mal

(Dementia)

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5 April 2012

Committee Secretary
Standing Committee on Health and Ageing
House of Representatives
PO Box 6021
Parliament House
CANBERRA ACT 2600
AUSTRALIA

Dear members of the House of Representatives Standing Committee on Health and Ageing,

# Re: Inquiry into Dementia Early Diagnosis and Intervention

The Victorian Office of the Public Advocate (OPA) has considered the terms of reference for the Inquiry into Dementia Early Diagnosis and Intervention, and would like to respond to two of the Committee's terms of reference:

- how early diagnosis and intervention of dementia can help people with dementia and their carers plan for their futures, including organising their financial and legal affairs and preparing for longer-term or more intensive care requirements; and
- how best to deliver awareness and communication on dementia and dementia-related services into the community.

OPA's response to these terms will be confined to the particular topics to which OPA can speak with authority and insight, namely guardianship of people with dementia, and delivering awareness and communication about enduring powers of attorney.

## **About OPA**

OPA is an independent statutory body with legislative requirements under Victoria's *Guardianship and Administration Act (1986)*. OPA is dedicated to upholding the rights and interests of Victorians with a cognitive impairment or mental illness, and works to eliminate abuse, neglect and exploitation of these individuals. OPA addresses this mission through a variety of advocacy, guardianship and investigation services. OPA also undertakes research and policy work that aims to improve the lives of people with disabilities.

OPA's Advocate/Guardian Program provides guardianship, investigation and individual advocacy services to Victorians with a cognitive impairment or mental illness. Guardianship orders and referrals for investigation are made by the Victorian Civil and Administrative Tribunal (VCAT) under the *Guardianship and Administration Act (1986)*. The advocacy component of the Advocate/Guardian program derives its authority from the powers given to the Public Advocate under the same Act.

In recent years, the Public Advocate has been appointed in approximately 65 percent of VCAT cases, with the other 35 percent appointed to a family member or friend. In the 2010/2011 financial year, OPA provided guardianship in 1,730 cases. Providing guardianship to this many Victorians provides OPA with a unique perspective on ageing and disability.

www.publicadvocate.vic.gov.au

### The profile of OPA's guardianship clients

Over the past 26 years of providing guardianship, OPA's client make-up has changed significantly. In 1986, it was thought the majority of people under guardianship would have an intellectual disability. In 2012, over half of OPA's guardianship clients have had capacity at some time in their life, with 33 percent of current guardianship clients diagnosed with dementia.

The demographic profiles of OPA's guardianship clients are indicative of the need for governments to focus resources on people with dementia and their carers. In the 2010/2011 financial year, 66 percent of OPA's cases involved people over the age of 65, with people over the age of 80 comprising 36 percent of the total guardianship clients. Dementia, either vascular or of the Alzheimer's' type, was the leading reason why older persons required a guardian to assume decision-making responsibility.

In 2011, OPA produced a report into guardianship and the ageing population that looked at the profile of Victorian guardianship clients aged over 65 (the report can be downloaded from OPA's website). The report indicated that for clients over the age of 65, the biggest single issue that arose in guardianship applications related to decisions concerning accommodation (66 percent). Decisions on health and medical treatment (10 percent), and issues regarding family or other conflict (9 percent) also constituted a significant part of OPA's work with this cohort. The report further showed how the issues facing this cohort changed as they aged. For example, for the 65-79 age group, there was a greater proportion of health care issues (15 percent, compared to 10 percent for the cohort as a whole), whereas, for the over 80 age group, there was a greater proportion of issues concerning accommodation (70 percent, compared to 66 percent for the cohort as a whole). The prevalence of accommodation and health care issues for clients over the age of 65 reflects the reality that the effects of disability and the need for health care and support is concentrated in the last decades of a person's life. OPA believes these issues should form the focus of plans people with dementia and their carers' make for the future.

#### Planning for the future through enduring powers of attorney

The primary way OPA invests its efforts in helping individuals plan for the future is through promoting the increased uptake of instruments such as enduring powers of attorney. Enduring powers of attorney are instruments that enable their creators to appoint people to represent them in the event that they subsequently become unable to make their own decisions. Victoria currently has three different types of enduring powers of attorney: the Enduring Power of Attorney (Financial), the Enduring Power of Attorney (Medical Treatment) and the Enduring Power of Guardianship. In recent years, OPA has coproduced Victoria's main resource on enduring powers of attorney – the *Take Control* kit and DVD. OPA also produces a range of fact sheets and forms for powers of attorney that the public can access through OPA's website.

OPA's Advice Service also plays a key role in OPA's efforts to support and guide individuals as they plan for the future. In the 2010/2011 financial year, OPA's Advice Service handled 13,243 calls, with nearly one-third of these calls relating to powers of attorney. OPA has identified from these calls that many members of the community

currently lack awareness about the role and use of enduring powers of attorney. Unfortunately, many members of the public view enduring powers of attorney as a simple form-filling exercise, and do not understand the important role these instruments play in planning. OPA's Advice Service indicates that problems in relation to enduring powers of attorney instruments tend to manifest in one of three ways:

- 1. the principal is not directing the process (e.g. a son or daughter is 'filling our the power of attorney for my mum');
- 2. the principal's capacity is not properly assessed (e.g. 'mum can sign her name but she's just happy for me to do everything'); and
- 3. the wrong people are appointed as representatives ('I felt I should appoint my eldest son').

The importance of correctly completing powers of attorney was the subject of a recent Victorian Parliament Law Reform Committee report (*Inquiry into Powers of Attorney*, 2010). This report made 90 recommendations about how the laws governing, and practices surrounding, powers of attorney might be improved. OPA played a key role in that inquiry, providing extensive written and oral testimony (OPA's written response to the inquiry can be downloaded from OPA's website). The conclusions of the committees' report accord with OPA's view: that while care must be taken in their execution, enduring powers of attorney are, overall, a positive means by which people can take control of their own affairs and future.

### Delivering awareness and communication into the community

OPA believes the challenge for public education in the field of guardianship, capacity and dementia is that information about guardianship laws and other relevant information about planning tends to be known only by professionals working in the disability field, or by individuals whose personal circumstances require a knowledge of these laws. OPA has attempted to address this issue by coordinating a Community Education Program through which staff address both professional and community audiences on a range of topics including guardianship and administration, enduring powers of attorney, medical consent, end-of-life decision-making, and elder abuse. In the 2010/2011 financial year, OPA delivered 182 presentations to a total audience of 6,729 people.

OPA is also currently creating an online, personalised and interactive facility that will lead users through the important legal and personal questions that need to be engaged when execution of an enduring power of attorney is being considered. This facility is funded through a Victorian Law Foundation grant, and will be released for public use in the second half of 2012.

OPA welcomes the Committee's inquiry into dementia early diagnosis and intervention and would be happy to respond to any further questions the Committee may have about the issues raised in this submission.

Yours sincerely,

Colleen Pearce Public Advocate