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10 February 2017

Human Services Inquiry  
Productivity Commission  
Locked Bag 2  
Collins Street East  
MELBOURNE VIC 8003

Via post and online submission

**MIGA submission - Productivity Commission Reforms to Human Services Inquiry**

MIGA appreciates the opportunity to make a submission on end of life care issues to the Commission's Reforms to Human Services Inquiry.

A copy of MIGA's submission is enclosed.

MIGA is a medical defence organisation and medical indemnity insurer advising, assisting and educating medical practitioners, medical students, health care organisations and privately practising midwives throughout Australia. Further details about its interest and involvement in end of life care issues are set out in its submission.

Please contact Timothy Bowen, telephone 1800 839 280 if  
you have any questions about MIGA's submission.

We trust our comments are of some assistance, and look forward to further engagement with the Commission and other stakeholders on these important issues.

Yours sincerely

**Cheryl McDonald**  
National Manager – Claims & Legal Services

**Timothy Bowen**  
Senior Solicitor – Advocacy, Claims & Education

**MIGA submission**

**Productivity Commission**

**Reforms to Human Services Inquiry**

**Issues Paper – End of life care**

**February 2017**

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## MIGA submission

### Productivity Commission – Reforms to Human Services Inquiry

#### End of life care

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##### Executive summary

1. MIGA's submission addresses a number of the issues raised by requests for information 19 and 21, relating to end of life care, in the Commission's Reforms to Human Services Inquiry Issues Paper (**the Issues Paper**).
2. Its submission reflects medico-legal issues it has encountered in advising and assisting its members in relation to end of life care issues, which have contributed to its advocacy and education activities on this issue.
3. In summary, MIGA supports:
  - working towards nationally consistent legislation, guidelines and education on end of life care
  - access to, clarity and implementation of advance care directives (**ACDs**), including:
    - a national framework whereby differing ACD requirements in various states and territories do not render an ACD invalid if made elsewhere, or if it is valid under common law, even if not complying with particular statutory requirements
    - nationally consistent guidelines for the health profession on locating, determining validity of, interpreting and applying ACDs
    - convening national working groups, with appropriate governmental, peak professional and community input, to develop model ACDs
    - examining ways to improve the storage of, and access to, ACDs
    - appropriate protections for health practitioners relating to the use of ACDs in good faith
  - consistency and clarity around assessing capacity, determining substitute decision-makers and their respective obligations and powers
  - clarifying access to and providing education about around dispute resolution mechanisms, including informal approaches, 'brokered' or facilitated resolution (such as mediation or neutral evaluation) and both when and how to access formal dispute resolution mechanisms (such as tribunals and courts)
  - clarifying and providing consistent education on a health practitioner's duties and protections, including on withdrawal, withholding or refusal of treatment, the doctrine of 'double-effect', declination to provide non-beneficial treatment and conscientious objection

## MIGA submission – Productivity Commission – End of life care

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### MIGA's interest

4. MIGA is a medical defence organisation and medical indemnity insurer with a national footprint which has represented the medical profession for over 115 years.
5. Its members and policy holders including significant numbers of medical practitioners, medical students, health care organisations and privately practising midwives working throughout Australia in a variety of settings, including in general practice, acute and palliative care, both in the community and in public and private hospitals.
6. MIGA's lawyers provide advice to its members on the often difficult and complex issues relating to end of life care, including ACDs, withdrawal and withholding treatment, patient or clinician refusals to provide treatment, capacity, consent, substitute decision-makers and guardianship. Its lawyers are familiar with situations where uncertainties and disputes arise, often involving family members, which can be very difficult to navigate.
7. Through its Risk Management Program, MIGA provides various education and resources, including materials specifically directed to ACDs.
8. MIGA also has significant involvement in end of life care issues on a professional advocacy and policy front, which most recently has included contributing to:
  - New South Wales Law Reform Commission Review of the New South Wales *Guardianship Act* (which began last year and is ongoing)
  - New South Wales Health Review of Advance Care Directives Project (ongoing)
  - Victorian Department of Health and Human Services Consultation on Simplified Medical Treatment Decision Making and Advance Care Planning, which led to the Victorian *Medical Treatment Planning and Decisions Act*, commencing in early 2018
9. Over the next few months, MIGA is hosting a series of high-level key opinion leader dinners where one of the topics of presentation and discussion is "*Improving End of Life Care – Can we overcome practical limitations?*"

