Inquiry into End of Life Choices

Submission to the Standing Committee on Legal and Social Issues (Legislation and References)

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Recommendations

Education for medical practitioners

**Recommendation 1.** The Victorian government should urge the Australian Medical Council to critically examine the adequacy of compulsory teaching in Australian medical schools about substitute medical consent.

**Recommendation 2.** The Victorian government should require the Postgraduate Medical Council of Victoria to ensure that medical interns are adequately trained on the subject of substitute medical consent.

Definition of medical treatment and health decision maker

**Recommendation 3.** The Victorian government should adopt the following recommendations made by the Victorian Law Reform Commission in its Guardianship Final Report:*

<table>
<thead>
<tr>
<th>Automatic appointment of a health decision maker</th>
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<tr>
<td><strong>204.</strong> New guardianship legislation should provide for the automatic (statutory) appointment of a substitute decision maker—to be known as a health decision maker—to make medical treatment decisions for a person who lacks the capacity to make their own decisions and who does not have an [existing personally-appointed or VCAT-appointed substitute decision maker in place] with the power to make those decisions for them.</td>
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**Significant and routine medical procedures**

**211.** New guardianship legislation should define ‘significant treatment’ as a medical or dental procedure, other than an emergency procedure or a special procedure that:

(a) involves a significant degree of bodily invasion, or
(b) involves a significant risk to the patient, or
(c) is likely to have significantly negative or unpleasant side effects for the patient, or
(d) is likely to result in significant distress for the patient, and
(e) would ordinarily cause a medical practitioner to seek specific consent from a person with capacity before proceeding.

**Definition of routine treatment**

**213.** New guardianship legislation should define ‘routine treatment’ as a medical or dental procedure that is not an ‘emergency procedure’, a ‘significant procedure’ or a ‘special procedure’.
Consent to significant medical treatment

214. New guardianship legislation should provide that if a person is unable to consent to ‘significant treatment’, the registered practitioner may undertake that procedure only with the consent of:

(a) a personal guardian with the power to make decisions about the matter, or if there is no such person or that person cannot be reasonably located

(b) a health decision maker, or if there is no such person or that person cannot be reasonably located

(c) the Public Advocate.

Consent to routine medical treatment

215. New guardianship legislation should provide that if a person is unable to consent to a ‘routine procedure’, the registered practitioner may undertake that procedure:

(a) with the consent of a personal guardian with the power to make decisions about the matter, or if there is no such person or that person cannot be reasonably located

(b) with the consent of a health decision maker, or if there is no such person or that person cannot be reasonably located

(c) in the absence of consent if the registered practitioner has taken reasonable steps to locate a personal guardian or a health decision maker and the registered practitioner believes the treatment will promote the personal and social wellbeing of the person concerned.

*If the following recommendations were adopted, OPA would want the specific wording of the legislative provisions to reflect current medical practice, according to which ‘treatment’ can often involve a series of ‘procedures’.

Substitute medical consent

The Medical Treatment Act 1988, the Guardianship and Administration Act 1986 and the Powers of Attorney Act 2014 should be amended as follows:

Recommendation 4. A specific provision should be enacted in the Medical Treatment Act 1988 stating that clinicians are under no obligation to offer or to provide medical treatment that is either futile or unduly burdensome to the patient.

Recommendation 5. The Powers of Attorney Act 2014 should be amended so that principals are able specifically to empower attorneys for ‘personal matters’ to refuse medical treatment, including where this refusal is likely to result in death. This power would not be contained in the routine powers of an attorney for personal matters, but would need to be the subject of a specific statement by the principal in the enduring power of attorney.
Recommendation 6. The Guardianship and Administration Act 1986 should be amended so that statutory health decision makers (currently ‘persons responsible’) are empowered to consent to, and to refuse, medical treatment on behalf of patients. However, the Guardianship and Administration Act 1986 should specify that statutory health decision makers are not able to refuse medical treatment in situations where this is likely to lead to death.

Recommendation 7. The Medical Treatment Act 1988 should be amended to provide that, aside from the patient themselves, only attorneys (appointed under the Powers of Attorney Act 2014) with power to refuse medical treatment, and guardians appointed by the Victorian Civil and Administrative Tribunal with health decision making powers, are empowered to refuse medical treatment where such refusal is likely to lead to death.

The basis on which such refusal of treatment can be made should mirror the current Medical Treatment Act 1988 provision to this effect (section 5B(2)). Such refusal of treatment should only be possible where ‘the medical treatment would cause unreasonable distress to the patient’ or where ‘there are reasonable grounds for believing that the patient, if competent, and after giving serious consideration to his or her health and well-being, would consider that the medical treatment is unwarranted.’

Personal wishes

Recommendation 8. The Victorian government should adopt the following recommendations made by the Victorian Law Reform Commission in its Guardianship Final Report:

‘Instructional directives’

134. An instructional directive should be able to provide:

(a) binding instructions or advisory instructions about health matters

(b) advisory instructions about personal and lifestyle matters, other than health matters and financial matters, that should be taken into account and followed where reasonably possible but should not be legally binding.

Replace ‘refusal of treatment certificate’ with ‘instructional health care directive’

135. The ability to make refusal of treatment certificates under the Medical Treatment Act 1988 (Vic) should be replaced with a statutory scheme that provides for binding instructional directives about health care to be made in a broader range of circumstances. To reflect these changes, the name ‘refusal of treatment certificate’ should be replaced with ‘instructional health care directive’.
Scope of instructional health care directives

138. An instructional health care directive should allow the principal to:

(a) give directions about health care and medical treatment for their future health care

(b) give information about their directions

(c) provide information about exercising the power.

151. A direction in an instructional health care directive does not operate if the maker would not have intended it to apply in the circumstances that have arisen. This occurs if one of the following applies:

(a) Circumstances, including advances in medical science, have changed since the completion of the instructional health care directive to the extent that the principal, if they had known of the change in circumstances, would have considered that the terms of the direction are inappropriate.

(b) The instructional health care directive is uncertain.

(c) There is persuasive evidence to suggest that the instructional health care directive is based on incorrect information or assumptions.
About the Office of the Public Advocate

The Victorian Office of the Public Advocate (OPA) is an independent statutory office empowered with a broad range of functions under the Guardianship and Administration Act 1986 (Vic).1 OPA works to protect and promote the rights, interests and dignity of people with disabilities in Victoria.2

OPA provides a number of services to work towards these goals, including the provision of advocacy, investigation and guardianship services to people with cognitive impairments or mental illness. In the last financial year, 2013-14, OPA was involved in 1,519 guardianship matters, 362 investigations and 365 cases requiring advocacy.

The Public Advocate’s functions can include acting as a guardian for an adult when appointed by the Victorian Civil and Administrative Tribunal (VCAT) with the power to refuse life-sustaining treatment.3 The Public Advocate was the plaintiff in the landmark BWV case, where the artificial provision of food and water was ruled to amount to ‘medical treatment’ which the guardian could refuse.4

OPA has a number of other relevant roles in relation to medical treatment decisions and legislative requirements, all of which will be discussed in this submission.

OPA is the coordinating body of five volunteer programs including the Community Visitors Program, the Community Guardian Program and the Independent Third Person Program.5 OPA provides support to over 900 volunteers.

Under the Guardianship and Administration Act, OPA is required to arrange, coordinate and promote informed public awareness and understanding through the dissemination of information about these substitute decision-making arrangements.

Advice and Education

OPA is a key expert and educator on substitute decision-making arrangements. This includes guardianship, administration, powers of attorney and medical decision making. OPA has developed a comprehensive education strategy drawing on our extensive experience gained from the work of our different program areas. OPA is routinely confronted with members of the public and the health services system who do not know the law in this area.

OPA provides an Advice Service which offers information and advice on a diverse range of topics affecting people with disability. The heavily utilised telephone advice line last financial year answered 13,795 calls, a substantial proportion of which relate to guardianship and administration (35 percent), and enduring powers of attorney and guardianship (25 percent). Calls relating to medical consent and end of life decision making were the other significant category of calls (11 percent). Many of the issues raised by people calling the Advice Service are often complex matters requiring a high level of sensitivity, expertise and sound judgment.

OPA coordinates a Community Education Program where staff address both professional and community audiences across Victoria on a range of topics including the role of OPA, guardianship and administration, enduring powers of attorney and medical decision making.

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1 Guardianship and Administration Act 1986 (Vic) pt 3.
2 Ibid.
3 The Medical Treatment Act provides that a guardian appointed by way of an “appropriate order” under the Guardianship and Administration Act may refuse treatment. This includes a VCAT appointed plenary guardian and a VCAT appointed limited guardian with power to make decisions about medical treatment: Medical Treatment Act (Vic) s 5A(1)(b).
4 See Re BWV; Ex parte Gardner (2003) 7 VR 487.
5 Other volunteer programs include the Supported Decision-Making Pilot Program and the Corrections Independent Support Officers’ Program.
Delivery of community education is consistent with the range of topics responded to by the Advice Service. During 2013-2014, the program delivered 180 presentations to a total audience of 7,023 people. The largest audience group for presentations was health and community professionals. The remaining presentations were to general public audiences, tertiary students, and legal and justice services. In relation to planning for the future, OPA’s objective is to provide useful resources for people considering planning for the future and the avenues available, and for clinicians wishing to clarify legal issues.

Presentations and publications on the topic of end of life decision making and planning for the future most often provide an overview of the area. When delivering face-to-face community education sessions, and in our online publications, OPA asks that people call our Advice Service for assistance to work through the various complex issues. The complexity arises from the overlapping legislation in this area, and the confusion is evident within all audiences, including the medical community. It is difficult for OPA to deliver simple, accurate information about the law in a way that is accessible to the community, and to medical practitioners.

Online Presence

OPA’s website is heavily and increasingly being utilised by members of the public, with hundreds of copies of various fact sheets and forms being downloaded each month. During 2013-2014 OPA’s website attracted 129,474 website users compared to 97,820 the previous year. The most visited pages contained information on powers of attorney and associated fact sheets and forms, followed by pages with information about administration and guardianship, ‘Take Control’ (discussed further below) and publications orders, and medical consent.

OPA produces a variety of well-utilised online and hardcopy publications about guardianship, administration, powers of attorney and medical decision making. OPA’s new website contains more accessible and user-tested information about those popular topics.

The new Powers of Attorney Act 2014

OPA has taken on a lead role in developing community education in relation to the new Powers of Attorney Act 2014 (Vic) which commences on 1 September 2015.

In the new Powers of Attorney Act, the Enduring Power of Attorney (Financial) and the Enduring Power of Guardianship have been replaced by a new Enduring Power of Attorney that will enable the appointment, on one form, of an 'attorney for personal matters' and/or an 'attorney for financial matters', though powers can be limited to one of these areas. An attorney for personal matters can include health care matters, including matters provided for in Part 4A of the Guardianship and Administration Act. The Act does not affect the Enduring Power of Attorney (Medical Treatment), an appointment which is particularly relevant to end of life decision making. The Powers of Attorney Act also provides for the appointment of a supportive attorney, which is discussed later in this submission.

Updated information about the Powers of Attorney Act, the Mental Health Act 2014 (Vic) and more detailed and useful resources about planning for the future are offered on the new website. The popular ‘Take Control’ kit, available in hardcopy and on OPA’s website, has undergone its twelfth edition update and will be released to coincide with commencement of the Powers of Attorney Act.

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7 Ibid.
8 Ibid 29.
Publications

‘Take Control’ is a self-help kit that aims to help people make enduring powers of attorney to plan for their future.\textsuperscript{9} It provides information about Enduring Power of Attorney (Financial and/or Personal) and Enduring Power of Attorney (Medical Treatment). It has step-by-step instructions and a complete set of all the forms required to make those appointments. ‘Take Control’ is one of the most popular publications distributed by OPA and by Victoria Legal Aid (VLA).

In 2013-2014 VLA distributed 39,579 copies of ‘Take Control.’ The booklet, also available to download from VLA’s website, was downloaded in PDF format 1,658 times, and 558 time in Word format. In 2014, OPA distributed approximately 5,000 copies of ‘Take Control.’ The number of visits to the OPA ‘Take Control’ webpage in 2013-2014 was 12,476 however the number of downloads of the publication cannot be accurately determined. OPA’s new website is equipped with the capacity to track the number of downloads to establish the exposure of ‘Take Control’ to the community.

The website will also host an updated ‘You Decide Who Decides’ online program to reflect those changes contained in the Powers of Attorney Act. ‘You Decide Who Decides’ was developed to help people to choose a power of attorney. Pre-September 2015 changes, OPA found that many people choose one person to be their Enduring Attorney (Financial), and a different person to be their Enduring Guardian, who may also be the person appointed as the Agent under an Enduring Attorney (Medical Treatment). The objective of this program is to navigate the complexity of the law and the values underlying it by asking questions to assist the person to appoint the appropriate person as their substitute decision maker in the event that they lose capacity.\textsuperscript{10}

OPA has also produced ‘Side by Side: A guide to appointing Supportive Attorneys’, which includes the appointment form, available on OPA’s website and in hardcopy.

OPA’s other relevant online and hardcopy publications will be updated to reflect the law as at 1 September 2015.

Advance Care Planning Strategy Implementation Advisory Group

OPA chairs the Advance Care Planning Strategy Implementation Advisory Group, and played an advisory role in the development of the then Department of Health’s \textit{Advance Care Planning: Have the Conversation: A strategy for Victorian health services 2014-2018}. The ‘Have the Conversation’ strategy, launched in 2014, aims to increase opportunities for people to develop advance care plans and for these to be activated, and implemented, by health services. The strategy sets key measures in four priority action areas:

1. establishing robust systems so that health services can have the conversation
2. ensuring health services have an evidence-based and quality approach to have the conversation
3. increasing health service capability to have the conversation
4. enabling the person a health service is caring for to have the conversation.\textsuperscript{11}


\textsuperscript{10} As of 1 September 2015, Enduring Powers of Attorney (Financial and/or Personal) can commence upon completion of the appointment form (this was possible in relation to the Enduring Power of Attorney (Financial) under the \textit{Instruments Act 1958} (Vic)).

Other relevant inquiries

As the Committee would be aware, two recent inquiries are relevant to this current inquiry. In 2010, the Victorian Parliament Law Reform Committee completed its Inquiry into Powers of Attorney. It considered the Enduring Power of Guardianship under the Guardianship and Administration Act, although the Enduring Power of Attorney (Medical Treatment) under the Medical Treatment Act 1988 (Vic) was not included in the inquiry’s terms of reference.12

The Second Reading Speech to the Powers of Attorney Bill 2014 noted:

The bill implements a majority of the recommendations made in the report by the Victorian Parliament Law Reform Committee (VPLRC) in its Inquiry into Powers of Attorney, which was tabled in Parliament in August 2010. The bill also reflects a number of recommendations from the Victorian Law Reform Commission in its Guardianship -- Final Report, which was tabled in Parliament in April 2012.13

In 2012 the Victorian Law Reform Commission (VLRC) completed a review on the desirability of changes to the Guardianship and Administration Act.

