

VICTORIAN PARLIAMENTARY ENQUIRY INTO END OF LIFE CHOICES

Submission by Lynne Barratt

End of life planning is not restricted to older people and it must be acknowledged that younger people can also suffer terminal illness and road trauma and can benefit from end of life planning.

However in this submission the author focuses on the human rights of older Victorians.

The material in this submission is adapted from a chapter entitled Health care and end of life written by the author as part of a new book entitled Elder Law in Australia to be published by Lexis Nexis in 2015.

Appendix 1 is a Discussion Paper prepared for the Elder Law section of the Law Institute of Victoria entitled Advance Care Directives: a discussion paper and written by the author in 2014.

Appendix 2 is a short outline of an approach to building an informed view on euthanasia.

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1. Assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life, including the role of palliative care.
2. Review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions
3. Consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation

Background

Over the past five decades concerns have emerged about end-of-life care in response to the increasing use of the motor vehicle and associated road trauma, and to some well-publicised and very sad cases of road trauma victims being maintained in a persistent vegetative state.

In recent years the attention of health administrators has moved from road trauma and is now focused on the ageing population and the acknowledgment that the longer life expectancy that we now enjoy “may be in a state of compromised health with an extended period of chronic progressive disease, discomfort, and/or increasing dependence and loss of cognitive ability.”¹

Medical innovation and technological advances allow medical practitioners to employ life-sustaining therapies that prolong a person’s life. The treatments might not restore a patient to health, but will ensure that the patient is alive. Examples of these technologies include breathing machines, machines to monitor and maintain blood pressure, feeding tubes inserted through the nose or abdomen, and intravenous medication and fluids.

The response from various quarters has been disquiet at the extent of medical intervention at the end of life. Some patients found the interventions invasive, uncomfortable and unwanted. Some felt human dignity was lost as a result. Some took the view that after weighing up the benefits and burdens, they would not elect to undergo the procedures, especially if doing so reduced the quality of life that they expected.

Legislative and administrative responses to end-of-life decisions

Life-extending medical advances led to people asserting their right not to be interfered with at the end of life. This right of the individual was in conflict with the legal and ethical obligations of medical practitioners to preserve life. This in turn led to medical practitioners being concerned about their legal responsibilities if they acted in accordance with instructions to cease treatment.

As usual the law lagged behind the debate, but in some jurisdictions legislation was enacted in an effort to resolve this uncertainty and to balance competing rights.

Legislative responses in the USA

¹ Department of Health, Victoria, *Advance care planning; have the conversation: a strategy for Victorian health services 2014–2018*, at p 5

In the United States of America two types of documents were developed. The first allowed people with a terminal illness to give instructions about their treatment. It was referred to as a “living will” pursuant to the Natural Death Act 1976 enacted in California, and eventually taken up by most of the other states.

The second type of document was developed at a later stage and allowed a competent person to appoint a healthcare proxy. It was referred to as “a durable power of attorney for health care.” The USA federal Patient Self-Determination Act 1990 took effect on 1 December 1991. It requires all hospitals, nursing homes, home and health agencies, hospices and health maintenance organisations that receive federal funding, as a condition of ongoing funding to provide patients with a written statement of their rights under state law to accept or refuse treatment and to prepare advance care directives for health care.²

Legislative responses in Victoria

In December 1985 the Parliament of Victoria Social Development Committee was given a reference to enquire into options for dying with dignity. The following is extracted from Hansard:³

As the terms of reference noted, the greatly increased technological capacity to sustain life has led to a number of difficult questions arising in relation to the extent to which medical treatment should be continued. The committee heard evidence over 18 months including many graphic accounts of individual cases where the emotional cost and suffering associated with further medical measures designed to sustain life are worse than allowing the patient to die peacefully.

The Social Development Committee made 31 recommendations but did not recommend that there be legislative enactment of a “right to die”. However, it did recommend:

- clarification of the common law right to refuse treatment;
- enactment of the offence of medical trespass; and
- that legislation should confer protection on medical practitioners who act in good faith in accordance with the express wishes of a fully informed competent patient who refuses medical treatment.

The passage of the Medical Treatment Bill through Parliament was subject to much debate and many amendments.⁴ As a result the *Medical Treatment Act* (VIC) (MTA) 1988 was enacted (and amended in 1989). Currently the MTA provides for:

- the appointment of a medical agent by a medical power of attorney;
- refusal of treatment by a competent adult to be certified;
- refusal of treatment by an appointed agent on behalf of an incompetent adult to be certified;
- prescribed forms for each purpose;
- protection for medical practitioners who act on a refusal of treatment certificate in good faith;
- establishes the offence of medical trespass.

² David John Doukas and William Reichel, *Planning for uncertainty: a guide to living wills and other advance directives for health care* Johns Hopkins University Press 1993 at p. 12

³ Parliament of Victoria, Legislative Assembly, Hansard 5 May 1988, p. 2165

⁴ See the case of *Gardner; re BWV* (2003) VSC 173 for a careful examination of the legislative development of the Act.

The *Medical Treatment Act* 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 and nor does it touch on medical service provision at all. In truth it might more accurately be entitled the "Refusal of Medical Treatment Act", but in that form would probably not have been enacted.

In 1999 the *Guardianship and Administration Act 1986* (VIC) (GAA) was amended to insert a new Part 4A, titled "Medical and other treatment". As a result:

- s 37 GAA was amended to provide a hierarchy of people who may be called upon to give consent to medical treatment in relation to a person under a disability; and
- s 42A GAA was amended to provide for emergency treatment without consent in some circumstances.

At the same time a new Division 5A was inserted into Part 4 to permit, pursuant to s 35A, a competent person to execute an enduring power of guardianship, appointing a guardian and giving powers to that person to be exercised if, and only to the extent that, the appointor subsequently becomes unable by reason of a disability to make reasonable judgments in respect of any of those matters.

Current law reform recommendations in Victoria

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". Recommendations 133 and 134 suggested 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 healthcare matters but non-binding in relation to other personal and lifestyle matters.

By way of example in 2013 the South Australian Parliament passed the Advance Care Directive Act 2013 (SA).⁵ The second reading explanation inserted into the Hansard explained that the stated intention of the Bill was to:

- combine the enduring power of guardianship, the medical power of attorney and the advance care directive (ACD) into one document;
- promulgate a single prescribed form for use in completing an advanced care directive which would require the assistance of neither medical nor legal practitioners;
- contain principles for the interpretation of ACDs;
- provide protections for healthcare practitioners that act on ACDs in good faith; and
- provide a regime for appointment and oversight of substitute decision-makers.

Also see: [Advance Care Directives: a discussion paper](#) prepared by the writer for Elder Law Section of the Law Institute of Victoria in 2014 and included here at Appendix 1.

Administrative responses in Victoria: medical service delivery

In 2011 the Australian Health Ministers Advisory Council produced the *National Framework for Advance Care Directives*. The document was intended to be used by healthcare services and provides a code of ethical conduct and an outline of best practice for the use of advance care

⁵ Commencement date 1 July 2014 (*Gazette* 6.2.2014 p 546)

planning. Advance care planning is now an expectation and priority for both Commonwealth and state governments and contained in National Safety and Quality Health Standards 1.18.4, 9.8.1 and 9.8.2.⁶

In Victoria in 2013 and some years after the rollout of a successful program developed at the Austin hospital in Melbourne entitled the “Respecting Patient Choices Program”, the Victorian Health Department produced its *Advance care planning strategy for Victorian health services 2013 to 2018* consultation discussion paper. The discussion paper noted “Advance care planning assists in...planning for and provision of, end of life care related to the ageing population and growing prevalence of chronic disease.”⁷

In March 2014 and after consultation the Victorian Health Department 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.”⁸

As will be seen in the following sections it is not entirely clear that this assertion is correct, or that the model of advance care planning undertaken largely administratively in Victoria is the best model to promote the human rights of Victorians.

Overlapping instruments

As a result of this administrative approach it is possible now in Victoria for a competent person to:

- execute an enduring power of attorney (medical treatment) to appoint a medical agent and to give that agent power to make decisions about refusal of care when the donor is no longer able to make those decisions;
- execute an enduring power of guardianship to appoint an enduring guardian to give that enduring guardian power to make decisions about lifestyle matters and health matters when the donor is no longer able to make those decisions and to specify in that instrument specific instructions about healthcare preferences;
- refuse medical treatment in relation to a current condition and to have that refusal certified by a medical practitioner and another person with the expectation that the decision to refuse will be observed; and
- complete an Advance Care Directive, currently a non-binding statement of choices or values statement about end-of-life treatment for the purpose of guiding future medical treatment. (This document is not prescribed by legislation in Victoria.)

⁶ Dr Kylie Staggard, 2013 Advance Care Planning and TCP (PowerPoint program) accessed internet 2 June 2014

⁷ *Advance Care planning strategy for Victorian health services 2013 to 2018* consultation discussion paper, p 4

⁸ *Advance care planning; have the conversation: a strategy for Victorian health services 2014–2018*, p 17

Advance care directives in Victoria - some definitions

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.⁹ 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.¹⁰

An advance care directive is an oral or written statement that tells a healthcare professional what forms of medical care a person would accept or refuse in a specific medical circumstance or, alternatively, who should make healthcare decisions if the person is unable to express his or her wishes.¹¹

In one sense the phrase “advance care directives” is a generic description for an array of legal instruments created to achieve these two purposes, but in limited ways and with limited effect. However, the phrase has most recently been used in other state jurisdictions to describe a new form of instrument, which combines into one instrument the enduring power of guardianship, medical power of attorney and anticipatory direction.¹²

Advance care directives sole are not referred to in any current Victorian legislation that covers medical treatment or consent to treatment or entitlement to medical services. They have quite simply developed outside the current legal framework. Some lawyers have not even heard of them.