### Commission's requests for information 19 and 21

10. MIGA's submission responds to the following requests for information in the Issues Paper:
  - information on ways to improve the implementation of choice in end of life care (request 19)
  - information on complementary measures to support greater use of choice in end of life care (request 21)

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11. In MIGA’s view, the following are critical components of improving choice in end of life care:

- **consistency of frameworks** - working towards nationally consistent end of life care legislation, policies and education wherever possible and practical is a key way to improve implementation of choice in end of life care, through providing better support for planning initiatives (including ACDs), the use of such initiatives by patients, carers and health practitioners, and to improve integration between various areas of health care
- **increasing advance care directive usage** – impediments and issues around the use of ACDs need to be dealt with in order to increasing ACD usage and implementation, given these are a critical component of effective end of life care planning
- **consistency of assessment and obligation** – clear and consistent understandings around capacity, substitute decision-maker hierarchy and their respective obligations and powers improves understanding around patient preferences, what needs to be planned, when a patient lacks capacity and what to do in those circumstances
- **available and knowledge of informal and formal dispute resolution mechanisms** – this assists in recognising and implementing patient preferences around of life care, particularly where a patient lacks capacity and both substitute decision-makers and health practitioners are trying to work out what care should be provided at the end of life stage
- **clarifying professional duties and protections** – this would reduce professional uncertainty and hesitation around end of life discussions, planning, advice and implementation.

### Consistency in legislation, policies and education

12. Wherever possible and practical, national consistency in end of life care legislation, policies and education is critical.

13. End of life care is governed by numerous pieces of legislation and common law doctrines in different parts of Australia. Clinical and other professional guidelines vary between location and context, such as public and private hospitals, acute and palliative care, and specialist and general practice settings. Available education varies significantly in content and context.

14. Throughout Australia:

- ACDs regulation varies considerably, being subject to statutory regimes in most states and territories, but common law regimes exclusively or in conjunction with statutory regulation in a number of states and territories. Even amongst statutory jurisdictions, there are considerable differences in ACD terminology, scope of directions which can be given, documentation requirements and methods of determining validity
- there are inconsistencies in terminology for substitute decision-makers, their hierarchy and their respective powers and obligations

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- there are differences in obligations on and protections for health practitioners providing end of life care
15. These national inconsistencies are a significant impediment to improving end of life care, both in planning and provision stages.
  16. Health practitioners, patients, their family and friends and the community lack certainty and clarity in navigating through these processes, which is of itself is a barrier, and can lead to inadequate planning and dispute.
  17. There are obvious difficulties in reaching national consensus on end of life care legislation. However, laws relevant to end of life care have either recently been under review, as in Victoria and South Australia, or are currently under review, as in New South Wales. This suggests there is considerable scope for various states and territories to look towards national consistent approaches and understandings, even within existing frameworks, wherever possible and practical.
  18. There is considerable guidance available, both in the form of clinical and professional guidelines, around end of life care, from government and peak professional bodies. However, these do not apply uniformly, nor do they necessarily address all relevant issues different practitioners in a variety of contexts may encounter. Knowledge of different policies also tends to be limited. It is important for there to be coordination between governmental, peak professional and community bodies over end of life care guidelines in different settings. Different guidelines are likely to be needed for different settings. However, agreement about and / or endorsement of various guidelines by key stakeholders, including government, professional bodies and the community, working towards uniformity and consistency wherever possible and practical, would be of considerable assistance.
  19. On the issue of education, more could be done to ensure better professional and community understandings of end of life care planning and implementation. Some education and training is already provided in various forms, with varying content. It would be helpful for national initiatives to be developed, with input and endorsement from key governments, professional and community bodies, producing education which is consistent, comprehensive and available in appropriate forms to health practitioners, patients and those close to them.

### **Advance care directives**

20. ACDs are critical complementary measures to improve, support and implement greater use of choice in end of life care.
21. As indicated above, the differing regimes throughout Australia ACDs, some statute-based, some common law-based and others using both regimes, can cause significant challenges.
22. A move towards national consistency and compatibility, where possible and practical, would be helpful.