The terms of reference directed the VLRC to:

consider the relationship and: the appropriateness of the current requirements for and criteria pertaining to, the treatment of a represented person under the Act, including a consideration of the existing provisions dealing with medical research, non-medical research, medical and other treatment, the appropriateness of the existing “person responsible” model in ... the Act and a consideration of any area of overlap between the operation of the Act and the Medical Treatment Act 1988 ...

Issues relating to end of life decision making other than those currently dealt with by the Medical Treatment Act were expressly excluded from the VLRC’s review.14

Need for reform

The law concerning substitute medical consent is complex, confusing and is not well understood by medical professionals, much less the general public.15

This confusion is caused in part simply because of the range of substitute decision-making laws that exist and the interrelated elements of the relevant legislation in this area: the Guardianship and Administration Act; the Medical Treatment Act and the Mental Health Act and, from 1 September 2015, the Powers of Attorney Act. These pieces of legislation provide a variety of ways by which decisions can be made for individuals upon them losing capacity.

Recent debate about what constitutes futile and unduly burdensome treatment and practice around Not For Resuscitation orders engages with assessing matters other than solely what is medically indicated. This is both problematic and progressive.

Confusion abounds regarding the legal status of common law advance directives and previous recommended reform on this matter should be implemented.

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13 Victoria, Parliamentary Debates, Legislative Assembly, 26 June 2014, 2392 (Rob Hulls MP, Attorney-General).
15 Indeed, in its final report the Victorian Law Reform Commission stated that ‘There appears to be a widespread lack of understanding about how the law regulates medical treatment for people who lack capacity to make their own decisions, perhaps because of its complexity’. Victorian Law Reform Commission, Guardianship Final report (2012) 276.
While reform is needed to clarify the law that exists, many initiatives are currently being undertaken in Victoria and at the national level to encourage people to think and talk about planning for the future. The ‘Have the Conversation’ strategy, as well as OPA’s various publications, discussed above, illustrate that significant practice reforms can occur without legislative changes. At the same time the existence of clear laws is needed in this area to ensure that planning for the future is practical, accessible and easily applied.

People want certainty that their wishes will be respected at their end of life, preserving their autonomy. People also want certainty that their pain will be managed appropriately, and that they will die comfortably.

Medical practitioners have an important role to play in assisting a person to exercise their end of life preferences. There is a critical need to improve doctor’s knowledge of the law and, to equip medical practitioners with accurate and clear information to assist people to conduct end of life discussions and to exercise their preferences at their end of life. Further clarity in this area will likely result in people having a greater say in end of life decision making.

An important part of creating a climate of reform in this area requires closer cooperation between parties; persons, families, medical practitioners, healthcare professionals, legal practitioners, and policy and law makers.

**About this submission**

OPA welcomes the opportunity to make a submission to the End of Life Choices inquiry.

This submission will address all three terms of reference. This submission will draw from our extensive experience in educating the community about substitute decision making, powers of attorney and planning for the future. The practical and anecdotal experience gathered from OPA’s various program areas will also inform this submission.

OPA’s objectives are:

- to promote the ability of individuals to plan for their future, and
- to better protect and promote the rights of persons who require a substitute decision maker to make important medical treatment decisions on their behalf when they do not have decision-making capacity.

This submission is divided into four parts to meet these objectives. The recommendations contained in this submission seek to minimise legal complexities and minimise practice confusion.

Part One of the submission deals with frameworks, philosophies and practices. The value of autonomy drives OPA’s exploration of the contractual and consensus decision making models that can operate where a substitute decision is required. Determining the matter of decision making, and the extent to which a decision can be driven by a bigger picture, or a medical matter, is also explored. This part concludes with a discussion about the process of advance care planning – what the process requires, and what can happen to a person’s autonomy when advance care planning, with its many elements, does not occur.

Part Two discusses current medical practices that exist to assist a person to manage their end of life preferences. An examination of the complex valuation of futile and burdensome treatment and confusion about not for resuscitation orders precedes a discussion about current planning for the future initiatives. Current research identifies gaps in medical practitioners’ knowledge of the law and uncertainty about their role in end of life discussions. We discuss opportunities for progress within current medical practice, and make recommendations to minimise practice confusion, requiring concerted professional education on laws concerning substitute medical consent. OPA refers to recommendations made by the VLRC and identifies these in our own recommendations.
Part Three discusses the current legislative framework for substitute medical consent, and identifies the key complexities in the application of the law. In this part, recommendations to minimise legal complexities seek to reduce confusion caused by overlapping guardianship and medical treatment laws and to provide clear legislative authority for advance directives (as recommended by the VLRC in its Guardianship Final Report). Part Four is the conclusion to the submission.

OPA is encouraged to see that this current inquiry engages with the matter of end of life decision making in what is a delicate and complex policy and legal environment. The recommendations included herein intend to contribute to this discussion.

1 Part One Frameworks, philosophies and practices

1.1 Autonomy

The overarching narrative to this submission is autonomy and personal choice. A person’s fundamental right to autonomy and self-determination is particularly pertinent in relation to exercising one’s end of life choices.

These rights are enshrined in the Convention on the Rights of Persons with Disabilities (the Convention) as the most comprehensive international human rights statement on the rights of people with disability. OPA notes that as a party to the Convention, Australia is obliged to implement its provisions in domestic law.

A key principle of the Convention is respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons. In the Convention, guarantees of freedom rights co-exist with guarantees of freedom from exploitation, violence and abuse. Recommended reform in the area of substitute decision making has engaged with these competing fundamental values. This submission focuses particularly on respecting a person’s autonomy and freedom of choice.

1.2 Contractual and consensus decision-making models

OPA has a great deal of experience of making health care decisions for other people. It is apparent that people and professions approach such decision making from different worldviews or paradigms, though they may not be aware that this is the case. In this section we will explore these different paradigms and the implications of this for practice.

The two key paradigms we identify are –

1. The contractual paradigm that locates authority and decision-making in the individual patient or their representative.
2. The consensus paradigm that locates authority and decision making in building a consensus of the key people being the patient, the patient’s family and close friends and the treating team.

17 Vienna Convention on the Law of Treaties, opened for signature 23 May 1969, 1155 UNTS 331, art 26 (entered into force 27 January 1980) ‘Every treaty in force is binding upon the parties to it and must be performed by them in good faith’.
20 OPA’s Advocate Guardian Program often engages in matters involving end of life decision making. OPA has also been involved in a number of high profile cases (see, for eg, Korp (Guardianship) [2005] VCAT 779; Re BWV; Ex parte Gardner (2003) 7 VR 487; Re Baby D (No 2) [2011] FamCA 176. Where OPA is involved as an Advocate Guardian, often the represented person has a cognitive impairment to the extent that it is difficult to ascertain their wishes, past or current, in relation to their end of life treatment preferences.
In addition to the exploration of the contractual and consensus paradigms provided below, each paradigm is referred to throughout the submission where relevant.

1.2.1 The contractual paradigm

This paradigm, which sees an ‘offer’ of medical treatment being ‘accepted’ or ‘not accepted’ by a patient or their representative, is underpinned with strong moral and legal force. Its moral basis, personal autonomy, is the grounded in respect for each person’s dignity. The Universal Declaration of Human Rights has as its first right that “All human beings are born free and equal in dignity and rights”. The Victorian Charter of Human Rights and Responsibilities Act 2006 translates this value into these words regarding medical practice –

A person must not be … subjected to medical or scientific experimentation or treatment without his or her full, free and informed consent.21

The legal basis of the paradigm is found in the civil tort law and the criminal law relating to assault. The paradigm is predicated on a person’s retaining the ability to make reasonable decisions about their health care. When a person is no longer able to make reasonable judgments and there is need for a substitute decision maker, the paradigm still operates but in a modified form.

- The paradigm is modified in that the person is no longer acting autonomously and is subject to the decisions of another. If that other is the person responsible under the Guardianship and Administration Act, that person must not only have regard to the patient’s wishes but also to the wishes of family members.22

- In Victoria, the paradigm subsists in a number of ways –
  - The person may appoint an agent under the Medical Treatment Act, an enduring guardian or from 1 September 2015 an attorney for personal matters, to make decisions for them.23 Further, an agent may refuse medical treatment where the agent considers “there are reasonable grounds for believing that the patient, if competent, and after given serious consideration to his or her health and well-being, would consider that the treatment is unwarranted.”24
  - If the person relies on the statutory scheme in Part 4A of the Guardianship and Administration Act, the person most likely to be the person responsible for medical treatment will be a partner or family member who, it is hoped, is familiar with the wishes, needs and aspirations of the patient. Section 38 of the Guardianship and Administration Act sets out how such decisions are to be made and this includes taking into account the person’s wishes. Section 4 of that Act requires that a person’s wishes be given effect to “wherever possible.”
  - If there is no such person and VCAT appoints a guardian to make decisions about medical treatment, the guardian must act in the patient’s best interests and in doing so
    - is to consult with and to take into account the person’s wishes and to give effect to a person’s wishes wherever possible25
    - to encourage and assist the person to make reasonable judgements26
    - by means least restrictive of the patient’s freedom of decision and action as is possible in the circumstances.27

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21 Charter of Human Rights and Responsibilities Act 2006 (Vic) s 10(c).
22 Guardianship and Administration Act 1986 (Vic) s 38(1)(b).
23 Medical Treatment Act 1988 (Vic) s 5A.
24 Ibid s 5B(2)(b).
25 Guardianship and Administration Act 1986 (Vic) ss 28(2)(e), s38(1)(a), s4(2)(c).
26 Ibid s 28(2)(c).
27 Ibid s 4(2)(a).
It is sometimes alleged that because the person responsible or a guardian is required to act in a patient’s best interests that this undermines the operation of this paradigm. However, this misrepresents the construction of “best interests” in the Guardianship and Administration Act. “Best interests” is a concept constructed to preserve a person’s autonomy but within limits in order to protect a vulnerable person.

An advantage of this paradigm is that it is clear who has decision-making authority – the patient or their representative. It is this person who can sign documents articulating decisions and responsibilities. It is this person who is accountable for the outcome of care.

1.2.2 The consensus paradigm

The NSW Health ‘Guidelines on end of life care and decision making’ helpfully describes the rationale and approach of the consensus paradigm.

NSW Health places a high priority on health professionals working collaboratively with each other, and with patients and their families throughout all phases of end-of-life care. Such care is dependent on open and early communication in an environment of trust. These guidelines set out a process for reaching end-of-life decisions. This process promotes such communication, compassionate and appropriate treatment decisions, fairness, and seeks to safeguard both patients and health professionals.

And …

A consensus building approach to end-of-life decision-making that considers the patient’s best interests as paramount is recommended where the patient lacks the capacity to determine his or her own care. This collaborative process aims to draw on the family and treating team’s knowledge and understanding of the patient’s personal values and medical condition. A consensus is sought within the treating team, and between the treating team and family about a plan of care that is as consistent with the patient’s wishes and values as possible, and which also supports the family in the degree of involvement it wishes to have.28

The process is led by the clinicians, but it places importance on the involvement of all – treating team, patient and families – in the development of a care plan.

At law, ultimately it is the clinician who is responsible for the outcomes for the patient.29

1.2.3 The consensus paradigm and the contractual paradigm – a process of constructive engagement or misalignment?

In the best of circumstances, the two paradigmatic approaches work well together to bring about the end of life care the patient wanted. This would be the aspiration of people and treating teams who work together in advance care planning processes such as Respecting Patient Choices. However, many, if not most, people do not prepare for their end of life care in this way.

Misalignment of the paradigms does not necessarily lead to conflict, but it does lead to confusion about roles and responsibilities.

29 Ibid 6: “The senior treating clinician is accountable, as leader of the treating team, to the patient, the family, the employing health authority, and ultimately the courts for the process whereby a consensus about end-of-life decisions is sought, and the reasonableness of the planned course of action.”
For example, a person is admitted to an aged care residential service and they are asked to complete an advance care plan that requires them to consider whether they want to be resuscitated. The aspiration to build a consensus as to resuscitation of the patient is understandably desirable. But in Victoria’s contractual paradigm of decision-making, this would constitute a refusal of treatment. If the patient had capacity to make that decision, that would be within the law. But if the patient lacked that capacity they could not make it. If they had not appointed an agent under the Medical Treatment Act or had a VCAT-appointed guardian with authority to refuse medical treatment, no-one would have legal authority to refuse resuscitation on that patient’s behalf. A doctor could determine that resuscitation would be futile or unduly burdensome treatment for their patient and so made a direction that their patient not be resuscitated.

In this example, what begins as an admirable desire by an accommodation service to build consensus could result in confusion for the patient who lacks capacity about what they can do, confusion for members of the patient’s family about what they can do, and ultimately it would come down to a decision of the treating doctor.

The paradigms may also come into conflict. The main criticism levelled at the consensus model is that power is located in the treating team and that this distorts the end of life experience. The patient is the person to whom treatment or palliation is provided, the patient is the object, no longer the subject, of their autonomous choices. The patient and their family feel disempowered.

This distortion may be exacerbated when clinicians and health service or accommodation providers fear that allowing the person to die as contemplated may breach their duty of care to preserve life. They proceed to treat and so the patient and/or their family feel powerless and frustrated.

Doctor Atul Gawande has argued that in the USA the commodification of medicine may distort the clinicians’ approach to end of life care. If something can be done to keep a person alive, then why not do it? As physicians are uniquely placed to propose treatment, the consensus model could result in patients unnecessarily undergoing treatments that merely prolong their dying.

1.2.4 Conclusion

We have set out these paradigms because it is difficult to understand the planning, decision making and treatment provided to patients at the end of their lives unless one is aware of:

- the law
- the key value of autonomy promoted by our society
- the practice of the health professionals in this area, and
- who has power.

1.3 Decision making about what

The terms of reference to this inquiry require the Committee to inquire into, consider and report on the need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices. The decision may be medical, but the choice may have many other aspects to it.

For example, a decision whether to resuscitate or not to resuscitate may be the focus of deliberation when completing a form on entering a nursing home, but for the resident completing the form, it is often not simply a decision about medical treatment, it is about the cessation of life or the continuation of life and what might that life be like. These types of decisions have many layers.

In this section we explore some of these layers.

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30 It is OPA’s experience that, as a person approaches death, there is often a family member (previously distanced from the patient) who finds this distressing and threatens the service with injunctions, coronial inquiries, guardianship applications, professional misconduct complaints, and so on.
1.3.1 Medical decision making or decisions about life?

