



Secretary
Standing Committee on Legal and Constitutional Affairs
House of Representatives
PO Box 6021
Parliament House
CANBERRA ACT 2600

Alzheimer's Australia would like to thank the Committee for this very important opportunity to comment on the adequacy of the current legislative regimes in addressing the legal needs of older Australians.

Our constituents have already identified a number of concerns in this area such as access to the law, the complexities of the Australian legal framework and the inconsistencies between the different State and Territory legislation. This submission focuses specifically on legal issues associated with losing decision-making capacity.

We are grateful to Margaret Brown (Research Fellow at the Hawke Research Institute for Sustainable Society, University of South Australia) and Professor Colleen Cartwright (Aged Services Learning and Research Collaboration, Southern Cross University) for their assistance with this submission and to Members of the Alzheimer's Australia National Consumer Committee for their input.

There are no sections in this submission which are confidential and we agree to the submission being published in its entirety.

Glenn Rees
National Executive Director
30 November 2006

**Alzheimer's Australia Submission to the House of
Representatives Legal and Constitutional Affairs Committee**

Inquiry into Older People and the Law

November 2006

To investigate and report on the adequacy of current legislative regimes in addressing the legal needs of older Australians in the following specific areas:

General and Enduring 'power of attorney' provisions

Financial Abuse

Fraud

Family agreements

Barriers to older Australians accessing legal services

Discrimination

This submission also addresses a number of other issues:

Informal Decision Making

Capacity Assessment

Guardianship Tribunals

Recommendations

A General and Enduring ‘power of attorney’ provisions (page 13)

1. The Australian Law Reform Commission should be given a reference to investigate the possibility of establishing nationally consistent legislation, terminology and documentation for Advance Care Planning by way of substitute decision-making and use of advance health care directives to the extent that this is constitutionally possible.
2. Attorneys General 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 ACP 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
 - ensuring that the need for accurate, timely and appropriate reporting to Centrelink by those exercising Enduring Powers of Attorney is recognised and mandated
 - the need for regular review of all advance directives
 - (e) different terminology
 - (f) the need for national strategies to improve knowledge about ACP:
 - in the community
 - for health professionals
 - for the legal profession.
3. Standardised information and guidelines be developed and provided to medical practitioners and organisations, such as Alzheimer’s Australia, to encourage the use of formal Advance Care Planning for people with dementia as soon as possible after diagnosis.
 4. Guardianship Tribunals be required to work more closely with organisations, such as Alzheimer’s Australia, so that these agencies in turn are better able to provide support for their clients (i.e. carers, family members) who need to apply for guardianship.
 5. Alzheimer’s Australia and other relevant organisations be supported to provide information seminars about Advance Care Planning for people with memory loss, including in regional and rural areas and minority groups (eg multicultural and indigenous groups).

6. Alzheimer's Australia be supported to include an additional module as part of the Living with Memory Loss groups to assist participants to discuss ACP.
7. Alzheimer's Australia be supported to establish '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 ACP documents and an appropriate witness as well as professional guidance and counselling.
8. 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.
9. There is a need to initiate discussions about education for health (General Practitioners in particular) and legal professionals on advance care planning including training for accreditation for all professionals who will be advising on ACP.

B Financial Abuse (page 18)

Alzheimer's Australia strongly recommends that the Federal Government implement the recommendations made in McCawley AL, Tilse C, Wilson J, Rosenman L, Setterlund D. Access to Assets: Older People with Impaired Capacity and Financial Abuse. *The Journal of Adult Protection* Vol 8 No 1 2006

1. Proactive measures for preventing both intentional and inadvertent abuse are urgently required
2. More education, monitoring and support should be provided so that those appointed with powers of attorney are aware of their responsibilities.
3. Community discussion about the meaning of 'family money', ownership of the assets and financial abuse to raise awareness is necessary.
4. People who strip older people of their assets intentionally are accountable.
5. Registration of EPAs and/or monitoring through accountability procedures
6. The development of clear and consistent protocols for aged care professionals about notification and intervention when financial abuse occurs.
7. Clarification of the protective measure for whistle blowers.
8. Engaging financial institutions to report suspected financial abuse

C Family Agreements (page 23)

1. Alzheimer's Australia recommends that the Federal Government commission a Discussion Paper on Family Agreements to commence the development of this emerging area of Elder Law.
2. Alzheimer's Australia recommends that Commonwealth legislation be enacted to govern exhaustively the area of family agreements, with agreed complementary legislation passed by State/Territory jurisdictions as necessary. Any such arrangements should be consistent with Centrelink requirements for gifting and reporting.

