



OFFICE OF THE
PUBLIC ADVOCATE

**Submission to the Alzheimer's Australia Discussion Paper 8
Decision making in advance: Reducing barriers and improving
access to advance directives for people with dementia**

31st July 2006

Introduction

The Office of the Public Advocate (OPA) welcomes the opportunity to respond to this paper. Over 60% of the guardianship work of the Office is with people over the age of sixty five with some form of dementia. The ageing population means that this number continues to grow as an increasing number of older people with dementia require the assistance of a guardian or administrator to make decisions on their behalf where there is no other less restrictive alternative. One such alternative is where the person themselves has previously appointed a substitute decision maker through an enduring power of attorney or guardianship that operates if and when they lose the capacity to make decisions at some future point. Whilst the Office provides education to the community on the benefits of making an enduring power of attorney, current research would suggest that approximately fifteen percent of the population have completed a power of attorney, with only 1.4% having an enduring power of guardianship for other matters (Rosenman, 2006) Furthermore the number of older persons being assisted to manage their finances is expected to increase (Tilse et al, 2003). Australian government policy shifts have impacted on the complexity of these asset management responsibilities in older age. Policies of self funded retirement (Office of Older Australians 1999) and the clawing back of expectations of government funded pension entitlements have added to the complexity of incomes and assets of older people. Not everyone will need a formal substitute decision-maker but the unfortunate consequence of this statistic is that a growing number of people will be required to go through a tribunal process to have a substitute decision maker appointed.

Powers of attorney/guardianship and advance directives

By way of clarity we emphasise that as there is a difference between a wish and a directive, we are using the term ‘directive’ as meaning a binding direction that must be followed. The term advance directive has been used in the discussion paper to cover two specific areas. The first is the appointment of substitute decision makers under enduring powers of attorney/guardianship. The second relates to advance directives which are

constituted by a document that purports to be legally binding and which outlines the person's stated wishes relating to medical treatment should they become incapable of indicating these to the treating doctor. Given the different nature of these documents and the fact that in some jurisdictions the position of advance directives is unclear legally it is not considered helpful to use the same title in referring to both documents given that they have different characteristics and effects.

Currently in Victoria the only legally binding advance directive is a Refusal of Treatment Certificate which can only be completed for a current condition and can only be signed by the patient themselves if they are competent or an agent appointed under an enduring power of attorney (medical treatment) or a guardian appointed by the Victorian Civil and Administrative Tribunal. Given that the appointment of an enduring power of attorney (medical treatment) is currently the most effective way of ensuring that your wishes are taken into account in relation to any treatment decisions should you lose the capacity to make them yourself, we will limit our discussion to the use of enduring powers of attorney or guardianship.

There are specific issues relating to the use of other forms of advance directives which list the wishes of the person in relation to medical treatment. I refer you to the following paper on our website should you be interested in this specific area. (Advance directives- The legal issues, Office of the Public Advocate, 2004).

The Office of the Public Advocate

The Public Advocate in Victoria is appointed by the Governor in Council pursuant to the *Guardianship and Administration Act 1986 (Vic)*. The Office represents the interests of people with a disability, aiming to promote their rights and dignity and to strengthen their position in society. It is a statutory office, independent of government and government services, and can highlight situations in which people with disabilities are exploited, neglected or abused.

The Public Advocate delegates his authority to his staff, who provide advocacy, guardianship and investigation services to people with disabilities. The office also coordinates the Community Guardians Program, the Community Visitors Program, the Independent Third Person Program and the Private Guardian Support Program in Victoria. Further material on the role of the office can be provided if required by consulting the Office of the Public Advocate's (OPA's) website: www.publicadvocate.vic.gov.au

While in other Australian states there are Public Advocates, please note that within this submission, when OPA is mentioned in text or as part of a citation, the reference is to the Victorian office.

Recommendation 1. The use of formal advance directives for people with dementia, as soon as possible after diagnosis should be encouraged by Alzheimer's Australia and other agencies.