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23. Careful consideration should be given to:

- mutual recognition of ACDs that satisfy common law requirements, even if not satisfying a particular state or territory statutory requirement – this occurs in a number of states and territories, but not throughout Australia
- deficiencies in form, as opposed to substance, not invalidating a statutory ACD
- working towards a model or mutually recognised ACD template or form, for use throughout Australia
- initiatives to improve storage of and access to ACDs
- clarifying obligations of, and protections for, health practitioners in relation to assistance with preparing, identifying, determining validity of and applying ACDs in good faith

24. There are potentially significant impediments to an ACD made in one part of Australia, or even overseas, being recognised in other parts of Australia. For instance, common law ACDs are not recognised in Queensland, and it is uncertain whether they are valid in Victoria (which will change in 2018, when they will be considered valid if made elsewhere). However, they are the only method for making an ACD in New South Wales and Tasmania. There are also differences between different states and territories over information which must be provided to a patient before making an ACD, the types of directives which can be given and the circumstances in which they can apply. ACD witnessing and certifications requirements also vary.

25. ACD clinical and professional guidelines are published by different governmental and professional bodies throughout Australia. However, these are not always well known, or cover all the different issues which patients, those close to them and health practitioners may encounter. Like as for guidelines around end of life care more generally, there is a need for national guidelines on ACDs, developed through working groups comprising of government, professional and community interests. These need to be endorsed by key stakeholders within those groups, well-publicised and available in a variety of platforms, including written, online and via apps. In particular, apps would be of great use to health practitioners working in a variety of care settings.

26. Steps have been taken in various Australian states and territories towards developing model ACDs. For example, the South Australian Government produced an ACD kit. In addition, NSW Health has been consulting over a model ACD. It would be very helpful for Australian states and territories to work towards a model national ACD template, which can be recognised and applied throughout Australia.

27. In terms of storage of and access to ACDs, the My Health Record system now provides scope for an ACD to be stored. However, this facility does not seem to be well-known either amongst health practitioners or the community. Options for encouragement of and incentives to patients and health practitioners to keep ACDs on record should be explored. Such initiatives may include keeping them in clinical records held by a patient's GP or a hospital where they have attended for

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significant health problems, or for patient to keep them available on their person, such as on mobile telephones.

28. Health practitioners can face considerable uncertainty about the steps which need to be taken to determine if an ACD exists, to locate it, to assess whether it is valid and to consider whether it can be applied to the circumstances in question. Differing state and territory regimes for the types of directives which can be given, witnessing and certification requirements, and when directives must be followed, confuse the picture further. Such uncertainty warrants nationally consistent protections for health practitioners who have made reasonable attempts in good faith to find, consider and apply an ACD.

### **Consistency on capacity and substitute decision-maker issues**

29. Resolving uncertainties around assessment of capacity, the identity of appropriate substitute decision-makers, and their respective obligations and powers, is needed to ensure implementation of choice in end of life care by patients so far as is possible.
30. The test for assessing decision-making capacity in health care is clear, being based on both common law in most Australian states and territories and clinical judgement. In MIGA's experience, health practitioners usually have a good understanding of clinical judgement issues around capacity, but they may not be as aware of common law issues. Widely available education and training nationally of the health profession in relation to these issues in the end of life care context, combined with appropriate resources which are easily and quickly available, including through innovative platforms such as apps, would assist.
31. The hierarchy of substitute decision-makers, and their respective obligations and powers, can vary between Australian states and territories.
32. In MIGA's experience, health practitioners can experience difficulty in determining who the appropriate substitute decision-maker is, and in knowing their obligations and powers. It is one thing for a health practitioner to recognise that the substitute decision-maker which has been appointed under an ACD or otherwise by a patient prior to losing capacity, or when it is agreed amongst family members. However, significant challenges can arise where there are differing views between family members on care to provide to a loved one and / or disputes over who should act as substitute decision-maker.
33. Even if the hierarchy of substitute decision-makers may be well known, there can be challenges in determining who should act, such as if two candidates have equal stature. Most legislation specifies a close friend or relative can act as a substitute decision-maker, without necessarily providing any hierarchy within those levels. These requirements do not necessarily reflect patient intent or the realities of familial, other kinship and societal relations.
34. Consideration needs to be given to how both the health profession and community can be better assisted in clarifying how substitute decision-making works in different realities, with a view towards national consistency where possible and practical.