While assertions are made that the Victorian law extends to support a common law advance care directive,¹³ it is probably more accurate to say that advance care planning documents are being promoted administratively, particularly in the form of a “statement of choices” that assists decision-makers to make healthcare decisions consistent with the individual's choice without ascribing rights to any person.

⁹ Victoria. Health department, *Advance care planning, have the conversation: a strategy for Victorian Health Services 2014–2018*, at p. 11

¹⁰ *Ibid.* p. 53

¹¹ David John Doukas and William Reichel, *Planning for uncertainty: a guide to living wills and other advance directives for health care* Johns Hopkins University Press 1993 at p. 1

¹² For example Advance Care Directives Act 2013 (SA) and Guardianship Act 1990 (WA) Part 9B

¹³ Willmott, L, White, B and Parker, M and Cartright, C: (2011) “The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment. Part 3” (Victoria) 18 *JLM* 777

Legal framework for end-of-life care in Victoria

Some key points

- Consent to medical treatment given to people over the age of 18 years with a disability is governed by Part 4 Div 1 of the Guardianship and Administration Act 1986 (VIC).
- Emergency treatment of a person with a disability may not require consent.
- The *Medical Treatment Act* 1988 (VIC) (MTA) governs the form and use of enduring powers of attorney (medical treatment) as well as the refusal of medical treatment by a competent person and on behalf of an incompetent person.
- Under the MTA treatment can only be refused for a “current” condition. This means that a refusal of medical treatment certificate cannot be executed before a condition develops.
- Under the MTA palliative care is excluded from the definition of “medical treatment” and cannot, therefore, be refused.

Consent to medical treatment – where appointment not necessary

In Victoria matters concerning consent to medical treatment given to persons over the age of 18 years with a disability are governed by Part 4A Div 1 of the Guardianship and Administration Act 1986 (VIC) (GAA).

The “person responsible”

Section 37 of the GAA provides a hierarchy of persons described as “the person responsible” who may be called upon to give consent to medical and dental treatment, save for “special procedures” which need not concern us here.¹⁴ The hierarchy of persons responsible contained in s 37 GAA should be examined with care as it will be noted that the patient’s spouse or family member is not automatically the first person to be consulted. A person’s agent appointed by an enduring power of attorney (medical treatment) is regarded as pre-eminent and takes precedence over a person appointed by the Victorian Civil and Administrative Tribunal (VCAT) to make decisions about medical treatment. (That is to say, the earlier exercise by the patient of their right of self-determination is supported.) By contrast a person appointed by VCAT as a guardian will take precedence over an enduring guardian appointed by an enduring power of guardianship. Following thereafter in the hierarchy are family members and others.

Additional powers given to an appointed medical agent under the Guardianship and Administration Act

Section 37(5) of the GAA provides that an agent appointed by an enduring power of attorney (medical treatment) has *additional* powers of decision-making under the GAA. Section 38 of the GAA provides for the manner in which a person responsible should decide whether or not a

¹⁴ See the definition of “special procedures” in s 3 GAA. These are: a procedure or sterilisation, termination of pregnancy or removal of tissue for transplantation into another person or any procedure listed in regulations.

proposed treatment or procedure is in the best interests of the patient. The person responsible is expected to approach the task of decision-making on a best interests model. The expressed wishes of the represented person are described as only one of the factors to be taken into account when deciding what it is in the represented person's best interests.

This has the effect of expanding the medical agent's powers to make medical treatment decisions which cannot be included in the enduring power of attorney (medical treatment) instrument under the MTA.

On the other hand the prescribed approach to considering proposed treatment on a best interests model appears to be in conflict with the requirement imposed by s 5B(2) of the MTA that an agent or guardian may only refuse medical treatment on behalf of a patient if the medical treatment would cause unreasonable distress to the patient, or there are reasonable grounds for believing that the patient, if competent, and after giving serious consideration to his or her health and wellbeing, would consider that the medical treatment is unwarranted.

Emergency treatment

Emergency treatment of a person under a disability for which consent may not be required is governed by Part 4A Div 3 of the GAA.

Section 42A of the GAA concerns urgent treatment and relevantly provides:

(1) A registered practitioner may carry out, or supervise the carrying out of, a special procedure, a medical research procedure or medical or dental treatment on a patient without consent under this Part or authorisation under section 42T if the practitioner believes on reasonable grounds that the procedure or treatment is necessary, as a matter of urgency—

(a) to save the patient's life; or

(b) to prevent serious damage to the patient's health; or

(c) in the case of a medical research procedure or medical or dental treatment, to prevent the patient from suffering or continuing to suffer significant pain or distress.

Section 42K of the GAA concerns the procedure to be followed when the person responsible cannot be contacted.

Healthcare decision-making

Appointment by VCAT of guardian on behalf of an incompetent person

The grounds for an order made by VCAT for the guardianship of a represented person are contained in Part 4 Div 2 and Div 3 of the GAA.

Section 22 of the GAA provides the grounds for an appointment. Section 24 of the GAA lists the powers of a VCAT-appointed guardian, including s 24(2)(d) GAA to consent to medical treatment.

Appointment of an enduring guardian by a competent person

The appointment of an enduring guardian by a competent person is governed by Part 4 Div 5A of the GAA. Section 35A of the GAA provides for the appointment of an enduring guardian and prescribes the form to be employed which is to be found in schedule 4 of the Act.

Section 35B GAA provides that in the absence of specified powers in the instrument the appointed guardian may assume the powers given under s 24 GAA (see above); that is to say the same powers exercised by a guardian appointed by VCAT, but only to the extent that the appointor subsequently becomes unable by reason of a disability to make reasonable judgments.

However as we have seen s 24(2)(b) of the GAA provides that the guardian may consent to any treatment “that is in the best interests of the represented person”. This may be in conflict with any pre-expressed advance directive to refuse treatment or in conflict with a request to undertake treatment that is not considered objectively to be in the represented person’s best interest.

Refusal of treatment

Persons permitted to make refusal of medical treatment decisions in respect of another person under s 5A(1) of the MTA are an agent, an alternate agent or a guardian appointed by VCAT, with an order that includes powers to make medical treatment decisions.

The appointment of an agent under an enduring power of attorney (medical treatment) is governed by s 5A(2)(a) of the MTA, which provides that the appointment of an agent by an enduring power of attorney (medical treatment) must be in the form contained in schedule 2 of that Act.

Commencement of powers under Medical Treatment Act 1988 (VIC)

Section 5AA(2)(b) of the MTA provides that the appointment of an agent only takes effect when the person who gave the power is incompetent

Section 5AB of the MTA provides that an alternate agent can only make decisions if they have first supplied a statutory declaration to the effect that the agent has either died, or is no longer competent or cannot be found.

Refusal of treatment by competent person

Section 5(1) MTA provides that if a registered medical practitioner and another person are each satisfied that a competent patient has clearly expressed or indicated a decision to refuse treatment relating to a current condition, and has done so voluntarily, is informed about the decision, appears to understand the information and is of sound mind and 18 years of age or over, the registered medical practitioner *may* sign a refusal of treatment certificate.

The certificate is prescribed in schedule 1 of the MTA. The certificate must be signed by at least one medical practitioner.

Pursuant to s 7(1) of the MTA the patient can cancel a refusal of treatment certificate in the same way; that is to say all that is required is that they clearly express to a registered medical practitioner their decision to cancel the certificate.

Refusal of treatment on behalf of incompetent person

By contrast, if a registered medical practitioner and another person are each satisfied that

- the patient's agent or guardian has been informed about the nature of the patient's current condition to an extent that would be reasonably sufficient to enable the patient, if he or she were competent, to make a decision about whether or not to refuse medical treatment generally or of a particular kind for that condition; and
- that the agent or guardian understands that information,

the agent or guardian, on behalf of the patient may refuse medical treatment pursuant to s 5B(1) of the MTA.

However, this power is subject to the restriction contained in s 5B(2) of the MTA that an agent or guardian may only refuse medical treatment on behalf of a patient if the medical treatment would cause unreasonable distress to the patient, or there are reasonable grounds for believing that the patient, if competent, and after giving serious consideration to his or her health and wellbeing, would consider that the medical treatment is unwarranted.

In these cases the agent or guardian is required to certify that the patient would consider that the treatment is unwarranted. The certificate requirements are prescribed in schedule 3 of the MTA.

The registered medical practitioner and another person must certify that they are satisfied:

- that the medical agent or guardian has been informed about the nature of the patient's current condition to an extent that would be reasonably sufficient to enable the patient, if he/she were competent, to make a decision about whether or not to refuse medical treatment generally or of a particular kind for that condition and that the agent/guardian understands that information; and
- that neither of them was a witness to the instrument appointing the medical agent.

Note that in this case, the degree of comprehension is required to be that which would enable the *patient* to make the relevant decision, even though it is quite clearly not the patient who is required to make it.

The registered medical practitioner is required to state the patient's condition and to certify that the patient is incompetent. Neither the registered medical practitioner or the other person may be the person who was a witness to the execution of the enduring power of attorney (medical treatment).

Supervision by VCAT

The MTA gives VCAT jurisdiction to suspend or revoke a power. Applications to suspend or revoke an enduring power of attorney (medical treatment) may be made by the agent or alternate agent, by the Public Advocate or by a person who has a special interest in the affairs of the donor under s 5 (2) MTA.

Statutory limitations regarding refusal of treatment

1. Requirement for a current condition

One of the biggest shortcomings of the MTA is the “currency” precondition contained in s 5(1). In short the MTA allows a competent person to refuse treatment in relation to a current condition, and to appoint a medical agent to make a decision to refuse treatment, at a time when the person giving the power is no longer competent. It does not acknowledge or provide a mechanism for a competent person wishing to refuse a treatment in advance of contracting the condition they seek to address.

