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**Alzheimer's Australia submission on  
*Ethical Issues involved in transitions to palliation and end of life care for people with chronic conditions: A Discussion Paper for patients, carers, and health professionals.***

Thank you for the opportunity to make a submission in this important area. This submission has been prepared in conjunction with our National Consumer Advisory Committee.

Alzheimer's Australia welcomes the increasing interest within the palliative care field in transitional and end of life care for those with chronic conditions including dementia. This paper explores a range of important issues and is a balanced addition to the debate around best practice in this area. It will be clear from our detailed comments that Alzheimer's Australia has serious concerns about the lack of recognition of cognitive impairment and its real implications for quality care at end of life.

Ethical issues in transitions to end of life care will affect all people with dementia and their family carers. Dementia is a terminal condition - caused by around 100 diseases - which is complicated by the inevitable loss of capacity as the condition progresses. The prognosis depends on the cause of the dementia. Dementia was the 4th leading cause of death in 2007.

Some people with early stage dementia may be in the later stages of another co morbid terminal condition. In this latter case, optimal care may be seriously jeopardised if health and care professionals do not understand the implications of dementia on self management and have sufficient knowledge of best practice including best communication approaches.

Further guidance about the preferred approach at end of life for people with dementia is available in our position statement on palliative care at <http://www.alzheimers.org.au/upload/PalCareStatementFeb09.pdf> .

Alzheimer's Australia has also produced the discussion paper, *Palliative Care and Dementia* available at <http://www.alzheimers.org.au/upload/PalliativeCare.pdf>

Further information about palliative care and dementia is in a keynote address by Professor Julian Hughes at the 2009 Alzheimer's Australia National conference – see

[http://www.alzheimers.org.au/upload/Pallative\\_Care\\_%20AA\\_Conf\\_2009.pdf](http://www.alzheimers.org.au/upload/Pallative_Care_%20AA_Conf_2009.pdf)

The remainder of this submission responds to the questions posed in the paper.

### **Have any issues been overlooked?**

The biggest omission in the paper is the lack of any detailed discussion around the important impacts of cognitive deficit including dementia on communication, decision making and the role of the family carer. This is only alluded to in the text. The issues are important and merit a separate section.

The needs of people with dementia have not been considered. Unfortunately, it generally becomes more difficult to exercise individual health rights and receive best practice care as cognitive deficit increases. For example there is evidence that people with dementia receive less pain relief than those who are cognitively intact.<sup>1</sup>

If the health professional is educated to understand the full implications of the condition including the best way to communicate, it is still possible to take into account the wishes of a person with severe dementia.

### **Do you suggest any changes to material?**

#### Section 2.4 on p16

The concept of 'hope' should be explained in this context, for example, hope of a 'good' or relatively pain free death.

#### Section 2.5 on p16

This section as written does not cover the circumstances of the vast majority of people who die of dementia. By the 'transition phase', it will be too late for them to participate in health decision making as cognitive impairment will have significantly reduced their capacity. Alzheimer's Australia encourages all people diagnosed with dementia to undertake their financial, legal and health/care planning as soon as practicable after diagnosis while they are still able to express their wishes. They are then able to regularly review their arrangements and update these as their circumstances and wishes change.

#### Section 2.5 on p17

The use of the word 'anecdotal' is inappropriate here as there is a body of evidence to indicate that many including people with dementia are under-medicated and/or over-medicated, for example, receiving appropriate pain relief is problematic for those who can not easily request it.

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<sup>1</sup> Further information is available at [http://www.pssru.ac.uk/pdf/MCpdfs/Pain\\_factsheet.pdf](http://www.pssru.ac.uk/pdf/MCpdfs/Pain_factsheet.pdf) and <http://www.ingentaconnect.com/content/bsc/jan/2009/00000065/00000001/art00002>

### Section 3.1 on p18

The section would be strengthened by adding some discussion after the quote to illustrate how the concepts of respect and in particular, the practice of 'empowering' can support someone with dementia. Similarly the subsequent paragraph on personal autonomy needs to recognise the needs of people with dementia as they lose capacity and need to rely on substitute decision maker(s).

Terms like 'autarky' should be avoided, particularly in any Plain English resources for the general public.