D Barriers to older Australians accessing legal services (page 29)

1. Alzheimer's Australia endorses the recommendations of Edwards and Fontana's report on the barriers that prevent older people from accessing information and support for legal information acquisition.
2. Alzheimer's Australia recommends that the Federal Government establish and fund a **Specialist Legal-Advocacy Service** for older people in each State and Territory.
3. Alzheimer's Australia recommends that the Federal Government support the development of Elder Law as a specialty in specific Universities across Australia.

E Discrimination (page 30)

Alzheimer's Australia recommends that the Federal Government collect further evidence of discrimination in employment, relating to people living with dementia to assist in future policy development and increase public awareness of the legal issues associated with discrimination relevant to people living with dementia.

F Other Issues

Informal Decision-making (page 31)

Alzheimer's Australia recommends that additional resources be developed to assist families in decision-making for vulnerable older people.

Capacity Assessment (page 33)

Alzheimer's Australia recommends that the Federal Government endorse the approach of the NSW Attorney General Discussion Paper *Are the rights of people whose capacity is in question being adequately promoted and protected* and commend it to the other State and Territory governments for consideration.

Guardianship (page 34)

1. Alzheimer's Australia recommends that the Federal Government develop **specialist legal and advocacy services** to assist families in the area of guardianship.
2. Alzheimer's Australia recommends that the Federal Government explore the possibility of harmonisation of Guardianship legislation with the National Guardianship Administration Network.

Introduction

Alzheimer's Australia is the National peak consumer organisation for the 500,000 Australians living with dementia¹. The National Association provides leadership in policy and services and the State and Territory member organisations provide information, support, advocacy and education services for their clients.

Alzheimer's Australia represents some of our society's most vulnerable older people. Individuals diagnosed with Alzheimer's disease or other dementias will at some stage during their illness lose decision-making capacity. It is therefore important that these potentially vulnerable, usually older, adults are encouraged and assisted in planning for their future in our complex society while they are still able and have legal capacity.

The ageing of the population means that the number of people who will develop dementia will continue to increase. This means that the number of older people who will need assistance in managing their affairs will also increase. Currently throughout the Australian jurisdictions over 50 % of cases referred to the Guardianship Tribunals involve older people, most whom have impaired decision making capacity. It is therefore very important that access to the relevant aspects of the legal system is available and that people's rights under the law are clearly understood.

In October 2005 the *National Consumer Summit on Dementia* was held in Parliament House in Canberra. More than 50 people with early stage dementia and family carers, representing every State and Territory, participated in the Summit. The Summit Communiqué summarises the concerns identified by the participants and represents the voice of people living with dementia in the "Seven Point Action Plan for Change".² **Action Point 5** is particularly relevant for this Inquiry and is therefore included in this submission (see next page).

Specific points will be addressed under the headings of the Terms of Reference.

¹ Alzheimer's Australia uses the term '*people living with dementia*' to mean people with dementia and their families and carers.

² Available on the web <http://www.alzheimers.org.au/upload/Communique2.pdf>

Action Point 5

Increase the recognition and understanding of the financial cost and legal implications of dementia.

*We need access to supports that will enable both carers and people with dementia to **retain employment for as long as possible**. We need access to better information on the benefits that are available to support people with dementia and their carers. We need more appropriate benefit options that adequately reflect the cost of care. We need more effective means of providing financial support to people with dementia and their families. **We need to ensure that adequate safeguards and protections are in place to support people with dementia and their carers.***

We recommend that:

- *Access to benefit information from Centrelink is improved so that it is simple and easy to understand.* A
- *Access to appropriate financial planning advice is made available so as to enable us to plan for our futures as best as is possible.*
- *Support from Centrelink is enhanced by establishing the role of a dementia adviser within each office. The role of the dementia adviser would not only be to assist people with dementia and their families but it would also support staff in the office in responding to the needs of people with dementia.*
- *Centrelink records be notated with a standardised symbol indicating that the individual either has dementia or cares for a person with dementia, for easy identification enabling appropriate service delivery.*
- *A review of the Department of Family and Community Services policy is undertaken in respect of people with dementia and their family carers to ensure the adequacy of the Carer Allowance.*
- *Determination of the Carer Payment be based on an individual's income and not their assets.*
- *Benefit payments be adjusted to recognise the real cost of the provision of support to a person with dementia and encompass greater assistance in the area of aids and equipment, recognition of travel costs and subsidies for medication. Medications recognised by the Therapeutic Goods Administration as providing benefit to people with dementia should be placed on the Pharmaceutical Benefits Scheme in a timely manner.*
- ***Uniformity between States and Territories be achieved to ensure consistency in legal provisions affecting people with dementia. These include, for example, advance care directives and enduring powers of attorney.***
- *An Ombudsman for Dementia be established to ensure that the rights of people with dementia are recognised and that they have access to the same safeguards and protections as the rest of the community.*

This submission will focus specifically on the legal issues associated with losing **decision-making capacity**.