This restriction of the “currency” precondition in s (5)(1)(a) makes it more likely that completing an enduring medical power of attorney or an advance care directive will be undertaken while a person is in hospital, or in an atmosphere of crisis. Those conditions are not conducive to thoughtful decision-making either by a patient or by a validly appointed medical agent.

Section 7(3) of the MTA which deals with cessation and cancellation of a refusal of treatment certificate reinforces this restriction by providing that a refusal of treatment certificate ceases to apply to a person if the medical condition of the person has changed to such an extent that the condition in relation to which the certificate was given is no longer current.

It is worth noting that the currency relates only to the medical condition and not to the maker’s views about their condition. So if a person has a particular religious conviction about certain medical procedures and later changes their mind, that change of mind does not amount to a change of the condition. In those circumstances a change of mind by the person should be evidenced in a cancellation of refusal of treatment certificate under s 7(1) MTA for a competent person or an application to VCAT under s 5C MTA for an incompetent person.

2. Palliative care

In case it wasn’t clear enough in s 3 that the definition of “medical treatment” did not include palliative care, s 4(2) of the MTA operates to exclude palliative care from the operation of the Act. In other words palliative care cannot be refused either by an individual or by a validly appointed agent on behalf of another, at least under this Act. As to the continued existence of common law rights see below.

What amounts to palliative care?

The case of *BWV*¹⁵ concerned a 68-year-old woman with an advanced form of dementia. She did not appear conscious for approximately three years. She received medications as well as artificial nutrition and hydration through a PEG feeding tube. The court was asked to make a declaration that PEG feeding was medical treatment and that refusal of further feeding in this way constituted refusal of medical treatment and not refusal of palliative care. The submission was made that the proper interpretation of the expression “reasonable provision of food and water” was the provision of food and water for oral consumption. It was put in the alternative that the provision of artificial nutrition and hydration by PEG was not “reasonable provision of food and water”.

¹⁵ *Gardner; re BWV* (2003) VSC 173

The court first considered each of the three alternative definitions of medical treatment and found that PEG feeding could be described as medical treatment. The court then considered after a careful examination of the legislative history and the preamble to the MTA, that the meaning of palliative care was “care, not to treat or cure a patient, to alleviate pain or suffering when a patient is dying.” The court held that PEG feeding is a procedure to sustain life, not a procedure to manage the dying process, so that it results in as little pain and suffering as possible. As such it did not fall within the definition of palliative care.¹⁶

The court went on to examine the second limb of the definition of palliative care, that is “the reasonable provision of food and water” and held that this expression meant the ordinary non-medical provision of food and water. His Honour went further to observe although it was not necessary for him to decide the case, that the continued provision of artificial hydration and nutrition would not be “reasonable” given evidence received concerning BWV’s condition, her prognosis and her previously expressed views.

3. The process of certifying refusal of care

The MTA permits two types of certificate of refusal of treatment to be created. One is used for competent patients to refuse treatment, and one is used for medical agents appointed under an enduring medical power of attorney to refuse treatment on behalf of their principal.

It is a little understood aspect of the refusal of treatment regime that the patient is not required to execute the refusal of treatment certificate. It is not their instrument. The patient’s role is to express their refusal in a way that satisfies the registered medical practitioner and another person that the refusal is voluntary and informed. This role of the medical practitioner is described later in s 5E(2) of the MTA as “the verification”. The requirement for verification is expressed in discretionary terms and the registered medical practitioner is not obliged to execute the certificate.

A description of the process of obtaining informed consent or informed refusal, involving the provision of all the relevant information, ascertaining comprehension of the information and ascertaining voluntariness is not specified in the legislation.

Although this prescribed procedure gives the impression that the medical practitioner is merely a witness to the certificate, it is clear that without his or her imprimatur the informed voluntary decision to refuse treatment whether or not it is in the form of a written advance directive, will be ignored and unwanted treatment will be provided, and in fact must be provided pursuant to s 4(4)(b) of the MTA.

It is difficult to reconcile this restrictive approach to refusal of treatment with an individual’s common law right to be free of interference. It is equally difficult to understand how this approach could be viewed as a reasonable limitation of the individual’s human right to be free of degrading treatment pursuant to s (10)(c) of the Charter of Human Rights and Responsibilities Act 2006 (VIC).

¹⁶ Ibid at para 80

How well are enduring powers of attorney (medical treatment) functioning in Victoria?

Key points

- There have been very few if any reported cases dealing with enduring powers of attorney (medical treatment) or refusal of treatment certificates.
- Both the legal and medical/health professions find enduring powers of attorney (medical treatment) and refusal of treatment certificates difficult to deal with.
- Despite these difficulties, the instruments can be very useful to avoid conflict between family members and family members and medical practitioners in end-of-life situations.
- It is unclear whether common law advance care directives exist in Victoria.

Criticisms of enduring powers of attorney (medical treatment)

While it seems that few if any reported cases that have considered enduring medical powers of attorney or the refusal of treatment certificates have been received in Victoria, we cannot assume that the instruments are functioning as well as they could be.

Some criticisms emanating from the legal profession are:¹⁷

- Reports that medical practitioners have on occasion refused to witness a refusal of treatment certificate, even at the request of a properly appointed medical agent where the medical practitioner had a conscientious objection to doing so.
- The capacity test for competence to execute the document is not prescribed in the Medical Treatment Act 1988 (VIC) (MTA); however, the witnesses are required to certify that they believe the donor appears to understand the information. It is difficult for a witness to explain how they satisfied themselves of this fact.

Some criticisms emanating from medical and allied health workers are:

- The instruments are usually needed urgently, and they often can't be found, or are stored in a lawyer's deed safe.
- Instruments are drafted in such a way that they cannot be understood by medical practitioners.
- Instruments are too prescriptive leaving no room for the "clinical judgment" which (it is asserted) should be reserved to medical practitioners.
- It is too demanding to expect a family member, or even a validly appointed agent, to make such a serious decision about withdrawal or rejection of a therapy on behalf of another family member. The argument is that the family member with responsibility to decide is not able to rationally process the treatment choices as he or she cannot separate their emotional response ("I am not ready for this person to leave me", or "I am not ready to

¹⁷ Author's notes. AMA Victoria. (2013) End of life care roundtables: 30 August 2013, 6 September 2013 and 20 September 2013.

accept the fact that death is near”) from the cognitive response needed to analyse what the donor would have wanted. It is asserted that it is the role of the medical practitioner to show “leadership” on the issue, where the patient or family members cannot decide.

- It has been reported that “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.”¹⁸
- It has been elsewhere argued that the complexity and divergence of laws makes it a difficult task for medical professionals to understand and apply the laws and that the difficulties encountered by medical professionals are a good reason why the law should be simplified and harmonised across the states.¹⁹

While we cannot offer any evaluation of the level of understanding of these laws by Victorian legal practitioners it is likely that testing of a random sample of lawyers would result in an equally poor level of knowledge of end-of-life laws.

Some of the conflicts that can arise at the end of life²⁰

- Ambulance drivers describe shocked family members urging them to attempt resuscitation of persons that have in fact passed away, or persons who have been without oxygen for such a period of time that if they were successfully resuscitated they would almost certainly suffer serious brain damage.
- Doctors describe conflict between family members or conflict between the family members and the patient, or conflict between the entire family and the doctor about withdrawal of treatment or refusal of treatment.
- Doctors describe conflict arising when patients or family members demand treatment which the doctor has not offered or attempted because he or she believes it is not beneficial to the patient.
- Allied health workers describe doctors deliberately not giving patients accurate advice about the terminal nature of their disease or the progression of their disease in an effort to buoy their spirits. Such a person is not able to make suitable treatment decisions because they do not believe that death is near. One palliative care nurse described a patient attending palliative care saying, “I don’t know why I am here. I am not dying.”
- Allied health workers also report difficulties in engaging a patient in discussion about advance care directives for the first time at the time the patient enters hospital for treatment. They describe patients being reluctant to commit themselves to refuse any treatment that is offered in case they miss out on some form of treatment that they might need.

¹⁸ “Doctors’ knowledge of the law on withholding and withdrawing life-sustaining medical treatment”, (2014) *Med J Aust* 201 (4), p 229 – 232.

¹⁹ Willmott, L, White, B, Parker M and Cartright, C: “The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 3”, (Victoria) (2011) 18 *J L M*, 773 at p 790

²⁰ Author’s notes, AMA Victoria (2013), End of life care roundtables: Ibid.

Problems that can arise in the absence of any pre-expressed healthcare directions

Despite the fact that the current administrative and legislative regime lacks clarity, is not well understood or applied by professionals, there can be no doubt that the existence of some form of advance care directive or medical power of attorney will serve to reduce conflict arising between family members or between family members and health professionals in end-of-life medical situations.

Even in circumstances where the document itself lacks legal force, it allows for resolution of conflict.

Barriers to the uptake of advance care directives

Some of the barriers to the uptake of advance care directives (ACDs) are that often people simply do not want to contemplate a time when they are not capable of decision-making or are in pain or debilitated. They do not want to think about contracting a terminal illness or enduring a painful treatment in the course of treating the illness.

Even those people who freely acknowledge that death is unpredictable and as inevitable as birth, growth and ageing will falter at the point of trying to compile a list of directions about treatment for illnesses that they do not yet have. We can only speculate about the future based on our current health status and any known risk factors. Uncertainty makes for complexity, and it is complexity that makes decision-making so difficult, not the consequences of the decision.

Enforcement of Advance Care Directives

The binding nature of the instrument varies from state to state. The Queensland document is expressed in terms of wishes, whereas the South Australian document is expressed to be binding in accordance with the legislation. The Victorian document also employs the language of “wishes” in the statement:

I request that my wishes, and the beliefs and values on which they are based, are respected. I have written on page 2 of this form the things that I value most in life, and other things that may help my doctors and other decision makers.