Doctor Atul Gawande wrote a book called Being Mortal. Illness, Medicine and What Matters in the End. Gawande is an American doctor and much of the book explores how he is challenged in his understanding of his role as a doctor as a person who is there to extend life when caring for someone who is dying. He quotes Sarah Creed, a nurse at a hospice to explore this:

The difference between standard medical care and hospice is not the difference between treating and doing nothing, she explained. In ordinary medicine, the goal is to extend life. We'll sacrifice the quality of your existence now – by performing surgery, providing chemotherapy, put you in intensive care – for the chance of gaining time later. Hospice deploys nurses, doctors, chaplains and social workers to help people with a fatal illness have the fullest possible lives right now – much as nursing home reforms deploy staff to help people with severe disabilities. In terminal illness that means focusing on objectives like freedom from pain and discomfort, or maintaining mental awareness for as long as feasible, or getting out with family once in a while.31

For Gawande as doctor, he is there to fix things, but sometimes things can’t be fixed. Gawande looks at what do people want during the final phase of life and he tells many stories of people he has met and some he has loved, such as his father. He writes compellingly about this time of life:

The battle of being mortal is the battle to maintain the integrity of one’s life – to avoid becoming so diminished or dissipated or subjugated that who you are becomes disconnected from who you were or who you want to be. Sickness and old age make the struggle hard enough. The professionals and institutions we turn to should not make it worse.32

Gawande also looks at the lives we live when we are growing old and frail, but are not in the terminal phase of a terminal illness. His book is replete with stories of people who seek to maintain authorship of their lives as they become dependent: often they don’t because of others, sometimes they do because of others. For example, in relating experiences of nursing homes, lives of “boredom, loneliness and helplessness” are transformed when others introduce dogs, cats and birds. In some stories, it is connection with others, or control over their lives, or the living out of what one wants to do, that keeps people going.

At various times people in these stories make decisions about treatment of a medical problem, but this treatment is not an end in itself, the amelioration of the condition is not an end in itself, these are instruments to achieve something else for the person.

Doctor Karen Hitchcock, a Melbourne physician writing in March Quarterly Essay this year, relates the story of Fred, a man she met in hospital who had “quite severe heart failure but still managed at home independently”. Fred thought himself to be a nuisance and wanted to go to a hospice and to die. After listening to Fred, Hitchcock advised him he was not a nuisance, that he should get another dog and if Fred died first she would find someone to care for the dog. Hitchcock says -

I called him two weeks after he [Fred] arrived home to see how he was and to discuss with him his wish not to come back to hospital. He was exuberant on the phone. A dog breeder had given him a retired show dog under the proviso that should Fred ever become unable to care for her, it would be returned to them. “Can you believe that?” he said. “The one thing I was worried about, and they wanted that too!”33

On Fred’s wish not to come back to hospital, Fred said “Of course I want to come back if I get sick. I get silly when I’m sick. I hate everything. I say silly things.”34

32 Ibid 141.
34 Ibid.
One wonders if Fred had not had something to live for whether he would have chosen to die. If a person’s life is miserable, might they be more inclined to make medical treatment decisions to bring life to an end? If life holds out some promise, some goal, might the person make different medical treatment decisions?

The quality of our lives is relevant to the decisions we make about our medical treatment.

1.3.2 How is this captured in our current law

At common law a competent person is able to make medical treatment decisions that take into account the quality of the life they want to live. This is the legal basis for making advance directives and advance care plans that set out a person’s wishes. In 1988 the Parliament passed the Medical Treatment Act that codified a process of making an advance directive through the making of a “refusal of treatment certificate.”

The common law has not allowed others to make such decisions for the person. The Medical Treatment Act does allow this. The Medical Treatment Act permits a person to appoint a medical agent who can consent to or refuse medical treatment for them. The grounds for refusing treatment are set out in section 5B(2):

(a) the medical treatment would cause unreasonable distress to the patient; or

(b) there are reasonable grounds for believing that the patient, if competent, and after giving serious consideration to his or her health and well-being, would consider that the medical treatment is unwarranted.

The first ground is similar to the ground a doctor has for not offering treatment where the proposed treatment would be unduly burdensome.

The second ground enables the agent to refuse treatment that may take into account the principal’s quality of life. The agent’s task is onerous. It requires them to be so familiar with the person that they can establish what the patient would consider unwarranted.

This provision was controversial when introduced to the Act. That it could include considerations about the quality of a person’s life was hotly debated. Robert Clark, later to become the Attorney General, expressed his reservations in these terms:

If one looks at the face of those words, the test laid down in proposed section 5B can be satisfied simply by the agent or guardian believing that the patient would rather be dead. If the agent or guardian believes the patient would rather be dead, he satisfies the test of there being reasonable grounds for believing the patient would consider the treatment was unwarranted and, accordingly, the agent or guardian could refuse treatment under proposed section 5B with the intention of bringing about the death of the patient because the criteria laid down in proposed section 5B have been met.

35 In Victoria, Part 4A of the Guardianship and Administration Act 1986 may affect the operation of an advance directive when a person loses capacity. Part 4A permits the person responsible to consent to medical treatment for the patient. The person responsible must take into account the patient’s wishes and give effect to those wishes wherever possible, but is ultimately to act in the patient’s best interests. If the person responsible forms the view that treatment that is declined in an advance directive is actually in the best interests of the patient, can the decision of the person responsible to consent to treatment override the direction? No court in Victoria has yet decided this point of law.

36 Medical Treatment Act 1988 (Vic) sch 1.

37 Victoria, Parliamentary Debates, Legislative Assembly, 3 April 1990, 621 (Robert Clark, MP).
It is difficult to know how this provision has operated in practice for agents. However, the Public Advocate has been appointed guardian with such powers on many occasions. In some cases, not all, the Public Advocate has been able to establish reasonable grounds as to what the patient would consider about proposed medical treatment or continuing existing medical treatment (for example PEG feeding). In a conference paper in 2007, the then Public Advocate, Julian Gardner, and Philip Grano presented a paper entitled “Standards of proof in end of life decision-making”. They concluded that, based on the test found in the High Court case of Briginshaw, there was a need for a high degree of probability that the patient would consider treatment unwarranted.

Mr Maclellan, then Shadow Attorney-General, also spoke against the Bill. One criticism was that there was no ability for the principal to express their wishes to their agent.

…there is no provision for a person appointing an agent to indicate the way he or she wishes the agent to exercise the trust given. The ability to write one’s wishes is stylishly absent from the donation of power. One might say that, if one becomes incompetent, one wishes the agent to exercise his or her judgment along certain lines and that the agent should be guided by those views, but that is not included in the Bill.

It is easier to establish to a high degree of probability what the patient would consider unwarranted if there is some record of their wishes.

Advance care planning is very important in this context. Some advance care plans are expressed in terms of outcomes. For example:

If I am acutely ill, unable to communicate responsively with family and friends, and it is reasonably certain that I will not recover, I want to be allowed to die naturally and be cared for with dignity.

Advance care plans may also set out people’s responses to particular treatments. These things help an agent to establish whether the patient would consider the treatment warranted or unwarranted. We discuss this further in the next section.

Karen Hitchcock’s article challenges how we go about determining a person’s wishes. For example, in her story of Fred (raised above), his wishes were coloured by his feeling “a nuisance to everyone/” Her essay is salutary.

OPA has developed a fact sheet to provide guidance to agents, about their various roles and responsibilities, including when refusing medical treatment. In relation to refusing treatment OPA “strongly recommends that agents contact the OPA Advice Service … for more information about this complex matter.”

Later in this paper we will discuss the legal mechanisms in greater detail.

1.4 Process of advance care planning

The process of advance care planning requires three key elements: conversations, appointments of people you trust and documentation of wishes and directions. Programs such as Respecting Patients Choices can assist a person to articulate their horizons – their bigger picture. Where a person does not follow this process it is less likely their end of life preferences will be put into effect.

1.4.1 Conversations

People are vulnerable in situations where others are making decisions for them. The individual values of family members and medical practitioners, and various interpretations of a person’s expressed wishes can be in conflict, particularly in times of crisis. The conversations that accompany making any legal documents and advance care plans are critical to ensuring a person’s end of life choices, and decisions, are respected.

38 Briginshaw v Briginshaw (1938) 60 CLR 336.
39 Victoria, Parliamentary Debates, Legislative Assembly, 3 April 1990, 671 (Robert Macellian, MP).
1.4.2 Appointments of people you trust

Where a person lacks capacity, their ability to ensure self-determination becomes less likely when their wishes are not documented.\(^{40}\) Appointing an attorney under an enduring power of attorney (financial and/or personal) or (medical treatment) provide greater autonomy for many people whose capacity is impaired, because a trusted person is well placed to know and implement the wishes of the person when it becomes necessary for someone else to make decisions.\(^{41}\)

A personal appointment of a substitute decision maker enables an adult with capacity to exercise significantly more autonomy than if an appointment is made by VCAT or if a decision maker is automatically appointed as a person responsible.\(^{42}\) The principle of best interests applies to all substitute decisions. For those persons who do not have capacity, and where they have not made or discussed plans for their future, it is less likely that their end of life choices will be put into effect.

1.4.3 Documentation of wishes, expectations and directions

At the end of life, what is clear is that a person’s wishes, expectations and directions will be best served by being prepared. Presently, this includes preparing an advance care plan, in the form of the Respecting Patient’s Choices Program, for example, and completing an advance directive in the form of a refusal of treatment certificate.

For people with cognitive impairment a number of barriers exist. The opportunity for a person with cognitive impairment to legally document their wishes in the form of an advance directive is unclear. The opportunity to appoint a supportive attorney under the Powers of Attorney Act 2014, when it commences on 1 September 2015, lends weight to this discussion. Supportive attorney appointments are designed to promote the rights of people with disability.

A person who makes a supportive attorney appointment gives power to the person they appoint as their supportive attorney to: access information about them from organisations (such as hospitals, banks and utility provides); communicate with organisations; communicate their decisions; and to give effect to their decisions (other than significant financial transactions). A supportive attorney can assist a person to make decisions around personal matters, which includes health care matters, and other matters.

The Second Reading Speech to the Powers of Attorney Bill 2014 noted:

> The provisions of the bill enabling a supportive attorney appointment are designed to support persons with impaired decision-making capacity to make and give effect to their own decisions. The bill recognises that a person has decision-making capacity if he or she can make a decision with appropriate support. The appointment is intended to promote the autonomy and dignity of people who have a disability. It will assist people whose ability to make decisions is questioned or impaired because of their disability and allow them to continue to exercise legal capacity. As such, the appointment promotes the right to recognition and equality before the law.\(^{43}\)

It is conceivable that a supportive attorney could assist a person to make an advance directive. OPA notes that the level of support provided by a supportive attorney could better enable a person to make an advance directive; it might make it easier.

OPA has produced ‘Side by Side: A guide to appointing Supportive Attorneys’, which includes the appointment form, available OPA’s website and in hardcopy.

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\(^{41}\) See also Office of the Public Advocate, *Submission to the Victorian Law Reform Commission in Response to the Guardianship Information Paper* (2010).


1.4.4 If you do not plan for your future

Devoid of written wishes prepared in advance, confusion in end of life decision making often results in collaborative discussion in terms of best interests, but not necessarily what the individual would have wanted. This consensus approach to decision making, led by the medical practitioner, can lead to confusion for the patient, who lacks capacity, and for their family members, who may be uncertain about what they can do, and uncertain about what the patient may have wanted.

What is clear is that a person’s desires, wishes or instructions will be best served by being prepared, in particular by appointing a person as an agent under the Medical Treatment Act to make decisions on their behalf. Failing to do this enables a number of alternatives, all of which are designed to bring about the best interest of the patient, but in a forum that is less than ideal compared to them being articulated through another, who has power, to bring about their wishes. On this point, OPA suggests there is considerable scope for improvement.

2 Part Two Current medical practice

Part Two of this submission will address the inquiry’s second term of reference.

This part will deal with current medical practices, including engagement with the matter of what constitutes ‘futile’ or ‘unduly burdensome’ treatment. This is a particularly grey area of practice.

In the consensus model there is a risk that the determination of what constitutes futile and burdensome treatment can stray from being a clinical decision to a decision based on quality of life considerations, leaving room for discrimination and ageism. Where the decision is one of quality of life, it is the decision of the person, their agent, guardian or their representative (including an attorney for personal matters). Where the decision is one of medical treatment, the determination is that of the medical practitioner.

Within the consensus paradigm there is a risk of the person not participating properly, where decisions are being made for the person in an environment of uncertainty.

In the contractual paradigm this is less difficult, because the law is black and white and it creates boundaries. In practice however, we know that many people do not appoint people to make decisions for them in the event they lose capacity. There is a need for the different paradigms to operate harmoniously, respecting the legal and medical characteristics aligned to each.

This part will examine current research showing problems in medical practitioners’ knowledge of the law in relation to substitute consent. Research into medical practitioners’ engagement, and responsibility for, progressing end of life discussions with their patients will also be considered.

Progress in current medical practices, focussing not on clinical practice but other practices, can occur without legislative changes. The recommendations contained in this part seek to minimise practice confusion requiring concerted professional education on laws concerning substitute medical consent.

2.1 Practices

Medical and healthcare professionals play a crucial role in assisting a person to exercise their end of life preferences. OPA’s experience is that the medical community faces difficulties in assisting a person to exercise their preferences. This is due to a variety of factors and in OPA’s view these factors do not relate to lack of care on the part of medical practitioners.
Where a patient presents for treatment, a medical practitioner must consider if it is medically appropriate to offer life-sustaining treatment to an adult. They also need to determine if life-sustaining treatment were to be futile, or where an urgent decision about whether or not to provide life-sustaining treatment is required. Where an urgent decision concerning life-sustaining treatment is required, the medical professional is the legal decision-maker, made possible by the relevant provision in the Guardianship and Administration Act and the common law.  

The role of a medical practitioner in making clinical treatment decisions is the most crucial role when it comes to medical treatment and end of life treatment options. This can often involve highly complex situations and intense disagreement in a time of crisis.

2.1.1 Futile and burdensome treatment

The Medical Board of Australia in its Code of Conduct states that good medical practice in end of life care involves a number of roles for Doctors, including:

... Understanding that you do not have a duty to try to prolong life at all cost. However you do have a duty to know when not to initiate and when to cease attempts at prolonging life, while ensuring that your patients receive appropriate relief from distress.

The Code of Conduct identifies a vital role for doctors in assisting the community to deal with the reality of death and its consequences. This includes facilitating advance care planning and understanding the limits of medicine in prolonging life and recognising when efforts to prolong life may not benefit the patient. There is no duty for a medical practitioner to provide treatment that is not in the best interests of the patient. Treatments that are futile or unduly burdensome are not in a patient’s best interests.

