End of Life Choices

SUBMISSION

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INTRODUCTION

The Law Institute of Victoria (LIV) welcomes the opportunity to make this submission to the Legislative Council Standing Committee on Legal and Social Issues on End of Life Choices.

The LIV has long advocated for policy and law reform in this area, specifically with respect to advanced care planning and substitute decision-making.

The legislative framework for end of life choices is fragmented and in some cases non-existent. The complexity of the framework and legislative gaps in this system has resulted in much uncertainty for both patients and the medical profession.

Key reforms being sought by the LIV include:

- Review of the legislative framework for consistency and certainty;
- Review all substitute decision-making legislation ensuring the autonomy of the decision maker is recognised; and
- Introduction of enforceable advance care directives.

In previous submissions, the LIV has sought reform of the Medical Treatment Act 1988 (Vic) (MTA), including the powers of attorney for medical treatment given to agents under the MTA. The LIV has also advocated for comprehensive review of all substitute decision-making legislation. The LIV has long pursued consistency and certainty in approach to such decision-making for the community and the medical profession. This advocacy continues with the inquiry into End of Life Choices.

There continues to be a gap between medical practice and the legal framework surrounding the autonomy of the decision maker and their medical care. In response this submission focuses on the current legislative framework for end of life choices (including substitute decision making, advanced care planning and advance care directives) and options for reform of the law governing the ability of people to give binding directions about future medical decisions. The submission does not make any comment about legislative reform regarding euthanasia.

The LIV has previously supported the introduction of enforceable advance care directives for all types of medical treatment together with a review of the numerous statutes relating to substitute decision making. It is suggested the current inquiry should consider the recommendations of the Victorian Law Reform Commission in the Guardianship report released in 2012.¹

¹ Victorian Law Reform Commission Guardianship (Report no 24) 2012
The submission consists of three sections. First, it considers an individual's autonomy and the role of advance care planning. Second, it considers problems with the current legal framework and issues that arise in practice. Finally, the submission sets out four key recommendations designed to address the problems with the current framework to promote an individual's autonomy in decision making so far as possible.
SECTION 1

Planning for the Future: Autonomy and Advance Care Planning

**Autonomy**

There is an expectation that individuals should be able to make their own decisions about their health and personal arrangements, and laws should preserve this right beyond loss of capacity. Autonomy and dignity of the individual has been emphasised in the most recent general comment to Article 12 of the UN Convention on the Rights of Person with Disability outlining States’ obligations in relation to human rights and capacity:

*The present general comment reflects an interpretation of article 12 which is premised on the general principles of the Convention, as outlined in article 3, namely, respect for the inherent dignity, individual autonomy — including the freedom to make one’s own choices —...*  

Across the common law world there has long been recognised “a competent adult’s right of autonomy or self-determination: the right to control his or her own body.” In accordance with that right:

*A competent adult is generally entitled to reject a specific treatment or all treatment, or to select an alternate form of treatment, even if the decision may entail risks as serious as death and may appear mistaken in the eyes of the medical profession or of the community … it is the patient who has the final say on whether to undergo the treatment.*

This common law right has been recognised as an aspect of a number of fundamental human rights, including the right to privacy, security, and protection from cruel, inhuman or degrading treatment.

This is also expressed by the Parliament of Victoria in the *Charter of Human Rights and Responsibilities Act 2006,* which includes the rights to privacy, security, and protection from cruel, inhuman or degrading treatment.

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3 Malette v Shulman 76 DLR (4th) 321 (1990)
4 See In re Quinlan 70 N.J. 10, 355 A.2d 647 (1976)
5 Fleming v Reid (1991) 4 O.R. (3d) 74
6 Charter of Human Rights and Responsibilities Act 2006 (Vic), s 10(c)
7 Charter of Human Rights and Responsibilities Act 2006 (Vic), s 1
8 Ibid s 13
9 Ibid s 21
10 Ibid s 10(c) ‘... A person must not be subjected to medical or scientific experimentation or treatment without his or her full, free and informed consent.’
Whilst the international conventions and the Victorian Charter support the right to self-determination and associated human rights, the fear of loss of autonomy and dignity is often evident where individuals are facing end of life choices. The rights of competent adults to refuse treatment are not usually challenged, but the right of a person to pre-express a direction, with the expectation that it will be followed, often falls away when that person can no longer advocate for themselves.

