Lawyers for the People

AUSTRALIAN LAWYERS ALLIANCE

Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

Submission to Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee

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Protecting and promoting justice, freedom and the rights of the individual

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Who we are

The Australian Lawyers Alliance (ALA) is a national association of lawyers, academics and other professionals dedicated to protecting and promoting justice, freedom and the rights of the individual.

We estimate that our 1,500 members represent up to 200,000 people each year in Australia. We promote access to justice and equality before the law for all individuals regardless of their wealth, position, gender, age, race or religious belief.

The ALA is represented in every state and territory in Australia. More information about us is available on our website.[1]

The ALA office is located on the land of the Gadigal of the Eora Nation.

[1] www.lawyersalliance.com.au.

Introduction

1. The ALA welcomes the opportunity to have input into the inquiry into aged care, end-of-life and palliative care and voluntary assisted dying ('VAD').

2. This response has been compiled by the Queensland State Committee whose members have substantial expertise in this area. It focuses predominantly on the introduction of a VAD scheme and the current legal framework regarding decisions to withdraw and/or withhold life-sustaining measures.

Voluntary assisted dying

Should VAD be allowed in Queensland? Why/why not?

3. The ALA submits that eligible persons in Queensland should be allowed to access VAD in certain limited circumstances regarding their end-of-life decisions.

4. In recent times, Australian healthcare has been strongly influenced by the principle of patient autonomy i.e. a patient's right to direct their own healthcare.[2] This principle is a fundamental part of Australia's common law with healthcare providers obligated to obtain consent from their patients prior to providing treatment.[3] In the context of withdrawing and/or withholding life-sustaining treatment, it is now uncontroversial at law that a competent patient can refuse life-sustaining treatment even if such a refusal will result in the death of that patient.[4] This is because for a competent patient the principle of autonomy takes precedence if it conflicts with the value of human life.[5] Enabling persons to access VAD in certain limited circumstances would be consistent with the principal of patient autonomy.

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[2] Ben White, Fiona McDonald and Lindy Willmott, *Health Law in Australia* (Thomson Reuters, 2nd ed, 2014) 28.

[3] Ibid 129 citing *Secretary, Department of Health and Community Services (NT) v JWB (Marion's case)* (1992) 175 CLR 218.

[4] *AK (Adult Patient) (Medical Treatment: Consent), Re* [2001] FLR 129; *B (adult: refusal of medical treatment), Re* [2002] 2 All ER 449, *C (Adult: Refusal of Medical Treatment), Re* [1994] 1 All ER 819; *PVM, Re* [2000] QGAAT 1.

[5] See *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229.

5. Advances in medicine mean that illness and disease that once resulted in early death are now routinely treated and managed and in some case cured. As a result Queenslanders are living longer and in many instances living with a distressing disability. In most cases pain and suffering can be treated to the satisfaction of the patient through palliative care and other health services and supports. However, pain and suffering in some persons cannot be adequately alleviated and those persons may wish to relieve their suffering by ending their life. The experience of dying is a personal experience and it may be important for persons to decide a number of factors regarding how they die, including:

    a. the time and place of death;

    b. the way in which they die;

    c. the presence of loved ones at the time of death;

    d. the chance to say goodbye to loved ones; and

    e. access to spiritual and emotional support in the lead up to their death.

6. Enabling persons in some circumstances to access VAD would be consistent with the increasing focus on patient-centred care, facilitating patient choice and enabling persons to die in circumstances that they consider to be dignified.

7. If persons do not have access to VAD, some may believe that they have no alternative but to commit suicide. In the *Inquiry into end of life choices – Final Report*[6] it was reported by the Coroners Court of Victoria that around 50 Victorians each year were taking their lives after experiencing an irreversible deterioration in physical health.[7] A number of individual submissions were also provided to that inquiry detailing the drastic measures that had been taken by people with serious and incurable conditions to end their lives.[8] These decisions affect not only the person making the decision but their family members, friends and emergency responders, such as police officers and paramedics. Although it is unknown

[6] Parliament of Victoria, 'Inquiry into end of life choices - Final Report' (2016) *Victorian Government Printer*.

[7] Ibid, 197-8.

[8] Ibid, 198-200.

whether persons would choose to access VAD instead of suicide, it would be preferable that they have the choice to access VAD in those circumstances.