Losing capacity means losing the ability to make informed decisions (see section on Capacity Assessment). In the early stages of dementia, the majority of individuals are still able to make most decisions about their health care, well being and financial matters. However, the disease process gradually erodes the capacity to reason and make responsible decisions. Therefore, planning ahead and appointing a substitute decision-maker becomes very important for all those diagnosed with some form of dementia, before they lose legal capacity. There are also many examples where the husband dies first and his wife is left to deal with the legal/financial issues with which she has had little previous exposure or experience.

Although there are legal instruments to appoint a substitute decision-maker across all Australian jurisdictions, the majority of people do not know about, and therefore do not execute, this right. *I had no idea that we needed to do this. Who would tell you? Carer.*

Decision-making in advance of loss of competence has legal, medical and social implications. It is about relationships, communication and families. Appointing another person to make one's decisions is complex and raises questions about trust, responsibility, competence and appropriate timing for the activation³ of enduring powers.^{4 5}

It also involves acknowledging one's frailty, future loss of competence and ultimately one's death. This confronts individuals with the 'big questions' that the majority of people are reluctant to talk about.

What appears to be a relatively simple process of completing forms and writing down one's wishes about future care is fundamentally about delegating one's decision-making powers to another person.⁶ It is investing one's autonomy in someone else. It cannot be simply categorised as a legal matter as many of the decisions that need to be made involve accommodation and finances, as well as medical and health care, and may impact on the dying process.⁷

As one of the many important issues identified by the participants at the National Consumer Summit in October 2005 was the need to address the legal issues faced by people with dementia and their families and carers, Alzheimer's Australia commissioned a Discussion Paper on *Decision making in advance: reducing barriers and improving access to advance directives for people with dementia*⁸.

³ This also includes revocation of enduring powers and understanding that powers of attorney cease once capacity is lost.

⁴ **Brown M**, The Law and Practice Associated with Advance Directives in Canada and Australia: Similarities, Differences and Debates. *Journal of Law and Medicine*. (2003) 11 (1) 59-76

⁵ The person appointed as the 'attorney' has a duty to exercise the power honestly and reasonably (in some jurisdictions it is an offence not to do so, eg section 66(1) of the *Powers of Attorney Act 1998* of Queensland), in some jurisdictions there are limits on the attorney's investment power, obligations to keep accurate records and accounts and to keep the attorney's property separate from the principal's property. However these requirements are not consistent across all Australian jurisdictions.

⁶ Advance health care directives are a record of the individual's wishes which by law should be adhered to.

⁷ **Brown M**, Decision Making in Advance: Reducing Barriers and Improving Access to Advance Directives for People with Dementia Alzheimer's Australia Discussion Paper 8 (2006)

⁸ Available on the web at <http://www.alzheimers.org.au/legal>

This Discussion Paper examines the issues associated with enduring powers and advance directives for people living with dementia. The objective of this paper was to provide a basis for an informed discussion by consumers about the complex and confusing area of advance care planning involving legal documents about health care and financial matters and, most importantly, to identify the action that consumers would like to see taken at the National and State and Territory levels.

General and Enduring ‘power of attorney’ provisions.

Alzheimer’s Australia would like to suggest that this item ‘General and Enduring Powers of Attorney provisions’ be widened to include other legal provisions for substitute decision-making in Australia, for example, enduring powers of guardianship, medical powers of attorney. Therefore, we will include the other legal instruments that enable people to plan ahead for their future decisions prior to losing legal capacity including advance health care directives and making a will.⁹

Advance Care Planning

For the purpose of this submission the generic term advance care planning¹⁰ will be used to describe appointing a substitute decision-maker and/or making an advance health care directive. One of the major issues requiring attention is that both the legislative provisions and the language used across the various Australian jurisdictions differ.¹¹ This lack of consistency and standardisation is creating additional difficulties for many people living with dementia. It is quite common for older people to move across State boundaries to be closer to their relatives. This can create problems when enduring powers have been executed in one State or Territory and are not recognised in another.^{12 13}

It is important for the Federal Government to establish clear definitions and identify the principals that underpin those definitions so that a national discussion can take place. (See attached Table 1: An overview of Advance Directive and Enduring Power of Attorney for Health/Enduring Guardianship legislation in Australia.)

⁹ Without a will a person’s estate goes to the next of kin in order of the established rules of intestacy. This can create additional dilemmas for the surviving family members.