To ensure Victorian legislation is compatible with and interpreted in line with human rights obligations, it is suggested that the Guardianship and Administration Act 1986 (‘GAA’), Powers of Attorney Act 2014 (POA), MTA and any future legislation for advanced care directives are consistent with the principle of autonomy and self-determination.

The LIV recommends that any legislation should ensure that the prior wishes of persons expressed when they had capacity are afforded the highest priority when these persons lose capacity and any substitute decision makers are given clear direction about their powers and responsibilities.

**Advance Care Planning**

- **Advance care planning** is the process of planning for future health and personal care whereby a person’s values, beliefs and preferences are made known so they can guide clinical decision making at a future time when that person cannot make or communicate their decisions due to lack of capacity\(^2\). Advance care planning supports substitute decision makers to make decisions that are as close as possible to the one that the person themselves would have made.\(^3\)

- **An Advance Care Directive is** an oral or written statement that tells a health care professional what forms of medical care a person would accept or refuse in a specific medical circumstance. It could also specify who should make health care decisions if the person is unable to express his or her wishes.

Currently the term “Advance Care Directive” is a generic term that describes an array of instruments created to achieve these two purposes, but in limited ways and with limited effect.

Advance Care Directives are not referred to in any current Victorian legislation that covers medical treatment or consent to treatment or entitlement to medical services. They have developed outside the current statutory framework.

While assertions are made that Victorian law extends to support a common law Advance Care Directive, it is probably more accurate to say that advance care planning documents being promoted administratively, particularly in the form of a “statement of choices”, assist decision makers to make a health care decisions consistent with the individual's choice without ascribing rights to any person.

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\(^2\) Victoria Health Department “Advanced Care Planning, have the conversation: a strategy for Victorian Health Services 2014 -2018 at p11

\(^3\) IBID p. 53
It is also not clear at what point the advance care planning documents are incorporated into medical treatment plans and whether this instructs the health professional in the type of medical care offered or whether it is left to the substitute decision maker to ultimately consent to or refuse treatment.

In 2012 the Victorian Law Reform Commission produced its report on Guardianship (Report no 24) and in chapter 11 made 35 recommendations concerning “documenting wishes about the future” including recommendations,

• that Guardianship legislation in Victoria be amended to permit a person with capacity to appoint an enduring personal guardian with or without instructions; or
• to make a stand-alone “instructional directive” which would be binding in regard to health care matters but non-binding in relation to other personal and lifestyle matters.\(^{14}\)

The Victorian Department of Health produced “Advance care planning, have the conversation: a strategy for Victorian Health Services 2014 – 2018” in an effort to promote the uptake of advance care planning. The document asserts that “Advance care planning can be delivered within Victoria’s existing legal framework.”\(^{15}\) However, common law Advance Care Directives have an uncertain legal status under Victorian law and should be clarified in legislation.

\(^{14}\) Victorian Law Reform Commission Guardianship (Report no 24) 2012 Recommendations 133 and 134 (also an example is provided in the Advanced Care Directives Act 2013 (S.A.))

\(^{15}\) Advance care planning, have the conversation: a strategy for Victorian Health Services 2014 – 2018. P17
SECTION 2

Problems with the Current Framework

Common law capacity

The law recognises that medical treatment can be administered to a patient only where the patient consents to that treatment.\textsuperscript{16} Where a patient lacks capacity, valid consent can be provided by the ‘person responsible’.\textsuperscript{17} Consent to treatment for a person who lacks capacity is not required in an emergency. A patient with capacity can refuse medical treatment, even where the refusal will result in the patient’s death.\textsuperscript{18}

Common law advanced care directives

A common law advance care directive will be valid where it is made by a competent adult, free from undue influence.\textsuperscript{19} The lack of formal requirements means that evidentiary problems (including rules relating to hearsay)\textsuperscript{20} often arise so that often advance care directives will not be effective in practice unless made in writing. Further, an advance care directive might be valid but might not be operative because it must clearly and unambiguously apply to a particular situation.\textsuperscript{21} A health professional will be required to justify his/her decision not to follow the advanced care directive. There is legal uncertainty in Victoria on whether civil or criminal sanctions apply to health professionals who act contrary to an advanced care directive.\textsuperscript{22}

Medical Treatment Act

In Victoria there are limited avenues for a patient with capacity to make a binding statement about what type of health care they consent to in the future. Under the current framework the only legislative document that has binding authority is a Refusal of Treatment Certificate (RTC) under the MTA which is restricted to a ‘current condition’. This restriction limits any flexibility in planning future treatment.