8. Assisted suicide is a criminal offence in all Australian jurisdictions, including in Queensland.[9] However, cases in Australia demonstrate that minimal penalties are often imposed when persons have been found guilty of assisting suicide in circumstances when the other competent person has been suffering grievously and requested assistance to end their life.[10] Although community standards and beliefs may support the imposition of light sentences in these circumstances, it would be more appropriate for persons suffering to end their lives through a VAD scheme where those assisting them are not at risk of criminal sanction.

9. There is some evidence to suggest that physician assisted suicide is currently being practised in Australia.[11] If this is correct then it would be more appropriate that it occur within a structured and properly regulated VAD framework to ensure that only eligible persons are accessing the scheme and that medical practitioners are not at risk of criminal sanction in those circumstances.

10. It has been suggested that the prohibition on VAD has no impact on its levels of occurrence. It has been reported that the incidence rates tend to be comparable between jurisdictions with prohibitions and those where it has been legalised.[12] If a strong regulatory framework were implemented, it would enable greater transparency and oversight of VAD and would arguably provide greater protection for vulnerable individuals.

If there is to be a VAD scheme, what features should it have?

11. If a VAD scheme is implemented in Queensland, it is imperative that a clear and transparent framework is developed to ensure that the activity being regulated is clear, the eligibility

[9] *Criminal Code 1899* (Qld), s311.

[10] See, for example, *R v Nicol* [2005] NSWSC 547; *DPP v Karaca* [2007] VSC 190; *DPP v Nestorowycz* [2008] VSC 385; *R v Nielsen* [2012] QSC 29.

[11] See, for example, Magnusson, Roger S, 'Angels of Death: Exploring the Euthanasia Underground (2002) *Melbourne University Press*.

[12] Above n 1, 538 citing L Bartels and M Otlowski, 'A Right to Die? Euthanasia and the Law in Australia' (2010) 17 *Journal of Law and Medicine* 532 at 551; M Otlowski, 'The Effectiveness of Legal Control of Euthanasia: Lessons from Comparative Law' (2002) *Recht der Werkelijkeid* 137.

requirements are unambiguous, the process is clear and not too burdensome on persons accessing VAD or on the health profession and that the VAD scheme can be closely monitored, regularly reviewed and reported on.

Activity being regulated

12. It is essential that any VAD scheme clearly identifies what activity is being regulated. The ALA supports a VAD scheme where eligible persons can be provided with an approved medication by an approved medical practitioner to be self-administered by the person. In circumstances where the person is physically unable to self-administer the approved medication, medical practitioners should be permitted to administer the approved medication to the person. This is to ensure that persons with a physical disability are not excluded from accessing VAD on account of their disability.

Eligibility requirements

13. The ALA consider that eligibility requirements should be met before a person is able to access VAD, as outlined below.

14. Minimum age – VAD should be available to persons 18 years and older. However, it should be considered whether persons under the age of 18 can access VAD. This issue will be discussed in further detail below.

15. Citizenship and residency requirements – to avoid VAD 'tourism', there should be a requirement that persons accessing VAD are either Australian citizens or permanent residents at the time of initiating their request to participate in a VAD scheme. In addition, persons should be ordinarily resident in Queensland and at the time of initiating their request, have been resident in Queensland for at least 12 months.

16. Capacity – a person must have legal capacity to make the decision to end their life through VAD. The ALA does not support a scheme where substitute decision-makers can decide to end the life of another person.

17. The meaning of capacity must be clearly defined and it would be preferable that the definition be consistent with definitions in existing legislation. Under the *Guardianship and Administration Act 2000* (Qld) ('GAA'), 'capacity' in the context of health care is defined as meaning that the person is capable of understanding the nature and effect of decisions about

the matter, freely and voluntarily making decisions about the matter and communicating the decisions in some way.

18. However, it should be considered whether additional requirements should be imposed before a person is deemed to have capacity to make decisions under a VAD scheme. For example, under section 42 of the *Powers of Attorney Act 1998* (Qld) ('PAA'), a person must understand a number of additional matters before they are considered to have capacity to make an advance health directive ('AHD'). Given the seriousness of a decision to participate in a VAD scheme, it may be appropriate to impose additional requirements before a person is deemed to have capacity.

19. Medical condition – an individual must be experiencing grievous and irremediable suffering related to an advanced and progressive terminal, chronic or neurodegenerative disease, illness or condition that cannot be relieved in a manner tolerable to the person.

20. Proximity to death – it should be considered whether a person should only be eligible to participate in a VAD scheme if their death is likely to occur within a particular timeframe from the date of their request. This issue is discussed in further detail below.