By comparison with the South Australian document the Victorian document is specifically expressed to be “a guide” (albeit in a footnote) as follows:

If you have specific health problems you may choose to complete a Refusal of Treatment Certificate which is legally binding (unlike the Statement of Choices which is a guide). Refer to Advance Care Plan Information Sheet.

The Victorian document is not prescribed by legislation but can be viewed at advancecareplanning.org.au. The form of document is promoted for use by the Victorian Health Department “*Advance care planning; have the conversation: A strategy for Victorian health services 2014–2018*” and was developed by the Respecting Patient Choices program at the Austin Hospital.

It is clear that what is currently recommended by health workers for use in Victoria is the use of a power of attorney (medical treatment) in combination with a non-binding statement of choices. The casual and ingenuous reference to the refusal of treatment certificate fails to mention the

restrictions imposed on the issue of a certificate by the MTA as described above. The consignment of the directions component of the document to the status of “guide” has the effect of reserving clinical judgment to medical practitioners and to family members along with the ability to simply disregard the written instructions of the maker.

Content of ACDs: what does a good ACD look like?

The drafting of a useful ACD requires thoughtful consideration by the maker of that person's values and medical information. It should include a statement of values as a guide to interpretation of the directions and a set of clear directions about the use of specified therapies and procedures.

None of the Australian forms includes an expanded values history first developed by Dr Edmund Pellegrino²¹ as a guide to interpreting the ACD. In a values history the person making the document (“the maker”) is required to firstly write their “values statement”. This involves describing what is most important to the maker, for example independence; dignity; pain relief and reduction of suffering; or gaining more time, or a simple desire to prolong life until a particular event or date.

This can take the form of statements used as prompts, for example “I do not want to live with a serious impairment that makes me reliant on others”, or “I do not want to prolong life if it means I cannot be mobile or cannot enjoy life the way I used to”, or “I want to keep my dignity at all times”. The purpose of the values statement is to assist with the interpretation of the directions for treatment contained in the document.

Directions for treatment are also important. Each specific therapy or procedure should be listed along with clear directions.

The directions part of the document should be quite specific and list certain life-sustaining therapies or procedures that the maker either:

- does want, or
- does not want; or
- wants to attempt on a trial basis only for a stated period; or
- wants to attempt on a trial basis to see if it is beneficial.

Coexistence of the common law and statutory regimes

As a result of the administrative rollout of the use of non-binding statement of choices it could be said that this form of ACD document has no legal force in Victoria, save for any instructions that might already legitimately be included in an enduring power of attorney (medical treatment).

There has been much discussion in the learned journals (but not elsewhere) as to whether common law advance directives exist in Victoria, whether they ever did, whether they survived the amendments to the GAA and whether they are currently enforceable.

²¹ Doukas Reichel Ibid at p. 67

The exact status of common law ACDs in Victoria is unclear. Nonetheless assertions are made in the learned journals that ACDs are a part of our law.²² The arguments in support of this position are generally based on:

- a conflation of the right to refuse treatment, expressed as an anticipatory direction combined with a description of the document as an expression of that right;
- the fact that ACDs have express recognition in most other common law countries; and
- in the case of incompetent persons, the assertion of the continued existence of the *parens patriae* jurisdiction.

It is even argued seriously that ACDs continue because they were not specifically abolished by the MTA, which presupposes that they were given legal recognition before that Act was promulgated.

Refusal of treatment

As a starting point s 4(1) of the MTA provides that “this Act does not affect any right of a person under any other law to refuse medical treatment”. So we can confidently say that the common law right of inviolability, in combination with the Charter of Human Rights and Responsibilities Act 2006 (VIC) (Charter) s 10(3) right to be free of medical treatment without giving informed consent and the standard of the duty of care of a medical practitioner exercising reasonable skill and care for the purposes of the law of negligence will continue to serve to protect the rights of competent adults who have the physical ability to voice their refusal of medical treatment at the time it is offered.

But what becomes of individuals who because of illness or disease are no longer able to communicate their wishes, some of whom will have formulated and expressed particular views at some time in the past? If human rights are universal is it acceptable that their rights should fall away?

The South Australian case of *H Ltd v J & Anor*²³ concerned a woman in residential care with a disabling and painful form of paralysis and diabetes who wanted to die. She had made a decision to refuse food and water and insulin. It was recognised by all that she was competent and had made a careful assessment of her condition, and that she was entitled to make this choice.

She realised that by following her chosen course of refusing medication and food she would lapse into a diabetic coma, and was concerned that once she lost consciousness, her directions would be disregarded and she would be administered hydration and nutrition and medication. She sent a letter to the management of the residential care provider requesting that advance directions be respected. She executed an anticipatory direction (the forerunner of the advance care direction in South Australia). Unfortunately this instrument had no application because at that time it applied only to persons with a terminal illness.

The residential care provider sought a declaration from the Supreme Court of South Australia as to whether it could lawfully follow her instructions. It was concerned that by doing so it could be

²² Willmot, L and White, B and Howard, M: Refusing advance refusals: advance directives and life-sustaining medical treatment. 2006 Melbourne University Law Review at p.1

²³ In *Re H Ltd v J & Anor* (2010) SASC 176

committing an offence, or failing in its duty of care or breaching its contract with the funding body by failing to meet quality of care standards, including the standard that prescribes patients' rights, and was concerned that it would be subjected to disciplinary action and to a review of its accreditation.

At the commencement of the hearing this brave seventy-four year old woman in poor health appeared unrepresented as the first defendant. During the course of the proceedings she obtained legal representation and on legal advice executed an enduring power of guardianship and appointed her children as guardians, giving them future instructions to refuse treatment.

The Commonwealth was the named second defendant and argued on behalf of the funders that the proposed action of failing to provide food, water and insulin would amount to a failure to meet the quality of care standards and the user rights standards issued pursuant to the Aged Care Act 1997 (CTH) and as a result disciplinary action could be taken in respect of accreditation of the aged care provider.

The South Australian Attorney-General intervened to seek a declaration that the action of complying with an advance direction refusing food, water and medical treatment would negate any offence being committed under the criminal code.

The considerable legal difficulty presented by this application was that the court was asked to make negative declarations contingent upon circumstances which could change in the future, and this included potential criminal offences. In the end, the court acknowledged J's common law right to refuse food, water and medical treatment. The court held that by following a rational direction to refuse food, water and medical treatment the provider would not fail to meet the relevant standards under the Aged Care Act 1997 (CTH). The court granted the residential care provider the declarations it sought, carefully crafted in terms of the correct interpretation of relevant provisions of each statute rather than in terms of approval of future actions.

Enforceability of common law advance care directives in Victoria

The case generally relied upon to assert that ACDs are binding is *Hunter v New England Area Health Service v A*.²⁴

In this case the plaintiff health service sought a declaration that an informal ACD was valid. The respondent Mr A was at all relevant times reliant on artificial respiration and dialysis. He made an appearance through his litigation tutor. He was not legally represented and there was no demurrer. The argument was presented by counsel for the health service. The case was decided by a single judge.

Prior to his admission to hospital Mr A had executed an enduring power of guardianship and had appointed two enduring guardians. The instrument appointing these gentlemen had clearly directed them to refuse consent for blood transfusions. He had separately completed a "work sheet" in which he had indicated he would refuse dialysis and a number of other life-prolonging measures. It was accepted in evidence that the work sheet was in common use amongst members of his congregation. However Mr A had not supplied this document to the lawyer who had drawn up the enduring power of guardianship.

²⁴ (2009) NSWSC 761

In the course of judgment, the court made the statement often quoted at para 40:

If an advance care directive is made by a capable adult, and is clear and unambiguous, and extends to the situation at hand, it must be respected.

The court considered a number of cases and affirmed the common law right to autonomy and self-determination and the requirement of informed consent, and made some observations about how consent may be given and about circumstances that would vitiate consent.

The application was made by the health service for a declaration that it could comply with an informal advance directive. It is not clear how well this case will stand as authority in circumstances where a dispute arises between family members about a proposed withdrawal of treatment, or where an ACD contains a positive direction for certain treatment to be attempted but the medical practitioner is reluctant to provide the treatment.

It has also been asserted that the case in Victoria of *Qumsieh v Guardianship and administration Board* (1998) VSCA 445 (unreported) “seemed to accept that a common law advance directive would be binding.”²⁵

Qumsieh’s case concerned a young woman whose condition deteriorated after postnatal complications. She was an adherent of the Jehovah’s Witness faith. Her husband produced to the treating team an advance directive stating that she refused blood transfusions. The hospital made an urgent application to the (then) Guardianship Board for an order for guardianship, which was granted and delegated to her husband who made the decision to consent to blood transfusions. The blood transfusions were given and she recovered.

After recovering she made an application to the Supreme Court in the nature of administrative review of the decision of the Guardianship Board to grant an order for guardianship. Neither of the named respondents appeared. The application was refused at first instance by a single judge and the appeal concerned the manner in which both the board and the single judge had conducted their deliberations.

The court noted in passing that the board had before it an enduring medical power of attorney that did not appear to be executed in a valid form and had received little indication of why the treatment had been refused. It does not seem that the Court of Appeal spent any time considering the actions of the treating team.

Special leave to appeal to the High Court was refused. It would be drawing a long bow to say that this case is authority for the existence and legal recognition of common law ACDs in Victoria.

In so far as ACDs are currently being promoted to improve the care planning process and are not intended to ascribe particular rights to any person, and might at some time in the future have evidentiary value as to a person’s intentions, it is probably true that they exist within the law.