In 2014 the Australian Medical Association (AMA) updated its Position Statement on End of Life Care and Advance Care Planning 2014. The updated Position Statement specifies the primary role of the medical practitioner in end of life care is to:

facilitate the provision of good quality patient-centred care that emphasises continuous, open, informed communication and collaboration between the patient, the health care team, and, where appropriate, the patient’s carers, family members and/or substitute decision-maker.

The updated Position Statement addresses a range of issues relevant to end of life care. One of the most complex areas relates to the assessment of what constitutes futile and burdensome treatment. The updated position in relation to medical futility now recognises the subjective nature of futility; that is, what is futile to the doctor may not be futile to the patient or their substitute decision maker. The AMA notes that this updated position reflects its commitment to respecting patients and supporting them in achieving their goals of care, where possible, at the end of life.

44 Guardianship and Administration Act 1986 (Vic) s 42A.
45 Medical Board of Australia, Good Medical Practice: A Code of Conduct for Doctors in Australia (2014) 7.
46 Ibid.
47 Ibid.
50 In the (now superseded) Position Statement on the Role of the Medical Practitioner in End of Life Care 2007 medical futility was addressed as follows: ‘Medical practitioners are not obliged to give, nor patients to accept, futile or burdensome treatments or those treatments that will not offer a reasonable hope of benefit or enhance quality of life’: Australian Medical Association, Of death and dying – the discussion we must have, 16 September 2014 <https://ama.com.au/ausmed/death-and-dying-%E2%80%93-discussion-we-must-have> accessed 25 July 2015.
OPA acknowledges the shift in the AMA’s position on understanding futile and burdensome as a broader concept than solely a clinical decision. Ascertaining a person’s wishes, or the wishes of those close to them who speak on their behalf, including substitute decision makers, can create an important climate of focus on the individual and their end of life preferences and not solely on treatment.

Following a consensus model of decision making, however, can create confusion where key parties are uncertain as to what they can do. OPA acknowledges, and has experience in, situations where different views of family members can create an environment of dispute, where matters can end up at VCAT and sometimes with the appointment of the Public Advocate as guardian.

In OPA’s experience, what constitutes futile treatment or unduly burdensome treatment is a calculation weighing up the benefits of treatment against its consequences. It is a calculation that is specific to this patient and their circumstances.

There is wide acceptance that assessment of what constitutes futile or unduly burdensome treatment often involves more than assessing what is medically indicated. This often involves a complex amalgam of factors:

- current and likely future medical presentation
- likely success of medical intervention
- some quality of life considerations (for example, pain, psychological elements)
- personality and preferences of the person.

The broad nature of relevant considerations raises questions about who makes this assessment, and with what expertise. It appears that the wider the range of matters that are taken into account in making decisions about whether treatment is futile or unduly burdensome, the less narrowly ‘medical’ those decisions become. On the point of quality of life considerations, Ben White, Lindy Willmott et al argue that awareness of the different legal roles and perspectives of key people will help separate some of the often interwoven medical and quality of life considerations that are involved, enabling persons to name and give weight to relevant considerations and to jettison irrelevant ones.51

The law has been cautious as to defining when medical treatment is determined to be futile or unduly burdensome. It has restricted the calculation to the treatment and the utility of the treatment to the health of the patient and eschewed any evaluation of the quality of the patient’s life.

51 See also Lindy Willmott, Ben White and Malcolm Smith, “Best interests” and withholding and withdrawing life-sustaining treatment from an adult who lacks capacity in the parens patriae jurisdiction', *Journal of Law and Medicine*, 2014, vol. 21, 936.
In the seminal case of Anthony Bland, a young man crushed in the collapse of the Hillsborough stadium in the UK and who was in a permanent vegetative state, Lord Goff wrote:

> But for my part I cannot see that medical treatment is appropriate or requisite simply to prolong a patient’s life, when such treatment has no therapeutic purpose of any kind, as where it is futile because the patient is unconscious and there is no prospect of any improvement in his condition. It is reasonable also that account should be taken of the invasiveness of the treatment and of the indignity to which, as the present case shows, a person has to be subjected if his life is prolonged by artificial means, which must cause considerable distress to his family — a distress which reflects not only their own feelings but their perception of the situation of their relative who is being kept alive. But in the end, in a case such as the present, it is the futility of the treatment which justifies its termination. I do not consider that, in circumstances such as these, a doctor is required to initiate or to continue life-prolonging treatment or care in the best interests of his patient. It follows that no such duty rests upon the respondents, or upon Dr. Howe, in the case of Anthony Bland, whose condition is in reality no more than a living death, and for whom such treatment or care would, in medical terms, be futile. 52

There was discussion of this case in the VCAT decision of BWV. 53 The BWV case involved the appointment of a guardian to refuse medical treatment under the Medical Treatment Act. Nonetheless VCAT’s reasons for its decision touch on this very point:

> We emphasise this point especially: the question is never whether the patient’s life is worthwhile but whether the treatment is worthwhile. 54

2.1.1.1 Consideration of the quality of a person’s life

There is conjecture that one cannot really calculate what is unduly burdensome or futile treatment without having regard to the person’s quality of life.

Whether or not that is so, it is clear from the wording of the Medical Treatment Act that a patient can make decisions about their medical treatment based on their perception of their quality of life. The Medical Treatment Act does this in two ways. It sets out a process by which a person can refuse medical treatment for a current condition. Further, it states that the Act does not affect any right of a person under any other law to refuse medical treatment. In the Bland decision, Lord Goff enunciated such a right at common law:

> it is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so. 55

The Medical Treatment Act was amended to include the right of a patient’s agent to make decisions that could include the quality of a person’s life. Section 5B(2)(b) sets out this ground upon which an agent may refuse medical treatment:

> there are reasonable grounds for believing that the patient, if competent, and after giving serious consideration to his or her health and well-being, would consider that the medical treatment is unwarranted. 56

If there are reasonable grounds for so believing, an agent may refuse the treatment.

52 Airedale National Health Trust v Bland [1993] AC 789 at 869.
53 BWV [2003] VCAT 121.
54 Ibid [21].
56 Medical Treatment Act 1988 (Vic) s 5B(2)(b).
There are several points OPA wishes to make about this exploration of futile and unduly burdensome treatment –

1. When it is a clinician’s decision, calculation is limited in scope to the medical considerations. The calculation does not extend to an evaluation of the person’s quality of life.
2. That the patient, or an agent they have appointed under the Medical Treatment Act, is able to make decisions having regard to quality of life issues.
3. There is value in the consensus paradigm approach to decision-making when it brings together these different authorities to establish the best outcomes for patients.

In Part Three of this submission OPA recommends that a specific provision should be placed in the Medical Treatment Act stating that clinicians are under no obligation to offer or to provide futile or unduly burdensome treatment. Rational for this recommendation is outlined in Part Three.

2.1.1.2 Medical practitioners’ consideration of the quality of a person’s life

Medical practitioners face a more comprehensive position than considering a treatment decision in isolation. In relation to the consideration of whether treatment is unduly burdensome and futile, medical professionals may consider that:

Treatment might be regarded as not worth doing because the chance of it working is too small or because the treatment might work but the resulting quality of life would be poor.
These are not medical assessments, although medical evidence would, of course, assist a decision-maker.57

White and Willmott et al in their article “Best interests” and withholding and withdrawing life-sustaining treatment from an adult who lacks capacity in the parens patriae jurisdiction’ speak of the risk that value judgments where exercised by medical professionals can create. They suggest that medical evidence be examined critically to separate opinion that is based on medical evidence and that which is values-based.58

On this point, White and Willmott et al further suggest that clinicians should be encouraged to recognise that a conclusion about whether a treatment is futile or unduly burdensome can easily stray from being a medical determination into being a value judgment, and that it is important for clinicians to be aware of this distinction.59

The law limits what factors are to be considered when determining if medical treatment is futile. It seems that in practice of medicine it is more difficult.

2.1.1.3 Not for resuscitation

The weighing up of what constitutes futile treatment or unduly burdensome treatment is particularly relevant in relation to “NFR” (not for resuscitation) orders. NFR orders are regarded as decisions by a clinician that resuscitation of the patient is either futile or unduly burdensome. Yet, when elderly, frail or terminally ill people are admitted to the health system, they may be asked to determine for themselves whether they want to be resuscitated. If the person is competent, or has an agent under the Medical Treatment Act, the patient or their agent may make such a decision by signing a refusal of treatment certificate.

However, the consensus model may ‘paper over’ a failure of process: that is, there may be a paper trail of decisions about NFR and like matters, but these papers are not the result of a consultative and informed process. They may be signed by people without authority.

56 Ibid 941.
50 Ibid 939-40.
Not all patients are competent or have agents to participate in discussions to refuse resuscitation and other treatments. Patients without competence or agents are not well placed to make these decisions and entrench the decisions in documents.

Not all patients are entering services where there is a medical practitioner available to determine whether resuscitation is futile or unduly burdensome. Yet these people may be asked to complete a form that determines whether they will be resuscitated or not, have an ambulance called or not, sent to hospital or not. The patient may not be able to complete the form, the form may be completed by a well-meaning but unauthorised person on their behalf.

It is OPA’s experience that patients and their family members are often given a form to fill out when entering aged care facilities. The form may introduce new concepts and posit alternatives never before considered by them. It is not uncommon that there is little or no assistance to complete the form. Many people feel they must complete the form, and staff sometimes react impatiently with those who have not done so.

Aged care facilities often send such forms to OPA for the guardian to complete. Yet the guardian may have no authority to make such decisions for the patient and may not know whether the patient would, after considering their health and well-being, consider resuscitation unwarranted. If the patient has a degenerative condition, it may be too late for the guardian to establish what the patient may consider warranted or unwarranted.

OPA is aware that family members are also frequently asked to determine whether their family member/represented person is NFR, where there is no need for them to do so and where they have no authority to do so. This is inappropriate and unfair to family members who may carry feelings of responsibility and guilt associated with the decision they assume they are being asked to make.

OPA acknowledges the benefit of establishing a person’s wishes about being resuscitated. But the consensus model through which these wishes are established may be seriously flawed. Accordingly the documents drawn up may not reflect a person’s wishes and may lack proper legal authority. There is a need for better training of health care and aged care staff to ensure the person’s autonomy is protected and promoted. Too often the process and documents are designed around the perceptions of the service provider’s legal authority.

2.1.1.4 Discrimination against people with disability and ageism

There are cases where it is patently wrong to make judgments about a person’s quality of life and OPA raises here a concern in relation to the risk of discrimination in treatment options for those people for whom OPA has particular responsibility.

OPA has anecdotal experience of discrimination against people with disability in end of life scenarios. This also relates to treatment of people with disability within the health system more broadly.

On the point of ageism, Hitchcock expresses the view that:

> Age discrimination in medicine is widespread, although often hidden behind benevolent aims: the promotion of patient autonomy, the wise allocation of health resources, the avoidance of what is futile, the primacy of quality of life.\(^{61}\)

\(^{60}\) Only an agent appointed under the *Medical Treatment Act 1988* or a guardian appointed by VCAT with such authority may refuse medical treatment for the patient.

The issue of futility of treatment versus futility of life and the discriminating view that a person with severe impairment has a life not worth living is real. This issue was captured in an important report released by Mencap titled *Death by indifference*, which reported about institutional discrimination within the National Health Service (UK), and pointed to people with a learning disability receiving poor healthcare.62

OPA has also seen cases where the concept of ‘diagnostic overshadowing’ – the phenomenon where symptoms or conditions are wrongly attributed to the person’s primary disability, rather than to a separate medical condition – have been applied. This has been a significant issue within the healthcare system for many years.

OPA has an important safeguarding role where we hold concerns about discrimination against a person with disability.

**Case Study One**

Case Study One describes a matter where an OPA Advocate Guardian held concerns about quality of life judgments being made on the basis of a person's disability, and where subjective medical decisions were apparently being made. The Advocate Guardian advocated for appropriate treatment to be provided to the person and requested removal of a NFR order, where the Advocate Guardian was of the view that the medical reasons for the NFR order were not clear.

**Dying or a Life Not Worth Living?**

Sophia was a woman in her early 40s who had severe life long intellectual and physical disabilities. Across a period of about six months, Sophia's health had begun to progressively deteriorate with significant weight loss due to decreased intake of food, coinciding with an increasing swallowing reflex issue. Early on her staff sought a PEG feed tube operation but treatment was not offered by the surgeon because he considered Sophia ‘Not for Resuscitation’. Sophia's health worsened and she had three hospital admissions in as many months due to aspiration pneumonia.

On Sophia’s third admission to hospital, she was transferred to a palliative care ward within the hospital.

Disagreement within the family over decisions made, and yet to make in the future, related to the palliative care for Sophia, and this led to an urgent application to VCAT for guardianship. The application resulted in the appointment of the Public Advocate with decision-making authority in relation to accommodation, healthcare and access to person.

The delegated Advocate Guardian first met Sophia and then the treating medical team at the hospital discharge planning meeting. At that point, Sophia had been in palliative care for several weeks and the team were planning to discharge her to a nursing home where the palliative care regime (water, ice cream, and keeping her comfortable) would continue until she died. When pressed to explain the decision to stop treating Sophia, the medical team could not rule out that her weak condition was due to inadequate nutrition rather than the initial explanation that it was an inevitability of her age and disabilities.

The Advocate Guardian's concern increased when several medical team members said they believed Sophia had made a choice to stop eating due to being depressed about significant changes to her home life routines and that they were respecting her decision to die.

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62 Mencap is a disability service provided in the United Kingdom who work in partnership with people with disability to support them to live the life they choose, and advocate for changes to law while challenging prejudice: Mencap, *About Us* [https://www.mencap.org.uk/about-us](https://www.mencap.org.uk/about-us) accessed 27 July 2015; Mencap, *Death by Indifference* (2007) [https://www.mencap.org.uk/death-by-indifference](https://www.mencap.org.uk/death-by-indifference) accessed 27 July 2015. This report follows on from Mencap's *Treat me right!* report and campaign in 2004, which ‘exposed the unequal healthcare that people with a learning disability often receive from healthcare professionals. The report made clear that much work needs to be done within the NHS to ensure that people with a learning disability are treated decently and equally.’
Given Sophia’s severe impairment it was not possible that she could have conceived or gone through the complex decision making process ascribed to her.

After debate, and with some flexibility, the medical team agreed that rather than be discharged to an unfamiliar nursing home, Sophia would go back to her group home where the staff ratios were better and importantly the staff knew Sophia very well and were familiar with her day to day care and how to communicate with her. The Advocate Guardian requested that a trial of anti-depressant medications and a nutritious liquid supplement be tried, which was agreed to. The medical team were insistent however that when Sophia deteriorated at the group home, staff should not call an ambulance or have her taken to the emergency department, and that she should just be kept comfortable. If the group home found they were unable to manage they would need to locate a hospice or somewhere other than that ward for Sophia to die.