Process

21. A VAD scheme should clearly set out the process that is required before an eligible person is permitted to self-administer medication or an eligible medical practitioner is permitted to administer the medication directly to the person. The details of the process proposed by the ALA is outlined below.

22. The person who wants to access VAD must initiate the request to a medical practitioner and the request must be made personally to the medical practitioner.

23. It must be determined by two eligible medical practitioners that the person meets the eligibility criteria, and each medical practitioner should provide the following information to the person about:

    a. The person's diagnosis and prognosis;

    b. The treatment options available to the person and the likely outcomes of that treatment;

c. Palliative care options available to the person and the likely outcomes of that care;

d. The potential risks of taking a substance likely to be prescribed under the VAD scheme for the purposes of causing the person's death;

e. That the expected outcome of taking a substance likely to be prescribed under the VAD scheme is death; and

f. That the person may decide at any time not to continue the request and the assessment process.

24. After the person is deemed by two eligible medical practitioners to meet the eligibility requirements, a written request must be made by the person in the presence of one of the medical practitioners to confirm that they wish to proceed under the VAD scheme.

25. The medical practitioner that witnesses the written request must then apply for a permit for the person to self-administer medication or for a permit to administer the medication to the person if they are physically unable to self-administer the medication. Once a permit is approved a person may access the medication from a prescribing body.

Safeguards

26. Any VAD scheme must have adequate safeguards to protect vulnerable persons and should include the following:

a. The establishment of a Board to monitor the VAD scheme, approve permits, review the exercise of any function under the VAD scheme, report to Parliament and promote compliance with the VAD scheme;

b. Health professionals should be prevented from initiating discussions with a person or make suggestions to a person about participating in a VAD scheme. Conduct of this nature should be considered unprofessional conduct within the meaning and for the purposes of the *Health Practitioner Regulation National Law Act 2009* (Qld).

c. A person should not be eligible to participate in a VAD scheme if they have only been diagnosed with a mental illness as defined in section 10 of the *Mental Health Act 2016* (Qld);

d. Eligibility criteria should be introduced for medical practitioners participating in a VAD scheme to ensure that they are appropriately experienced and qualified and have completed a minimum level of training regarding the VAD scheme;

e. Medical practitioners should be required to provide minimum levels of information to a person seeking access to VAD, as detailed above, to ensure that the person understands what all of their treatment options are and the consequences of participating in a VAD scheme;

f. After the person is deemed to meet the eligibility criteria by two medical practitioners, the person must make a written request in the presence of one of the medical practitioners and another witness. To be an eligible witness, they should be over the age of 18, not be the person's health care provider and not someone who is likely to benefit financially from the person's death;

g. Medical practitioners should be required to obtain permits from the Board before medication can be prescribed and dispensed to a person. The request should be accompanied by the written request of the person and the written assessments of the medical practitioners;

h. Pharmacists should be required to give information to persons when dispensing medication about how the medication is to be stored safely, labelling requirements and what will happen if the medication is administered;

i. Pharmacists must notify the Board when medication is dispensed;

j. Measures should be implemented to ensure that dispensed medications are safely stored, persons who decide not to proceed with VAD return the unused medications to the dispensing pharmacist within a specified timeframe and if some but not all of the dispensed medication is ingested, that the unused medication is returned to the dispensing pharmacist;

k. If a medical practitioner is permitted to administer medication to a person, the medication must be administered in the presence of an eligible witness and the Board must be notified within a reasonable timeframe after the medication is administered;

27. If a person dies as a result of their participation in a VAD scheme, the Registry of Births, Deaths and Marriages and the Coroner should be notified.

28. Eligible applicants should be able to apply to the Queensland Civil and Administrative Tribunal ('QCAT') if they consider a person does not meet eligibility requirements. Alternatively, a person should be able to apply to QCAT if their request to participate in the VAD scheme is denied.

29. Offences should be created for the following situations:

    a. Another person other than an authorised medical practitioner administers medication to a person obtained under a permit;

    b. A medical practitioner administers medication knowing that it has not been authorised by the VAD scheme;

    c. A person induces another person to request VAD;

    d. A person induces another person to self-administer medication obtained through VAD;

    e. Medical practitioners fail to notify the Board of various matters and provide documents as required under the VAD scheme.

Are there aspects of VAD schemes in other jurisdictions that should, or should not, form part of any potential VAD scheme for Queensland, and why?

