



Avant Position Paper

Advance care planning and
end-of-life decision-making

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Avant recognises the importance of patient-centred care and the use of advance care planning at the end of life.

Avant believes that a nationally consistent approach to advance care directives (ACDs) will reduce medico-legal risk for practitioners and ensure the wishes of patients are upheld.

Avant calls for:

- ▶ harmonisation of relevant legislation relating to ACDs and substitute decision-making as a priority
- ▶ continued and further education for medical practitioners about the issues, process and legal requirements in the jurisdictions in which they practise
- ▶ continued and appropriate funding to support the process of advance care planning.

Avant supports the promotion of wellbeing of practitioners dealing with this emotionally fraught area in managing patient death and end-of-life care decision-making.

November 2015

Background

End-of-life decision-making involves difficult conversations not only for patients and family members, but also for medical practitioners involved in their care.¹ In Australia, end-of-life decision-making is a contentious topic with uncertainty in the medical profession about its management. A recent survey showed 86% of doctors find discussions about end-of-life decision-making very challenging.²

Advance care planning can provide some direction to these hard discussions for health practitioners and patients' families about a patient's wishes.³ Advance care planning⁴ is a process that allows patients to outline their decisions about how they would like to be treated if they lose capacity to make decisions or communicate their wishes.

An advance care directive (ACD), resulting from a collaborative advance care planning process between the patient and the treatment team, is one way of formally recording a person's preferences for future care and/or can appoint a substitute decision maker to make decisions about future healthcare.⁵ An ACD is a written legal document, recognised by common law or authorised by legislation.

The use of ACDs ensures people's wishes for the end of life are met and promotes patient autonomy and dignity. ACDs may also reduce the significant cost of resources and technology at the end of life by encouraging the provision of care in the most appropriate way and limiting the inappropriate use of invasive and expensive treatments.⁶

Medical practitioners play a critical role in providing medical care at the end of life. The law in this field is complex and differs between states and territories. Avant is concerned that this lack of consistency and legal uncertainty impacts upon the advance care planning process and exposes practitioners to medico-legal risk.

This paper focuses on advance care planning, and the legal instrument of the ACD, as one aspect of end-of-life decision-making. Many of the issues raised regarding ACDs are also relevant at times of temporary or permanent loss of patient capacity, which may not be restricted to the end of life.

