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17 April 2012

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

Dear Sir or Madam,

***Inquiry into Dementia: Early Diagnosis and Intervention***

I am writing on behalf of AGAC (the Australian Guardianship and Administration Council). AGAC is comprised of the Public Guardians, Adult Guardians and Public Advocates, the Boards and Tribunals who deliberate upon applications under guardianship and administration legislation and the State Trustees or Public Trustees.

All members of AGAC are State-based statutory authorities. Dementia is the most common disability indicated in applications and appointments in guardianship and administration (financial management) practice. AGAC aims to promote consistency in approaches between jurisdictions and to work towards international best practice in guardianship and administration (financial management) for people with disabilities.

This submission relates particularly to the Committee's inquiry into how early diagnosis and intervention can help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements.

The appointment of a responsible enduring attorney or enduring guardian can avoid the need for an application to a guardianship tribunal and can avoid the appointment of a statutory authority of 'last resort' such as the Public Advocates/Guardians or the Public Trustees. Sadly, many people put off consideration of appointment of an attorney or guardian until well after a diagnosis has been made, because it can be emotionally difficult, may involve the expense of consulting a trustee company or a legal practitioner or is administratively demanding. Often people do not consider it necessary until the stage at

which the person with dementia is admitted to a nursing home. At that stage, the person's dementia may be so advanced that they are incapable of executing a valid instrument. This has a number of negative consequences, including:

- (a) The opportunity to express their wishes for the future management of their estate or their future medical and care needs in a legally binding document has been lost. This loss of opportunity can cause uncertainty or hesitation in substitute decision making or, worse, inflame intra-family disputes about decision making.
- (b) An application may be required to a guardianship tribunal, where sensitive evidence about their personal and financial circumstances will be discussed in a public forum.
- (c) There is a risk, when an application is made to a guardianship tribunal, that the tribunal will appoint the Public Advocate/Guardian or the Public Trustee to make decisions on their behalf rather than a relative or friend who they know and trust. Where a Public Trustee is appointed, this can involve costs which may have been avoided by the appointment of a private individual under an enduring instrument.
- (d) There is also a risk that even though the person lacks capacity, unscrupulous persons will proceed with the execution and operation of invalid instruments, which can lead to questionable transactions and financial abuse.

Similarly, a person who executes a valid statutory Advance Care Directive (not available in all States) can avoid the need for tribunal-appointed guardians or guardianship tribunals to become involved in decisions about end-of-life treatments. Not having a valid statutory Advance Care Directive may mean that a person's opportunity to express his or her wishes regarding their future medical and care needs in a legally binding document has been lost.

Having a diagnosis of dementia does not, of itself, render a person incapable of validly executing an enduring instrument and advance care directives. If dementia is diagnosed sufficiently early in the trajectory of the disease, it is possible that a person will retain sufficient capacity to execute such an instrument. Addressing these problems requires two things:

- (i) earlier identification of the disease, and
- (ii) strategic responses to the diagnoses which prompt persons diagnosed to create enduring instruments and statutory advance directives while they retain capacity and there is medical evidence of their capacity.

One possible example of a strategic response would be to promote more education for General Medical Practitioners and persons in the Aged Care Sector with a view to persons in those roles encouraging people to create enduring instruments and statutory advance care directives earlier in the disease's trajectory rather than later. Such encouragement may include the provision of a Medicare item for assessments of a person's capacity to execute an enduring instrument or the inclusion of enduring instrument information in the ACAT assessment process (for instance, an assessment of capacity to execute such instruments

together with instruction for referral to an agency such as Public Guardians/Advocates and Public Trustees to assist with drafting and execution of such instruments). Education campaigns for the wider community would also enhance the take-up rate for people making arrangements for decision making after a loss of capacity.

The development of strategic responses would be significantly aided by uniform laws and processes relating to enduring powers, guardianship or administration and advance directives. Unfortunately, laws vary significantly in each State and Territory as to the requirements for creation, execution and registration of enduring instruments and operation of advance care directives. Although there have been discussions in the Standing Committee of Attorneys-General (now the Standing Council on Law and Justice) about uniformity or harmonization of these instruments, such discussions have not resulted in actual reform. Uniform laws would make education campaigns easier and more effective.

If harmonization or uniformity cannot be achieved, then the creation of a nationally funded register of enduring instruments and tribunal guardianship and administration orders would enhance certainty and accessibility in substitute decision making.

With the ratification of the *United Nations Convention on the Rights of Persons with Disabilities* comes the need to develop supported decision making frameworks, such as those suggested in the recently tabled report of the Victorian Law Reform Commission. AGAC members look forward to the development of new legislation which enhances the compliance of laws relating to enduring powers, guardianship or administration and advance directives with the Convention. People with early stage dementia will benefit from the development of supported decision making frameworks which, if effective, will reduce the need for substitute decision making systems. In future, it is likely that the process of organising financial and legal affairs and preparing for longer-term or more intensive care requirements will also involve selecting a group of supporters to assist with decision-making with a view to a person with a disability remaining actively involved in decision-making as long as possible.

Although this written submission is brief, AGAC members could give numerous examples of the consequences of late diagnosis and intervention regarding dementia in evidence before the Committee. We would be happy to send a representative to your inquiry.

We acknowledge that this submission is a public document and will be available on the Committee's website.

Yours faithfully

Anita Smith  
CHAIR