For a number of years this Office has actively promoted the use of enduring powers of attorney and guardianship to the Victorian community. We would certainly support the education of older people by both Alzheimer's Australia and indeed other agencies of the benefits of completing powers of attorney and guardianship. Our preference would be for this education to occur before diagnosis so there can be no question that the person was able to understand and complete the form. Where a document is signed after diagnosis it would be important for the professional who has assessed the person's dementia to clearly indicate the person's capacity to sign a power of attorney or guardianship, so that the validity of the document is less likely to be subsequently questioned.

Having provided public information in this area for some years we are aware that it is important to provide information in a variety of formats. Whilst the number of people downloading information on powers of attorney/guardianship from our website continues to grow, some older people may be unable to access this information on a website. Consequently we continue to produce a hardcopy publication called *Take Control*, now in

its ninth edition which in 2005/06 we sent out to 18,695 people, with a further 4,294 being downloaded from the website. This publication provides all the necessary details to enable people to complete the various powers of attorney/guardianship themselves. Despite the existence of this kit we suspect that many people still feel the need to seek costly legal assistance to complete the forms.

Recommendation 2. Alzheimer’s Australia should consider working more closely with Guardianship Tribunals to provide support for their clients who need to apply for guardianship.

It is recognised that many people who suffer dementia have not completed a power of attorney, and that as a consequence there will be the need to appoint guardians and/or administrators in some of these instances. To assist families who need to make such applications the Office responds to over 13,000 calls every year, mostly from family to help them with this process. The Office also produces a range of publications (provided in eleven different community languages) and presents to a wide range of groups about the process of applying for a guardian or administrator as well as powers of attorney. The Office would welcome any additional support from Alzheimer’s Australia and indeed would be keen to partner where appropriate in providing this information and support to families.

There will be variations between states about whether the Tribunal or the equivalent of OPA will be central to this activity.

Recommendation 3. Alzheimer’s Australia should provide information seminars for all people with memory loss. This could be open to the public for a fee.

As mentioned previously the Office currently provides information sessions to a wide range of groups across the community, including seniors groups. This information covers a range of areas such as the use of guardianship and administration, powers of attorney/guardianship and medical consent issues. We often deliver these sessions in

partnership with other organisations during specific existing events/forums/workshops and would welcome the opportunity to work collaboratively in delivering joint information sessions. We are currently developing a video with the assistance of the Victorian Law Foundation, which will help to explain the benefits of having one or more of the current powers of attorney/guardianship. Alzheimer's Australia is a member of the advisory group the Office has formed to consult and engage with external agencies who also undertake enduring powers of attorney and guardianship community education. This video will be available for use of these and other organisations.

As identified by Alzheimer's Australia research, there is a need to move beyond the mere provision of 'information' to providing more detailed assistance at these sessions to people completing the forms.

Recommendation 4. Alzheimer's Australia should include an additional module as part of the Living with Memory Loss groups to assist the participants to discuss advance directives.

If information on both powers of attorney/guardianship as well as guardianship and administration is not already provided as part of these groups then it would be useful for it to be included.

Recommendation 5. Alzheimer's Australia should consider establishing 'a one-stop shop' service (perhaps through the new Dementia Memory Community Centres) run by well-informed, accredited professionals who understand the difficulties and disruption that a diagnosis of Alzheimer's disease can bring. This would include access to the documents and an appropriate witness as well as professional guidance and counselling.

Certainly our experience would suggest that families find the service system a very daunting place to try and navigate their way through to find what they need. Given the information and support role of the new Dementia Memory Community Centres it would

be helpful for these centres together with others resources such as Carerlink and Carerespite services to offer information on powers of attorney/guardianship and guardianship and administration.

