



Submission to the Consultation Draft of
"A National Framework for Advance
Care Directives 2010"

October 2010

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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Title: **CA Submission to the consultation draft of
"A National Framework for Advance Care Directives"**

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About Carers Australia

Carers Australia is the national peak body representing those Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia's members are the Carers Associations in each state and territory that deliver specialist information, counselling and others services to carers in the community. Carers Australia is informed about carer issues through its member Carers Associations (the Network of Carers Associations) and its participation in national and international forums.

We believe that all carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education.

About Australia's Carers

Australia has almost 2.6 million carers, and nearly 500,000 of these are primary carers – the people who provide the most care.¹

Carers are the foundation of our aged and community care systems, and the annual replacement value of the vital care they provide is over \$30.5 billion. In 2005 it is estimated that carers provided 1.2 billion hours of unpaid care and the productivity loss of this care is approximately \$4.9 billion.²

Diversity of carers

Carers are from all walks of Australian society and come into the caring journey at various stages throughout their life. Carers are young, of working age, older, Aboriginal and Torres Strait Islanders, they live in rural and remote areas, and may have been born outside Australia. The Australian Bureau of Statistics has identified:

- 350,000 Australians under the age of 25 provide care to a family member who has a disability, or a mental or chronic illness³
- 170,000 carers under the age of 18⁴
- 31,600 Indigenous carers over the age of 15⁵
- 620,000 of Australia's carers born outside Australia⁶
- 366,700 of those born in other than main English-speaking countries.⁷

Summary

Carers Australia welcomes the opportunity to respond to this key draft document. Carers Australia views 'future planning', such as the establishment of advance care directives (ACDs), as important for many carers. Substitute decision-making (SDM) often falls to family carers and for many it is a key part of their caring responsibilities. Substitute decision-making in many cases occurs informally in caring arrangements and it can be beneficial to all parties involved to have formal processes in place. This framework makes a significant contribution toward greater uptake of ACDs.

Carers often mention they would like to be better informed about formal decision-making processes such as Advance Care Directives. Ultimately, increased awareness among carers and in the community is still greatly needed in addition to the Framework. This is a second and essential component in the successful application of ACDs nationally.

The draft National Framework demonstrates the clarity that advance care directives can bring to sometimes critical and often highly emotionally-charged situations. It provides excellent guidance on the national harmonisation of legislation, policies and practice across the states.

The standards are particularly effective in outlining the key issues that may confront people requiring an ACD. Notably, that any written information is valid as an instruction for the wishes of a person for medical treatment or care, that ACDs may take many different forms and that usefulness to the person's circumstances should be the focus; specific proforma are not required.

The focus on encouraging people to communicate and discuss their values and views, as opposed to recording specific medical interventions, is positive. It takes into account that there are potential points of confusion arising in real-life situations that may be difficult to reconcile with the restrictive details contained in an ACD.

For many family carers or others responsible for substitute decision-making, and the general public, the information they can access to inform themselves will be most pertinent part of the process. The Framework suggests this information provision may take the form of a brochure in many cases. This is an important inclusion in the draft document that may have positive implications for guiding later practice.

These elements of the framework will greatly simplify the process for many people but again, they must be clearly communicated in an effective way to ACD users beyond the direct application of this framework and resulting policies. Carers Australia believes there are still a number of considerations and changes that could enhance the document. Implementation and communication strategies, including a public awareness campaign, are needed to increase the impact of the Framework.

Support for improving ACD practices

Support for the need for improvements to the ACD process nationally is found in *Who Cares? The report of the inquiry into better support for carers*. The report states that such improvements will assist family carers and recommends "That the Attorney-General promote national consistency and mutual recognition governing enduring powers of attorney and advanced care directives to the Standing Committee of Attorneys-General." Putting aside who will deliver this reform, the need for national consistency is clearly supported in the report.