²⁵ Willmot, L and White, B and Howard, M: Refusing advance refusals: advance directives and life-sustaining medical treatment. 2006 *Melbourne University Law Review* at note 7

Exercise of the parens patriae jurisdiction

In the case of *BWV*²⁶ above, a single judge of the Supreme Court was invited by the Attorney General appearing as intervenor to forego the making of a declaration sought in favour of an exercise of the parens patriae jurisdiction. Ultimately though it was not necessary to decide the issue of parens patriae jurisdiction. The court declined to exercise its discretion stating:

Although the parens patriae jurisdiction of the court is of considerable historical interest, I doubt if it should play any current role in the day to day administration of Guardianship matters. Victoria has comprehensive law in relation to Guardianship and Administration matters. These laws have established the statutory office of public advocate, with roles and responsibilities somewhat akin to those which might have once been adopted by the Court. A wide jurisdiction is also vested in the Victorian Civil and Administrative Tribunal to resolve disputes concerning Guardianship matters and to consider an application where there is some perceived threat to the integrity of the Guardianship system. The Medical Treatment Act sets out parliament's intent in relation to the procedure whereby a person may refuse medical treatment; and, further, the procedure whereby an agent may make a decision about medical treatment on behalf of an incompetent person... The fact that a type of reserve power exists provides no logical justification for bypassing the Guardianship and Administration Act and the Medical Treatment Act.²⁷

Despite this pronouncement four years later in the case of *Herrington*²⁸ the Supreme Court of Victoria exercised its parens patriae jurisdiction even though an application to VCAT for guardianship orders was on foot.

Mr Herrington made an application to the Supreme Court in the exercise of its parens patriae jurisdiction for orders that medical treatment be provided to his partner Ms King. Ms King was a young woman with hypoxic brain injury, said to be in a persistent vegetative state. Ten days prior her treating team and made the decision to discontinue PEG feeding because of the danger of vomiting. The treating team proposed that feeding, antibiotics and blood examinations be stopped and reversion to palliative care. Mr Herrington wanted the treatment continued at least until he could arrange a second opinion about the proposed withdrawal of treatment.

The court noted that an application to VCAT for a guardianship order was on foot. The court heard evidence from the Public Advocate that VCAT had been provided with a report that "intervention was not necessary because the hospital was not offering treatment which could be refused." It was accepted that VCAT had not ruled on the issue of guardianship. The Court proceeded on the basis that it had the parens patriae jurisdiction and that the test to be applied was the best interests of Ms King.

The court heard evidence concerning aboriginal traditions and evidence of relatives concerning their belief that Ms King could understand and respond to them and that given treatment she might recover. Medical evidence was accepted that if Ms King were to be given fluid treatment for re-hydration, she could suffer from pulmonary oedema or infection as a result and that intravenous fluids would be painful because of deterioration of her veins. The court ruled that it was not in the best interests of Ms King for her to receive treatment over and above palliative care.

No reference appears to have been made to the Charter although the relevant provision commenced operation on 1 January 2007.

²⁶ *ibid*

²⁷ *Ibid* at para 99

²⁸ *In the application of Herrington, re King* [2007] VSC 151

Note that the *parens patriae* jurisdiction in the United Kingdom has been swept away by statute, this being noted in the case of *Re F*²⁹ where it was stated that:

...so much of the *parens patriae* jurisdiction as related to persons of unsound mind no longer exists...the revocation by Warrant under the Sign Manual of the last Warrant dated 10 April 1956, by which the jurisdiction of the Crown over the persons and property of those found to be of unsound mind by inquisition had been assigned to the Lord Chancellor and the judges of the High Court, Chancery Division.

The effect of section 1 of the Act of 1959, together with the Warrant of revocation referred to above, was to sweep away the previous statutory and prerogative jurisdiction in lunacy, leaving the law relating to persons of unsound mind to be governed solely, so far as statutory enactments are concerned, by the provisions of that Act.

A positive directive for treatment: is there a right to demand medical treatment?

Legal practitioners are accustomed to clients attending to execute enduring powers of attorney (medical treatment) having quite definite ideas about treatment they do not want at the end of life. It comes as a surprise then to hear that medical practitioners report conflicts emerging when a demand for treatment at the end of life is made by a patient or on behalf of a patient, which the medical practitioner does not believe will be beneficial to the patient.

In these situations it is steadfastly asserted that there is no common law obligation for a medical practitioner to provide treatment that is futile. While the “ability to consistently define ‘futile treatment’ has eluded academics across the disciplines”³⁰ it continues to be the reason given for unilateral withdrawal of treatment without consent. The case of *Herrington* above is an example.

The assertion is based on a classical contractual analysis of the relationship between the patient and the medical practitioner, where the medical practitioner offers services to the patient who chooses whether to accept the service. The medical practitioner is under no obligation to offer a particular treatment he or she does not consider to be effective.

This analysis is carried further in cases where the issue arises as to whether a guardian should be appointed, as it is asserted that as no offer has been made, then no decision arises that needs to be made and accordingly a Guardian is not needed. That is, the threshold case for guardianship cannot be made out. In *Herrington's case* evidence was accepted that a report had been prepared by the Office of the Public Advocate for consideration by VCAT, which report advised that “intervention was not necessary because the hospital was not offering treatment which could be refused”.

The assertion that there is no right of the patient to demand treatment has received legislative recognition in South Australia in s 6 of the Advance Care Directive Act 2013 (SA) which provides that healthcare professionals cannot be compelled by an ACD to provide particular care, and adds this note into the legislation for the sake of clarity: **Note—**

Whilst a person can indicate his or her wishes in respect of the health care he or she wishes to receive, ultimately the question of what form of health care should be provided to a patient is a matter for the health practitioner to decide (however, a person is entitled to refuse health care of any kind, or to require it to be stopped, including health care that saves or prolongs his or her life).

²⁹ Note *Re F* (1990) 2 AC 1

³⁰ Wilmot, I and White B and Downie, J: (2013) Withholding and withdrawal of “futile” life--sustaining treatment: unilateral medical decision making in Australia and New Zealand. JLM 20 (4) p. 908.

LEGISLATIVE REFORM - A DECISION TREE

Before proposals for legislative amendments can be entertained a series of decisions need to be made. The purpose of the section is to guide the reader through a series of philosophical choices without first having to decide the exact form any changes should take.

1. Should we recognise a person's right to make decisions about their end of life care in advance with an expectation that those pre-expressed directions will be followed?
2. If we are to acknowledge a person's right to make pre-expressed directions about their end of life care, should we afford legislative recognition of a process for enforcing those pre-expressed directions? (This decision can be made for the time being without consideration of the conditions for recognition and enforceability.)
3. If the proposed legislation provides for acknowledgement and enforceability of end of life health care decisions, should it govern only refusal of treatment or should it also include consent to treatment and positive directions for treatment?
4. If such pre-expressed directions for end of life care are to be acknowledged and enforceable by legislation, should the conditions and procedure be in the form of "stand-alone" legislation or of amendments to current legislation?
5. If the "stand-alone" approach is taken, should such legislation compile in one place the necessary instruments, conditions and procedures governing all pre-expressed directions about end of life planning including not only health care and treatment but those decisions about personal affairs generally allocated to a guardian such as accommodation, access to services, access to visitors, care for pets and so on.
6. Should the present restrictions on refusal of treatment continue? That is the exclusion of palliative care, the requirement for currency, and the process of certification being in the control of medical practitioners.

Armed with answers to these questions, the reader might like to consider what the proposed legislation could look like by considering the options outlined in the Discussion paper contained in Appendix 1.

ADVANCE CARE DIRECTIVES

Discussion paper prepared by Lynne Barratt for Elder Law section LIV 2014

Definitions

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.³¹ 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.³²

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 or, alternatively, who should make health care decisions if the person is unable to express his or her wishes.³³

So in one sense the term "Advance Care directives" is a generic term that describes an array of legal instruments created to achieve these two purposes, but in limited ways and with limited effect. However, the term has most recently been used in other state jurisdictions to describe a new form of instrument, which combines into one instrument the enduring power of Guardianship, medical power of attorney and anticipatory direction.³⁴

Advance Care Directives sole are not referred to in any current Victorian legislation that covers medical treatment or consent to treatment or entitlement to medical services. They have quite simply developed outside the current legal framework. Some lawyers have not even heard of them. While assertions are made that 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" assists decision makers to make a health care decisions consistent with the individual's choice without ascribing rights to any person.

The question remains, is this largely administrative approach the best model to promote the rights of Victorians?

Current law reform and recommendation

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 133 and 134, 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.

By way of example in 2013 the South Australian parliament passed the Advance Care Directive Act (2013). The Act is expressed to operate from 1st July 2013, but is described as not commenced at the time of writing. The second reading explanation inserted into the Hansard explained that the stated intention of the Bill was to:

- combine the Enduring power of guardianship, the Medical power of attorney and the Advance care directive (ACD) into one document,

³¹ Victoria. Health department. "Advance care planning, have the conversation: a strategy for Victorian Health Services 2014 – 2018 at p.11

³² Ibid. p. 53

³³ .David John Doukas and William Reichel . Planning for uncertainty: a guide to living wills and other advance directives for Health care. Johns Hopkins University Press 1993 at p. 1

³⁴ for example Advance Care Directives Act (2013) S.A. and Guardianship Act (1990) W.A Part 9B

- promulgate a single prescribed form for use in completing an advanced care directive which would require the assistance of neither medical nor legal practitioners
- contain principles for the interpretation of ACD
- protections for health care practitioners that act on ACD in good faith
- and provide a regime for appointment and oversight of substitute decision makers,

Administrative responses - medical service delivery

In 2011 the Australian Health Ministers Advisory Council produced the National Framework for Advance Care Directives. The document was intended to be used by health care services and provides a code of ethical conduct and outline of best practice for the use of advance care planning.

In March 2014 and after consultation the Victorian Health department 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.”³⁵

³⁵ Advance care planning, have the conversation: a strategy for Victorian Health Services 2014 – 2018 p. 17

QUESTIONS FOR DISCUSSION

Q. 1 Compilation of subject matter - some options

Current position

Advance care directives have no legal recognition under the Victorian law, save to the extent that the directives might be supported by existing rights or to the extent that directives can be the subject of one of the instruments currently recognised.

