



**LEGISLATIVE ASSEMBLY**  
FOR THE AUSTRALIAN CAPITAL TERRITORY

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**SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT**

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Mrs Elizabeth Kikkert MLA, Ms Caroline Le Couteur MLA.

## Submission Cover Sheet

### End of Life Choices in the ACT

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Secretary  
Select Committee on End of Life Choices  
In the ACT  
Legislative Assembly for the ACT  
GPO Box 1020  
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By email: [LACommitteeEOLC@parliament.act.gov.au](mailto:LACommitteeEOLC@parliament.act.gov.au)

Dear Committee Secretary

### **Select Committee on End of Life Choices in the ACT**

Thank you for the opportunity to provide input into the Select Committee's inquiry on end of life choices in the ACT.

Avant is Australia's largest medical defence organisation, providing professional indemnity insurance and legal advice and assistance to more than 75,000 medical and allied health practitioners and students around Australia, including the ACT.

In addition to assisting members in claims and complaints under our insurance policies, Avant has a medico-legal advisory service (MLAS) that provides support and advice to members when they encounter medico-legal issues. Our members have contacted us for advice about issues relating to end of life care and we have assisted our members in various matters in which end of life issues have been raised.

### **Avant's experience**

Practitioners are often uncertain about their obligations when treating patients at the end of life. The calls we have received from our members include issues such as who is the appropriate substitute decision-maker when a patient lacks capacity and there are several family members, and how to proceed in the face of an advance directive where it conflicts with their clinical judgment, or where there is conflict.

Based on our experience of assisting members, the key concerns we have identified in this area are:

- Lack of understanding of medical practitioners about their legal obligations regarding advance care directives and substitute decision-making, including identifying who is the appropriate substitute decision-maker.
- Lack of consistency of the law across jurisdictions in Australia, leading to uncertainty and confusion.
- Difficulty dealing with situations where there is disagreement among or between family members, the patient and the treatment team about treatment options.

Practitioners worry about getting it wrong. In our experience, practitioners are often challenged by the implications of an advance care directive. Some practitioners can feel very uncomfortable about proceeding on the basis of a refusal of treatment. On the other hand, some practitioners express concern about providing increasing pain relief and sedation in the terminal phases of illnesses because of the concern that they may be subject to prosecution. The doctrine of double effect is often not well understood.

In light of this experience, our submission provides some general comments on three key areas relating to end of life choices:

1. National consistency.
2. Substitute decision-making.
3. Voluntary assisted dying.

### **1. National consistency in the legal framework**

As a national organisation we support national consistency of approach in legislation and national consistency of terminology.

Each state and territory in Australia has a different legal framework for end of life decision-making. As a result there are different terms for similar concepts.

In the context of advance care planning, although advance care directives (ACDs) are used in all states and territories, the terminology, format, documentation requirements, the application of ACDs in practice and even the hierarchy of substitute decision-makers, differ markedly from state to state.<sup>1</sup>

In the ACT there are three ways in which a person can plan for their future health care in advance. These include appointing an enduring power of attorney, completing a health direction under the *Medical Treatment (Health Directions) Act 2006* and completing an advance care plan statement of choices.

Lack of consistency between states and territories and legal uncertainty impacts upon the ability of doctors to provide appropriate care at the end of life, and exposes doctors to medico-legal risk including criminal and civil claims and disciplinary or coronial proceedings. The intricacies and varied legal requirements across states and territories surrounding advance care directives and substitute decision-making cause confusion and have significant implications for doctors and patients.

In 2012, the Senate Community Affairs References Committee's report, *Palliative Care in Australia*, found that differences in state and territory legislation and complexities with advance care planning were hampering greater take-up. The Senate Committee recommended that "national model legislation for advanced care planning be developed, and that all governments pursue harmonisation of legislation as a high priority".<sup>2</sup> Avant supports the development and use of consistent terminology across Australia as a matter of

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<sup>1</sup> See Carter R, Detering K, Silvester W and Sutton E "Advance care planning in Australia: what does the law say" *Australian Health Review* 2016, 40, 405-414. See also QUT End of Life Law in Australia <https://end-of-life.qut.edu.au/>

<sup>2</sup> Senate Community Affairs References Committee. *Palliative Care in Australia*. 2012. See also Deeble Institute "Improving end-of-life care in Australia" Issues brief no. 19, 14 December 2016

priority. We believe that the legislation around Australia that impacts on end of life choices should be harmonised.<sup>3</sup>

The legislative framework should be clear in its application and should facilitate appropriate end of life decision-making. The National Framework for Advance Care Directives (National Framework) released in 2011<sup>4</sup> and the Australian Commission on Safety and Quality in Health Care's National Consensus Statement: Essential elements for safe and high-quality end of life care are a useful start towards a nationally consistent approach to end of life care.