¹⁰ In some States ‘advance directive’ is also used in this context. The term ‘advance directive’ was used in the Alzheimer’s Australia Discussion Paper 8.

¹¹ Please see *Legal Planning and Dementia*, Alzheimer Australia Position Paper 5 April 2005 Available on the web at <http://www.alzheimers.org.au/legal>

¹² See Submission No 12 to the House of Representatives Standing Committee on Legal and Constitutional Affairs 2005.

¹³ See section 18A of the ACT *Powers of Attorney Act* which expressly provides for the recognition in the ACT of enduring powers of attorney made in other States or in another Territory. And section 40 of the Queensland *Powers of Attorney Act* which expressly provides a mechanism for the recognition in Queensland of documents similar to Queensland enduring health care documents made in another State or Territory. There appears to be no equivalent in the Queensland Act to section 18A of the ACT Act.

Advance Care Planning (ACP) is a generic term that covers:

- **Enduring Power of Attorney (EPA)**, which appoints a substitute decision-maker for financial and business matters (however in Queensland and the ACT an EPA can cover personal/lifestyle and certain health decisions).
- **Enduring Power of Guardianship (EPG)**, which appoints a guardian to make decisions about lifestyle and health care; (in some states/territories this is called Enduring Guardianship or Enduring Power of Attorney for personal/health matters)
- **Medical Power of Attorney (MPA)**, which appoints a medical agent to make decisions about medical treatment when the person is no longer competent.
- **Advance Health Care Directive (AHCD or AD)**: a written document stating what medical treatment the individual may or may not want after he or she is no longer able to make these decisions. (There is a considerable difference between States/Territories in these documents, when they may be used, how many and which ones are required in different States and Territories and under what circumstances; for example, under Victorian legislation, a Refusal of Treatment Certificate can only be completed for a current condition, which does not have to be terminal, whereas under South Australian legislation, such a document may be completed at any time but it only applies to a terminal illness.¹⁴

Enduring Power of Attorney

The most commonly known and used legal instrument is the enduring power of attorney for financial and property matters. In some Australian jurisdictions the enduring power of attorney covers personal/lifestyle and health care decisions as well as financial decisions. This is not the case in all jurisdictions. There is considerable confusion across the different jurisdictions about the terminology, the extent of the decision making under enduring powers and when they are activated for example:

A study in Queensland in 2000¹⁵ found that 39% of respondents had given EPA for financial matters to another person (up from 30% in 1995)¹⁶. As this study involved a large random sample drawn from the Queensland Electoral Roll, with rigorous methodology, the results are considered to be generalisable to the wider community; 39% of Queensland's adult population is approximately 1.2 million people.

Only 12% of respondents had given someone EPA for personal/health matters and only 3% had completed an Advance Health Directive (AHD). (Note, however, that at the time of the study, enabling legislation for EPA health & AHDs had been in force for less than 2 years while EPA finances legislation had been in force for 10 years).

¹⁴ *Consent to Medical Treatment and Palliative Care Act 1995 (SA)*

¹⁵ **Cartwright CM**, Williams GM, Steinberg MA, Najman JM. *Community and Health/Allied Health Professionals' Attitudes to Euthanasia: What are the Driving Forces?* Report to the National Health and Medical Research Council, August 2002.

¹⁶ Steinberg MA, **Cartwright CM**, Najman JM, MacDonald SM, Williams GM. *Healthy Ageing, Healthy Dying: Community and Health Professional Perspectives on End-of-Life Decision-Making*. Report to the Research and Development Grants Advisory Committee (RADGAC) of the Commonwealth Department of Human Services and Health, February 1996.

There is some evidence of abuse in the management of financial affairs under an EPA¹⁷ (see also Section 2 – Financial Abuse) and this issue demands action including encouragement of consistency from the Federal Government even though it is primarily a State/Territory matter. However, the percentage of abuse is not high in relation to the number of people making such appointments, and the benefits of peace of mind and legal certainty that completion brings means that use of such instruments should be encouraged. Please refer to: *Decision making in advance: reducing barriers and improving access to advance directives for people with dementia*¹⁸.

There is increasing evidence that people require assistance when making their advance care plans including the decision about who to appoint and what types of decisions they need to make about their future care. The Respecting Patient Choices program¹⁹ is based on trained ‘consultants’ who assist people with their decisions and to understand the legal documents.