The Medical Treatment Act (1988) (“MTA”) deals with refusal of treatment certificates and the appointment of medical agents pursuant to a medical power of attorney, and prescribes forms for each purpose. It provides protection for medical practitioners who act on a refusal of treatment certificate in good faith and establishes the offence of medical trespass.

The Act 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 nor does it touch on medical service provision at all.

In Victoria matters involving the issue of consent to medical treatment given to persons with a disability and over the age of 18 years is governed by Part 4A Div 1 Guardianship and Administration Act (1986) (Vic) (“GAA”)

s. 37 GAA provides a hierarchy of persons described as “the person responsible” who may be called upon to give consent to medical and dental treatment, save for “special procedures” which need not concern us here. S. 38 GAA provides for the manner in which a person responsible should decide whether or not a proposed treatment of procedure is in the best interests of the patient.

Matters involving the appointment of an enduring Guardian is governed by Part 4 Div 5A Guardianship and Administration Act (1986) (Vic) s. 35A provides for the appointment of an enduring Guardian and prescribes the form to be employed which is to be found in schedule 4 of the Act. s. 35B provides that in the absence of specified powers in the instrument the appointed Guardian may assume the powers given under s. 24 GAA, that is to say plenary powers, but only to the extent that the appointor subsequently becomes unable by reason of a disability to make reasonable judgements.

Matters involving the appointment of a Guardian by VCAT is contained in Part 4 Div 2 and Div 3 Guardianship and Administration Act (1986) (Vic) s. 22 GAA provides the grounds for an appointment. S. 24 GAA provides the powers of an appointed Guardian, including s. 24 (2) (d) to consent to medical treatment.

Emergency treatment for which consent may not be required is governed by Part 4A Div 3 Guardianship and Administration Act (1986) (Vic) s.42A GAA.

Should the Parliament make efforts to draw together aspects of the current legislation that deal with future health care, and if so in what way?

Some alternatives for compilation of legislation might be;

1. A compilation of the laws regulating all matters concerned with health service delivery and incorporating reference to the human rights of patients. Such an effort would probably face a lengthy journey through the Parliament.
2. Legislation that gathers together all aspects of consent to medical treatment (including the description of a consent hierarchy), refusal or medical treatment, emergency treatment and application for special procedures in one Act. An example would be the Consent to Medical Treatment and Palliative Care Act (1995) (S.A.)

At the same time but separately, legislation that provides for the creation of an instrument that gives binding advance directions on all aspects of future health care, including refusal of treatment, and also using that same instrument, deal with the appointment of a decision maker with power to make binding decisions about all aspects of future health care, including refusal of treatment, in defined circumstances. An example would be the Advance Care Directives Act (2013) (S.A.)

3. Legislation that gathers together all aspects of consent to medical treatment including the description of a consent hierarchy, refusal or medical treatment, emergency treatment and application for special procedures, **and** all current forms of instrument that give instructions for future health care and appoint decision makers such as the current Enduring Power of Guardianship, Medical Power of Attorney and the Advanced Care Directive.
4. Enactment of stand-alone legislation to recognise the new Advance Care directive and provide a regime for recognition of human rights of the maker, recognition of the instruments and the powers conferred by them, to provide for the limitations on their use, provide criteria for their valid execution and providing for their manner of revocation and for dispute resolution, and administrative or judicial oversight. Consequential amendments would be required to ensure consistency of terminology between this and other Acts.

2. **Simplification of instruments**

Q.2.1 Use of a single form

Would the replacement of the existing Enduring Power of Guardianship, Medical Power of Attorney and the Advance Care Directive with the use of a single form of Advance Care Directive pertaining to future health care, facilitate ease of use and promote the uptake of Advance planning for future health care?

An alternative might be to enact amending legislation to ensure consistency between these three Acts.

Q.2.2 Standardised nomenclature:

Is it important to adopt a standardised nomenclature around Australia and other parts of the world? What should the descriptors be?

- The following alternative terms are in use to describe the instrument: Advance Care Directive, Advance Healthcare Directive, Anticipatory Direction, Living Will
- The following alternative terms are in use to describe the person executing the Advance Care Directive: Patient, Donor, Maker
- The following alternative terms are in use to describe the person appointed to make decisions: Substituted decision maker, Attorney, Agent, Health care proxy, Guardian, Enduring Guardian.

The South Australian legislation employs the term “substituted decision maker” appointed under an instrument and the reserves the term “Guardian” for those people appointed by a tribunal.

Q. 2.3. Prescribed forms

Should legislation require that only prescribed forms may be used to complete an Advanced Care Direction?

If yes, should such a form be prescribed in regulations, or in a schedule to the legislation, or in a form approved by a government minister such as the Victorian Health Minister.?

Who should be responsible for the drafting approval and periodic reviewing of the prescribed form?

If a prescribed form is to be made available through a government department, should it be contained within a kit or be accompanied by a set of instructions or guidelines?

- An example of legislation providing refers to a form that must be approved by the Minister for Health and Aging is s.3.(1) Advance Care Directives Act (2013) (S.A.)
- An example of a form being prescribed in a schedule to the Act is contained in the current Medical Treatment Act (1988) (Vic) in section 5 (2).
- An example of a form being prescribed by regulations in contained in s. 110Q Guardianship and Administration Act (1990) (W.A.)
- An example of a form and accompanying guidelines emanating from a private source without reference to any governing legislation is to be found on the website of Advance Care Planning Australia. The forms carry the claim that copyright vests in the Austin Hospital.

Should such a form (and any guidelines) be written in simple language and with the intention that individuals can complete the form without the assistance (and expense) of a lawyer or a doctor?

Q. 1.4 English language preferred?

Should an advanced care directive be prescribed to be in English in order to be valid?

- An example of how an individual can complete an advance care directive if English is not his or her first language is contained in s.14 Advance Care Directives Act (2013) (S.A.)

3. Competence and capacity

Q. 3.1 Requirement for capacity to execute an advance care directive.

Should the legislation require that an individual completing an advance care directive must be an adult and have capacity to make and to revoke the document?

Should the legislation state that it may be presumed that an adult is competent to complete an Advance Care Directive unless there is evidence to the contrary?

It is submitted that it is of the utmost importance that an individual completing the form must understand what an Advance Care Directive is and the consequences of completing one. The consequences of an advance direction to refuse life-sustaining treatment in certain circumstances might well result in death.

- An example of a requirement that the Donor must have capacity and an accompanying exposition of the requisite capacity test is contained in s. 114 and s.118 of the Instruments Act (Vic) in relation to an enduring financial power of Attorney.

Should the witnesses be required to state their honest belief that the individual completing the Advance Care Directive has the capacity to do so?

If so, should the witnesses be required to state their reasons for holding that view?

Should the witnesses be required to note their reasons for holding that view?

Should the legislation define the capacity test for executing the document, and a requirement that witnesses consider and note each aspect of the definition?

- The current legislation governing appointment of an enduring Guardian requires the witnesses to state that “the appointor signed the instrument freely and voluntarily in our presence and that the appointor appeared to understand the effect of this instrument”.
- The current legislation governing appointment of a Medical Agent requires the witnesses only to state that they each believe that (named person) in making this enduring power of attorney (medical treatment) is of sound mind and understands the import of this document.
- The suggested form of Statement of Choices on the Advance Care Planning Australia website requires that the witnesses sign the document, and requires that a registered Medical Practitioner certify that he or she believes that (named person) is competent and understands the importance and implications of this document.

Q 3.2 Threshold for implementation of the advance directive

The importance of establishing a threshold test for the implementation of an advance directive is that, up until that moment, an individual retains the right to express directly his or her own preferences for a range of health care and other decisions such as accommodation.

Should an advance care directive be expressed to take effect in a particular set of circumstances, such as when it is established that the person’s decision-making capacity is impaired?

If the impaired decision making threshold test is to be used, should the legislation contain a definition of impaired decision - making capacity, including the ability to consider information, weigh up options, make a decision based on the information provided and communicate those decisions in some manner .

Should such a definition contain a statement that impaired decision making is not necessarily related to a diagnosis or condition?

Should such a definition accommodate temporary and fluctuating decision-making capacity? In particular, the needs of people with a mental illness or dementia whose capacity to make decisions may fluctuate?.

Should the legislation recognise that different decisions require varying levels of decision-making capacity, and encourage the support for an individual making less difficult decisions for as long as that person is able?

If the impaired decision making threshold test is to be used, should the legislation contain a requirement that the person acting upon the Advance care directive to note his or her reason for activating the advance care directive.

Should the substitute Decision-Maker or medical practitioner have recourse to seek advice about whether the individual has the capacity to make a relevant decision from the Office of the Public Advocate?

Or should the threshold simply be whenever the person cannot express their view or cannot advocate on their own behalf?

4. What subject matter may be lawfully contained in an Advance Care Directive?

4.1 Scope

Should the legislation take a broad view of health and well-being which extends beyond medical treatment instructions at the end of life?

Should the legislation enable competent adults to give directions about their future health care, residential and accommodation arrangements and personal affairs and other matters?

Should the legislation enable individuals with mental illness to give binding directions about their mental health treatment?

The following is extracted from the second reading explanation inserted into the Hansard Parliament of South Australia in advance of the Advance Care Directives Bill.

“Growing numbers of South Australians live alone. Being able to include instructions in an Advance Care Directive about health care, residential, accommodation and personal matters such as not being transferred from a care home to hospital to die or who should look after their dog or cat often brings peace of mind.

Mental health consumers and older people indicated that people want the option to be able to write down their wishes, preferences and instructions for matters beyond medical treatment decisions at the end of life, without appointing Substitute Decision-Makers.