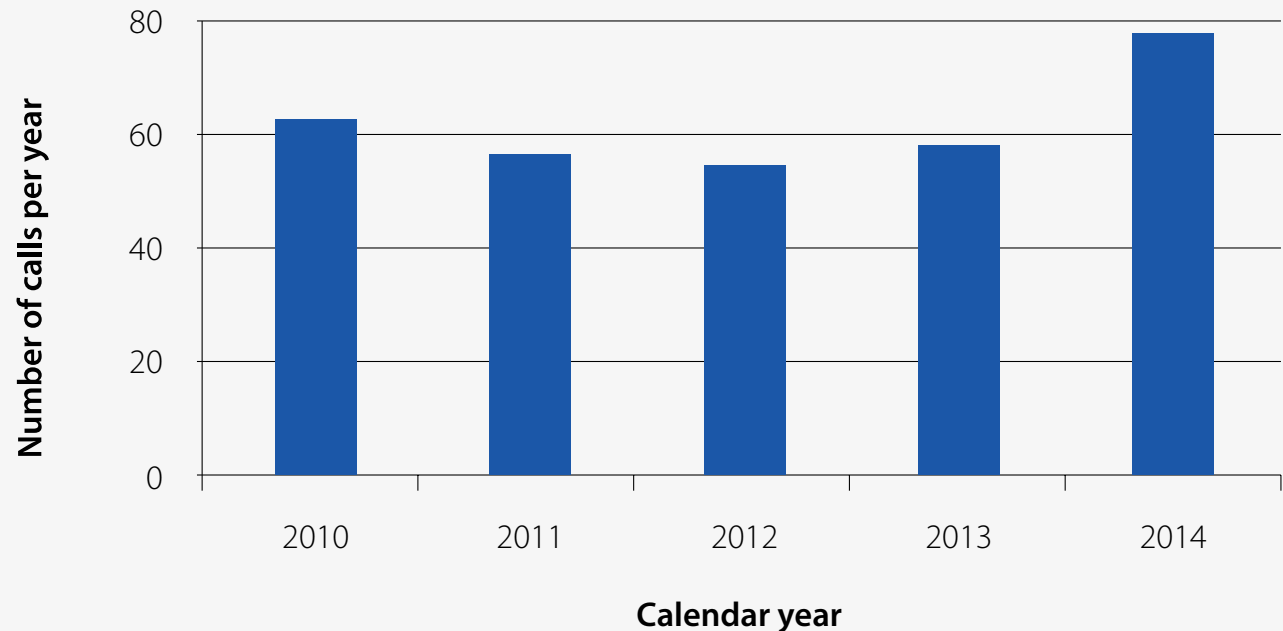
Avant's experience

Avant is Australia's leading medical defence organisation (MDO) representing more than 64,000 healthcare practitioners and students. Avant's Medico-legal Advisory Service (MLAS) provides support and advice to members when they encounter medico-legal issues.

Avant receives a number of requests for advice from members seeking legal guidance on a range of clinical issues associated with advance care planning. Avant is concerned that many practitioners still do not completely understand their legal obligations surrounding this aspect of end-of-life decision-making.

Queries by members focus particularly on the identification of the correct substitute decision-maker when a patient lacks capacity to make decisions for themselves. For example, many MLAS calls focused on clarifying who can give consent to treatment if there is no ACD in place, seeking advice over the validity of powers of attorney as well as seeking advice about providing a report to a guardianship tribunal.

Figure 1: Number of MLAS calls related to end-of-life decision-making, advance care planning and substitute decision-making – 2010-2014.



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The following examples from previous years illustrate the range of concerns expressed by doctors.

Dr X, a GP, was asked by an elderly patient, who was in her eighties and of sound mind, to record that in the event of a stroke or other incapacitating illness she did not want to be resuscitated.

Dr X sought the advice of Avant, asking how she would record the patient's wishes and if there is an official form to fill out. Further, Dr X asked what steps she has to take, if any, to communicate a patient's wish not to be resuscitated, to her family.

Medico-legal Advisory Service call

Dr Z, a GP, filled in for another GP who was the regular doctor at a nursing home. Dr Z was looking after a patient with Alzheimer's who had suffered a fall three days previously.

Dr Z was aware that the patient had a current ACD and had appointed a substitute decision maker, the patient's daughter. The ACD said that in the event of the patient becoming sick, only comfort measures should be provided.

Dr Z was concerned that the patient had a head injury that required treatment and the treatment may have been against her wishes.

Medico-legal Advisory Service call

Dr Y, a cardiologist, was asked by palliative care services to turn off the implanted defibrillator of a terminally ill elderly patient, who was unable to consent to the procedure, due to lack of capacity. Dr Y was not aware of any ACD made by the patient and was confused about who can legally "call the shots".

Dr Y discussed the implications with the patient's family and they were comfortable with the decision.

Dr Y sought advice from Avant about whether this is sufficient, including how best to deal with family and colleagues regarding futile treatment, and any applicable legislation.

Medico-legal Advisory Service call

Practitioners also worry about making incorrect decisions surrounding end-of-life care. Medical practitioners are not under any legal obligation to provide "futile" treatment.⁷ Nevertheless, sometimes there is a concern expressed by doctors about their potential criminal or civil liability when a clinical decision is made to recommend that treatment be withheld or withdrawn,⁸ or managing conflicting pressures from patients, their families and the clinical recommendations about futile treatment.

Analysis and recommendations

Inconsistent legislation and legal uncertainty

The difficulty of achieving uniformity within the Australian legal framework for delivery of health services has resulted in jurisdictional differences.⁹ This lack of national consistency and legal uncertainty is problematic in many areas of healthcare; however the impact is particularly fraught in the emotionally charged area of end-of-life decision-making.¹⁰ This is particularly so in relation to advance care planning and the legal status of ACDs.

As a result of differing state and territory legislative regimes there are different terms for similar concepts.¹¹ In practice, this means that although ACDs are used in all states and territories, the terminology, format, documentation requirements, how the ACD applies and even the hierarchy of substitute decision-makers differ markedly from state to state.

In Avant's view, these intricacies and varied legal requirements across states and territories surrounding ACDs cause confusion and have significant implications for practitioners, especially those who work across jurisdictions.