## 2. Substitute Decision-Making

Determining the appropriate substitute decision-maker for a patient who lacks capacity, is an important legal role that practitioners play in decision-making at the end of life.<sup>5</sup>

A lack of knowledge among medical practitioners about who is the correct substitute decision maker can present challenges to making treatment decisions. It can impact on the ability of the profession to resolve conflict and deliver appropriate care.

In the ACT there are several potential substitute decision-makers for decisions at the end of life, when a patient lacks capacity:

- an attorney appointed under an enduring power of attorney for a health care matter
- a guardian appointed by the ACT Civil and Administrative Tribunal
- a health attorney (a hierarchy of default decision-makers).

Where there is an enduring power of attorney and a valid health direction, the relationship between the two is not so clear. Some practitioners are unsure of which instrument takes precedence.

In addition, in our experience many practitioners believe that a patient's next of kin is the appropriate substitute decision-maker for medical treatment decisions. "Next of kin" has no legal status at common law.

The existence of three pieces of legislation relevant to decision-making at the end of life, the *Medical Treatment (Health Decisions) Act 2006*, the *Guardianship and Management of Property Act 1991* and the *Powers of Attorney Act 2006* can cause confusion and consideration should be given to simplifying the legislation.

We would also support more education and information for those working within a healthcare setting about these issues.

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<sup>3</sup> Avant Position Paper: *Advance care planning and end-of-life decisions making* 26 November 2015

<sup>4</sup> The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council. A National Framework for Advance Care Directives. September 2011: 1-76

<sup>5</sup> White B et al. The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 1 (New South Wales). *Journal of Law and Medicine* 2011; 18: 498-522

### 3. Voluntary Assisted Dying

As a membership organisation, Avant recognises that our members hold a range of views on VAD. Because of this, we do not take a position on the substantive issue of whether or not VAD should or should not be permitted at law.

Avant has published a [position statement of VAD](#). Our key points are:

1. Any legislative framework for VAD must incorporate sufficient protections for those doctors who choose to participate, and those who choose not to participate.
2. Any legislation needs to provide a clear framework within which patients and doctors can operate.
  - a. As a matter of general principle, legislation should balance the need for clear and unambiguous wording with the need to leave sufficient scope for the exercise of clinical judgment, consideration of the patient's individual circumstances and changing standards of medical practice.
  - b. If legislation is too prescriptive, compliance will be difficult and may leave limited room for clinical judgment and increase medico-legal risk. Legislation that is too flexible may be open to interpretation and retrospective criticism.
3. The following protections should be included in the legislation:
  - a. That a doctor is not required or compelled to comply with a patient's request, or to be involved in assisted dying at all.
  - b. That a doctor should not face any criminal, civil, administrative or disciplinary action for refusing to participate, or for choosing to participate.
  - c. That doctor is immune from criminal and civil liability, and disciplinary action for providing treatment that causes death if they have acted in accordance with the requirements of the legislation in good faith and without negligence.
  - d. That this immunity be extended to a doctor being present when the patient takes the medication.
4. Any legislation should not include a prescriptive requirement for referral in the case of conscientious objection. Issues relating to conscientious objection and referral should be dealt with under current ethical guidelines.

#### Additional matters

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.

We attach our position paper [Advance care planning and end-of-life decision making](#) which provides further information about issues under consideration by the Committee.

Please contact me on the details below if you require any further information or clarification of the matters raised in this submission.

Yours sincerely



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# Avant Position Paper

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

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

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.<sup>1</sup> 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.<sup>2</sup>

Advance care planning can provide some direction to these hard discussions for health practitioners and patients' families about a patient's wishes.<sup>3</sup> Advance care planning<sup>4</sup> 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.<sup>5</sup> 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.<sup>6</sup>

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.