Reasons for this included:

- no-one to appoint or could not choose who to appoint
- did not want to burden family/friends with such decisions
- complicated family relationships such as second or third marriages or families
- religious reasons for example Jehovah Witnesses refusing blood transfusions”

Q.4.2 Options: appointment or written preferences or both

Should the legislation allow for either written instructions and expressed preferences and values, or the appointment of one or more decision-makers, or both instructions and appointment?

Q. 4.4 Restrictions on the terms of an advance care directive – current condition

Should an individual completing an Advance Care Directive be permitted to list medical therapies that he or she wishes or does not wish to undergo, in advance of contracting a particular illness?

It is submitted that one of the biggest shortcomings of the Medical Treatment Act (1988) (Vic) is the “currency” precondition contained in s. 5. (1) which states that:

- a s. 5 (1) (a) If a registered medical practitioner and another person are each satisfied that patient has clearly expressed or indicated a decision
- (i) to refuse treatment generally, or
 - (ii) or to refuse medical treatment of a particular kind,
- in relation to a *current* condition” (Italics added) and

While the Act allows a competent person to refuse treatment in relation to a current condition, and to appoint a Medical agent to make a decision to refuse treatment, at a time when the Donor is no longer competent, it does not contain a mechanism for recognising that a competent person may refuse a treatment in advance of the contracting the condition they seek to address.

This restriction of the “currency” pre-condition makes it more likely that the exercise of completing an advance care directive is undertaken while in hospital, or in an atmosphere of crisis. Those conditions are not conducive to thoughtful decision making either by a patient or by a validly appointed medical agent.

How then should we best deal with the vexed problem of currency and change of circumstances? Should there be regular periodic reviews required? This is recommended every two years in the guidelines on the website of Advancecareplanning.org.au

Or, should the legislation provide that advance care directives do not operate, if at any time the circumstances have changed that the person giving the power would not have known?

- An example is contained in s110S (3) GAA (W.A.):

- (3) Subject to subsection (4), a treatment decision in an advance health directive does not operate if circumstances exist or have arisen that —
 - (a) the maker of that directive would not have reasonably anticipated at the time of making the directive; and

- (b) would have caused a reasonable person in the maker's position to have changed his or her mind about the treatment decision.

Q 4.5 . Should certain directions in an Advance Care Directive be excluded?

s. 4 (2) Medical Treatment Act (1988) (Vic) excludes palliative care from the operation of the act. "Palliative care" is defined in s. 3 as:

"the provision of reasonable medical procedures for the relief of pain suffering and discomfort or the reasonable provision of food and water."

In other words palliative care cannot be refused under the current law.

If palliative care is excluded should palliative care" be defined as the reasonable provision of food and water by non-medical means.? (Post BWV's case)

Should some types of directions contained in an advance care directive be proscribed? For example:

- Refusal of palliative care
- unlawful instructions or instructions which would require an unlawful act to be performed such as voluntary euthanasia or aiding a suicide
- Refusals of mandatory treatment such as compulsory mental health treatment.
- actions which would result in a breach of a professional code or standard, for example a Code or Standard issued by the Medical or Nursing and Midwifery Boards of Australia.

If such directions were included in an Advance Care directive what should be the effect on the validity of the document? Should the document be regarded as void in its entirety, or should the direction be treated as severable?

4.6. Positive directions – should they be binding?

If a wide ranging instrument is to be used, one that covers not only health care but instructions and preferences relating to accommodation, residential and personal matters, should such directions (those other than health care directions) be regarded as binding?

Some expressed preferences will be subject to external criteria for eligibility, for example entry to residential care. Should the legislation state that such expressed preferences are for the guidance only of health care providers or decision makers, and not binding?

Should the legislation contain a provision that states that medical practitioners cannot be completed to provide treatment?

This is asserted to be a statement of common law principle, that a person can consent to treatment that is offered, and refuse treatment that is offered, but cannot demand treatment that is not offered.

- An examples of legislation providing that a medical practitioner cannot be compelled to provide health in s.6 Advance Care Directives Act (2013) (S.A.)

Should the legislation state that if a person has expressed a direction that there is a specific therapy or treatment to which they consent, such a direction would not be binding on the Health care practitioners and would offer guidance rather than a demand?

Q. 4.7. Statement of specific directions or values statement or both

Should individuals be encouraged to write down whether they would refuse treatment, request treatment or attempt a trial of certain treatment to see if it is beneficial?

It is claimed that these types of instructions are not helpful to health practitioners having the task of interpreting them at a later stage. Instructions are often either too specific or not specific enough, or crucially do not relate to the current circumstance or condition. Medical practitioners would prefer to be given as much latitude for clinical judgement as possible, and would rather deal with an expression of values which are capable of being “interpreted” and applied to the situation at hand.

It must also be conceded that the task of considering a range of therapies for a yet unknown illness proves too difficult for many people.

On the other hand, a clear written declaration of refusal of types of medical treatment is as clear an assertion of that person’s human right of autonomy as one would ever see. That right only exists where the individual has the corresponding legitimate expectation that his or her rights will be respected, regardless of whether he or she is in a position to enforce them. It follows therefore that if every Advance Care Directive is subject to interpretation, it is not possible to be certain that one’s rights are being respected.

Alternatively should individuals only write down their values and goals of care, what is important to them when decisions are being made for them by others, what levels of functioning would be intolerable, and where and how they wish to be cared for when they are unable to care for themselves.

5. Obligations of health care practitioners

Should the legislation set out the rights and responsibilities of health practitioners in relation to Advance Care Directives?

Should health practitioners be afforded protections from criminal and civil liability for acting on a valid Advance Care Directive in good faith and without negligence?

Should the definition of health practitioners registered health professionals such as medical practitioners, nurses and midwives, psychologists and pharmacists.? Should the definition extend to other allied health and aged care workers such as ambulance officers or aged care staff?

Should the legislation impose a positive duty upon a health practitioner that he or she:

- must comply with binding refusals of health care

- should as far as is reasonably practicable to do so, comply with non-binding provisions
- must endeavour to seek to avoid an outcome or intervention that the person has indicated that they want avoided
- Must act in accordance with any principles set out in the Advance Care Directives legislation.

What should be the consequence of failing to comply with a binding refusal of health care contained in an advance directive?

s. 6 Medical Treatment Act (1988) (Vic) creates the offence of medical trespass, and states that the offence carries a penalty of 5 penalty units (currently about \$600.) There does not seem to be a recorded case of a prosecution under this provision.

Should the consequences of non-compliance with an Advance Care Directive be liability to criminal prosecution? Or should the consequences be a report of professional misconduct, or liability to a civil suit for battery?

What should be the consequence for health practitioners who do not have to be registered with a professional standards board?

In view of the consequences of non-compliance, should health care practitioners have recourse to seek advice about their responsibilities from the OPA?

6. Formalities

Q 6.1 Involvement of legal and medical practitioners

Should there be a requirement that an Advance Care Directive has to be legally or medically informed to be valid?

The current Medical Treatment Act (1988) (Vic) s. 5 (1) provides that if a registered medical practitioner and another person are each satisfied that a patient has clearly expressed or indicated a decision to refuse treatment relating to a current condition, and has done so voluntarily, is informed about the decision, appears to understand the information and is of sound mind and over the age of 18 years, the registered medical practitioner *may* sign a refusal of treatment certificate. The certificate is invalid unless one of the persons executing it is a registered medical practitioner.

Although this prescribed procedure gives the impression that the medical practitioner is merely a witness to the certificate, it is clear that without his or her imprimatur the informed voluntary decision to refuse treatment whether or not it is in the form of advance directive, will be ignored and unwanted treatment will be provided, and in fact must be provided pursuant to s.4 (4) (b) MTA.

Should the legislation or any accompanying guidelines encourage an individual to seek medical or legal advice to ensure that their Advance Care Directive will achieve its intended purpose?

- An example of legislation containing a provision that the person giving the power should be encouraged to seek legal or medical advice is contained in s. 110Q (1) (b) Guardianship and Administration Act (1990) W.A

Should the legislation provide that the Advance Care directive be provided to a medical practitioner?

The introduction of electronic health records will enable the Advance Care Directive to be scanned and included as part of the person's electronic health record so that it can be accessed when needed.

If the current Medical Treatment Act (1988)(Vic) is not to be amended, and insofar as an Advance Care Directive provides a statement of values, it will assist medical practitioners to understand the extent to which the individual's refusal of treatment is informed, and voluntary.

Q. 6.2 Witnesses

Should the witness be required to sign a statement to confirm that they are satisfied that to the best of their knowledge, that the person completing the Advance Care Directive understands the nature and effect of the Advance Care Directive and is completing it free of coercion.?

Should the Act or regulations provide for guidelines for witnesses as to how they might satisfy themselves of this fact?

Should the guidelines for witnesses state that if the person's competence to complete an Advance Care Directive is questionable, the witness should refuse to sign the form or request advice before they witness the document?

Should the Act create offences for witnesses knowingly giving false or misleading statements?

Q. 6.3 Qualifications of witnesses

Should witnesses be restricted to persons over 18, or restricted to "professional witnesses" similar to the list of suitable persons for witnessing Commonwealth documents?

Q. 6.4 Proscribed witnesses

Should certain witnesses be proscribed witnesses to avoid conflict of interest?

Should the legislation contain a provision that witnesses cannot be:

- Decision-makers appointed under the Advance Care Directive
- persons with a direct or indirect interest in the estate of the person giving the Advance Care Directive
- health practitioners responsible for the health care of the person giving the Advance Care Directive
- persons in a position of authority in a hospital, nursing home or other similar facility in which the person resides.

7 Decision makers

Q. 7.1 Joint, several or multiple

Should the legislation provide for the appointment of more than one decision maker?

Should the legislation provide for joint decision makers, and if so, should they be joint and several or either?

Or should the legislation provide that decision makers must be expressed to be alternates in the event that an appointment is revoked or fails for some other reason?..