### Section 3.3 on p25

The section would be improved if the subjective nature of the term 'best interests' was clarified. Outcomes are very dependent on individual value judgements. What one person regards as another's 'best interests' could be very wide of the mark as judgement is influenced by cultural expectations, personal experience and beliefs. This is just one of the difficulties inherent in asking someone to be your medical power of attorney and in accepting that power for someone else.

Also the concept of 'duty of care' may be used by health/care professionals to justify why an individual's wishes are not met. It would be helpful if there were a definition of this concept and a brief explanation of how it should be practiced including the rights of both parties if there is disagreement.

*In my own situation with my wife, I was challenged by the RACF staffs' claim of "duty of care" while I tried to ensure that her wishes were respected and because I was unaware of the true legal or ethical realities, I battled with them for an extended period of time. Being a little more aware now, I know that the claim of duty of care was for the staffs' own protection and not duty of care to my wife. So "loved ones and carers" need to know what support they might get in ensuring that the person's best interests are respected and what legal protection they have in pursuing those interests – I did not know that I could have threatened the RACF staff with an assault charge for trying to force feed and hydrate my wife when her advance directive specifically stated that these actions were not to happen! – how many other carers know this? Family carer of person with dementia*

### Section 3.4 on p27

The section on 'Justice' should be renamed, as 'Fairness' would encapsulate the concept more correctly. Although the text goes on to refer to both justice and fairness in resource allocation, many readers would gain the impression that justice related to what was legally due to a person, while fairness relates more to equity in resource allocation, and therefore would be a more accurate term to use.

The burden on family carers should be included in 'The inequitable distribution of resources places unfair burdens on those who live and work in rural and remote areas.' (para 3) Denying access is always inequitable. (para 4)

### Section 5.1.3 on p32

This section refers to an Advance Care Directive or similar legal instrument. The section should be strengthened by making reference to the variety of different legal documents that someone in their last year of life should have organized, such as a legal will, estate planning document, an enduring power of attorney, and any other form of preparatory planning document that would ensure that their wishes can be implemented after they are dead or when they are not able to ensure this for themselves.

The AMA definition as used needs further clarification. While it is true that an individual needs to be competent in the legal context when making an Advance Care Plan, it needs to be explained that an existing directive can still be used to demonstrate their views when the individual has lost capacity due to dementia. Also competence should be considered in the context of the particular decision that needs to be made.<sup>2</sup> This is in line with the discussion on p19 of the paper.

Alzheimer's Australia encourages people with dementia to make sure that their legal and financial planning instruments are in place as soon as practicable after diagnosis. It follows that the best time for anyone to make decisions about their future care is while they are well and cognitively intact.

Our resources in this area include help sheets as well as a detailed publication, *Legal Planning and Dementia*. This publication and its associated web pages containing legal resources for each jurisdiction are available at [www.alzheimers.org.au/legal](http://www.alzheimers.org.au/legal)

### Section 5.1.6 on p33

The second part of the definition of end of life care has a system focus. It does not include any outcomes from the point of view of individuals ie caring for people so that they die with dignity, pain free and where they want to die.

Further comment on the questions follows.

### **Comments on sample questions in Section 3**

Any consumer resource would need to carefully define palliative care and describe its relevance and accessibility to those with conditions other than cancer.

Individuals and their family carers need resources that will provide at least some alternative answers to these questions rather than just leaving people to work out the answers for themselves. Also, some clarification should be made to indicate how the questions for the person in transition should be handled.

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<sup>2</sup> See discussion in *Who can decide? : the six step capacity assessment process*, Peteris Darzins, D. William Molloy, David Strang (editors), Adelaide, Memory Australia Press, 2000.

The text seems to assume that they will be well enough to read and comprehend the questions suggested, as well as formulate a detailed position. What are the relative roles of the family carers and health professionals in helping individuals address the questions posed? What information do they need?