The MTA deals with RTCs and the appointment of medical agents pursuant to a medical power of attorney. It prescribes forms for each purpose. It also provides protection for medical practitioners who act on a refusal of treatment certificate in good faith and establishes the offence of medical trespass. Section 6 of the MTA provides that a medical practitioner who knowingly ignores an RTC

\textsuperscript{16} Secretary, Department of Health and Community Services (NT) v JWB and SMB (Marion’s Case) 175 CLR 218.
\textsuperscript{17} S37 Guardian and Administration Act 1986; Re T (Adult: Refusal of Treatment) [1993] Fam 95.
\textsuperscript{18} Re B (Adult: Refusal of Treatment) [2002] 2 All ER 449.
\textsuperscript{19} Cite
\textsuperscript{20} Cite
\textsuperscript{21} Hunter and New England Area Health Service v A (209) 74 NSWLR 88 at [1][2]
\textsuperscript{22} Cite
and provides medical treatment commits an offence of medical trespass. The MTA does not purport to regulate the relationship between patient and health practitioner in general, much less to be a source or acknowledgment of patients’ rights or autonomy. Nor does the MTA touch on medical service provision. An RTC only permits a person to make a binding future direction about refusing treatment for a current condition23, and limits an individual’s ability to plan in relation to possible future health issues.24

Guardianship and Administration Act

A person’s wishes about medical treatment (so far as they can be ascertained) must also be taken into account by the person responsible under section 38 of the GAA and given effect to wherever possible (section 4) when that person is determining what is in the patient’s best interests.

There is currently no avenue to provide advance consent to treatment in Victoria. Where a patient lacks capacity, and a valid RTC has not been made, a substitute decision-maker will be required to consent or withhold consent to treatment under the GAA.

There is general confusion about the difference between the ability of persons responsible to withhold consent to medical treatment under the GAA and the ability of guardians and medical agents to refuse medical treatment under the MTA. The decision to withhold consent to treatment may have the same effect as a refusal of treatment, but:

• different criteria apply to such decisions, a person responsible must comply with section 38 of the GAA whereas an agent or guardian refusing medical treatment must comply with section 5B(2) of the MTA;

• There are different processes for a health professional to challenge the decision. If a doctor thought the person responsible’s decision to withhold consent to treatment was not in their patient’s best interest, they could challenge it through a notice under section 42M of the GAA. If the doctor thought an agent or guardian was not acting in the patient’s best interest in refusing medical treatment, the doctor would have to apply to VCAT for a replacement agent or guardian.

Whilst there is a rationale for the different approach that is valuable in law (in that the patient has appointed the agent or VCAT has appointed the guardian and so their decisions have a higher status than that of a person who has their position through the statutory framework), they are nonetheless difficult for health practitioners to know and negotiate, especially in emergency situations.

The distinctions between refusing treatment and withholding consent and the relationship between the GAA and the MTA are unreasonable and confusing for both the general community and health professionals.

23 which is inconsistent with South Australia, Western Australia and Queensland statutory schemes
**Resulting uncertainty and risk**

An advanced care plan involves the person making the plan and, eventually when relevant, the health professionals caring for the person consulting the plan. This will include medical practitioners, nurses and allied health professionals. At present, there is legal uncertainty over whether a health professional is obliged to give effect to an advanced care plan.

There is currently no statute in Victoria that deals with advance care plans. The common law is unclear. There is authority for the proposition that a medical practitioner is bound to give effect to a patient’s wishes as set out in an advance care plan. However, the uncertainty of the legal position in Victoria exposes medical practitioners and other health professionals to legal action:

- For negligence from family and friends of a patient where medical practitioners decide to respect a patient’s wishes and offer no active treatment contrary to the family’s wishes; or
- for medical trespass by the patient where the medical practitioner decides to treat the patient contrary to the patient's expressed wishes in the advance care plan.25

**Issues Arising in the Field**

There is currently a gap between medical practice and the legal framework surrounding ‘advance’ refusal of medical treatment and end of life choices. In 2012, the LIV co-hosted a forum on advanced care directives with the AMA (Vic). Participants at the forum, who included medical and legal practitioners, discussed practical issues arising from the complexity of the current law. Participants reported that RTCs under section 5 of the MTA are rarely made. Participants further stated that there appears to be widespread non-compliance with aspects of section 5E of the MTA, which requires a copy of a RTC to be placed on the patient’s record, given to the chief executive officer of the hospital or aged care home and given to the principal registrar of VCAT within seven days after the certificate is completed.