The committee also highlights in the report that "There is a lack of awareness in the general community of issues in relation to substitute decision-making, including guardianship, enduring powers of attorney and advanced care directives."⁸

Submissions to this inquiry from Alzheimers Australia and The Mental Health Council of Australia (MHCA) among others, discussed the difficulties associated with advance care planning, particularly for the demographics they represent: older people with dementia and their carers, and people with a mental illness and their carers. The Framework should also be applicable to the needs of these groups.

Response to consultation questions

Carers Australia provides the following response to the questions outlined in the consultation companion guide. These comments have been informed by our state and territory associations Carers ACT, Carers Victoria and Carers WA.

1. Does the Framework meet its objective to provide guidance to policy makers and legislators to enable harmonisation of legislation, policy and practice for Advance Care Directives over time?

The Framework provides a good start to meeting these objectives. However, more work is required to achieve national agreement on legislation, policy and practice in relation to Advance Care Directives (ACDs). The harmonisation of legislation would provide a solid basis from which to apply the Code for Ethical Practice and Best Practice Standards. Nationally agreed standards will be a significant component of a robust and effective National Framework.

Unless there is agreement from all governments to work in partnership, the Framework will remain an aspirational document. There is currently no consistency even in terms of terminology across the states and territories, highlighting that there is still a long way to go to achieve national consistency. It is important that there is effort to coordinate terminology as a key part of the harmonisation process.

To this aim, further explanation of terminology currently in use nationally may be beneficial to the Framework. Terms such as nominated representative, substitute decision-maker, donee etc. could be included in a glossary of terms within the document.

2. Would the Framework assist with awareness of, and respect for, a person's wishes?

The Framework will raise awareness of, and respect for, a person's wishes within the legal, policy and health sectors only. It is important that the Framework is coupled with appropriate training for professionals within these sectors.

For both health professionals and substitute decision makers, the Framework articulates the primary importance of respect for a person's wishes and the role of the Substitute Decision Maker (SDM) in 'giving voice' to a person's wishes during any period when they do not have capacity. Use of the term Advance Care Directives, rather than the clinical or health care focus of Advance Care Plans, also supports a national focus on the wishes of the person.

However, the Framework itself is not sufficient to promote awareness of, and respect for, a person's wishes. Achieving this will require strategies to achieve nationally consistent legislation and the associated implementation of major public education and awareness campaigns.

3. Would the Framework make it easier to recognise and apply Advance Care Directives across jurisdictional boundaries?

Carers Australia believes the Framework will make it easier to recognise and apply Advanced Care Directives across jurisdictional boundaries if it is agreed to and effectively implemented across all jurisdictions.

This will require national leadership and agreed implementation processes and timelines. Greater recognition and application of ACDs would be further facilitated through the introduction of national standardised forms, guidelines and information. The framework does have the potential to encourage greater similarities nationally in currently existing forms.

4. Is the structure of the draft Framework appropriate? Useful?

The document's structure is useful. The case studies in particular serve to highlight the importance of a person making a written record of their wishes and views to guide future decision-making.

The structure of the draft Framework also appropriately emphasises the importance of discussion and acknowledges the difficulties for individuals and families of expressing advance care wishes in writing.

The case studies are excellent illustrations of the practical application of complex decision-making. It would however be helpful to include additional case studies that illustrate the process for resolving disagreement between multiple SDMs or between an SDM and a Monitor.

5. Is the Code for Ethical Practice clear? Appropriate?

The code of ethical practice is clear and appropriate to supporting all the parties; the person making the ACD, their appointed SDM(s) and treating health professionals and care staff.

The description of autonomy included in the Code is especially useful for considering potential cultural differences as well as the key role of the input of family members as part of the concept of an autonomous decision-making process.

6. Are the Best Practice Standards helpful? Practical?

Within this context of the target audience, the Best Practice Standards are useful and helpful. Having an evidence-based best practice framework is both helpful and practical.