30. A number of jurisdictions require that a person's illness, disease or medical condition will result in their death within a particular timeframe from the date they request access to VAD. For example, in Oregon, a person must have a terminal disease from which they will die within six months.[13] In Victoria, a person must be diagnosed with a disease, illness or medical condition that is expected to cause death within a period not exceeding 6 months.[14] However, if the person suffers from a neurodegenerative condition, that period of time is extended to 12 months.[15]

[13] *Death with Dignity Act 1994* (Oregon).

[14] *Voluntary Assisted Dying Act 2017* (Vic), s 9(1)(d)(iii).

[15] Ibid, s 9(4).

31. The ALA submits that the imposition of a condition requiring a person's disease, illness or medical condition to result in their death within a specific period of time is problematic because it can be uncertain when a patient may die, there may be differing views within the medical profession as to when a patient's death is likely to occur and it would prevent persons with incurable chronic diseases, illnesses or medical conditions from accessing VAD when their disease, illness or medical condition may cause immense pain and suffering without any hope of reprieve.

32. There are a number of examples in the context of decisions to withdraw life-sustaining treatment that illustrate how proximity to death as an eligibility requirement would prevent certain individuals from accessing the scheme. In *Re JS*,[16] a 27 year old man who had been a quadriplegic for 20 years experienced a significant deterioration in his health and required the assistance of full time carers within a hospital setting. Due to the deterioration in his health, he decided that he no longer wished to live and asked for his mechanical ventilation to be withdrawn. Because the decision focussed on JS's capacity and potential criminal liability of his carers, specific comments were not made regarding his life expectancy. However, if he was expected to continue living with adequate supports, he would not be eligible to access a VAD scheme that imposed limits based on proximity to death. It is unclear why persons living with chronic diseases, illnesses or medical conditions should be excluded from a VAD scheme if they otherwise meet the requirements because their death is not likely to occur in the near future. In addition, those persons may decide to end their lives by withdrawing and/or withholding medical treatment. It is arguable that those methods of dying may cause additional pain and suffering to those persons than ending their lives through a VAD scheme.

Who should be eligible to access VAD and who should be excluded?

33. The eligibility requirements have been discussed in detail above.

Should the scheme be limited to those aged 18 and over? If so, why? If not, why not?

34. The ALA submits that it could be appropriate to enable children to access VAD provided that they have capacity to make that type of decision and they otherwise meet the eligibility

[16] [2014] NSWSC 302.

requirements under the VAD scheme. The ALA recognises that there would be a range of views regarding the involvement of children in a VAD scheme and that there may be strong objection to children being included. However, if adults are allowed to access VAD, it needs to be carefully considered why children should be prevented from accessing VAD if they otherwise meet the eligibility requirements of the scheme. Denying children access to VAD could subject them to pain and suffering and the ALA considers that children should have the same options as adults for end-of-life care, unless there are strong reasons not to.

35. The ALA only supports children accessing VAD if they have the capacity to make such decisions. The ALA does not support substitute decision-makers, including parents, making those decisions on behalf of children. In Queensland, the test for capacity for children is governed by the common law, which establishes that children may have the capacity to lawfully consent to their own medical treatment when he or she has *'a sufficient understanding and intelligence to enable him or her to understand fully what is proposed*'.[17] A parent's right to consent to treatment for a child terminates if and when the child has capacity to consent to the particular treatment.

36. If a child has capacity, the Supreme Court of Queensland has power through its *parens patriae* jurisdiction to override a child's decision if they consider it would be in the best interests of the child. The Court's *parens patriae* jurisdiction can be invoked by any person having the care of a child, including a doctor. Therefore, if a person was concerned about a child's participation in a VAD scheme, they could apply to the Supreme Court and the Court could overturn the child's decision to prevent their participation in VAD even if they had the capacity to make such a decision.

37. If eligible children were able to access VAD in Queensland, it would need to be considered whether a declaration should first be sought from the Supreme Court approving the child's decision to access VAD, before it could be permitted. The resources of the Court and the time and cost involved in seeking such a declaration would need to be considered before making this a mandatory requirement.

[17] *Secretary, Department of Health and Community Services (NT) v JWB and SMB (Marion's case)* (1992) 175 CLR 218 at 238-239 per Mason CJ, Dawson, Toohey and Gaudron JJ, 311 per McHugh J.

Under what circumstances should a person be eligible to access VAD?

38. This issue has been discussed above.

What features should be included in a process to allow a person to legally access VAD?