Several days following Sophia's discharge, and in discussion with the group home and OPA management, the Advocate Guardian decided on Sophia’s behalf that an ambulance should be called and Sophia taken to the Emergency Department if she deteriorated. The Advocate Guardian contacted the medical team and requested the Not For Resuscitation order be removed from Sophia’s medical file. The medical team refused and as medical guardians cannot oblige medical practitioners to offer treatment, the order stayed in place.

Fortunately, Sophia had no need to return to the hospital. With the use of medications and liquid supplements, Sophia quickly began to thrive and within several months put the lost kilograms back on. Family, staff and other residents, who had known Sophia for years, were thrilled as she recovered and engaged with everyone again. Before long she had returned part time to her day placement and subsequently back to full time.

Positive discussions took place between the hospital and OPA management about this incident. The NFR was removed from Sophia’s file, protocols to prevent similar situations arising were developed and education about rights and people with intellectual disabilities was given.

**Case Study Two**

Case Study Two explains an instance where OPA's Advice Service queried discrimination against a person with disability. Short term advocacy followed, and upon further investigation it was discovered that there were legitimate reasons for not offering the treatment, which would have been futile and burdensome, given the nature of the patient’s intellectual disability.

**No offer of treatment to a person with disability: Advice Service concern**

Late one Friday afternoon OPA's Advice Service received a telephone call from a doctor who wished to explain that she was not proposing to offer dialysis to a woman with an intellectual disability who was suffering renal failure. It was unclear why the doctor felt it necessary to advise OPA of this decision but it seemed she had some doubt about whether this clinical decision was justifiable and she conceded that a patient without intellectual disability and with the same presenting physical condition would be offered dialysis.

OPA's Advice Service suggested that we would provide short-term advocacy to ensure that patient was not being discriminated against on the basis of her intellectual disability. The doctor was open to some independent scrutiny of the decision-making process. An OPA Advocate Guardian, in an advocacy capacity, attended at the hospital and met with the woman, and with her family, and spoke with the doctor. The Advocate Guardian was satisfied that the patient was not being discriminated against and that there were legitimate reasons for not offering the treatment which would be futile and burdensome, given the nature of the patient's medical condition.
2.1.2 Planning for the future initiatives

It is widely reported that as a community we struggle to talk about death.63 OPA spends significant time discussing matters relating to planning for the future; as community educators, publishers, Advocate Guardians, Advice Service staff, as systemic advocates and in Chair and advisory positions.64 OPA’s resources include ‘You Decide Who Decides,’ ‘Securing their Future,’ ‘Planning for the Future (ACP),’ ‘Take Control,’ (the new) ‘Side by Side’ and ‘In Their Shoes,’ all of which are being updated with the passage of the Powers of Attorney Act and are available on OPA’s new website and some in hardcopy.

OPA wishes to acknowledge a number of important initiatives underway in Victoria that assist the health and disability service sector to talk about end of life with the community. These focus largely on health care preferences and up-skilling health professionals. The Austin Hospital’s Respecting Patients Choices Program and the Northern Hospital’s Advance Care Planning Service target education resources at both health professionals and the community to assist them to plan for the future.65 The ‘Have the Conversation Strategy,’ referred to in the introduction to this submission, is a significant step forward in the education of health services to develop, review and activate advance care plans across and beyond their organisations.66

OPA acknowledges an important initiative led by Karingal disability service in the Barwon area of Victoria, ‘Living for Today, Planning for Tomorrow’, focusing on advance care planning for people with a disability and their families. This has led to the formation of the Barwon Disability Palliative Approach Advisory Committee, made up of people with disability and their families. The focus of their work is to promote discussion regarding living, dying and death. A major goal of the next phase of this initiative is the development of a toolkit which can be used in the disability sector as an easy-to-use resource and reference guide.67

Another important project to which OPA wishes to refer is being undertaken by the University of Sydney and project partners in relation to people with intellectual disability and end of life. The ‘Dying to Talk’ project is developing a research-based toolkit to support staff and caregivers with the intention to deliver individual information to adults with intellectual disability, and discuss end of life planning in everyday contexts.68 This project is discussed further below.

These initiatives contribute to informing the health sector, and the community, about the opportunity to plan for the future, including future health care preferences. OPA considers there is scope for improvement in this area, and the office works to improve our own practice in this area in the provision of accessible education to professionals and the community in relation to making powers of attorney and medical substitute decision making.

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64 For example, OPA chairs the Advance Care Planning Strategy Implementation Advisory Group, and played an advisory role in the development of the then Department of Health’s Advance Care Planning: Have the Conversation: A strategy for Victorian health services 2014-2018.
2.2 Research showing problems

There is a considerable amount of research published or underway that considers the service system and legal framework guiding end of life choices.

Research undertaken by the Grattan Institute identifies problems with current medical practice in providing people an opportunity to die well. Research by Ben White, Lindy Willmott and their team that identifies gaps in medical practitioners’ knowledge of the law will also be considered, leading to OPA’s recommendations on this matter contained at the end of Part Two.

2.2.1 Grattan Institute on dying well

The Grattan Institute’s Dying well report states that:

Very few people discuss their preferences for end-of-life care with health professionals. Even fewer have made formal plans to ensure their wishes are followed even when it is clear they likely to die in the relatively near future. In part this is because health professionals are uneasy about discussing death and dying with patients.69

On this point, the Grattan Institute report that ‘doctors often do not feel they have the skills to conduct end of life discussions.’ Even in imminent death, the report notes, ‘professionals are often overly optimistic about the potential for treatment to succeed, then pursue it far too long, at significant cost and little benefit to the patient.’70

On this point of medical decision making the Grattan Institute further state

When death is near and quality of life is low, it is hard to know how far to pursue treatment, especially when the treatment is stressful, intrusive and likely to further reduce quality of life. Decision making is even more stressful when treatment preferences have not been previously discussed, and choices are being made in the pressure cooker environment of a hospital. The problems are exacerbated when there has been insufficient discussion with close relatives or when health care staff are anxious about their legal obligations.71

OPA understands well the experience of loved ones and carers in a hospital environment. This comes from our experience as Advocate Guardians, but also as an advice service for the community and health professionals, as well as educators in this sphere.

While Dying well focuses on reforms to ensure people die comfortably and in surroundings they choose, mostly at home, its sentiment is relevant to the broader discussion about end of life health care preferences.

On the matter of choice the Grattan Institute report’s that it is a critical issue as baby boomers age, and that often people don’t die at home, although this is the choice most would make. According to the Grattan Institute’s research, only about 14 percent of people die at home although 70 percent of people would prefer to.72 This is either because support services are inadequate or because people have not had a chance to articulate and implement their choice through proper discussion and planning.73 This point is considered further below.

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72 Ibid 4.
73 Ibid 8.
2.2.2 White, Willmott et al on medical practitioner’s knowledge of the law

OPA has been a project partner in research undertaken by the Health Law Research Centre at Queensland University of Technology which is investigating medical practitioners’ knowledge of this area of the law. The research has resulted in a number of publications.74

Some of that research undertaken by Ben White, Lindy Willmott, Colleen Cartwright, Malcolm Parker and Gail Williams, published in a series of three articles, examines the legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment from adults who lack capacity. White, Willmott and their team analysed survey data from doctors which indicates considerable gaps in doctors’ knowledge of the law concerning substitute medical treatment decision making.75

The article that considers the position in Victoria – ‘The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: part 3 (Victoria)’ – states:

The law governing the withholding and withdrawing of life-sustaining treatment from adults who lack capacity is not only complex, it is also at times uncertain, internally inconsistent, inconsistent with good medical and ethical practice, and counterintuitive.76

Furthermore:

medical professionals play a significant legal role in these decisions, but that the state of the law in this area is problematic, and this contributes to deficits in the legal knowledge of medical professionals.77

White and Willmott et al report widespread uncertainty in the medical profession regarding substitute decision making.78 This is combined with critical gaps in the legal knowledge of many doctors who practice in end of life matters, which in turns leads to non-compliance with statutory provisions.79

On the point of medical practitioner education, White and Willmott et al surveyed three medical schools in Victoria as part of their research. During the undergraduate period of study, White and Willmott et al identifies:

significant coverage of ethical and legal aspects of withdrawing and withholding treatment, with one requiring students specifically to understand the legal requirements of appointing a guardian or an agent pursuant to an enduring power of attorney (medical treatment) under the Guardianship and Administration Act 1986 (Vic) and the Medical Treatment Act 1988 (Vic), the role of guardians and appointed agents, and indeed to recognise the complexities regarding the law in withdrawal of treatment. The third school also covered these areas, but in less depth … instruction is necessarily and correctly, more introductory and less theoretical.80

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74 These publications are referred to throughout this submission, and cited where relevant.
Commenting also on the lack of systematic teaching in these areas for junior doctors, specialist trainees, or those in private practice in Victoria, White and Willmott et al conclude that there are clear knowledge gaps. Drawing from the only empirical study in Victoria, which contained a random sample of 983 general practitioners in Victoria, to which there was a 55 percent response rate, White and Willmott et al note that ‘44 percent of respondents described themselves as having no or little understanding of the legal effects of the Medical Treatment (Enduring Power of Attorney) Act while a further 48 percent described themselves as having on ‘some knowledge.’

Recommendations to improve medical practitioner’s knowledge of the law are contained at 2.4.

2.2.2.1 Current research in relation to people with intellectual disability and end of life

On matters relating to people with disability in particular, OPA acknowledges some important research that is currently underway. This research questions why people with intellectual disability are not routinely afforded self-determination about the end of life as are other members of the community. Michele Wiese et al argue that people with intellectual disability should know about dying and death, and experience the opportunity equal to other members of the community to plan for it. This results in a paradoxical situation, where research and policy recommends that people with intellectual disability should know about and plan for death and dying, but in practice have very limited opportunity and support to do so. While raising many of the problems ‘but few solutions,’ the research by Weise et al suggests a number of possible research avenues for more work in the future. OPA encourages engagement with people with intellectual disability in assisting them to talk about death and plan for their future.

OPA’s own experience exposes that very many people with disability, particularly those with higher support needs, continue to lead a precarious life. This relates to the ability of people with disability to talk about end of life, and their ability to document wishes about their future. Particular challenges include:

- being socially isolated, even excluded
- having few or no friends
- having most of their relationships with people paid to be with them
- being dependent on others for everyday assistance causing a power imbalance in their relationships
- actual or threatened violence, neglect or exploitation
- being brutalised and bullied
- pervasive discrimination and devaluation; being treated as a second-class citizen or not a full person; de-individualisation

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81 Ibid 789.
82 Willmott et al qualify this point, referring to research by Darvall, McMahon and Piterman: ‘It should be noted that it appears from the article that general practitioners were asked about the amending Act (the Medical Treatment (Enduring Power of Attorney) Act 1990 (Vic)) rather than the Medical Treatment Act 1988 (Vic) itself (see the above quote as to what respondents were asked). The goal was to assess legal knowledge specifically in relation to the appointment of an agent under an enduring power of attorney (medical treatment) and the provisions governing such appointments were introduced by this amending Act. However, it is possible, depending on the wording used in the questionnaire, that this reference to the amending Act may have confused respondents. For example, some respondents may have known about the Medical Treatment Act 1988 (Vic) and felt they understood the relevant provisions relating to the appointment of agents but were confused by the reference to this later amending Act and so lowered their rating of knowledge’ at Willmott, L, White, B, Parker, and Cartwright, (2011) The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: part 3 (Victoria). Journal of Law and Medicine, 18(4) 773-797 789.
difficulties in communication and being listened to
• having their capacity to make personal decisions and to be in charge of their life constantly questioned or disregarded
• having people speak for them or being treated as if they are invisible
• having people, sometimes including your parents or other loved ones, make substituted decisions for you without them putting first their wishes and personal and social wellbeing.85

On the particular challenges faced by people with intellectual disability, the ‘Dying to Talk’ research intends to enable autonomy and independence for people with intellectual disability, and to build the skills of staff in disability services to assist with talking about end of life.86

2.3 How to make progress

OPA does not wish to comment on reform to medical practices, including palliative care, to assist a person to exercise their preferences for the way they want to manage their end of life. OPA does wish, however, to propose improvements in the context of our own experience, drawing also from current research in this area.

OPA sees progress in this area focusing on conversations and training and education.

2.3.1 Conversations

It is difficult to determine the extent of the responsibility of medical practitioners to talk about end of life with their patients, and when this should occur. Equally, it is difficult to determine the extent of the responsibility of a patient to both come to terms with their impending death and to engage in discussions with their medical practitioner about effective palliation and end of life goals, if this is even possible.

The Grattan Institute found that failure to talk about and plan for death is one of the most significant obstacles to improving the quality of dying.87 Palliative Care Victoria also discussed this in its submission to the Australian Senate Community Affairs Reference Committee’s Inquiry into Palliative Care in Australia (2012).88

Recent media coverage has been engaging with what it takes to die well and suggests that conversations are crucial to this. Some suggest that patients who can get even part of the way to acknowledging their mortality ultimately do themselves an untold favour.89

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85 Office of the Public Advocate, Submission to Submission to the Parliament of Victoria, Family and Community Development Committee Inquiry into the social inclusion of Victorians with a disability (2014) 8. OPA’s submission to this inquiry discussed the notion of ‘precarious lives’ extensively, particularly in relation to the compounding disadvantage of people with high support needs.
88 Palliative Care Victoria discussed this in its submission to the Australian Senate Community Affairs Reference Committee’s inquiry into Palliative Care in Australia: Mrs Odette Waanders, Palliative Care Victoria, Committee Hansard, 4 July 2012, p. 42. See also Submission 108 (Palliative Care Victoria) to the Senate Inquiry available at <http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Completed_inquiries/2010-13/palliativecare/submissions>.
Dr Ranjana Srivastava writes that such a patient’s concession:

permits their oncologist to open up new conversations that don’t include the latest million-dollar blockbuster therapy with a bleak survival curve but do mention the therapeutic benefit of teaming up with hospice workers to write letters, preserve photos and record memories.  

The role of family is also crucial here, as it can often be a family member who is impeding the opportunity for their loved one to talk about death, and it may be difficult for a medical practitioner to have access to the patient alone.

This reinforces the importance of successful implementation of the ‘Have the Conversation Strategy’ across health services in Victoria. Two priority areas of the strategy – increasing workforce capability to have the conversation, and enabling the person cared for to have the conversation – work directly to the role of health services, and individuals, in assisting a person to exercise their preferences for the way they want to manage their end of life.

OPA also stresses the importance of community engagement with the philosophical debate about what matters at the end of life, and notes that there is evidence of growing community action to create community awareness of death, dying and bereavement. Having a conversation about end of life should not be solely driven by the hospital system.