In terms of changes to this section of the Framework, the document may also benefit from the following additions to the Best Practice Standards:

- A discussion of the potential need for dispute resolution or mediation, as well as potential strategies for people to use in order to progress or instigate such discussions. While this is discussed elsewhere it would fit well under the Best Practice Standards section.
- As a principle of best practice, guidance on how to begin a conversation regarding what your wishes would be under an ACD or once decisions are made, and processes for communicating wishes to others would be very useful to consider in any documents designed to inform people about ACDs.
- Under the diagram on page 21, care of family and friends is only outlined in the 'dead' stage. Carers Australia believes that ongoing support for carers, family and friends of a person who is 'unwell' is an important part of the picture. If it cannot be included in the diagram, a written statement may be included outlining that support for carers, family and friends may be provided alongside the provision of care to the 'unwell' person at all stages included in the diagram.
- The diagram on page 21 of the document could be modified to include expression of wishes after the death such as organ and tissue donation, autopsy and funeral arrangements. It could also better reflect chronic and mental illness in the unwell and very unwell columns.
- In the discussion on page 36 where witnesses may be advised to decline signing off on an ACD, it would be beneficial for the document to advise that they be informed of other avenues for reporting concerns regarding the establishment of a person's competence.

7. Is the decision-making pathway clear? Useful?

The decision-making pathway as outlined in the Framework document may be too simplistic to reflect the reality of the process. The decision to develop an Advanced Care Directive often involves a number of steps that may be revisited over a period of time; it may not progress in a single direction. It also may not operate in a linear fashion and a flow chart that allows for divergent pathways may be required.

In addition, the pathway does not appear to reflect that the decision-making process may be impacted by diversity of culture, values and ethnicity and this needs further consideration.

Further, although this decision-making pathway for SDMs has been included, the document may benefit from a potential decision-making path for health professionals who need to implement an ACD, or contact family members to gain an insight into the person's wishes. While health professionals may be informed of this through another process, such a pathway could present useful information for those wanting a better understanding of these operations.

8. Are there gaps in the draft Framework? What are they?

The document states that ACDs operate within a broad context, including an episode of mental illness, however the focus of the Framework is almost entirely on serious health and end-of-life issues. The use of ACDs in the case of acute episodes of mental illness has to a large extent been overlooked in the literature, but there is a strong argument for advocating their use, particularly as part of a relapse prevention plan.

The Framework acknowledges cultural diversity and different approaches to personal autonomy and collective decision-making however more attention needs to be given to the implications of cultural diversity in developing ACDs and in working with multiple SDMs.

The way in which competency is determined for some individuals may not be addressed fully in the document. For example, in the discussion on page 35, it is assumed that all people requiring an ACD can sign on their own behalf. This is not always the case. The Framework should apply to all Australians and as such should also consider appropriate mechanisms such as supported decision-making for people with long term decision-making disabilities who are unable to make an ACD or appoint an SDM. This may be relevant for example in the case of people with severe intellectual disability.

The need for review of ACDs at intervals is mentioned but its role may be able to be further encouraged as part of a nationally consistent process, for example through the addition of a statement such as “Where possible, formal processes for review should be established and encouraged.”

The role of monitors as opposed to SDMs and the benefits or reasons for including both roles in an ACD should be carefully outlined. Further while the framework states that processes for ‘reporting’ between the two roles should be provided in an ACD it provides no details of what such reporting arrangements may look like in practice. An additional discussion of this would benefit the document and must be made clear to those being informed about ACDs. Also, a discussion of what the responsibilities of the SDMs and monitors may be at different points in the ACD process, including ongoing responsibilities, may improve the document.

One of the responsibilities that may fall to SDMs, the transfer of directives between care providers, could be further explored. It is suggested that ACD documents should be transportable between care settings but it is not discussed who should, or may, be responsible for ensuring that this occurs. This may require greater consideration to ensure national consistency. Guidelines for formal care providers who have access to ACDs could be included in the Framework. This would be important for many carers to whom this responsibility may otherwise fall when the person they care for transfers from one care setting to another.

Finally, the Framework would benefit from discussion of the potential for individuals to decline substitute decision-making roles where they feel they cannot take on the responsibility. There must be safeguards in place to ensure individuals are not unfairly burdened with decision-making responsibilities. This is particularly important where the nominated SDM may also be a carer given that this could add additional emotional distress to the high amounts of stress that many carers already face because of their circumstances. There must be the capacity for individuals to ‘opt-out’ of nominated roles.