Terminology used for advance care directives (ACDs) by state and territory	
ACT	Health Direction
NSW	Advance Care Directive (recognised at common law)
NT	Direction
QLD	Advance Health Directive
SA	Advance Care Directive (effective from 1 July 2014) (Anticipatory Direction still valid if made prior to 1 July 2014)
TAS	No statutory document regarding Advance Care Directives or refusal of medical treatment
VIC	Refusal of Treatment Certificate
WA	Advance Health Directive

Research has highlighted the challenges that practitioners face when end-of-life decisions arise, including identifying legally valid ACDs¹² and uncertainty about who is the authorised substitute decision-maker. In a survey of NSW medical practitioners, 94% agreed it would be beneficial to know who has the legal authority to make decisions at the end of life, when the patient has lost capacity.¹³

Some states have provisions¹⁴ facilitating the mutual recognition of interstate ACDs. However, it has been highlighted that due to the variation in state requirements it would be difficult for some jurisdictions to recognise an ACD from elsewhere.¹⁵ Further, practitioners may not be aware that an interstate ACD is considered valid.

Avant is concerned as this uncertainty leaves many practitioners unsure about whether they can legally act in accordance with a patient's ACD. There are significant potential consequences for practitioners who do not comply with a patient's wishes or comply with an invalid ACD¹⁶ or even allow someone to make decisions on behalf of the patient without authority to do so.

For example, criminal responsibility could arise for murder or manslaughter where treatment was withheld or withdrawn unlawfully.¹⁷ Practitioners could also be held liable for assault if treatment was provided without appropriate consent or authorisation.¹⁸ Practitioners may be subject to a civil claim by the patient and/or patient's family, or be subject to disciplinary or coronial proceedings.¹⁹

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Additionally, the uncertainty about how these ACDs will be followed can impact upon timeliness in decision-making and the ability to provide patient-centred care.

In 2012, the Senate's Community Affairs References Committee released its report on Palliative Care in Australia. The committee recommended that "national model legislation for advanced care planning be developed, and that all governments pursue harmonisation of legislation as a high priority".²⁰

The Senate Committee found that the differences in state and territory legislation and complexities with advance care planning were hampering greater take-up.²¹ Awareness of advance care planning remains very low throughout the Australian community and especially amongst residents of residential aged care facilities.²² This is despite survey results in which 93% of health professionals agreed or strongly agreed that advance care planning is a valuable and worthwhile activity for patients.²³

Avant agrees with the Senate Committee's recommendation and believes that harmonisation of legislation will provide a nationally consistent approach to end-of-life decision-making, not only in terms of process, but also in terms of outcomes, for patients and practitioners alike.

Avant calls for the development and use of consistent terminology as a matter of priority and welcomes moves to harmonise formats and terminology in this difficult area. The National Framework for Advance Care Directives²⁴ and

the National Consensus Statement: Essential elements for safe and high-quality end-of-life care²⁵ are a useful start towards a nationally consistent system regulating ACDs.²⁶

Avant supports the use of national guidelines in enabling health services to develop systems for delivering appropriate, high-quality care to patients both at the end-of-life and during the advance care planning process.

Education

Decisions regarding life-sustaining treatment are part of mainstream medical practice. However, the legal role that practitioners play in end-of-life care is less recognised.²⁷ Legal commentators have highlighted that medical practitioners perform critical legal functions during end-of-life decision-making including:²⁸

- ▶ assessment of capacity
- ▶ identification of possible decision-makers
- ▶ determining whether the decision-maker possesses the legal power to make the relevant decision.

In providing end-of-life care, practitioners must be aware of their clinical, ethical and legal responsibilities. Avant is concerned that practitioners lack a comprehensive understanding of the law regarding ACDs and this confusion reduces patient autonomy and puts practitioners at risk. This is consistent with Australian research which

indicates there are significant knowledge gaps amongst practitioners regarding their legal obligations,²⁹ particularly when faced with the often fraught decision of withholding or withdrawing life-sustaining treatment.³⁰

The need for further education and experience dealing with end-of-life care issues for practitioners is supported by the literature. A recent Australian study suggests that earlier exposure to palliative care can enhance junior doctors' professionalism, provision of patient-centred medicine, psychosocial and spiritual aspects of palliative care, and communication.³¹ Colyer highlights that there needs to be more legal training on end-of-life issues throughout the career of medical practitioners.³² Cartwright and Montgomery et al recommended further education for practitioners to reduce medico-legal risk and promote patient autonomy.³³

Avant agrees with these recommendations and supports further and continuing education for practitioners on the legal and clinical aspects of end-of-life decision-making, including ACDs. Avant believes continuing education will clarify the role and legal authority of decision-makers³⁴ for practitioners and reduce some of the uncertainty in this complex area.