In 3.1.1:

- Some questions appear to be assuming that advanced care planning is not in place. Everyone should be encouraged to have advanced care plans regardless of whether or not they have a chronic condition and these plans should be in place before people enter the transition stage. Plans should ideally include some explanation of what the individual sees as being in their 'best interests'.
- Questions for people facing transition might include  
*What do I need to do to ensure that everyone who needs to know, does know that I have an advanced care plan?*  
*Where and with whom do I 'lodge' my advance care plan?*
- It is important for health professionals to be supported to observe the previously expressed opinions of those with impaired cognition, regardless of the jurisdiction(s) in which the directive was made and the care is being provided. This implies that across Australia directives need to be respected when made by people with dementia, easily accessible to health professionals and recognised under the relevant local legislation so that both health professionals and individuals are protected.
- There is no mention of loss of dignity in the questions. For people diagnosed with dementia, this is the phrase that best captures what the condition will mean.
- Quality of life is an important concept to include. A relevant question might be *For how long can I preserve a quality of life and dignity that is acceptable to me?*
- Question d should address more specific issues than 'eventual dying' such as 'what treatments I do/don't want and under what circumstances' and if appropriate culturally, 'what I want for my funeral and burial arrangements'. The context appears to imply that treatments are a given.

In 3.2.1:

- It is crucial that consumers have information available about transition/ end of life options as early as possible.
- It is important for family carers to consider what support they need.
- Health professionals should always consider both the individual and their family carers.

- Possible questions to add for people facing transition  
*What does palliative care offer for my condition (eg in terms of pain management, dignity) and is it accessible?*  
*What are the consequences of withdrawal of a particular treatment?*  
*What are the likely consequences of continuing treatment over a prolonged period?*  
*Are there alternative non-medical treatments to consider at this time?*
- Possible questions to add for carers  
*Do I have the right to expect that the wishes of the individual will be respected by medical staff?*  
*How will I know when to 'relinquish' care?*  
*Where do I go to get advice and additional services?*
- As it is not simply a question of medical excellence, add the following questions for professionals  
*How do I achieve person centred care that respects the emotional, spiritual and cultural needs of an individual?*  
*How do I discuss with the patient and/or their family/carers/MPoA that it is time to change the treatment regime?*  
*What support can be offered (and where can it be sourced) to all concerned at this time?*

#### In 3.3.1:

- This section assumes that individuals are not cognitively impaired. Those without capacity are unable to appoint a representative. Palliative care services should be consulted earlier by people with dementia.
- Most people will need information about the broad range of consequences that are attached to appointing a representative both for them and for the representative – being appointed could be extremely burdensome and thus asking someone to be a representative and accepting that appointment should not be things to be done lightly.
- Add a question to people facing transition  
*Will my expressed wishes be respected?*
- Questions c and d are service questions rather than ethical questions.
- Add a question for carers  
*Do I have the right to expect that the wishes of the individual will be respected by medical staff?*
- Family carers may need to consider when another setting may be more appropriate and better meet the wishes of the individual.

- Add questions for health professionals  
*Is there an advance directive in place?*  
*How would I deal with a situation where an advance directive states wishes that I do not agree with and am unwilling to comply with?*

In 3.4.1:

- Question a considers the issue of 'being a burden'. Is this an appropriate question given the current legal situation in Australia?
- The carer questions relate to non-ethical issues which should be handled much earlier, particularly for those with dementia.
- Handling grief and letting go should be included somewhere. Family carers may feel that it is their duty to continue to care even when the individual feels that they may be better off in some other setting. Both parties need sensitive professional support to resolve the situation if the carer is not to be alienated.
- The community needs education and understanding before they can be sensitive to end of life issues.

#### **Are the issues presented understandable?**

The paper is comprehensive but generally quite readable. Alzheimer's Australia would encourage the NHMRC to provide both guidelines for professionals as well as shorter, simpler resources for the lay audience including consumers and care staff.

In this context, you may be interested in the recent work on dementia by the Nuffield Council on Bioethics in the UK. Outputs include a short guide in Plain English. The reports were released after a lengthy process including widespread public consultation – see

<http://www.nuffieldbioethics.org/go/ourwork/dementia/introduction>

If you require further information, please do not hesitate to contact our National Policy Manager, Anne Eayrs, on 6254 4233 or by email to [anneeayrs@alzheimers.org.au](mailto:anneeayrs@alzheimers.org.au)

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