39. The issue has been discussed above.

What safeguards would be required to protect vulnerable people from being coerced into accessing such a scheme, any why?

40. There are a number of safeguards that would be required to protect vulnerable persons. A person should be required to initiate the request personally to a medical practitioner to give the medical practitioner an opportunity to explore why the person is making the request and whether there are any third parties placing pressure on the person to initiate the request. The imposition of eligibility requirements for medical practitioners participating in the scheme would ensure that only experienced and skilled medical practitioners with knowledge of the VAD scheme would be able to apply for permits. The requirement for the Board to issue a permit before medications are dispensed not only provides protections to medical practitioners but ensures that if there are any concerns regarding the application that those issues are investigated further before a permit is issued. A robust reporting scheme and the creation of offences for non-compliance with the VAD scheme should also provide protections for vulnerable persons.

Should people be provided access to counselling services if they are considering VAD? If so, should such counselling be compulsory? Why?

41. The ALA supports the availability of counselling services for persons wishing to access VAD. However, we do not consider that it should be a mandatory requirement for medical practitioners to offer access to counselling services or to compel a person's participation in counselling before they can access VAD. In this regard, it is anticipated that there would be a component of counselling provided during the assessment by the two medical practitioners involved in the VAD process. The requirement to participate in counselling sessions could prevent persons in rural and remote areas of Queensland from accessing VAD. It could also

delay the VAD process and cause additional distress and suffering to the person seeking to access VAD.

Should medical practitioners be allowed to hold a conscientious objection against VAD? If so, why? If not, why not?

42. The ALA submits that medical practitioners and other health practitioners should be allowed to conscientiously object to VAD and should not be forced to participate in assisted dying. The ALA recognises that there is a wide range of personal views and beliefs that will determine whether individuals support the introduction of a VAD scheme in Queensland, including within the health profession. If a VAD framework is introduced the ALA strongly believes that the personal beliefs and values held by medical practitioners and other health practitioners should not be devalued by their forced participation in assisted dying.

43. Enabling medical practitioners and other health practitioners to conscientiously object to VAD would also provide consistency with other legislative schemes. For example, s8 of the *Termination of Pregnancy Act 2018* (Qld) enables a registered health practitioner to conscientiously object to providing information about termination services or to be involved in performing or assisting in termination of a pregnancy. In the context of VAD, s7 of the *Voluntary Assisted Dying Act 2017* (Vic) allows a registered health practitioner to conscientiously object to VAD and sets out a number of circumstances in which a health practitioner has the right to refuse.

44. Conscientious objection to VAD would also provide consistency with codes of conduct and ethics of the medical profession. For example, the Medical Board of Australia's 'Good Medical Practice: A Code of Conduct for Doctors in Australia' states that good medical practice involves 'Being aware of your right to not provide or directly participate in treatments to which you conscientiously object…'[18]

45. For the above reasons, the ALA reiterates that medical practitioners and other health practitioners should be allowed to conscientiously object to VAD.

[18] Medical Board of Australia, 'Good medical practice: A code of conduct for doctors in Australia' (March 2014) *Medical Board of Australia*, [2.4.6-7].

If practitioners hold a conscientious objection to VAD, should they be legally required to refer a patient to a practitioner that they know does not hold a conscientious objection or to a service provider that offer such a service? If so, why? If not, why not?

46. If a practitioner holds a conscientious objection to VAD, the ALA is of the view that they should be legally required to advise the patient that they hold a conscientious object to VAD and refer a patient to another practitioner. While practitioners should not be forced to participate in VAD, it is important that practitioners continue to respect their patients' rights to make their own decisions and to ensure that their personal views do not adversely affect the care of their patient and prevent their access to VAD.

47. Requiring practitioners to refer a patient to another practitioner in these circumstances would also be consistent with concepts of good medical practice in codes of conduct and medical ethics.[19]

48. It may be onerous for medical practitioners to refer persons to another practitioner that they know does not hold a conscientious objection. This information may not be in the medical practitioner's means of knowledge unless a central database of medical practitioners available to participate in the VAD scheme is accessible. However, medical practitioners with a conscientious objection should be prevented from referring a person to another medical practitioner that they know also has a conscientious objection to VAD.

End-of-life and palliative care

How can the delivery of palliative care and end-of-life services in Queensland be improved?

49. Over the last decade, there has been an increasing focus on incorporating advance care planning ('ACP') strategies into health services to support patients to make decisions regarding their end-of-life care.[20] Although ACP is not confined to decisions to withhold and/or

[19] Ibid, [2.4.6].

