country of birth ($P = 0.008$).

Doctors who had received CPD training had greater knowledge than those who had not, and the association between knowledge and recency of training was significant and linear (Box 2; $P = 0.007$ for linear trend in mean scores, after adjusting for state, specialty, sex and country of birth).

2 Mean correct responses to seven statements relating to knowledge of the law regarding end-of-life care, and number of respondents scoring ⩾ 4, by perception of knowledge, number of decisions made in relation to withholding and withdrawing life-sustaining treatment, and timing of most recent continuing professional development (CPD) training

	No. of respondents	Mean correct score (SD)	Adjusted mean score*	No. of respondents scoring ⩾ 4 (%)
Perceived knowledge of law†				
Very little	136	2.83 (1.25)	2.84	39 (28.7%)
Some	330	3.15 (1.21)	3.06	129 (39.1%)
Moderate	258	3.42 (1.39)	3.31	117 (45.3%)
Considerable	42	4.14 (1.34)	4.03	30 (71.4%)
No. of decisions†				
None	60	3.00 (1.30)	2.86	21 (35.0%)
1–10	345	3.08 (1.25)	3.10	122 (35.4%)
11–30	249	3.31 (1.34)	3.26	112 (45.0%)
31–50	105	3.60 (1.39)	3.44	54 (51.4%)
51–100	68	3.44 (1.30)	3.21	33 (48.5%)
> 100	34	3.88 (1.32)	3.51	21 (61.8%)
Most recent CPD training†				
None	343	3.07 (1.37)	3.07	126 (36.7%)
⩾ 5 years ago	107	3.30 (1.26)	3.20	46 (43.0%)
3–4 years ago	132	3.33 (1.32)	3.14	59 (44.7%)
1–2 years ago	143	3.36 (1.25)	3.29	63 (44.1%)
Within past year	126	3.60 (1.30)	3.43	67 (53.2%)

*Adjusted for state, specialty, sex and country of birth. †101, 6 and 16 respondents did not answer the questions on knowledge, number of decisions and CPD training, respectively. ◆

Discussion

Our results demonstrate critical gaps in the legal knowledge of many doctors who practise end-of-life medicine. Before considering the consequences of these gaps, and the implications of these results, we make two general observations.

First, doctors in NSW had the highest level of knowledge, followed by those in Victoria and then Queensland. Research into reasons for the disparity between states is needed and may provide guidance for successful education and training strategies. Is the law easier to understand in some jurisdictions? Does the law reflect good medical practice to a greater extent in some jurisdictions? Are doctors in some jurisdictions better trained in the law? Further, respondents in some specialties were more knowledgeable than those in other specialties.

Second, the results indicate that doctors have an accurate perception of their level of knowledge. This may be useful if doctors are persuaded that it is important to be familiar with the law in the course of their clinical practice. As they have insight into their level of knowledge, they will know whether further efforts are needed to augment that knowledge.

There are limitations to research of this kind. Doctors with an interest in law may be more likely to respond, so our sample may be more legally knowledgeable than the wider medical population. Also, not all aspects of legal knowledge about withholding or withdrawing treatment can be tested. However, two important aspects of the law were explored: validity and effect of advance directives and the authority of substitute decisionmakers. The results show that many doctors do not possess sufficient legal knowledge to determine whether an advance directive presented to them is valid. Further, even if they are confident that it is valid, many doctors do not know whether they are legally obliged to follow a directive that refuses treatment in a situation when providing treatment is clinically indicated. The results also indicate doctors' lack of knowledge in determining the legally authorised decisionmaker for medical treatment where there are various people who have an interest in the wellbeing of a patient.

Significant consequences for patients can flow from a failure to know and comply with the law. Life-sustaining treatment may be unlawfully withheld or withdrawn; for example, where the purported decisionmaker lacks legal authority. For patients, the outcome of such decisions is that, at least as a matter of law, their lives are being ended wrongly. Conversely, life-sustaining treatment may be unlawfully provided; for example, despite a lawful refusal of treatment through an advance directive or by a substitute decisionmaker. This may infringe a patient's legal rights, including their right to bodily integrity,[7] and cause patients to survive

with poor quality of life, which they had sought to avoid.[8]

For medical professionals, criminal responsibility could arise for murder or manslaughter (where treatment is withheld or withdrawn unlawfully)[9] or for assault (where treatment is provided without appropriate consent or authorisation).[10] A lack of legal knowledge will not excuse a medical professional from liability.[11] Claims of civil liability may also flow from such actions, along with disciplinary or coronial proceedings.[12]

In addition, conflict may arise where medical professionals and patients' family or friends have little or no legal knowledge, or different understandings of what the law requires, leading to adverse consequences for everyone involved.[13]

Our findings strongly suggest that doctors in a specialty involving end-of-life decision making should improve their knowledge of the law, in the interests of their patients and for their own protection. To achieve this goal, three things must occur: legal reform; improved training and resources; and a shift in doctors' attitudes to knowing the law.

We have argued elsewhere that there are problems with the law in NSW,[2] Victoria[3] and Queensland,[4] and have identified aspects that could be simplified. Some level of legal complexity in this area is unavoidable, but where it is unnecessary, the law should be reformed. There is also an urgent need for a national approach to the law in this area.[14] For medical professionals, a single Australian legislative framework, or a harmonised national approach, is likely to be easier to know and understand.

Training in medical law remains uneven and unsystematic at all stages of medical education.[15] This is reflected in the general knowledge deficits and variations by specialty demonstrated by our research, only partly offset by knowledge gained by practical involvement (the number of decisions). Nevertheless, the correlation between knowledge level and recent CPD training is promising. Even if a harmonised national approach to the law in this area were to be achieved, the need for a substantial increase in educational effort would remain to ensure that all doctors involved in end-of-life care know and understand the applicable law. We advocate a broad approach to improving doctors' knowledge of the law across the three main stages of medical education and note those with responsibility for change:

- undergraduate training in basic ethical principles and the related law at the end of life, within a wider framework of dedicated coursework in ethics, law and professional practice (universities and medical schools, Australian Medical Council);
- continuing training for interns and junior doctors in the hospital setting, in relevant rotations, as components of educational packages under accreditation requirements (hospital executives, directors of clinical training, medical education officers, specialist consultant leaders, intern training accreditation bodies, Medical Board of Australia); and
- specialist college-sponsored, non-elective training programs in all specialties concerned with end-of-life decision making (specialist colleges, Australian Medical Council).

However, providing training opportunities and resources — even in the format and at the times most desired by doctors — is not enough. Attitudes must also shift; doctors who are under ever-increasing time pressures must be satisfied that knowing the law is valuable. Learning about and understanding the law that applies at the end of life will require significant intellectual engagement and commitment of time. The challenge is convincing doctors that it is worth the effort. A good start is to ensure that doctors recognise that lack of legal knowledge places their patients' interests and rights at risk — and them at legal risk.

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