Recommendation 6. Attorney Generals should convene a forum including Alzheimer’s Australia and the National Guardianship Administration Network to discuss the issues associated with the law and practice of advance directive legislation within each state and across state boundaries. Some of the issues that require a national approach include:

- a. clarification of when legally appointed decision makers are necessary**
- b. need to establish clear pathways to appoint substitute decision makers**
- c. mutual recognition and harmonisation of the respective laws across state boundaries.**
- d. the lack of consistency in the legislation across and within the states, for example**
 - when enduring powers are activated**
 - ensuring enduring powers of attorney are properly exercised once the donor becomes legally incapacitated**
 - the need for an annual review of all advance directives**
- e. different terminology**
- f. the need for national strategies to improve knowledge about advance directives**
 - in the community**
 - for health professionals**
 - for the legal profession.**

The Office would support the convening of a forum to further discuss the range of issues raised. improve the clarity and consistency of approaches in the various areas outlined. The more consistency across these areas, the easier education of the community becomes.

The Public Advocate, Julian Gardner, was until recently Chair of the Australian Guardianship and Administration Committee, which consists of Public

Advocates/Guardians, heads of Guardianship Tribunals and Public Trustees. The Committee has already a number of initiatives aimed at increasing national consistency and reciprocity of laws. He will raise with that Committee this recommendation.

Recommendation 7. There is a need to establish a community education campaign with a specific day per year as a prompt for people to consider their future planning.

We would welcome the opportunity to co-ordinate our existing community education strategies with a national campaign. Having a focus on a day each year when people should consider completing a power of attorney/guardianship may prove useful as part of this campaign. If there was to be such a campaign it may be useful for it to follow existing national dementia awareness campaigns.

A national ‘day’ requires significant funding to support marketing/promotional activities in mainstream media to create the ‘need’ for information and education.

The Office’s experience in getting people to attend ‘created’ general public community education events around enduring powers of attorney and guardianship has been mixed. It is our experience that without feeling a specific ‘need’ for this information – which can be created through advertising - people will not seek to attend such events.

Our recent experience of the effectiveness of advertising was in implementing a campaign to inform Victorians about changes to enduring power of attorney (financial). With a very small budget of \$50,000, the campaign ran advertising in major print and radio media. The result was a significant increase in demand for enduring powers of attorney and guardianship information:

- Telephone calls to the Office/advice service
 - 31% increase in calls to advice service related to enduring power of attorney (114)
 - 50% increase in calls to reception (1,053) - during launch week
- Website
 - 48% increase in visits (7114)

- 362% increase in downloading of Take Control (550)
- 186% increase in total publications downloaded (4403)
- Publications distributed
250% increase in distribution of Take Control (700)

8. There is a need to initiate discussions about education for health and legal professionals including training for accreditation for all professionals who will be advising on advance directives.

We are aware through calls to our advice service that there is a limited understanding of powers of attorney/guardianship amongst the legal and health professionals generally. The Office currently undertakes education sessions with a range of professional groups including doctors, lawyers and social workers, however more could be done to integrate such training into the curriculum for these and indeed other professions who are likely to become involved in such situations.

There is a need to engage with the peak bodies of health and legal professionals to align enduring powers of attorney and guardianship education within current recognized events, forums, networks and literature. As with education of the community, the Office's experience with professional groups is the need to work within existing forums, events, networks to gain the greatest access to people. Unless otherwise supported by large promotion and marketing activities, staging additional 'stand alone' events may not succeed in attracting audiences that are already 'too busy' reading existing educational literature or attending existing education/professional development events.

Groups such as Divisions of General practice have already identified the unmet need among GPs for more information on enduring powers of attorney and guardianship.

References

Office of Older Australians 1999 Independence and Self Provision Discussion Paper. Aged and Community Care, Department of Health and Aged Care, Canberra.

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Tilse, C, Wilson, J, Setterlund, D, Robinson, G, Rosenman, L (2003) Families, Asset management and Care giving: Developing issues in policy, research and practice. Symposium: Assets, ageing and abuse - emerging issues for families, 8th Australian Institute of Family Studies Conference, Melbourne 12-14 February 2003.