Research in South Australia confirmed this need for support with the actual process. The interviews with people diagnosed with early memory loss suggest that a ‘one stop shop’ would be appropriate for those struggling with a diagnosis of dementia so they could receive appropriate advice, counselling and support with their advance care plans. A suggestion was made that Alzheimer’s Australia initiate a ‘one-stop shop’ or ‘Do-it-Yourself forums’, including access to the documents and an appropriate witness as well as professional guidance. This easy access could make a significant contribution in alleviating some of the burdens that disease and the process of aging impose. If it were open to the public (for a small fee) as well as clients and their families it would improve the current situation, which can leave families struggling not only with the diagnosis of Alzheimer’s disease but also the need to arrange enduring powers and advance directives. A single venue where people could get the information and the advice that covers both the legal and medical aspects of the process, as well as the sensitive personal issues, would encourage more people to put their powers in place and consider their future decisions in a safe environment²⁰.

There is also confusion in the community between the legal documents and the informal or policy documents, for example, residential aged care facilities (RACF) require the resident (or the family when the resident has lost capacity) to complete a facility specific Advance Care Plan on admission.²¹ There is a need for older people to be better informed about the legal status of these different types of documents including clarification of the rights of the ‘next of kin’ and informal decision maker once a person has lost capacity.²²

¹⁷ D Setterlund, C Tilse, and J Wilson, Substitute Decision Making and Older People. *Australian Institute of Criminology: Trends and Issues in Crime and Criminal Justice*. No 139 December 1999

¹⁸ Available on the web <http://www.alzheimers.org.au/legal>

¹⁹ The Commonwealth Government’s “Respecting Patient Choices” initiative is an Advance Care Planning program. See <http://www.respectingpatientchoices.org.au/>

²⁰ **Brown M**, Jarrad S. Putting the Powers in Place: Planning for the Future. Final Report. Alzheimer’s Australia SA Inc. 2005.

²¹ **Brown M**, Grbich C, Maddocks I, Parker D, Roe (Connellan) P, Willis E. (2005) Documenting End of Life Decisions in Residential Aged Care in South Australia. *Australian and New Zealand Journal of Public Health*. 29: (I) 85-90

²² Comments from members of AA SA

There is strong support for Advance Care Planning in Australia, including support for National legislative consistency. This includes:

Australian Medical Association: The Australian Medical Association Position Statement on Advance Care Planning, released in August 2006, calls for uniformity of legislation and documentation across Australia.²³

Respecting Patient Choices: The Commonwealth Government's "Respecting Patient Choices" initiative is an Advance Care Planning programme now running in most States and Territories to encourage people to plan for their future.²⁴ The lack of harmonisation of enduring powers and advance health care directives across State/Territory boundaries creates dilemmas and challenges in implementing this programme.

House of Representatives Standing Committee on Legal and Constitutional Affairs 2005: Submission No 12 to the House of Representatives Standing Committee on Legal and Constitutional Affairs 2005²⁵ provides an example of the difficulties created for families/carers because of the lack of recognition of enduring powers across state borders. The problem is exacerbated when caring for family members with dementia who live interstate.

Callers to the National Dementia Helpline²⁶ reported the following issues relating to Powers of Attorney:

Some disagreement has occurred especially when there are a number of family members. However these families are often reluctant to talk to tribunal. Some callers to helpline also report Tribunal attendance was an experience that was distressing.

Also there are callers to the helpline who are unclear about difference between Power Of Attorney and Enduring Power Of Attorney and confusion around legal competence and who should determine this.

Some families have reported difficulties because they have not been given a diagnosis by the doctor although the person appears to have dementia and the doctor is not willing to communicate with family members.

Other difficulties for families are that the person living with dementia will not attend a doctor for diagnosis. Many families who have people living with dementia are unsure of what they can do legally once the person is no longer at a point in the progression of the dementia to have legal competence.

²³ Position Statement: The Role of the Medical Practitioner in Advance Care Planning – 2006
<http://www.ama.com.au/web.nfs/doc/WEEN-6SY6U8>

²⁴ <http://www.respectingpatientchoices.org.au/>

²⁵ Available on the web at <http://www.aph.gov.au/house/committee/laca/harmonisation/subs/sub012.pdf>

²⁶ National Dementia Helpline 1800 100 500

Recommendations:

Alzheimer's Australia recommends the following

1. The Australian Law Reform Commission should be given a reference to investigate the possibility of establishing nationally consistent legislation, terminology and documentation for Advance Care Planning by way of substitute decision-making and use of advance health care directives to the extent that this is constitutionally possible.²⁷
2. Attorneys General 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 ACP legislation within each state and across state boundaries.²⁸

Some of the issues that require a national approach include:

- (a) clarification of when legally appointed decision makers are necessary²⁹
- (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
 - ensuring that the need for accurate, timely and appropriate reporting to Centrelink by those exercising Enduring Powers of Attorney is recognised and mandated
 - the need for regular review of all advance directives
- (e) different terminology
- (f) the need for national strategies to improve knowledge about ACP:
 - in the community
 - for health professionals
 - for the legal profession.