Education targeting doctors' legal responsibilities in this area should begin at university, continue during training and be included as part of continuing professional development

provided by the specialist colleges throughout the career of practitioners.³⁵ This education should cover relevant legislation, regulatory frameworks and provide the skills to have difficult conversations regarding advance care planning and end-of-life decision-making.

The importance of education notwithstanding, until the inconsistencies within state and territory legislation and the legal uncertainty surrounding end-of-life decision-making are resolved, Avant is concerned that practitioners will continue to struggle with understanding their legal obligations. Consistent implementation of any national guidelines³⁶ will be difficult as health professionals view the lack of health service, state or national policy regarding ACDs as a compounding factor in their implementation.³⁷

Health and wellbeing of practitioners

Discomfort with or fear of death and dying is experienced by patients and practitioners alike. Death is often viewed as a medical failure³⁸ and the potential impact upon practitioners' health and wellbeing of providing care at the end-of-life should not be minimised.³⁹

In Avant's experience, practitioners have difficulty dealing with situations where there is disagreement among or between family members, the patient and the treating team about treatment options. Further, poor communication and uncertainty about the management of end-of-life care may result in loss of dignity for the patient and additional distress for family members and

practitioners.⁴⁰ This has implications for safe and competent quality patient care⁴¹ as practitioners report feeling less successful addressing care needs when conflict is present.⁴²

Studies have predominantly focused on nurses' moral distress in end-of-life care.⁴³ This impact and experience can be extended to healthcare professionals facing difficult end-of-life care decisions.

The literature indicates that in situations involving disagreement, practitioners can experience moral distress, with significant personal and professional impact.⁴⁴ For example, differing views about the suitability of end-of-life care between the patient and practitioner, can be a source of moral distress for the practitioner.⁴⁵

Other barriers to providing good end-of-life care were identified in a survey of physicians and included: ⁴⁶

- ▶ family conflict about the best course of action
- ▶ patient / family discomfort with or fear of death
- ▶ cultural / religious beliefs of the patient or family.

Avant believes that there should be better support and due regard for the wellbeing of practitioners dealing with this emotionally fraught area. This should include education and training to ensure practitioners know when and how to access peer support, mentoring and clinical supervision as well as having access to appropriate support and services for counselling or debriefing, including external health programs.

There is a general consensus⁴⁷ within the community and healthcare industry that advance care planning would make end-of-life care more consistent with the patient's wishes, improve care and alleviate stress associated with difficult decisions faced by family members and practitioners.

Appropriate funding

The literature highlights that one of the reasons attributed to the low level of uptake of advance care planning in Australia is current financial disincentives.⁴⁸

Avant believes appropriate and continued funding of end-of-life care, including supporting the process of advance care planning and palliative care services, will raise awareness of end-of-life choices, support high quality decision-making, improve patient outcomes and further contribute to a health care system that is person-centred.

Avant believes appropriate funding and rebates for advance care planning will support the process of advance care planning for the end of life and encourage early and open communication between practitioners and patients. Funding should recognise that advance care planning is a process and would cover the time practitioners spend with the patient (often more than one visit); time spent with the patient's family or carer; time organising palliative services; and case conferencing with other practitioners.

Avant's position

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Key links

- ▶ Avant's Risk IQ webinar 'Professional morality: difficult ethical issues in medicine'
- ▶ Avant's video 'Breaking bad news'
- ▶ Avant's submission to the Legal and Social Issues Committee Inquiry into End of Life Choices (Vic)
- ▶ Avant's submission to the Australian Commission on Safety and Quality in Health Care's Consultation on the draft National Consensus Statement on end-of-life care in acute hospitals
- ▶ Avant's position paper on the impact of complaints on health and wellbeing
www.avant.org.au/complaints-handling

Further reading

- ▶ Atul Gawande's latest book *Being Mortal: Illness, Medicine and What Matters in the End*
- ▶ Karen Hitchcock's Quarterly Essay 57, Dear Life: On caring for the elderly

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