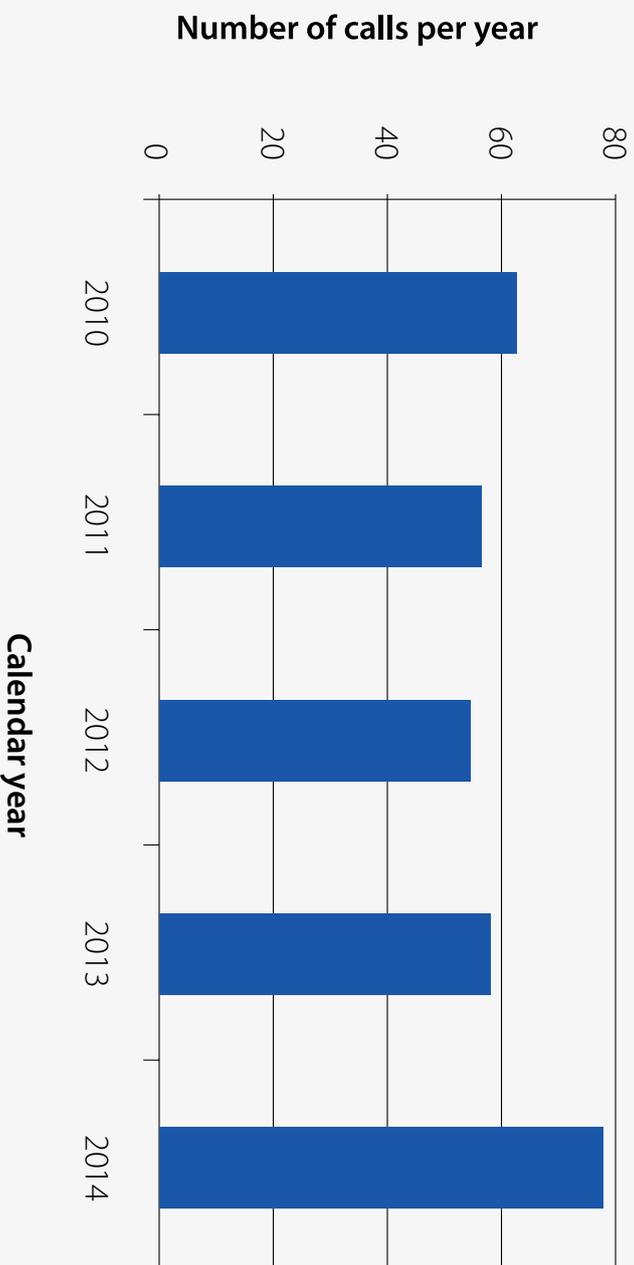


Figure 1: Number of MLAS calls related to end-of-life decision-making, advance care planning and substitute decision-making – 2010-2014.

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

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.<sup>7</sup> 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,<sup>8</sup> 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.<sup>9</sup> 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.<sup>10</sup> 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.<sup>11</sup> 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 ACDs<sup>12</sup> 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.<sup>13</sup>

Some states have provisions<sup>14</sup> 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.<sup>15</sup> 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 ACD<sup>16</sup> 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.<sup>17</sup> Practitioners could also be held liable for assault if treatment was provided without appropriate consent or authorisation.<sup>18</sup> Practitioners may be subject to a civil claim by the patient and/or patient's family, or be subject to disciplinary or coronial proceedings.<sup>19</sup>

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

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".<sup>20</sup>

The Senate Committee found that the differences in state and territory legislation and complexities with advance care planning were hampering greater take-up.<sup>21</sup> Awareness of advance care planning remains very low throughout the Australian community and especially amongst residents of residential aged care facilities.<sup>22</sup> 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.<sup>23</sup>

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 Directives<sup>24</sup> and

the National Consensus Statement: Essential elements for safe and high-quality end-of-life care<sup>25</sup> are a useful start towards a nationally consistent system regulating ACDs.<sup>26</sup>

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.<sup>27</sup> Legal commentators have highlighted that medical practitioners perform critical legal functions during end-of-life decision-making including:<sup>28</sup>

- ▶ 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,<sup>29</sup> particularly when faced with the often fraught decision of withholding or withdrawing life-sustaining treatment.<sup>30</sup>

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.<sup>31</sup> Colyer highlights that there needs to be more legal training on end-of-life issues throughout the career of medical practitioners.<sup>32</sup> Cartwright and Montgomery et al recommended further education for practitioners to reduce medico-legal risk and promote patient autonomy.<sup>33</sup>

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-makers<sup>34</sup> 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.<sup>35</sup> 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 guidelines<sup>36</sup> 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.<sup>37</sup>

### 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 failure<sup>38</sup> and the potential impact upon practitioners' health and wellbeing of providing care at the end-of-life should not be minimised.<sup>39</sup>

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.<sup>40</sup> This has implications for safe and competent quality patient care<sup>41</sup> as practitioners report feeling less successful addressing care needs when conflict is present.<sup>42</sup>

Studies have predominantly focused on nurses' moral distress in end-of-life care.<sup>43</sup> 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.<sup>44</sup> 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.<sup>45</sup>

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

- ▶ 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 consensus<sup>47</sup> 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.<sup>48</sup>

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

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.

## 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](http://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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