OPA suggests the Committee consider the Grattan’s Institute recommended reforms in the formulation of its own recommendations to the Victorian Government, noting however that some of those reforms are nationally based. OPA considers those reform ideas would contribute to Victorians making informed decisions about the way they wish to manage their end of life. Key recommendations are:

- Implement a national Public education campaign on end-of-life
- Ensure end of life discussions and plans occur
- Better coordination and implementation of end-of-life plans
- Provide home based support for carers to support people to die at home.

### 2.3.2 Training and education

Medical practitioners should be aware that the physician-led consensus model of determining a person’s end of life treatment must work harmoniously with the contractual model that authorises treatment or its refusal.

It is OPA’s view that the most significant problem is medical practitioners not knowing when substitute consent is required, and/or not getting such consent when it is required. Furthermore, medical practitioners may not fully engage with a substitute decision maker as they would a competent person. This can make it difficult for a substitute decision maker to give effect to the person’s end of life treatment wishes.

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90 Ibid.
91 For example, in 2013 the GroundSwell Project launched Dying to Know Day - a national annual day of action dedicated to bringing to life conversations and community actions around death and dying and bereavement: The GroundSwell Project, Dying to Know Day <http://www.thegroundswellproject.com/dyingtoknowday/> accessed 7 August 2015. Dying to Know Day is on August 8 2015 and a variety of events are being held across Australia to help people to: develop their death literacy; make their end of life plans such as a will and advance care plan; share these wishes with their families; get informed about end of life and death care options such as dying at home, home and community led funerals and; natural burial be better equipped to support family and friends experiencing death, dying and bereavement: at <http://www.thegroundswellproject.com/dyingtoknowday/>. See also Radio National Breakfast < http://www.abc.net.au/radionational/programs/breakfast/dying-to-know-day-discussing-death-dying-and-bereavement/6679810>.
The legal requirements with which medical practitioners must engage can be complex. There is a need for there to be a clear understanding of the law by clinical teams. OPA’s experience in undertaking education sessions for medical practitioners and health services, which supports research undertaken in relation to this, is that medical practitioners’ knowledge of the law concerning substitute consent is not strong. OPA agrees with White and Willmott and their team that education must be improved to enhance medical professionals’ understanding of the law in this area.93

2.4 Recommendations

In order to improve medical practitioners knowledge of the law OPA makes the following recommendations:

2.4.1 Education for medical practitioners

<table>
<thead>
<tr>
<th>Recommendation 1.</th>
<th>The Victorian government should urge the Australian Medical Council to critically examine the adequacy of compulsory teaching in Australian medical schools about substitute medical consent.</th>
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</thead>
<tbody>
<tr>
<td>Recommendation 2.</td>
<td>The Victorian government should require the Postgraduate Medical Council of Victoria to ensure that medical interns are adequately trained on the subject of substitute medical consent.</td>
</tr>
</tbody>
</table>

OPA notes however that education alone will not suffice to better promote the law in this area. Even the most informed doctors encounter difficulty with the complexity of decision-making regimes that exist. Part Three of this submission discusses in detail the key complexities in this area of law and recommends changes to minimise those legal complexities.

3 Part Three Current legal framework

OPA’s experience relates to the making of end of life decisions when a person has lost capacity, and this is our focus in this part of the submission.

If a person is unable to make a decision about their medical treatment, the following laws could apply –

1. if it is first aid, a non-intrusive examination for diagnostic purposes, or the administration of a pharmaceutical drug, a medical practitioner can perform this without consent if it is in the best interests of the patient. This is permitted under the definition of medical treatment in the Guardianship and Administration Act which excludes these things from the definition of medical treatment.

2. if it is an emergency, medical treatment can be provided without consent to save the patient’s life, prevent serious damage to their health or prevent significant pain or distress.94

3. if it is “any medical or surgical procedure, operation or examination or any prophylactic, palliative or rehabilitative care carried out by, or under the supervision of a medical practitioner” a person responsible (as defined in Part 4A of the Guardianship and Administration Act) may consent (or withhold consent) to this if it is in the person’s best interests.


94 Guardianship and Administration Act 1986 (Vic) s 42A.
4. If there is a decision to be made to refuse medical treatment that is being offered by a health service or to cease on-going medical treatment, such as dialysis or life support, an agent appointed under the Medical Treatment Act or a guardian appointed by VCAT with that authority is empowered to make this decision by making a refusal of treatment certificate.

5. If the person is a compulsory patient under the Mental Health Act⁹⁵ and requires medical treatment, the following persons may consent to it:
   a. An agent appointed by the patient under the Medical Treatment Act,
   b. A person appointed by VCAT to make decisions about the treatment,
   c. A person appointed by VCAT under the Guardianship and Administration Act to make decisions about the treatment,
   d. An enduring guardian appointed by the person or, post 1/9/2015, an enduring attorney with authority to make decisions about personal matters that include medical treatment, or
   e. An authorised psychiatrist.

6. If the medical practitioner considers that treatment is futile or unduly burdensome to the patient, the medical practitioner is not required to provide that treatment.

People become confused about who has responsibility. The roles come with different powers and responsibilities. This adds to the confusion. This confusion is an unnecessary complication to a person’s care at the end of life. There is no formal legal acknowledgement of the consensus model of making decisions in this schema.

If a person does not have a substitute decision maker from the list above, medical treatment as understood can be provided by the doctor without consent so long as the doctor provides the Public Advocate with a notice.⁹⁶

In this section we shall explore in greater specificity these complexities.

**3.1 Complexity One: What is medical treatment?**

Medical treatment is defined differently in three Acts of the Victorian Parliament. While the inclusion or exclusion of pharmaceutical drugs in the definition is a key difference, it is not the only one.

The definition in the Guardianship and Administration Act deals with what a substitute decision-maker can consent to for a patient. Pharmaceutical drugs are excluded from this definition.

The definition in the Mental Health Act is similar to that in the Guardianship and Administration Act, but includes pharmaceutical drugs.

The definition in the Medical Treatment Act needs to accommodate a patient’s possible refusal of all treatment except palliative care, and so it includes the administration of pharmaceutical drugs.

Many complications arise from the different definitions of medical treatment in the relevant Victorian statutes. In OPA’s experience, this makes the delivery of education and the provision of advice very difficult. This also makes the legal role of medical professionals in making decisions to withhold or withdraw life-sustaining treatment significant and problematic.⁹⁷

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⁹⁵ Mental Health Act 2014 (Vic) s 75.
⁹⁶ Guardianship and Administration Act (Vic) s 42K.
⁹⁷ For more on this point see broadly Willmott, L, White, B, Parker, and Cartwright, (2011) The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: part 3 (Victoria) Journal of Law and Medicine, 18(4), pp. 773-797.
The medical profession also has an understanding of what constitutes medical treatment that relates to the practice of medicine, not to the needs of the law. Doctors and other health professionals have indicated to OPA that they find the legal definitions contrary to their experience of their profession.

The experience of the medical profession is relevant to the interpretation of the definition as becomes apparent in case study 3 below. One aspect of that case is whether the insertion of a cannula through which drugs will be administered to a patient is medical treatment under the definition of medical treatment in the Guardianship and Administration Act. OPA’s view is that the insertion of the cannula is medical treatment as it is a surgical procedure. But there is an argument that it is part of the administration of certain pharmaceutical drugs and therefore outside the definition. That the administration of pharmaceutical drugs is not medical treatment under that Act is out of touch with the reality of medical practice.

OPA notes that it is sometimes difficult to determine what constitutes the beginning and end of treatment. The insertion of the cannula for the administration of palliative care drugs is an example of this.

In order to work out which definition applies, the substitute decision maker and the health professionals need to know which Act applies.

OPA experiences difficulties in providing information to the public as to what constitutes medical treatment given the different definitions in the laws operating in this area. These definitions are set out in appendix 1 to this submission.

### 3.2 Complexity Two: Difficulty in application of the law

In OPA’s view, there are a number of permutations of the following that affect which law applies in a given situation:

1. **The type of patient**
   
   i. A person who is considering refusing medical treatment for a current condition (or their agent or guardian with that authority) would come under the definition of medical treatment in section 3 the Medical Treatment Act.
   
   ii. A patient who is unable to consent to treatment for whom treatment is offered would come under the definition in section 3 of the Guardianship and Administration Act.
   
   iii. A patient as defined in the Mental Health Act would come under the definition of medical treatment in section 7 of that Act.

2. **The type of substitute decision maker**
   
   i. A person responsible has authority as set out in Part 4A of the Guardianship and Administration Act to consent to medical treatment. This person cannot consent to or withhold consent to the administration of pharmaceutical drugs and cannot consent to treatment for a compulsory patient under section 75 of the Mental Health Act.
   
   ii. But some persons responsible may have other authority
      
      o An agent under the Medical Treatment Act has authority to consent to, or withhold consent to, treatment under the Guardianship and Administration Act or to consent to or refuse medical treatment as the term is defined in the Medical Treatment Act. The agent can also make decisions about medical treatment under the Mental Health Act. In this case the definition of medical treatment in that Act may apply but as the agent also has authority under the Medical Treatment Act, that definition of medical treatment would also apply.
o An enduring guardian, and from 1 September 2015, an attorney for personal matters, has authority to consent to or withhold consent to medical treatment as that is defined in the Guardianship and Administration Act. The enduring guardian also has authority to make decisions to medical treatment for a compulsory patient under the Mental Health Act and possibly enlivening the definition of medical treatment in that Act.

o A VCAT appointed guardian with plenary authority would have the same authority as an enduring guardian or attorneys for personal matters, and may also have authority equivalent to that of an agent under the Medical Treatment Act. The plenary guardian would also have authority to make decisions about treatment if the patient were a compulsory patient under the Mental Health Act.

o A VCAT appointed guardian with limited health care authority would have similar authority to that of an enduring guardian or attorney for personal matters. Sometimes VCAT appoints this person with powers under the Medical Treatment Act and so invokes the definition in the Medical Treatment Act. This person is also mentioned in section 75 of the Mental Health Act to make decisions about medical treatment for compulsory patients.

3. The way the substitute decision-maker’s authority is worded.
   i. Different terms are used to describe the decision-maker’s authority
      o Consent to and withholding consent to treatment
      o Refusing treatment
      o Making decisions concerning treatment.
   ii. The authority of the person responsible is expressed in terms of consent to treatment in the Guardianship and Administration Act.
   iii. The authority of the enduring guardian, or, from 1 September, attorneys for personal matters, is expressed in terms of consent and withholding consent in the Guardianship and Administration Act.
   iv. The authority of the agent is expressed in terms of refusing medical treatment in the Medical Treatment Act.
   v. Section 75 of the Mental Health Act is expressed in terms of making a decision concerning treatment. This is not consistent with the wording of the enduring guardian’s or a limited guardian’s powers in the Guardianship and Administration Act which uses terminology of consent to treatment.

4. The different responsibilities of the substitute decision makers
   i. A person responsible must comply with the best interests requirements set out in section 38 and the objects of the Guardianship and Administration Act set out in section 4(2).
   ii. An enduring guardian, an attorney for personal matters, and a VCAT appointed guardian have, in addition to these responsibilities, to comply with the best interests criteria in section 28 of the Guardianship and Administration Act.
   iii. An agent or a VCAT guardian with Medical Treatment Act powers who is refusing medical treatment will have to comply with section 5(2)(b) of that Act and the requirements set out in relation to completing a refusal of treatment certificate.
   iv. When a substitute decision-maker is making decisions pursuant to section 75 of the Mental Health Act, it may be that they need to consider the principles set out in section 11 of that Act.

By way of the examination outlined above, OPA hopes to highlight the complexities of this area of law. One can comprehend the difficulties medical practitioners, and the community, encounter when attempting to engage and apply these legal frameworks.
3.3 Complexity Three: Distinction between withholding consent and refusing consent

A significant area of legal confusion concerns the distinction between withholding consent to medical treatment and refusing medical treatment. Furthermore, medical practitioners are often uncertain as to whether or not substitute consent is needed. This often results in failure to obtain the requisite consent. OPA can attest, through the work of our Advocate Guardians, and through telephone calls to OPA’s Advice Service, that even skilled practitioners are unable to understand the legal distinction between withholding consent to treatment and refusing treatment.98

OPA raised this complexity in our submission to the VLRC’s Guardianship Information Paper, and we wish to restate that position here:

A ‘person responsible’ under the guardianship legislation can withhold consent to medical treatment, while only a small number of people can refuse medical treatment under the Medical Treatment Act (namely an agent appointed under an Enduring Power of Attorney (Medical Treatment), a guardian and the person themselves). Part of the reason for the confusion stems from the fact that the two concepts can overlap. But withholding consent to treatment relates generally to the decision whether or not to initiate new treatment, while refusing treatment covers both current and proposed treatment.99

The Guardianship and Administration Act and the Medical Treatment Act were developed at different times, in response to different concerns, and for different purposes. They do not deal with the complex issue of lack of consent for medical treatment in a clear and consistent manner.100 The VLRC captured the distinction in its Guardianship consultation paper

The Medical Treatment Act seeks to protect the interests of both a person and their medical practitioners when that person, or their agent, makes a positive decision to refuse medical treatment. Part 4A of the G&A Act seeks to protect the interests of both a person who is in need of medical treatment and their medical practitioners when that person is unable to consent to treatment because of impaired decision making capacity. The Medical Treatment Act is primarily concerned with processes for refusing treatment, while part 4A of the G&A Act is primarily concerned with identifying a person to provide substitute consent for medical treatment so that it may be given expeditiously.101

Further elaboration on this point is captured in section 3.2.

3.4 Section 42K process – where there is no person responsible

Another area of confusion for medical practitioners relates to the statutory appointment of a ‘person responsible’ and their ability to consent and withhold consent to medical treatment that is being offered.102

In non-emergency cases where a person requires medical treatment, but cannot consent to that treatment, and where a medical practitioner cannot locate a person responsible, the medical practitioner can proceed with that treatment if they consider it to be in the person’s best interests.103

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99 Ibid 36.
100 For more on this point, see Victorian Law Reform Commission, Guardianship Consultation Paper (2011) 299.
102 OPA has also identified confusion within the medical community about the reach of the power to withhold consent and the power to refuse treatment. Both powers can only be exercised in the context of treatment which is actually offered. OPA occasionally deals with situations where relatives would like to force medical practitioners to continue or initiate treatment: see also Office of the Public Advocate, Submission to the Victorian Law Reform Commission in Response to the Guardianship Information Paper (2010) 17.
103 Guardianship and Administration Act 1986 (Vic) s 42A.
A medical practitioner must submit a ‘Section 42K Notice’ to OPA where medical treatment is to be provided but there is no ‘person responsible’ available to consent to it. Section 42K notices are routinely submitted to OPA (470 were lodged with OPA in the last financial year). OPA notes that most section 42K notices do not relate to end of life treatment decisions.