Forum participants also noted anecdotal feedback from hospital emergency physicians that patients are only very rarely admitted with any type of advance care directive (usually a ‘statement of choices’) on their person and, where this does occasionally occur, it is rarely relied upon because often the document is unclear and poorly written.

Further, it has been identified that doctors are generally not familiar with the ‘person responsible’ provisions of the GAA, and have no way to easily ascertain whether a medical agent has been appointed. Consequently they usually seek out and deal with the ‘next of kin’ where a patient lacks capacity and medical treatment decisions need to be made. Problems generally arise where there is conflict between family members about treatment decisions for an incompetent patient; where family members disagree with previously expressed wishes of a now incompetent patient; or, where family members disagree with the views of the treating physician. Conflict with family members can make doctors fearful of medico-legal consequences of treatment decisions. Emergency physicians have previously expressed the view that a legally binding directive would

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25 Medical trespass is specifically restricted under s.6 MTA to treatment contrary to the RTC. Currently no consequences attach to defying an Advance Care Directive.
assist with managing anxious and argumentative family members at the time of treatment and provide medical staff with certainty and legal immunity when complying with the wishes of the patient and respecting their autonomy.

Traditionally, medical treatment decisions are made in a health care paradigm where clinicians work towards a consensus regarding treatment. Lawyers report, however, that increasingly clients who are currently in good health choose to make an enduring power of attorney (medical treatment) as part of general estate planning, such as when they are completing wills and powers of attorney. It is likely that those appointed medical agents will increasingly be called upon to make decisions on medical treatment as the principal grows older, loses capacity and powers are activated. It is unclear to what extent the principal of enduring powers (medical treatment) discuss their wishes and preference about future medical treatment with their medical agent.

It has also been suggested that there is a reluctance and a lack of expertise in the aged care sector to facilitate any discussion about advance care directives because they are viewed generally as a ‘legal minefield’ or involve difficult conversations about death. This can be contrasted with a growing number of hospitals with advance care planning programs, which focus on planning for future health and personal care in discussions between patients and their treating doctors and family members.

Failure to prepare an advanced care plan means that, where medical emergencies occur in aged care settings and residents lose capacity to make medical decisions, family members are often required to make decisions without any understanding of the person’s wishes or the legal framework.

Even where there is a clear advanced directive, such as a RTC, the ability of a health professional to act on the directive is uncertain. This is exacerbated both in emergency situations; and in situations where the treating health professional is not a ‘registered medical practitioner’. The offence of medical trespass established by s 6 of the MTA is limited to ‘registered medical practitioners’, which do not include paramedics and others who form part of an emergency response.
## Common scenarios

### Scenario 1

Errol has end stage cardio vascular disease. Errol has signed a Refusal of Treatment Certificate that he not be resuscitated. He has chosen to die at home in the company of his partner. Errol is so distressed one evening that his partner calls an ambulance. The partner shows the ambulance officers the Refusal of Treatment Certificate. The ambulance officers are not doctors and, when Errol subsequently has a cardiac arrest, they have to make a decision about whether to resuscitate him. The ambulance officers are not proscribed from providing resuscitation under section 6 of the MTA.

### Scenario 2

Mary has dementia. During its early onset, Mary signed a Refusal of Treatment Certificate in relation to her dementia. In the Refusal of Treatment Certificate she stated

> In relation to my current condition, I refuse—
> *medical treatment generally

Mary’s dementia worsened significantly over the next four years and she lost the ability to make decisions about her health care, was bed bound, unable to communicate with others or recognise anyone who visited her. She developed pneumonia and a question arose about whether to provide her with antibiotics. Pneumonia was not a current condition when she signed her Refusal of Treatment Certificate and so the document was not relevant to a determination about this treatment.

If Mary had also made an advance care plan, she would have been able to set out what she would like to happen if this common scenario arose. This would not give rise to a direction about treatment, but would assist an agent or a person responsible to consent to, withhold consent to or refuse treatment.

Both scenarios demonstrate the current legal uncertainty facing health professionals and medical decision-makers in these situations.
SECTION 3

Recommendations for Reform

The LIV recommends that the Government amend existing legislation. Currently the legislative framework for end of life choices comprises the GAA, POA and the MTA. The Minister for Health is responsible for the MTA, while the Attorney General is responsible the POA and the GAA. There needs to be a collaborative approach between government departments to overcome what is currently a fragmented system.