²⁷ Consideration be given to a reference being given to the ALRC to draft legislation for the Commonwealth, with a recommendation that the States and Territories enact corresponding legislation.

²⁸ A starting point might be consideration of the Queensland *Powers of Attorney Act 1998* and the ACT *Powers of Attorney Act 1956* and the *Medical Treatment Act 1994*. One addition to the Queensland Act would be to include a provision similar to section 18A of the ACT *Powers of Attorney Act* covering recognition of EPAs in other jurisdictions.

²⁹ For example, when the person has lost legal capacity and does not have a formal advance health care directive or an enduring power of attorney for health care decisions but the 'next of kin', together with the family doctor make the decisions about end of life care. These decision are not always respected by health professionals.

3. Standardised information and guidelines be developed and provided to medical practitioners and organisations, such as Alzheimer's Australia, to encourage the use of formal Advance Care Planning for people with dementia as soon as possible after diagnosis.
4. Guardianship Tribunals be required to work more closely with organisations, such as Alzheimer's Australia, so that these agencies in turn are better able to provide support for their clients (i.e. carers, family members) who need to apply for guardianship.
5. Alzheimer's Australia and other relevant organisations be supported to provide information seminars about Advance Care Planning for people with memory loss, including in regional and rural areas and minority groups (eg multicultural and indigenous groups).
6. Alzheimer's Australia be supported to include an additional module as part of the Living with Memory Loss groups to assist participants to discuss ACP.
7. Alzheimer's Australia be supported to establish '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 ACP documents and an appropriate witness as well as professional guidance and counselling.³⁰
8. 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.³¹
9. There is a need to initiate discussions about education for health (General Practitioners in particular)³² and legal professionals on advance care planning including training for accreditation for all professionals who will be advising on ACP

³⁰ **Brown M**, Jarrad S. Putting the Powers in Place: Planning for the Future. Final Report. Alzheimer's Australia SA Inc. 2005

³¹ This could include forming links with other disability groups and/or provider organisations where these issues are of importance.

³² GPs are a key information source for many older people. They need to be well informed about advance care planning and appropriate services they can refer patients to for assistance with documentation.

Financial Abuse

In many jurisdictions around the world, including Australia, older people are encouraged by governments to make a formal donation of asset management power through some type of power of attorney that continues if the donor loses capacity. (See earlier section on EPA) Families are therefore increasingly undertaking the role of substitute decision making for elderly relatives³³. With the increasing financial complexity in our society, banks and financial institutions will no longer accept a family member's signature when attending to an older parent's financial affairs.

We can no longer pop down to the bank, to see the bank manager to sort out mother's accounts because she is not making "good decisions" about her finances any more.

In most Australian jurisdictions, enduring power of attorney forms are available on the web, as well as from post offices, news agents and other service offices, such as Legal Services and Public Advocate Offices; people can purchase them without any legal advice. The *Do it Yourself Kits* are a way of making it easier for people to access this legal right. People are obtaining the documents and completing them without fully understanding the implications of the power bestowed on the substitute decision maker. Family members are appointed in absolute trust, on the assumption that they will always act in the best interest of the older person whose capacity is diminishing.³⁴

Research conducted at the Australian Institute of Criminology indicates that older people are more likely to be the victims of financial abuse, for example, fraud, deception, and commercial exploitation than physical crimes against the person. As people become less able to manage their affairs they may (and are encouraged to) choose to appoint an enduring power of attorney to assist them in decision making about their financial affairs. Adam Graycar (Director of the Australian Institute of Criminology) stated that the Powers of Attorney was the most abused legal document in America. Advocacy organisations in Australia reported similar cases of abuse in Australia.³⁵

McCawley et al. found clear evidence of financial abuse, which challenges the assumption that families always act in the best interest of the older person. While most families manage the assets of their family member with diminished capacity well, some families have good intentions but limited education and/or ability to negotiate complex and time consuming tasks resulting in negligence whereas, "others simply use the older persons' assets as their own and intentional financial abuse occurs."³⁶

³³ McCawley AL, Tilse C, Wilson J, Rosenman L, Setterlund D. Access to Assets: Older People with Impaired Capacity and Financial Abuse. *The Journal of Adult Protection* Vol 8 No 1 2006

³⁴ There needs to be more emphasis on the legal obligations of the person appointed as the 'attorney'

³⁵ Setterlund D, Tilse C, and Wilson J, Substitute Decision Making and Older People. *Australian Institute of Criminology: Trends and Issues in Crime and Criminal Justice*. No 139 December 1999

³⁶ McCawley et al p 21

The authors examined a sample of cases from the files of the Guardianship and Administration Tribunal of Queensland. The findings from this research indicate that the present system of educating, monitoring and intervening in financial abuse of older people with impaired capacity is not working well. Changes are required with the policies that promote appointing enduring powers of attorneys. Currently the problem is pervasive without any satisfactory means of monitoring or intervening when financial abuse occurs.