OPA’s Advice Service spends a significant amount of time addressing Section 42K notices submitted to the office. Standard practice involves an OPA Advice Service staff member calling the submitter of the Section 42K Notice to talk through the legislative criteria that must be met to successfully lodge the notice. The Advice Service staff member asks questions in relation to the content of the notice, and the person to which the notice relates. For example: what is the person’s disability; what is the person’s capacity assessment; what reasonable efforts has the medical practitioner made to locate the person responsible; what are the risks of the treatment; what are the person’s wishes; is the treatment in the person’s best interests; is there a less restrictive option.

While the Guardianship and Administration Act does not give OPA a greater role than maintaining a register, OPA Advice Service staff members sometimes undertake short term advocacy on behalf of the person to whom the Section 42K Notice relates (see Case Study Two on this point). On a related point, OPA’s Advice Service frequently receives calls from persons responsible who are unclear about their legal power to consent or withhold consent to treatment in relation to a loved one.

We know there is significant non-compliance with the Section 42K process under the Guardianship and Administration Act. During 2014-2015, 81 percent of notices met the legislative requirements which is a decrease on previous years where the figure was static at 83 percent percent). The most common reasons why a notice did not meet legislative requirements was because there was a person responsible who could provide consent or the procedure did not meet the definition of medical treatment under the Act. This speaks to the reported gaps in medical practitioner’s knowledge of the law.

OPA’s experience is that there is an uneven usage of Section 42K Notices across Victoria. Some hospitals submit more than other hospitals. OPA suspects that medical practitioners may be proceeding with treatment where consent is required, but where there is no person responsible available to consent, and where the medical practitioner has not submitted a 42K Notice to OPA. The extent of this non-compliance is unclear, but OPA suspects the

Case Study 3

Confusion around definition of ‘medical treatment’ and section 42K process

The Coroner completed an investigation and made a finding following an inquest into the death of a man who lived in a group home. The Coroner reported that the man died from aspiration pneumonia while in hospital. The man was not capable of giving consent to medical treatment under the Guardianship and Administration Act due to his disability and therefore the definition of ‘medical treatment’ under that Act applied. The man had no ‘person responsible.’

One matter investigated by the Coroner related to the ‘uncertainty surrounding the interaction between the definition of medical treatment, palliative care, administration of pharmaceutical drugs and section 42K of the Guardianship and Administration Act as to when notice should be given to the Public Advocate.’

In this case, the medical practitioner proceeded with the administration of pharmaceutical drugs, via a subcutaneous cannula, on the basis of their understanding that the administration of pharmaceutical drugs was ‘palliative care’ and not ‘medical treatment’ within the meaning of the Guardianship and Administration Act, and therefore there was no need to submit a section 42K notice.

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104 Office of the Public Advocate, internal data 2014-2015.
107 Ibid [39].
In response to a request by the Coroner, OPA’s Principal Legal Officer expressed the office’s view that insertion of a cannula itself is ‘medical treatment’ within the meaning of the Guardianship and Administration Act, although the administration of pharmaceutical drugs is ‘not medical treatment.’

The Coroner reported that there is ‘confusion in relation to this area of law and its interpretation among medical practitioners. A broad interpretation of the meaning of medical treatment enlivens the section 42K process.’

The Coroner reported that ‘the section 42K process is not onerous or highly prescriptive. In the absence of consent however it does act as an important procedural check with respect to the oversight of medical treatment provided for people in the man’s position who cannot consent and do not have a ‘person responsible.’

This case study demonstrates confusion about the current law, and shows that it can create disparate views as to what is required; is the insertion of a cannula for the purposes of palliative medication medical treatment, and does it therefore require consent? In OPA’s view the insertion of a cannula is medical treatment under the Guardianship and Administration Act, and as such, requires notification to the Public Advocate via a Section 42K Notice.

3.5 Section 42M process – where the person responsible does not consent

Another point of confusion stems from the authority of a medical practitioner under the Guardianship and Administration Act to proceed with treatment in some circumstances where the person responsible does not consent (that is, they withhold consent). Where a medical practitioner believes on reasonable grounds that the proposed treatment is in the best interests of the patient then they can complete a section 42M statement and provide this to the person responsible and OPA.

If the person responsible does not apply to VCAT within 7 days of receiving this notice then the practitioner may proceed with the treatment. This power is linked to duty of care considerations. Medical practitioners can serve as an important safeguard where they consider the family or the person responsible is not, in their view, acting in the person’s best interests.

On this point OPA notes that this process, undertaken by lodging a Section 42M Notice with OPA, is not utilised. Since 2011-2012 OPA has received three 42M Notices, and only one met legislative criteria (the other two were section 42K Notices submitted incorrectly as Section 42M statements). It appears that often practitioners appear to be applying to VCAT for guardianship in such cases, which may be a more restrictive intervention than is needed. OPA restates its earlier call for a targeted education campaign towards medical practitioners in order to advise them of this less restrictive option.

OPA questions the value in the 42M process. OPA notes that recommendations made in this submission, if adopted, would impact on the operation of this provision in the Guardianship and Administration Act.

The patterns of usage of sections 42M, and 42K, notices once again exhibit the need for an improvement in medical practitioners’ knowledge of this area of law. While not always related to end of life decision making, the information provided here exhibits more broadly medical practitioners’ unfamiliarity with the law concerning substitute consent for medical treatment.

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108 Ibid [45].
109 Guardianship and Administration Act 1986 (Vic) s 42L.
110 See also Victorian Law Reform Commission, Guardianship Final Report (2012) 280. The medical practitioner must believe that the treatment is in the patient’s best interests and they must advise the person responsible and OPA of their intention to proceed. The person responsible has a minimum of seven days to apply to VCAT to challenge that decision before the medical practitioner can proceed. See Guardianship and Administration Act 1986 (V) ss 42L(2)(a), 42N(6).
3.6 Recommendations

3.6.1 Definition of medical treatment and health decision maker

OPA considers that categorising medical treatment into significant and routine medical procedures will be part of an improved process for providing medical treatment to people who are unable to consent to it. Allowing an automatic statutory appointment of a health decision maker for significant procedures will promote efficiency in decision making.

The VLRC expressed its view that the term person responsible was not widely known or understood, and that this person should be referred to as the ‘health decision maker’ because this term clearly describes the nature of the role.112

OPA is of the view that the main VLRC recommendations on medical treatment should be adopted, with some minor changes (see *).

**Recommendation 3.** The Victorian government should adopt the following recommendations made by the Victorian Law Reform Commission in its Guardianship Final Report:*  

<table>
<thead>
<tr>
<th>Automatic appointment of a health decision maker</th>
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<tr>
<td><strong>204.</strong> New guardianship legislation should provide for the automatic (statutory) appointment of a substitute decision maker—to be known as a health decision maker—to make medical treatment decisions for a person who lacks the capacity to make their own decisions and who does not have an [existing personally-appointed or VCAT-appointed substitute decision maker in place] with the power to make those decisions for them.</td>
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<tr>
<th>Significant and routine medical procedures</th>
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</thead>
<tbody>
<tr>
<td><strong>211.</strong> New guardianship legislation should define ‘significant treatment’ as a medical or dental procedure, other than an emergency procedure or a special procedure that:</td>
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<tr>
<td>(a) involves a significant degree of bodily invasion, or</td>
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<tr>
<td>(b) involves a significant risk to the patient, or</td>
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<tr>
<td>(c) is likely to have significantly negative or unpleasant side effects for the patient, or</td>
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<tr>
<td>(d) is likely to result in significant distress for the patient, and</td>
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<tr>
<td>(e) would ordinarily cause a medical practitioner to seek specific consent from a person with capacity before proceeding.</td>
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<table>
<thead>
<tr>
<th>Definition of routine treatment</th>
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<tbody>
<tr>
<td><strong>213.</strong> New guardianship legislation should define ‘routine treatment’ as a medical or dental procedure that is not an ‘emergency procedure’, a ‘significant procedure’ or a ‘special procedure’.</td>
</tr>
</tbody>
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**Consent to significant medical treatment**

214. New guardianship legislation should provide that if a person is unable to consent to 'significant treatment', the registered practitioner may undertake that procedure only with the consent of:

(a) a personal guardian with the power to make decisions about the matter, or if there is no such person or that person cannot be reasonably located

(b) a health decision maker, or if there is no such person or that person cannot be reasonably located

(c) the Public Advocate.

**Consent to routine medical treatment**

215. New guardianship legislation should provide that if a person is unable to consent to a 'routine procedure', the registered practitioner may undertake that procedure:

(a) with the consent of a personal guardian with the power to make decisions about the matter, or if there is no such person or that person cannot be reasonably located

(b) with the consent of a health decision maker, or if there is no such person or that person cannot be reasonably located

(c) in the absence of consent if the registered practitioner has taken reasonable steps to locate a personal guardian or a health decision maker and the registered practitioner believes the treatment will promote the personal and social wellbeing of the person concerned.

*If the following recommendations were adopted, OPA would want the specific wording of the legislative provisions to reflect current medical practice, according to which 'treatment' can often involve a series of 'procedures'.

**3.6.2 Power to refuse treatment**

OPA considers that there should be reform concerning who should have power to refuse treatment.113

In seeking to achieve this aim, one possible approach would be to empower all health decision makers (currently ‘persons responsible’) to consent to, and to refuse, medical treatment where the patient does not have capacity to make these decisions. This would vest considerable power in an automatic statutory appointment who would have the same powers as an agent appointed by the patient under the Medical Treatment Act. This would not be appropriate as there is a vast difference between a person appointing an agent to refuse treatment at the end of their lives and having someone have this responsibility through the automatic operation of the law.

A provision could be added in the Guardianship and Administration Act (similar to VLRC recommendation 207)114 to provide that where a health decision maker has withheld consent to, or refused, treatment on a patient’s behalf, a registered practitioner could nonetheless proceed with treatment after providing the health decision maker and OPA with a notice to this effect (challengeable at VCAT).

113 As further discussed elsewhere in this submission, currently, aside from the patients themselves, only agents under Enduring Powers of Attorney (Medical Treatment) and guardians (with appropriate powers) can refuse medical treatment on behalf of adult patients, while persons responsible can only withhold consent to treatment.

114 New guardianship legislation should contain a process similar to that set out in sections 42L, 42M and 42N of the Guardianship and Administration Act 1986 (Vic), which permits a registered practitioner to proceed with treatment when consent has been
OPA, however, does not favour this approach for two reasons. First, it vests too much authority in a person whose power stems not from being appointed by the patient but from the simple fact of their relationship to them. Second, the override power vested in medical practitioners would be similar to the current Section 42M process (under the Guardianship and Administration Act) under which medical practitioners can challenge a decision by the person responsible. This process could not be said to be a successful or meaningful safeguard, since OPA has only received three such notices in the four years, and only one met legislative criteria (the other two were section 42K Notices submitted incorrectly as Section 42M forms).

Instead OPA recommends that a new approach to medical treatment decision making be adopted that places additional safeguards around decisions that will likely lead to a patient’s death. All statutory health decision makers (currently persons responsible) should be able to consent to, or refuse, medical treatment (where the patient themselves does not have the capacity to make the decision). However, only individuals specifically appointed by patients to be able to refuse medical treatment, and guardians appointed by VCAT with requisite powers, should be able to refuse treatment where such a decision will likely lead to death. OPA considers that the Powers of Attorney Act 2014 be amended to allow a principal to appoint an attorney for personal matters to refuse medical treatment in the same way that a medical agent is currently authorised to do so.

The benefits of adopting this new approach to end of life decision making is that it removes the need to distinguish between withholding consent and refusing medical treatment. It would preserve the approach taken in the Medical Treatment Act that a only a person or VCAT can appoint another to make the sorts of decisions to refuse treatment in the terms set out in section 5B(2) of that Act. Such authority does not fall to a person by the mere fact of their relationship with the person.

One concern generated by this new approach might be that it appears to limit, in some situations, the current powers of statutory health decision makers, who would no longer have the technical ability to ‘withhold consent’ to treatment where this withholding of consent may result in death. In a typical scenario a patient may be nearing the end of life having lost the ability to make treatment decisions and without having appointed an attorney with power to refuse medical treatment. A concern might be that the person’s family would no longer, under OPA’s recommended reforms, allow the patient to die.

OPA thinks that this concern is unwarranted. As discussed above, physicians will explore with the person (to the extent able) and the person’s family and very close friends what is in the patient’s best interests and try to build a consensus about what should happen.

If a consensus can’t be reached, there are ways to bring about resolution.

Firstly, OPA’s recommended reforms would only give rise to a conflict between medical practitioners and a patient’s family where medical practitioners wished to continue treatment, and the patient’s family did not wish to continue treatment. In such cases clinicians are likely to apply to VCAT for the appointment of a guardian to make decisions about treatment.

Secondly, if treatment were being provided and the family wished for it to cease (where there had been no appointment by the patient of an Attorney with the power to refuse treatment), an application for a guardianship order could be made by the family to VCAT. A guardian would then have the power to end treatment. Please see Recommendation 7 on this point.

As a matter of principle, OPA considers in such disputes it is appropriate that a decision to refuse treatment, where this will likely result in death, should only be made by a person specifically appointed by the individual (or by VCAT) to make such a decision.

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withheld by the health decision maker after the health decision maker and the Public Advocate have been given a reasonable opportunity to seek a ruling from the tribunal about the proposed treatment.’ Victorian Law Reform Commission, Guardianship: Final Report (2012) [rec 207] lix.
Also, OPA considers that as clinicians are under no obligation to provide futile and unduly burdensome treatment, it may assist that this be codified in the Medical Treatment Act. Such assessments are often key to building a consensus as to a course of action to cease treatment and the process can be assisted by the obtaining of second opinions where necessary.

3.6.3 Substitute medical consent

The Medical Treatment Act 1988, the Guardianship and Administration Act 1986 and the Powers of Attorney Act 2014 should be amended as follows:

**Recommendation 4.** A specific provision should be enacted in the Medical Treatment Act 1988 stating that clinicians are under no obligation to offer or to provide medical treatment that is either futile or unduly burdensome to the patient.

**Recommendation 5.** The Powers of Attorney Act 2014 should be amended so that principals are able specifically to empower attorneys for ‘personal matters’ to refuse medical treatment, including where this refusal is likely to result in death. This power would not be contained in the routine powers of an attorney for personal matters, but would need to be the subject of a specific statement by the principal in the enduring power of attorney.

**Recommendation 6.** The Guardianship and Administration Act 1986 should be amended so that statutory health decision makers (currently ‘persons responsible’) are empowered to consent to, and to refuse, medical treatment on behalf of patients. However, the Guardianship and Administration Act 1986 should specify that statutory health decision makers are not able to refuse medical treatment in situations where this is likely to lead to death.