To guarantee the provision of enforceable advance care plans and for the sake of clarity and certainty, this legislative framework must operate harmoniously. The LIV recommends that the legislative framework be amended as follows:

- The MTA (possibly re-titled the Advance Care Planning Act) should be about autonomy and planning for the future. It should incorporate provisions for Refusal of Treatment Certificates and Advance Care Directives.
- The GAA should be an instrument that is operative in the default situation – that is where an individual has not made plans under the MTA.

Summary of recommended legislative reforms

<table>
<thead>
<tr>
<th>GAA</th>
<th>The ‘person responsible’ provisions should be amended as recommended by the VLRC in its report on Guardianship.</th>
</tr>
</thead>
<tbody>
<tr>
<td>POA</td>
<td>Extend the enduring power of attorney for personal matters to include decisions to refuse medical treatment and remove the enduring power of attorney (medical treatment) from the MTA</td>
</tr>
<tr>
<td>MTA</td>
<td>Change title of the Act to reflect something more positive and relevant: ie Advance Care Planning Act</td>
</tr>
<tr>
<td>MTA</td>
<td>Provide provision for enforceable Advance Care Directives and protection for health professionals who follow them,</td>
</tr>
<tr>
<td>MTA</td>
<td>Extend the provision of refusal of treatment beyond a current condition.</td>
</tr>
</tbody>
</table>

What is required?

Legislative reform is required to remove the legal uncertainty and to minimise risks of legal action against health practitioners.

This includes cases where:
• a medical practitioner follows a patient’s wishes as set out in an advanced care plan; and
• a medical practitioner decides not to follow the patient’s wishes.

This could be achieved by amendments to the MTA or to the GAA.

**Specifically the LIV makes the following recommendations:**

**Recommendation 1: Enforceability of advance care plans**

The LIV considers that the MTA should be amended to ensure that advance care plans are enforceable. Specifically, a plan should be enforceable if it is valid (eg executed in writing, witnessed, made when the person had capacity and has not been superseded).

The LIV further considers that an advance care plan should not apply if the person who made the plan would not have intended it to apply to the particular circumstances. This may be because medical science has advanced since the plan was made and consequently the plan is no longer appropriate. Alternatively, it may be that the meaning of the plan is unclear or based incorrect information.

Any amending legislation will require a definition of “advance care plan”. This definition together with any other legislative requirements (eg that the plan be in writing and witnessed with an assessment of capacity) will determine whether the plan is valid.

**Recommendation 2: Protection for health professionals for compliance with an advance care plan**

The LIV considers that health professionals should be protected if they rely on an advance care plan or refusal of treatment certificate in good faith to refuse treatment. Specifically, the MTA should include protection for health professionals who comply with an advance care plan or rely on a refusal of treatment certificate in good faith to refuse to perform or continue treatment. The health professional should have reasonable grounds for believing that the refusal is in accordance with the MTA or an advance care plan. In this situation, the health professional should not be guilty of professional misconduct or an offence. Nor should the health professional be liable in any civil proceedings for failing to provide treatment.

If a health professional relies in good faith on a refusal or treatment certificate or advance care plan which has been cancelled or is invalid, but the health professional is not aware of the cancellation or invalidity, they should be deemed to have acted in good faith.

**Recommendation 3: Protection for health professionals for non-compliance with an advance care plan**

The LIV considers health professionals should also be protected from any liability if they fail to comply with an advance care plan when they did not know that the person had an advance care plan.

To justify this protection, the LIV considers that a health professional must take reasonable steps to determine if a person has made an advance care plan, and if so, to obtain a copy of it before determining treatment to offer (if any). If the health professional fails to take these reasonable steps, then they should not be protected from liability if they fail to comply with an advance care plan. A hospitals failure to keep adequate records will not exempt the hospital from liability.

This requirement should not apply in the case of emergency treatment.
**Recommendation 4: Emergency treatment**

In cases of emergency treatment, the LIV considers that if a health professional is aware of an advance care plan, but does not have time to determine if it is valid or whether a particular provision of the plan should apply, the health professional should not be liable for not following the plan if they believe on reasonable grounds that:

(a) circumstances have changed since the plan was made so that if the person had known of the changes, they would not have believed the terms of the plan to be appropriate, or
(b) the terms of the plan are uncertain, or
(c) there is evidence to suggest the plan was based on incorrect information or assumptions at the time it was made.