[20] See, eg, Commonwealth of Australia, *Supporting Australians to Live Well at the End of Life: National Palliative Care Strategy 2010* (2010)

withdraw life-sustaining treatment, it is an important facet of end-of-life care, with an estimated 40,000 deaths occurring in Australia each year following a decision to withhold and/or withdraw life-sustaining treatment and with only 5% of those patients having capacity at the time the decision is made.[21] For this reason, the ALA have limited their submissions to discuss how Queensland's legal framework regarding decisions to withhold and/or withdraw life-sustaining treatment should be amended to improve the delivery of palliative care and end-of-life services.

Current legal framework

50. In Queensland the law is overwhelmingly clear that a patient with capacity can refuse medical treatment even if the decision to refuse medical treatment will result in the patient's death.[22] The decision does not have to be an 'informed' decision[23] and it does not matter whether the reasons for making the decision are 'rational, irrational, unknown or even non-existent'.[24] In this context it has been determined that the principle of patient autonomy prevails over the principle of sanctity of life. Despite the clarity of the law controversies may still exist in practice, particularly when the patient refusing treatment is not in the final stages of a life-limiting illness and their instructions conflict with the recommendations of the clinical team.

51. Prior to the introduction of the GAA', a competent person could complete an advance directive ('AD') directing how they wished to be treated if they lost capacity in the future, including the withholding and/or withdrawal of life-sustaining treatment.[25] If the AD was valid the only restraint on exercising that power was that the directive must have been applicable to the circumstances that had arisen.[26] Through this mechanism, the law attempted to balance

<https://www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BDB047E2FCA257BF000206168/$File/NationalPalliativeCareStrategy.pdf>.

[21] Ben White, Lindy Willmott, Colleen Cartwright, Malcolm H Parker and Gail Williams, 'Knowledge of the law about withholding or withdrawing life-sustaining treatment by intensivists and other specialists' (2016) 18(2) *Critical Care and Resuscitation* 109, 109.

[22] Above n 4.

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

[24] *Re T (Adult: Refusal of Treatment)* [1992] 4 All ER 649.

[25] above n 23, [40(6)].

[26] See, for eg, *Re T (adult: refusal of medical treatment)* [1992] 4 All ER 649, 662-663.

the principle of autonomy with the sanctity of life. If there was any doubt about the validity or applicability of the AD, it was resolved in favour of the preservation of life.[27] Although the common law principles for making an AD were settled law, controversies existed in practice for a variety of reasons, including the perception that ADs were not contemporaneous and patients may have been uninformed at the time their AD was made.[28] As a result, medical practitioners may have been reluctant to follow the patient's wishes as expressed through an AD, particularly if the directions were inconsistent with what they considered was clinically indicated.[29]

52. In 1998 and 2000, the PAA and the GAA (collectively referred to as the guardianship legislation) was enacted to clarify the law in relation to decision-making for adults with impaired capacity. The PAA enables an adult with the requisite capacity to give directions about their future health care through an advance health directive ('AHD'), including the withholding or withdrawal of a life-sustaining measure.[30] A 'life-sustaining measure' specifically includes cardio-pulmonary resuscitation ('CPR'), assisted ventilation and artificial nutrition and hydration.[31] However, blood transfusions are specifically excluded.[32] In addition to meeting the test of 'capacity' as defined in the legislation, there are a number of additional matters that an adult must understand when making an AHD.[33] There are also a number of formal requirements that must be satisfied in order for an AHD to be valid.[34]

53. However, even if an adult has the requisite capacity and all the formal requirements are met, an AHD to withhold/withdraw life-sustaining treatment can only operate if a number of additional requirements are satisfied. The first requirement is that the adult must be

[27] See *Airedale NHS Trust v Bland* [1993] AC 789, 891.

[28] See, eg, Lindy Willmott, 'Advance directives and the promotion of autonomy: A comparative Australian statutory analysis' (2010) 17 *Journal of Law and Medicine* 556, 563-4.

[29] See, eg, Rebecca E Wong, Tracey J Weiland and George A Jelinek, 'Emergency clinicians' attitudes and decisions in patient scenarios involving advance directives' (2012) 29 *Emergency Medicine Journal* 720.

[30] *Powers of Attorney Act 1998* (Qld), s 35.

[31] Ibid sch 2 s 5A.

[32] Ibid.

[33] Ibid s 42.