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### Clarification and education over resolving disputes in end of life care

35. Implementing choice in end of life care can be challenging if there are contested views over what a patient, who lacks capacity, would have chosen in a particular situation or, if this is uncertain, what is in their best interests.
36. In many circumstances, such disputes can be resolved relatively quickly and informally.
37. Some situations, such as NSW public hospitals, have clear and helpful guidelines over processes to follow where there are disputes involving end of life care.<sup>1</sup> Development of comparable guidelines via national working groups, with governmental, professional and community input, for endorsement by those interests at a national level, would be very helpful.
38. MIGA sees potential scope for various informal or non-binding mechanisms for dispute resolution, such as mediation or neutral evaluation. Often the introduction of an independent person, skilled and experienced in the relevant issues, to act as a mediator or facilitator may be a critical component of resolving a dispute over what care should be provided to a patient. However, there are understandable limitations over access and use of such persons. It may be that there are options or trials and / or incentives around the use of such persons in particular settings, perhaps as part of institutional research and with a view to determining whether there is utility in extending their use more broadly.
39. Finally, health practitioners and families can be uncertain about their options to resolve disputes where agreement cannot be reached. Various tribunals and courts can operate as dispute resolution bodies, but access to them may not be well known and the circumstances in which they can be approached uncertain. Again, professional and community education on these options would be important, together with provision of information about who and where to approach at any particular time.

### Health practitioner protections

40. Although common law and statute may be relatively clear, health practitioners can be reluctant to involve themselves in certain situations or make particular decisions because of uncertainty about their legal rights and obligations and / or fear of civil, disciplinary or criminal sanction.
41. Areas in which this reluctance or fear can be seen include:
  - deciding whether to withhold or withdraw of medical treatment
  - being comfortable with a patient refusing treatment
  - practitioners being willing to decline to provide requested treatment

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<sup>1</sup> NSW Health Policy, End of Life Care and Decision Making Guidelines – available at [www.health.nsw.gov.au/policies/gl/2005/GL2005\\_057.html](http://www.health.nsw.gov.au/policies/gl/2005/GL2005_057.html)

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- the doctrine of 'double effect', which is the provision of treatment with an intent to relieve pain and suffering, but a commensurate or corresponding effect of which is to hasten death
  - uncertainties around the scope for conscientious objection
42. The Medical Board of Australia's *Good Medical Practice: A Code of Conduct for Doctors in Australia* provides a good starting point to assess how medical practitioners should handle the situations outlined above.<sup>2</sup> It set outs the need to understand:
- the limits of medicine and prolonging life
  - recognising when efforts to prolong life may not benefit the patient
  - there is no duty to try and prolong life at all cost
  - there is a duty to know when not to initiate and when to cease attempts at prolonging life, while ensuring patients receive appropriate relief from distress
  - patients have the right to refuse medical treatment and / or to request withdrawal of treatment already started
  - medical practitioners have a right not to provide or directly participate in treatments to which they conscientiously object, informing their patients and, if relevant colleagues of their objection and not using their objection to impede access to treatments that are legal
43. The considerations set out in the Code reflect professional regulator expectation of medical practitioners. With appropriate modification for context, they are broadly applicable to the health profession more generally.
44. Furthermore, health practitioners need clarity around circumstances in which medication can be given which would have the unintended effect of hastening death, relying on the doctrine of double effect. This is clear at common law, but there is considerable professional concern around the clarity and limits of this protection.
45. There is a need to reinforce requirements and protections for health practitioners which reflect these professional obligations. Whether this is through clearer and detailed statutory requirements and protections, or through overarching statutory requirements which are then developed in detailed codes and guidelines, is a matter for further consideration. There are a variety of views over whether it would be helpful to enshrine legal positions in legislation, or through professional guidelines. There is some attraction to a legislative solution, but it may have unintended effects. A policy driven approach using guidelines may provide better clarification than legislation, but offer the perception of reduced security for those involved in care at end of life. Any national working groups tasked with working towards uniformity in end of life care legislation should also be given the task of considering this issue.

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<sup>2</sup> See clauses 2.4.6 and 3.12 of the Code, which is accessible at [www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-Conduct.aspx](http://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-Conduct.aspx)

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46. The end result must be to ensure that health practitioners acting in good faith in relation to end of life care of a patient are protected from civil liability when acting without negligence, from disciplinary sanction if acting within recognised clinical guidelines or standards, and from criminal sanction if acting in good faith and without gross dereliction of professional duties or with other elements of criminal acts.