National Framework for Advance Care Planning Documents –

consultation draft January 2020

Dementia Australia

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About Dementia Australia

Dementia Australia (formerly known as Alzheimer’s Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 459,000 Australians living with dementia and the estimated 1.6 million Australians involved in their care.

Dementia Australia works with people of all ages impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with individuals and communities means that we can advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people of all ages living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.

Does the revised framework achieve its purpose of providing principles-based information about considering, developing and implementing ACP Documents in a nationally consistent way?

Some of the key information requires reworking to ensure the principles-based information about considering, developing and implementing Advance Care Planning (ACP) documents will reflect a nationally consistent approach. This is particularly true with regard to creating a more consistent approach to the use of ACP terminologies. The Framework could also be restructured to reflect a reconsideration of presenting ACP in three phases, especially in the initial phase of "*ACP and considering an ACP Document*", as these do not appear to be fit for the intended audience.

Whilst including information on this initial phase may be useful background information for health professionals and consumers, it seems to dilute the purpose of this Framework, that is, *to assist jurisdictional policy makers and administrators to increase consistency of the use and application of advance care planning documents in their jurisdiction within the context of agreed national principles and practice*.

It may be more effective for the Framework to directly address the barriers that it outlines within it, particularly those around systems, quality and workforce capability. Given that previous work around one of the major barriers to people completing an ACP is often the reluctance and lack of confidence and competence of health professionals to commence these discussions.

Dementia Australia recommends tailoring the underlying ethical considerations and guiding principles to the main identified barriers, which include:

1. Ongoing misunderstanding of what should be in an ACP document
2. Lack of progress towards mutual recognition between states and territories
3. Storage and access remains as barriers in the practical use of ACP documents
4. Capability issues to workforce implementing ACP documents at the end-of-life care
5. Inconsistency in terminologies and approaches between jurisdictions
6. Clinicians concerns about ACP Documents' validity and legal ramifications.

The inclusion of this additional information will promote understanding across the different state and territories to avoid further confusion. This should be supported by jurisdiction specific strategies and data.

The framework also is silent on the emerging area of supported decision making approaches and this needs to be added to ensure that the framework covers all forms of decision making.

Is the content and level of detail provided appropriate in assisting policy makers and administrators to –

- develop guidance, procedures and protocols at a service level;
- design templates for ACP Documents; and
- educate new members of the health and carer workforces about ACP Documents?

The current level of detail is appropriate, though it would be strengthened by including examples of what good ACP documents look like across a range of consumer case scenarios. Dementia Australia suggests that the framework also addresses ethical considerations and guiding principles in the context of various health conditions, such as dementia.

By including a person-centred approach to ACP, the Framework will demonstrate the importance of choice, dignity and independence that respects the human rights of the person. This is particularly important for people living with dementia, their families and carers, as capacity will decline over the trajectory of the disease. As such, ACP needs to be completed as early as possible to enable decision-making capacity, and we recommend that the Framework acknowledge the importance of both supported decision-making and substitute decision makers, once decision-making capacity is compromised.

Additionally, for people living with dementia, the Framework should consider referencing the importance of supported decision making, which is a practice that enables people to make decisions about their own life and enables them to be involved in decisions that affect their care. Dementia Australia recommends the framework references the Cognitive Decline Partnership Centre's policy guideline for supported decision making in aged care, which can be found via this link https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/SDM-Policy-Guidelines.pdf

It is also recommended that the Framework include information on the various terminologies for ACP Documents that are currently in use (across jurisdictions), their scope and their relevant legislation. This will better assist policy makers and administrators in providing tools and supports to help guide and inform aged care and health service providers to better understand the ACP needs of people, ACP legislation and requirements in their state or territory, and processes to implement them.

The Framework would also be more translatable into practice if it clearly articulates what is required for policy makers, as there appears to be more of a focus on what is required of the workforce. This is particularly apparent in section 4.1. Greater emphasis on the structures needed to embed ACP documents across the health and aged care systems would complement and strengthen the process-related information that is currently in the Framework.

Dementia Australia supports the recommendation of Advanced Care Planning Australia to include an additional dot point stating '*experience of health care during a loss of capacity'*, and to amend Figure 4 to reflect the inclusion of loss of capacity.

Are the ethical considerations appropriate and useful? Why, or why not?

Dementia Australia generally supports the ethical considerations and sees them as appropriate and useful. We are pleased to see that autonomy, and self-determination of the individual is respected and upheld throughout the Framework.

We support ACP discussions being '*held at any point in time'*; however, we strongly urge that the Framework encourages the health and aged system workforce to have these conversations as early as possibly once a diagnosis of dementia is made, in order to optimise choice and decision-making while the person still has capacity.

Consideration 4 would have more impact if it includes information about accessing and appointing substitute decision-makers that an individual knows and trusts to understand and respect their wishes. As it is currently written, the importance of this and the process involved is not clear.

It is important that Consideration 6 provides a clear definition of '*capacity*.' An example of such a definition can be found in *Who can decide?: the six step capacity assessment process* (Darzins et al, 2000). Here the cognitive elements of capacity usually comprise combinations of the following abilities:

1. To understand the specific situation, relevant facts or basic information about choices

2. To evaluate reasonable implications or consequences of making choices

3. To use reasoned processes to weigh the risks and benefits of the choices

4. To communicate relatively consistent or stable choices.

Even if a person lacks capacity, it is important to emphasise that they are enabled to participate in ACP conversations. A person living with dementia should have the opportunity to be supported by a family member, carer or advocate to support them to make the decision for themselves.

In Appendix C (of the National Framework of the ACP Documents) there appears to be two contradicting checklist items:

- *Record preferred outcomes and goals of care rather than medical directions*
- *Record specific treatment-related directions and make it clear whether these directions are intended to apply only to end-of-life circumstances*

Dementia Australia suggests these be reworded to make clear that the preferred outcomes and goals of care are not overwritten by medical directions, particularly at end of life. It is of utmost importance that the wishes of the person take priority.

Are the best practice principles appropriate and useful? Why, or why not?

Dementia Australia broadly supports the best practice principles.

Specifically in principle one, we support the statement '*individuals should be prompted to consider who they would like to be involved in making decisions about their future care.*' In addition to this, we recommend the inclusion of the involvement of carers and advocates of people living with dementia in the list of people who could be involved in the ACP document conversations.

Regarding principle two, around decision makers being involved in the ACP process as early as possible, this aligns with the experiences and preferences of people living with dementia, families and carers. People with dementia face additional barriers in making informed choice, given the progressive nature of the disease. People's cognitive abilities can change quite rapidly, impacting their capacity to make decisions. As such, it is important that people living with dementia, their families, decision-makers and health professionals engage in ACP conversations at the point of diagnosis to facilitate choice and control over the care and treatment they wish to receive, particularly during the more advanced stages of the disease.

Regarding principle three, Dementia Australia supports Advance Care Planning Australia's recommended amendment. Specifically the statement '*where an individual lacks capacity or competency, they may still record their values, beliefs and preferences in non-statutory ACP documents*' should be replaced with '*where an individual lacks capacity or competency, they* *may still have their values, beliefs and preferences documented with or for the person, in an advance care plan*.’

Any other comments?

Thank you for the opportunity to provide feedback on this framework. The topic on advance care planning is of high relevance and importance for people living with dementia, their families and people involved in their care.

We trust that our response has raised some key points and has been helpful with the development of the final version of the National Framework for Advance Care Planning Documents.