The legal interventions which are in place in all jurisdictions are too slow and cumbersome and by the time they are engaged the financial abuse has occurred and the “older person with impaired capacity is poorer and detrimentally affected”.³⁷

McCawley et al. recommended

1. Proactive measures for preventing both intentional and inadvertent abuse are urgently required
2. More education, monitoring and support should be provided so that those appointed with powers of attorney are aware of their responsibilities.
3. Community discussion about the meaning of ‘family money’, ownership of the assets and financial abuse to raise awareness is necessary.
4. People who strip older people of their assets intentionally are accountable.³⁸
5. Registration of EPAs and/or monitoring through accountability procedures
6. The development of clear and consistent protocols for aged care professionals about notification and intervention when financial abuse occurs.
7. Clarification of the protective measure for whistle blowers.
8. Engaging financial institutions to report suspected financial abuse.³⁹

This research identifies a problem that is pervasive throughout Australian jurisdictions.

Over 50% of all cases referred to Guardianship Tribunals throughout Australia are older people with dementia. A high proportion of these relate to financial issues, including when enduring powers of attorney are not working well. A common trigger is when the residential aged care facility (RACF) fees are not paid and the facility staff are alerted to the fact that the family member responsible for paying the bills is not acting responsibly with the assets of the older person with impaired capacity.⁴⁰

³⁷ McCawley et al p30

³⁸ It is worth mentioning that such people may be potentially liable to “account” or “compensate” at law or equity, as well as potentially under legislation (see eg section 106(1) of the Qld *Powers of Attorney Act*). Also under the Queensland Act, for example, it is an offence for an attorney not to exercise their power of attorney honestly and with reasonable diligence to protect the principal’s interest – see section 66(1), and in addition to any other penalty the court may order the attorney to compensate the principal for loss arising out of the attorney’s failure to act honestly and with reasonable diligence (see section 66(2)).

³⁹ *ibid* p 30

⁴⁰ Interview with Acting President of Queensland Guardianship and Administrative Tribunal

In March 2006 Alzheimer's Australia prepared a **Briefing Note on Elder Abuse and Dementia**⁴¹ including several points related to financial abuse, for example:

There is a need to review and analyse the legal issues around dementia to ensure individual rights and property are protected in the context of the Dementia as a National Health Priority including inter alia, guardianship, mental health, enduring powers of attorney, advance directives.

Helpline data from the Elder Abuse Prevention Unit Queensland for the two years ended 30 June 2005 suggest that psychological (42%) and financial (33%) were the common forms of abuse reported

Assault and some other forms of abuse such as theft and fraud are criminal offences.

Alzheimer's Australia would like to draw the Committee's attention to the inconsistencies that currently prevail in the community. That is, stealing and exploiting another person's finances is called theft and is a criminal offence. However when misappropriation of finances occurs with an enduring power of attorney or a family member, it is currently referred to as financial abuse and frequently there are no consequences for the abuser.^{42 43} This inconsistency needs to be addressed as it affects mostly older people many of whom have impaired decision-making capacity.

Alzheimer's Australia would like to stress that the misuse of enduring powers of attorney including financial mismanagement of assets is an increasing problem for people living with dementia. **This is an urgent problem that requires urgent attention**

The National Dementia Helpline responses

As part of the research into this Submission, Alzheimer's Australia asked the State and Territory member organisations to comment about the types of calls they receive on the National Dementia Helpline as they relate to the Inquiry's Terms of Reference. Examples of responses are:

There have been a couple of clients who have had their EPOAs effectively abused. One was put into residential care without consultation and was a person in early stage who had believed she was only in for respite. Her house was sold and she had no alternatives. Another has had properties sold etc.

⁴¹ Available of web <http://www.alzheimers.org.au/legal>

⁴² Many older people with dementia who are exploited are not in position to recognise the misappropriation of their finances or report it.