9. Would the Framework adequately inform future review and development of policy on Advance Care Directives?

Yes, with the addition of the areas outlined above to ensure that the Framework will be useful to a wider range of policy applications. It is however unclear how the adoption of reform will be encouraged at a state and territory level or how such reforms will be reviewed for consistency with the national Framework.

10. What opportunities would the Framework provide to promote and assist with revising your State or Territory’s legislation?

Carers Australia is advised that in Victoria, there are presently four different ACDs under three different Acts and the Respecting Patient Choices Program Statement of Choices is not a statutory ACD. It is believed this level of inconsistency can begin to be addressed under the Framework.

Further that the improved clarity for those appointed as SDMs to make decisions may result in reduced incidences of health professionals applying for the appointment of an independent guardian when they disagree with the decisions undertaken by carers or other family members.

It has been advised that in the ACT, that the adoption of a Framework would provide an opportunity to review existing legislation to achieve national consistency and the adoption of a best practice approach to ACDs.

Implementation and practice

As discussed, the Framework does not include an implementation strategy. There is a need for national leadership and direction so that national agreement on policy and legislation occurs and is supported by appropriate implementation strategies.

In order to achieve the objectives of a greater number of people making ACDs and having well informed SDMs, a significant investment in community education and national media campaign is required. This needs to be accompanied by a communication and education strategy to target policy makers and legislators, the legal and health professions and the media.

The places where people may come into contact with ACDs and the impact of this should be considered. The paper suggests that this will in most cases occur through a formal process or setting such as a medical practitioner, hospital, residential aged care facility or through contact with health or legal professionals (for example where there are palliative care arrangements in place). However there must be clear channels for accessing ACDs, even where individuals are not in contact with a professional or formal process. Individuals must be well informed enough to take it upon themselves to create an ACD.

For this reason, a plain English version would be required to assist SDMs to understand their responsibilities. Terms such as the contemporaneous substituted judgement decision-making standard and the best interest standard should be made more easily understandable.

There is also an urgent need for community consultation to engage the general population in the process for successful implementation and consistent practice. Such consultation needs to be inclusive of people with a disability and their family carers, culturally diverse communities and Indigenous people.

Awareness campaign

A National Public Awareness Campaign would play a vital role in raising awareness among the broader population and in supporting the broader objectives and application of the National Framework. It will be essential that any education and awareness raising campaign is conducted through the health sector, but also effectively targeted to the general public. The fact that the uptake of ACDs to-date has generally been low supports this approach.

In the discussion of the need for reform of ACDs in the *Who Cares?* report, the need for a national information campaign is recognised as a central part of the reform process under recommendation 16

“That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing and the Attorney-General fund a national information campaign to raise awareness about the need for, and

benefits of, enduring powers of attorney and advanced care directives in the general community and among health and community care professionals.”⁹

As discussed, the case studies included in the Framework are excellent and would greatly assist in any broader awareness campaign or educational booklet. It is recommended that a wide variety of case studies indicating the potential complexities of ACD be included in any developed materials.

Reference

- ¹ Australian Bureau of Statistics (2004) 2003 Disability, Ageing and Carers: Summary of Findings, Australia, Canberra
- ² Access Economics (2005) The Economic Value of Informal Care, prepared for Carers Australia, Canberra
- ³ Australian Bureau of Statistics (2005a) 2003 Disability, Ageing and Carers, Australia: Caring in the Community, Cat No 4430.0.55.003 Canberra
- ⁴ *ibid*
- ⁵ Australian Bureau of Statistics (2008) The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples, 2008 Cat No 4704.0, Canberra, April 2008
- ⁶ Australian Bureau of Statistics (2003) Migrants, Disability, Ageing and Carers, Australia, 2003 Cat No 34150DS004, Canberra November 2007
- ⁷ *ibid*
- ⁸ House of Representatives Standing Committee on Family, Community, Housing and Youth (2009) Who Cares? Report on the inquiry into better support for carers. Canberra
- ⁹ *ibid*