**Recommendation 7.** The Medical Treatment Act 1988 should be amended to provide that, aside from the patient themselves, only attorneys (appointed under the Powers of Attorney Act 2014) with power to refuse medical treatment, and guardians appointed by the Victorian Civil and Administrative Tribunal with health decision making powers, are empowered to refuse medical treatment where such refusal is likely to lead to death.

The basis on which such refusal of treatment can be made should mirror the current Medical Treatment Act 1988 provision to this effect (section 5B(2)). Such refusal of treatment should only be possible where ‘the medical treatment would cause unreasonable distress to the patient’ or where ‘there are reasonable grounds for believing that the patient, if competent, and after giving serious consideration to his or her health and well-being, would consider that the medical treatment is unwarranted.’
3.7 Advance care directions and personal wishes

It is frequently observed that conversations about patient wishes regarding end of life are occurring far too late.\(^ {115}\) The appropriate use of an advance directive would occur in the context of individuals with a ‘strong and sustained wish to avoid particular interventions that might be offered to them in the future’.\(^ {116}\)

OPA has published widely on the importance of advance directives in planning for one’s end of life:

An advance directive is typically defined as a document which is created by a person while they are competent, that defines the medical treatment that the person wishes to refuse should they become incompetent in the defined circumstances. There are direct benefits in the active use of advance directives, namely, an effective advance directive will promote autonomy, it will remove the decision-making burden from the shoulders of family members or friends, and a treating doctor’s decision to treat or not to treat is settled. However, it is found that an equally significant advantage of advance directives is to encourage discussion between patients and health care professionals and between patients and their families about important health care issues.\(^ {117}\)

In relation to whether the law should provide guidance about the relationship between the wishes a person expresses at the time a decision is made, and any past wishes, views, beliefs and values the person has expressed, OPA has proposed previously:

the law should not elaborate how much weight should be given to current or past wishes. The law should provide merely that these matters need to be taken into account when a substitute decision maker is making a decision. There will be occasions when a person’s current wishes conflict with their past wishes. In such circumstances, there will be times when it is in the interests of a person’s personal and social wellbeing for their current wishes to prevail, just as there will be times when it is past wishes, beliefs or values that should prevail. In giving particular weighting to one or the other, the danger is that substitute decision makers will be unduly constrained in their ability to make decisions that improve the personal and social wellbeing of the person in question.\(^ {118}\)

Notwithstanding this, OPA considers that the autonomy afforded to a person by making an advance care directive is valuable, and should be further enabled by law. OPA notes the important exceptions contained in a further recommendation of the VLRC, that ‘a direction in an instructional health care directive does not operate if the maker would not have intended it to apply in the circumstances that have arisen.’ See OPA recommendation 8 and VLRC recommendation 151 outlined below.

Following further discussion below on these points, OPA’s makes recommendations in relation to personal wishes at 3.8.


\(^{118}\) Office of the Public Advocate, *Submission to the Victoria Law Reform Commission Consultation paper* (2011) 36. Note, however, OPA’s position ‘that the legislation must require the person appointed to a decision-making role to identify and follow the represented person’s wishes wherever possible, but not in situations where to do so would cause undue harm. Persons appointed to formal decision-making roles should never become agents of harm, but should consider and balance the positive and negative consequences of risks:’ at 36.
3.7.1 Common law advance directives

In OPA’s experience, confusion abounds regarding the legal status of common law advance directives.

The VLRC in its Guardianship Consultation Paper identified a number of specific problems associated with medical instructional directives made either through a refusal of treatment certificate under the Medical Treatment Act or at common law.119 Where a person has expressed wishes in a common law advance directive the ability of a guardian, or any other substitute decision maker, to provide legally effective consent to medical treatment that is contrary to those expressed wishes is unclear.120

The legal status of common law advance directives about medical treatment has not been resolved by the High Court and is untested in Victoria.121 Given there have not been any cases concerning the relationship between common law advance directives about medical treatment and a statutory substitute decision-making regime, the VLRC reported that:

… it is unclear whether a common law advance directive is binding on a substitute decision maker or is merely one of the matters that must be taken into account in determining the best interests of the patient.122

White and Willmott et al consider advance care directions an area of difficulty for medical practitioners. The uncertain legal status as to the legal effect of a statement refusing medical treatment, where it is not contained in a refusal of treatment certificate, is likely to make knowing the law in this area more difficult for medical professionals.123

3.7.2 Refusal of treatment certificates

A refusal of treatment certificate is the most authoritative advance directive that can be made in Victoria. The authority of a refusal of treatment certificate is limited.

A refusal of treatment certificate, where signed by a competent person or by an agent or VCAT-appointed guardian:

- provides only advance refusal
- can only be completed for a current condition124
- the patient must receive medical information about their condition
- does not allow a person, or their agent or guardian, to refuse palliative care.

It should be noted that a medical practitioner would not be unequivocally bound to implement an advance directive which conflicts with a personally held view. Referral to another medical practitioner would be the adequate procedure in this regard.

119 The identified problems read as follows: a refusal of treatment certificate under the Medical Treatment Act may only be made in limited circumstances—for a current condition; uncertainty about whether common law advance directives are binding on substitute decision makers or merely provide non-binding guidance to them in reaching a decision; difficulties in identifying that an advance directive exists, which means they might not be followed; lack of community and professional awareness about common law advance directives and refusal of treatment certificates; instructional directives, such as a refusal of treatment certificate, may not provide an accurate reflection of a person’s wishes because their views may change over time, and because of changes in medical treatment options; uncertainty about whether the current law allows a person to give an enduring guardian binding directions: Victorian Law Reform Commission, Guardianship Final Report (2012) 213.
124 The five Australian jurisdictions, other than Victoria, that have enacted legislation about advance directives all allow directions about treatment for a future illness: see Victorian Law Reform Commission, Guardianship Final Report (2012) 210.
The case studies below illustrate two situations where OPA was involved, firstly as a guardian, secondly as an advocate. Both relate to refusal of treatment certificates, and the different cases in which they can be utilised.

**Case Study Four**

**Refusal of Treatment Certificate - by Guardian**

OPA was guardian for a man who was residing in supported accommodation. He was dying and the plan was for him to die in his own home. His doctor had indicated that from a clinical perspective he should not be resuscitated. However, due to the fact that a death in such accommodation becomes a reportable death to the Coroner, there was concern that the accommodation support staff might consider that their duty of care required them to call an ambulance once it was clearly apparent that he was dying. In order to avoid the calling of an ambulance and possible futile resuscitation, the OPA Advocate Guardian completed a Refusal of Treatment Certificate: Agent or Guardian of Incompetent Person. This was in order to assure the patient that he would be supported to die in his own home, consistent with his wishes.

**Case Study 5**

**Case Study Five – Refusal of Treatment Certificate by Competent Person**

Brent had muscular dystrophy. He was not able to consume food and water and had a PEG feeding tube so he could receive artificial nutrition and hydration. He decided he wished to discontinue PEG feeding, knowing that he would shortly thereafter die. OPA was involved in an advocacy basis for Brent. All the workers associated with Brent respected this decision. Brent's mother, who had been appointed his medical agent, also respected this decision. Brent's doctor, who had known him for a long time, was of the view that Brent was capable of making this decision. No one challenged that Brent had capacity to make this decision. Brent completed a Refusal of Treatment Certificate, then discontinued PEG feeding, and soon afterwards, died.
3.8 Recommendations

In making recommendations on the matter of a refusal of treatment certificate, the VLRC recommended ‘refusal of treatment certificates’ be replaced with ‘instructional health care directives.’ Further, the VLRC recommended that the Medical Treatment Act provide for binding instructional directives about health care to be made in a broader range of circumstances. OPA makes the following recommendation, referring to the VLRC’s recommendations on these matters.

Medical treatment and health decision maker

**Recommendation 8.** The Victorian government should adopt the following recommendations made by the Victorian Law Reform Commission in its Guardianship Final Report:

<table>
<thead>
<tr>
<th>Instructional directives</th>
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<tr>
<td>134. An instructional directive should be able to provide:</td>
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<tr>
<td>(a) binding instructions or advisory instructions about health matters</td>
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<tr>
<td>(b) advisory instructions about personal and lifestyle matters, other than health matters and financial matters, that should be taken into account and followed where reasonably possible but should not be legally binding.</td>
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Replace ‘refusal of treatment certificate’ with ‘instructional health care directive’

135. The ability to make refusal of treatment certificates under the Medical Treatment Act 1988 (Vic) should be replaced with a statutory scheme that provides for binding instructional directives about health care to be made in a broader range of circumstances. To reflect these changes, the name ‘refusal of treatment certificate’ should be replaced with ‘instructional health care directive’.

Scope of instructional health care directives

138. An instructional health care directive should allow the principal to:

(a) give directions about health care and medical treatment for their future health care

(b) give information about their directions

(c) provide information about exercising the power.
151. A direction in an instructional health care directive does not operate if the maker would not have intended it to apply in the circumstances that have arisen. This occurs if one of the following applies:

(a) Circumstances, including advances in medical science, have changed since the completion of the instructional health care directive to the extent that the principal, if they had known of the change in circumstances, would have considered that the terms of the direction are inappropriate.

(b) The instructional health care directive is uncertain.

(c) There is persuasive evidence to suggest that the instructional health care directive is based on incorrect information or assumptions.

4 Part Four Conclusion

Navigating the end of life landscape is complex. End of life scenarios are rarely identical and law and practice in this area must be sufficiently flexible to cater for the needs of many. It should also best enable a person’s end of life wishes to be implemented and respected wherever possible. One’s views about end of life decision making may be influenced by many factors: cultural background; religious beliefs; ethics and values; family situation and personal experience.

In its final report the VLRC stated that:

In order to provide the maximum respect for each person’s dignity and to allow them to guide decision making in a way that reflects their values and preferences, it is desirable to provide a range of mechanisms that enable people to guide decision making about them beyond the loss of capacity.\(^{125}\)

OPA is of the view that the current legislative framework does contain a great deal of flexibility to account for the various end of life scenarios that may arise, but it is encumbered by being difficult to understand and negotiate.

In this submission, OPA sought to set out the complex inter-relationship of law, policy and medical practice and the complexity of the law itself. OPA has proposed recommendations that build upon the work of the Victorian Law Reform Commission in relation to guardianship. OPA hopes these recommendations will result in better outcomes for people during the end of their lives by allowing citizens to make informed decisions.

\(^{125}\) Victorian Law Reform Commission, *Guardianship Final Report* (2012) 220. This comment was made in relation to guardianship and administration more broadly.
The greatest protection for a person to best ensure their end of life preferences will be respected is to appoint a trusted substitute decision maker who ideally has taken part in discussions about those end of life preferences. OPA acknowledges however that some people may not hold strong views about their end of life choices. Notwithstanding this, there is a need to educate people so that they reflect and engage with what end of life choices they may have. This takes time and often an examination of broader matters; whether in relation to ageing more generally, illness or planning for the future financially. It is desirable that community discussions about planning for the future and end of life care become normative; where a person is encouraged to talk about ageing, and where this encouragement is not solely originating from the hospital system. There have been numerous initiatives to promote conversations to this end, including the ‘Have the Conversation strategy’ and OPA’s ‘You Decide Who Decides’ enduring powers of attorney facility, in addition to OPA’s various factsheets, which attempt to address planning for the future in an accessible way.
### Appendix 1 – Comparison of the definitions of Medical Treatment

<table>
<thead>
<tr>
<th>Guardianship &amp; Administration Act 1986</th>
<th>Mental Health Act 2014</th>
<th>Medical Treatment Act 1988</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>medical or dental treatment</strong> means—</td>
<td>In this Act, <em>medical treatment</em> means—</td>
<td><em>medical treatment</em> means the carrying out of—</td>
</tr>
<tr>
<td>(a) medical treatment (including any medical or surgical procedure, operation or examination and any prophylactic, palliative or rehabilitative care) normally carried out by, or under, the supervision of a registered practitioner; or</td>
<td>(a) medical treatment (including any medical or surgical procedure, operation or examination and any prophylactic, palliative or rehabilitative care) normally carried out by, or under, the supervision of a registered medical practitioner; or</td>
<td>(a) an operation; or</td>
</tr>
<tr>
<td>(b) dental treatment (including any dental procedure, operation or examination) normally carried out by or under the supervision of a registered practitioner; or</td>
<td>(b) dental treatment (including any dental procedure, operation or examination) normally carried out by or under the supervision of a registered dental practitioner; or</td>
<td>(b) the administration of a drug or other like substance; or</td>
</tr>
<tr>
<td>(c) any other treatment not referred to in paragraphs (a) and (b) that is prescribed by the regulations to be medical or dental treatment for the purposes of this Act—</td>
<td>(c) the administration of a pharmaceutical drug for which a prescription is required; or</td>
<td>(c) any other medical procedure— but does not include palliative care;</td>
</tr>
<tr>
<td>but does not include—</td>
<td>(d) any other treatment that is not referred to in paragraph (a), (b) or (c) and is prescribed by the regulations to be medical treatment for the purposes of this Act—</td>
<td>but does not include palliative care;</td>
</tr>
<tr>
<td>(d) a special procedure; or</td>
<td>but does not include—</td>
<td>(a) the provision of reasonable medical procedures for the relief of pain, suffering and discomfort; or</td>
</tr>
<tr>
<td>(da) a medical research procedure; or</td>
<td>(e) a special procedure or medical research procedure within the meaning of the <em>Guardianship and Administration Act 1986</em>; or</td>
<td>(b) the reasonable provision of food and water;</td>
</tr>
<tr>
<td>(e) any non-intrusive examination made for diagnostic purposes (including a visual examination of the mouth, throat, nasal cavity, eyes or ears); or</td>
<td>(f) any non-intrusive examination made for diagnostic purposes (including a visual examination of the mouth, throat, nasal cavity, eyes or ears); or</td>
<td></td>
</tr>
<tr>
<td>(f) first-aid treatment; or</td>
<td>(g) first-aid treatment; or</td>
<td></td>
</tr>
<tr>
<td>(g) the administration of a pharmaceutical drug for the purpose and in accordance with the dosage level—</td>
<td>(h) any treatment for mental illness or the effects of mental illness.</td>
<td></td>
</tr>
<tr>
<td>(i) if the drug is one for which a prescription is required, recommended by a registered practitioner; or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(ii) if the drug is one for which a prescription is not required and which is normally self-administered, recommended in the manufacturer's instructions or by a registered practitioner; or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(h) any other kind of treatment that is prescribed by the regulations not to be medical or dental treatment for the purposes of this Act;</td>
<td></td>
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<tr>
<td></td>
<td><strong>palliative care</strong> includes—</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(a) the provision of reasonable medical procedures for the relief of pain, suffering and discomfort; or</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(b) the reasonable provision of food and water;</td>
<td></td>
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</tbody>
</table>