[34] Ibid s 44.

sufficiently unwell and have an illness or condition that falls within one of four categories.[35] Secondly, the adult must have no reasonable prospect of regaining capacity for health matters.[36] Finally, for a direction to withhold or withdraw artificial nutrition or hydration, the commencement or continuation of the measure would be inconsistent with good medical practice.[37]

54. Although there are no provisions that render an AHD invalid if they meet the above requirements, medical practitioners are protected from liability if they choose not to follow an AHD that they reasonably consider would be inconsistent with good medical practice.[38] Unfortunately, there are no comprehensive and nationally consistent ethical standards that guide medical practitioners as to what constitutes 'good medical practice'. In addition, there have only been a handful of Tribunal decisions where the meaning of 'good medical practice' has been considered.[39] In those decisions, the Tribunal has focused on whether there is a 'net benefit' in treating the patient. If there is no 'net benefit' in treating the patient, it is consistent with good medical practice to withhold or withdraw life-sustaining measures. However, this does not necessarily mean that the commencement or continuation of such measures is inconsistent with good medical practice.

55. In the absence of a valid AHD, medical practitioners can withhold or withdraw life-sustaining treatment without the consent of a substitute decision-maker in limited circumstances.[40] They can also provide life-sustaining treatment without consent if urgent health care is required to meet imminent risk to the adult's life or health,[41] unless the adult has objected to the

[35] Ibid s 36(2)(a).

[36] Ibid s 36(2)(c).

[37] Ibid s 36(2)(b).

[38] Ibid s 103.

[39] *TM, Re* [2002] QGAAT 1, *MC, Re* [2003] QGAAT 13, *MHE, Re* [2006] QGAAT 9; *HG, Re* [2006] QGAAT 26; *SAJ, Re* [2007] QGAAT 62.

[40] *Guardianship and Administration Act 2000* (Qld) s 63A.

[41] Ibid s 63(1)(b)(i).

proposed treatment in an AHD.[42] In this circumstance, consent must be obtained from the substitute decision-maker before treatment is provided.[43]

56. If urgent health care is not required, consent must be obtained from a substitute decision-maker in the order of priority as set out in s 66 of the GAA. However, a substitute decision-maker's consent is generally ineffective if the adult has objected to the treatment.[44] However, a substitute decision-maker cannot consent to the withholding or withdrawal of a life-sustaining measure unless the commencement or continuation of the measure would be inconsistent with good medical practice.[45]

57. One of the aims of the guardianship legislation was to promote the rights of individuals with impaired capacity to participate in decision-making to the greatest extent possible and to restrict and interfere with their rights, to the least possible extent.[46] Despite these purported aims, the legislative scheme has been comprehensively criticised for:

    a. Failing to preserve common law ADs;[47]

    b. Significantly restricting the situations in which an AHD to withdraw/withhold life-sustaining treatment will operate;[48] and

    c. Permitting medical practitioners to disregard an AHD if it is inconsistent with good medical practice.[49]

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[42] Ibid s 63(2).

[43] Ibid.

[44] Ibid s 67(1).

[45] Ibid s 66A.

[46] Ibid ss 5-6.

[47] See, eg, Ben White and Lindy Willmott, 'Will you do as I ask? Compliance with instructions about health care in Queensland' (2004) 4(1) *Queensland University of Technology Law and Justice Journal* 77; Lindy Willmott, 'Advance directives to withhold life-sustaining medical treatment: eroding autonomy through statutory reform' (2007) 10 *Flinders Journal of Law Reform* 287, 293.

[48] See, eg, Willmott, above n 47, 304.

[49] See, eg, Lindy Willmott, Ben White and Michelle Howard 'Refusing advance refusals: advance directives and life-sustaining medical treatment' (2006) 30 *Melbourne University Law Review* 211, 236; Willmott, above n 47, 304-5.

58. In 2010, the Queensland Law Reform Commission released their Final Report following a comprehensive review of Queensland's guardianship regime and provided an extensive list of recommendations.[50] However, to date, very few changes have been implemented.

59. No studies have specifically explored medical practitioners' compliance with Queensland's legal framework. However, a small number of empirical studies, which have included responses from Queensland clinicians', indicate that knowledge of the law is limited, even in specialties where decisions to withhold/withdraw life-sustaining treatments are frequently made.[51] Paternalistic themes also remain prevalent in situations where legal compliance is inconsistent with what medical practitioners' believe is clinically indicated.[52] For example, one study of Australian intensive care doctors found that many intensivists believed end-of-life decisions remained medical decisions and that enduring powers of attorney and advance care plans only needed to be respected when they accorded with the practitioner's treatment decision.[53] Similar results were obtained following a study of emergency clinicians.[54]

60. It has been recommended by a number of commentators that further training is required to increase medical practitioners' knowledge of the law and use of directives in the clinical

[50] Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws,* Report No 67 (2010), vol 2, 1.