If they are expressed to be alternates, should the legislation provide that the alternate decision maker must satisfy the health care practitioner as to their appointment?

- An example of this requirement is contained in s.5AA Medical Treatment Act (1988) (Vic)

Should the legislation provide for an individual to appoint different decision makers for different purposes and describe the manner in which they are to consult with each other?

Q. 7.2 The scope of decision maker's authority

Should the legislation provide a statement of the scope of the decision-maker's authority such as: the appointed decision-maker can make all the health care, residential, accommodation and personal decisions the person could lawfully make if they had decision-making capacity?

Or "A decision of a decision-maker has the same legal effect as if it were a decision of the individual themselves. "

Q. 7.3 Statement of duties

Should the legislation require that decision makers must:

- act in good faith, without negligence and in accordance with the wishes and values of the person for whom they were appointed,
- make the decision they believe the person would have made in the current circumstances, if they had access to the same information.

Given that serious consequences that might result from a decision, should decision-makers have recourse to seek advice from the Office of the Public Advocate if they are unsure of their role?

Q. 7.4 Manner in which decisions are made

Should the legislation prescribe that the decision maker is to act in the appointor's best interests?

- An example might be s. 24 (2) (b) GAA

Or should the decision maker be required to make the decision that the appointor would have made?

Q7.5 Proscribed decision makers

Should the legislation contain any proscription of suitable persons to ensure that appointed decision makers do not have a conflict of interest or duty?

Suggestions might be:

- health practitioners directly or indirectly responsible for the individual's health care
- paid carers, but not a close friend or relative in receipt of Carers Allowance
- Person with an interest or expectation in the individuals' estate

This last suggestion is an extremely difficult choice. While the potential for conflict exists, it would likely exclude the closest relatives and those the individual would likely know and trust.

Q. 7.6 Restrictions on the powers of a decision maker.

Should the legislation provide that a decision to refuse palliative care is not permitted?

If so, should this properly be expressed as a restriction on the powers of the decision maker, rather than as currently expressed, as an exclusion from the operation of the Act?

Q. 7.7 Consequences for decision makers

Should the legislation create offences for decision makers for obtaining an Advance Care Directive by fraud, or using undue influence to induce another to give an Advance Care Directive.?

Should the legislation provide that a person who procures the execution of an Advance Care directive by fraud or undue influence should forfeit any interest under a will or intestacy of the person so defrauded?

- An example is contained in s. 5F Medical Treatment Act (1988) (Vic)

Should the legislation empower VCAT to hear applications for an order to revoke an Advance Care Directive obtained by fraud or undue influence?

If so, should VCAT have power to order any form of punitive damages?

8. Revocation

8.1 Revocation of a specific appointment

Should the legislation specify grounds for revocation by VCAT of a specific appointment for example if VCAT is satisfied that the decision maker:

- is a person who must not be a decision-maker (proscribed)
- is no longer willing to act as a Substitute Decision-Maker
- no longer has the same relationship with the person

- has been negligent in the exercise of their powers
- Has wilfully made decisions inconsistent with the Advance Care Directive.

Q. 8.2 Manner of revocation of the instrument

Should the legislation provide for revocation of the instrument by the person who made it while competent?

- by signing , dating and having witnessed a section on the form
- Automatically by making a fresh Advance Care Directive

Should the legislation provide a requirement for notification to all persons who may have a copy, of its revocation?

Should the legislation provide that those acting in good faith on what they believe to be a current and valid Advance Care Directive should be afforded protection from liability?

Q. 8.3 Revocation by Tribunal where person no longer competent

Should the legislation provide for a process for the revocation of an Advance Care Directive by VCAT when a person is no longer competent?

In what circumstances should VCAT act to revoke an Advance Care Directive?

9. Resolution of disputes

When disputes arise concerning the application and interpretation of an Advance Care Directive:

9.1 Advice, mediation

Should there be a less formal option than seeking an order from VCAT?

- An example is contained in Advance Care Directives Act (2013) (S.A.) which confers advisory, voluntary mediation and also limited declaratory functions on the Office of the Public Advocate as less formal ways of resolving disputes.

9.2 Jurisdiction of VCAT

Should VCAT have jurisdiction to hear disputes arising concerning the application or interpretation of an Advance Care Directive?

If so, what powers should VCAT have to determine the matter?

If a declaration is issued by VCAT in what manner should it be enforced?

10 Recognition of interstate instruments

Should Advance Care Directives or equivalent instruments created in another state be recognised in Victoria?

If so, should instruments containing provisions that would be considered unlawful or non-binding in Victoria be treated as void and of no effect?

Appendix 2

POST SCRIPT ABOUT EUTHANASIA

It is greatly to be lamented that the phrases "palliative care" and "euthanasia" seem to be widely misunderstood in the common parlance as being in some way equivalent. This perception stops some Victorians from engaging in a discussion of palliative care as an option for end of life care for themselves or for their family members and to be suspicious of any person who seeks to engage them in a discussion about it.

My purpose in writing this submission is to promote the rights of persons to determine in advance their end of life treatment with a legitimate expectation that their directions will be followed. It is not to make a case for or against euthanasia. However, what follows might serve as a pathway towards building an informed view on euthanasia.

It has proven nigh impossible for previously constituted Parliaments to reach an agreement about the need for reform, let alone what form such change might take. The LIV and AMA are not likely to be drawn into adopting or promoting a particular position on Euthanasia because it would be impossible to say that in doing so they represent the consensus of the views of all their members.

Medical practitioners are guided through the legal framework governing end of life by the philosophical doctrine of "double effect". That is, where an action is taken which has a primary intended effect (usually of pain relief) and a secondary unintended effect (usually of foreshortening a person's life, hastening death).

We became used to dealing with the doctrine of double effect during the abortion debate. The offence then alleged to be committed was procuring an abortion, contrary to s. 65 of the Crimes Act. The Menhennitt ruling³⁶ provided guidance about lawful actions to terminate a pregnancy that concerned necessity and proportion.

The ruling gave medical practitioners and others guidance about how to regulate their conduct. In reality, medical practitioners ensured that their record-keeping reflected the circumstances of a life threatening risk of continuing the pregnancy, for example, a high risk of suicide by the mother.

In the decades after the ruling, thousands of terminations took place in such numbers which if they truly represented numbers of women enduring life- threatening pregnancies, or suffering such deep depression, would have represented a crisis in public health. Some might have described it as a medico-legal fiction. It proved to be a workable guideline, even though the philosophical basis underlying it was later rejected and the law repealed.

Turning now to the current issue, the legal framework to be navigated by medical practitioners in relation to euthanasia is the law prohibiting murder, not procuring an abortion.

It is established and well understood that it is unlawful to cause the death of another by an act which causes that death, while at the same time intending that the act should cause the death, or with the knowledge or belief that death would result, and to do so amounts to murder. (It is also possible to commit a murder when the intention is to commit a violent felony that causes the death of another.) The intention, the action, the death and a clear chain of causation must all be proven beyond a reasonable doubt.

³⁶ R v Davidson (1969) VR 667

Intention

Enter the doctrine of double effect again. In Victorian hospitals, lives are foreshortened by the administration of pain relief for the purest of motives that is, the relief of suffering. This may be done with or without the intention of hastening death.

If the death of a person is caused by such an action, accompanied by an intention to relieve pain then it is claimed that the secondary consequence of hastening death was not intended even if it might have been predictable.

However, where there is an intention to cause or hasten the death of the patient, it appears that it would be very easy to do in a medical setting. Pain relief medication has a secondary effect of depressing the respiratory system. It can be administered by an apparatus where the dosage is controlled by a variable dial. It is a relatively simply matter to “dial-down” and then “dial-up” the dosage of the medication to a lethal dose.

If it is easy to do, how prevalent is it that Victorian lives are foreshortened in circumstances where the intention of hastening death is an equal or greater intention than the intention to relieve pain? That question will only be answered by medical practitioners giving evidence to this enquiry and being prepared to give their honest estimation, anonymously if necessary.

As to the philosophical basis of the doctrine of double effect this enquiry can seek submissions from philosophers and ethicists as to the ethical basis for the continued adoption of the doctrine.

If we are to continue to adopt this differential approach the Parliament might choose to amend the Crimes Act or other legislation by the insertion of a “sole purpose” or “dominant purpose” test as can be found in other legislation, some of which prescribes offences and establishes criminal penalties.

Causation

The above discussion concerns the issue of intention to cause or hasten death where it is not disputed that the action directly caused the death. By contrast, refusal or withdrawal of treatment is not considered to be an action which causes death, but rather the death is caused by the underlying condition.

A person has a right to refuse treatment, and to indicate their decision in advance to refuse treatment as an exercise of their bodily integrity.

A medical practitioner may separately make a decision to withdraw treatment (or not to offer treatment) when it is considered ineffective. The decision to withdraw is usually a matter of professional judgement by the treating medical practitioner and does not require the consent or approval of the patient or the family. The decision is usually made with the knowledge that death will result due to the operation of the underlying condition.

It is asserted in legal academic circles that a medical practitioner is not obliged to offer any form of treatment if it is considered not to be effective and this decision whether or not to offer is usually characterised in classical contractual terms of offer and acceptance.

Death certificates commonly list all the conditions the deceased suffered at the time of their death, but do not always specify which of the medical conditions caused the death.

The circumstances of a decision to refuse treatment or to unilaterally withdraw treatment resulting in death may be interpreted by family members as an 'action' which causes death and which is worthy of censure. The Parliament may be informed by the extent of this conflict by seeking honest and if necessary anonymous answers from the medical profession and the public.

If we are to continue to permit medical practitioners to obey the pre-expressed directions of patients to refuse treatment, or to make unilateral decisions to withdraw ineffective treatment or to simply not offer ineffective treatment, the Parliament may choose to adopt a legislative requirement for evidencing those pre-expressed directions and for recording that exercise of medical judgement.

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