[51] See, eg, Ben White, Lindy Willmott, Colleen Cartwright, Malcolm H Parker and Gail Williams, 'Knowledge of the law about withholding or withdrawing life-sustaining treatment by intensivists and other specialists' (2016) 18(2) *Critical Care and Resuscitation* 109.

[52] See, eg, Benjamin P White, Lindy Willmott, Gail Williams, Colleen Cartwright and Malcolm Parker, 'The role of law in decisions to withhold and withdraw life-sustaining treatment from adults who lack capacity: a cross-sectional study' (2016) *Journal of Medical Ethics* 1.

[53] Charlie Corke, Sharyn Milnes, Neil Orford, Margaret J Henry, Claire Foss and Deborah Porter, 'The influence of medical enduring power of attorney and advance directives on decision-making by Australian intensive care doctors' (2009) 11(2) *Critical Care and Resuscitation* 122.

[54] Wong, above n 29.

setting.[55] However, it has also been suggested that for ACP tools, including directives, to be effective in the clinical setting, a culture of ACP must be embraced.[56]

Recommendations

61. The ALA is of the view that palliative care and end-of-life services would be improved if the legislative framework regarding AHDs were amended as follows:

    1. Common law ADs were specifically recognised in ss 65(2) and 66(2) of the GAA and given precedence over the wishes of substitute decision-makers. This would legitimise the decisions recorded in ACP forms, including the Statement of Choices form developed by the Metro South Hospital and Health Service;[57]

    2. The restrictions on when directives to withdraw or withhold life-sustaining treatments in an AHD under the PAA were removed. This would ensure consistency with common law ADs and would restore a person's autonomy to direct their own healthcare if they later lose capacity to make such decisions;

    3. Any references to 'good medical practice' in the GAA, which allow medical practitioners to ignore a person's directive to withdraw and/or withhold life-sustaining measures and a substitute decision-maker's decision to withdraw and/or withhold life-sustaining measures, be removed from the GAA for the following reasons:

        a. The meaning of 'good medical practice' remains unclear except in the most extreme cases;

        b. The provisions unduly restrict the autonomy of adults to direct their future health care through AHDs;

[55] See, e.g., Colleen Maria Cartwright, Ben P White, Lindy Willmott, Gail Williams and Malcolm Holbrook Parker, 'Palliative care and other physicians' knowledge, attitudes and practice relating to the law on withholding/withdrawing life-sustaining treatment: Survey results' (2016) 30(2) *Palliative Medicine* 171; White, above n 52.

[56] Queensland Law Reform Commission, above n 50, vol 2, 3.

[57] See Queensland Health, 'Statement of Choices' (2018) *Queensland Health*.

c. The provisions fail to provide further protection to adults with impaired capacity and unnecessarily complicates the statutory scheme; and

d. The provisions expose substitute decision-makers and medical practitioners to liability in circumstances where their decisions to withhold or withdraw life-sustaining treatment are consistent with 'good medical practice'.

Conclusion

62. The Australian Lawyers Alliance (ALA) welcomes the opportunity to have input into the inquiry into aged care, end-of-life and palliative care and VAD and is available to appear before the Committee to provide further explanation for the matters raised in this submission.

63. As discussed above, the ALA supports the introduction of a VAD scheme allowing eligible persons to self-administer medication to end their lives and if physically unable to, to allow an approved medical practitioner to administer the medication.

64. The activity being regulated must be clear and there are a number of eligibility requirements that should be implemented, including the requirement that a person have capacity to access the scheme. The process to access VAD should be clear and include a number of safeguards to ensure that only eligible persons can access the scheme, to protect vulnerable persons and to protect members of the medical profession that choose to participate in the scheme. A Board should be created to oversee the VAD scheme and offences should be created to deter those from acting outside of the scheme.

65. With regards to end-of-life decisions, the ALA is of the view that palliative care and end-of-life decision-making would be improved if common law ADs were specifically recognised in the GAA, that restrictions on when directives to withdraw and/or withhold life-sustaining treatments in an AHD were removed and that a number of references to 'good medical practice' in the GAA were removed.

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