⁴³ If an attorney misappropriates the finances of the principal under an EPA, then potential offences may have been committed. Reference has already been made to section 66(1) of the Queensland *Powers of Attorney Act*, but in addition the offence of theft or similar offences such as fraudulent misappropriation may have been committed, as well as specialist offences such as section 142 of the Criminal Law Consolidation Act 1935 of SA (Dishonest exploitation of position of advantage). Criminal action will depend on the victim making a complaint to the appropriate authorities, and those authorities investigating the allegations and then a prosecution being commenced. There are also potential civil consequences such as compensation

When a donee is appointed, the EPOA is immediately effective, the client does not have to have necessarily lost the ability to make decisions and either the person must fight their own battle or is dependent on another person in the community to challenge the abuse if perceived.

The most common Helpline calls in this area are around Powers of Attorney and Guardianship. Many calls talk of needing to take legal or financial action when the person of concern is not capable of understanding what is happening (in other words when the crisis has come). Financial abuse by rival siblings –real or claimed - would be the next most common.

Sometimes we don't get the whole picture from the client and there are often two sides to a story. In those situations where there is real grounds for suspicion of elder abuse it is generally to do with financial exploitation, mistreatment by nursing staff or emotional abuse. Sometimes the abuse is reported as purposefully carried out by others, and other times, abuse occurs through the misunderstanding of dementia by others (e.g. a husband who continues to yell at and upset his wife because she is not 'making sense').

We sometimes get complaints about salesmen and tradesmen taking advantage of persons of concern (usually who are living alone).

Most common ... calls (relate) to financial abuse and family agreements. The financial abuse reported or of concern is generally by friends, neighbours and family members – or concerns that such abuse is occurring but is unsubstantiated. This abuse is generally due to the person living with dementia revealing pin numbers and providing automatic teller cards (ATM cards). In the case of family disputes these issues are relating to care of the person with dementia and sale of assets of person living with dementia.

Recommendation

Alzheimer's Australia strongly recommends that that the Federal Government implement the recommendations noted by McCawley AL, Tilse C, Wilson J, Rosenman L, Setterlund D. Access to Assets: Older People with Impaired Capacity and Financial Abuse. *The Journal of Adult Protection* Vol 8 No 1 2006:

1. Proactive measures for preventing both intentional and inadvertent abuse are urgently required
2. More education, monitoring and support should be provided so that those appointed with powers of attorney are aware of their responsibilities.
3. Community discussion about the meaning of 'family money', ownership of the assets and financial abuse to raise awareness is necessary.
4. People who strip older people of their assets intentionally are accountable.
5. Registration of EPAs and/or monitoring through accountability procedures
6. The development of clear and consistent protocols for aged care professionals about notification and intervention when financial abuse occurs.
7. Clarification of the protective measure for whistle blowers.
8. Engaging financial institutions to report suspected financial abuse

Fraud

Other family abuse that has been noted by callers includes businesses who have been opportunistic – either over charging for services, being paid up front for services and not returning to perform work. Another couple of businesses were also taking advantage of a person dealing in materials bought and sold at a loss to person living with dementia

National Dementia Helpline

Most issues relating to fraud have been covered in the previous section.

Family Agreements

Some callers to Helpline phone with difficulties regarding family members agreeing to care arrangements and sale of assets and the person living with dementia is reported to be coerced by one of the family members into changing agreements, wills or selling assets .

National Dementia Helpline

Family agreements are also called *family care agreements* and *private care agreements*, *independent care agreements*, *personal service contracts* and *lifetime contracts*.

There is little written about family agreements and little information to guide people if they want to consider making such an agreement. Currently Australian families provide a significant amount of care to older people at home in the community. The question about who cares for the ageing population and the increasing number of older people who will develop dementia is a significant question and highlights the need for well-thought-through guidelines within a legal framework to support the many families who choose to care for their elderly relative within the family.

Family Agreements have been described as “the transformation of a cultural duty into a compensatable, contractual obligation of care”⁴⁴ or more simply “when a family member promises to provide long-term care to an older person in exchange for a promise by the older person to transfer property or provide services to the caregiver. Arrangements of this nature can take the form of a formal written agreement or informal agreement, plan or compact”.⁴⁵

The family agreement is a private commitment between older people and their relatives, friends and carers which is designed to accommodate the needs and wishes of the older person as they age and are consistent with the needs, resources and aspirations of the other person/s who assume the position of counterparty (often the carer). Some family agreements are made *ad hoc*, others involve a significant amount of money and or property. Most commonly family agreements are between parents and children.⁴⁶

Herd argues that; “Documenting, in a written agreement, a loving caring or supportive personal relationship, for example, is probably an anathema to many Australians.”⁴⁷

It could be argued that the term ‘Family Agreement’ is a way of formalizing filial obligation in western culture where the responsibility of caring for older parents has moved away from the obligation to do so.⁴⁸ Prior to the end of World War II, most families had no alternative but to make whatever arrangements they could to care for ageing parents or relatives with the resources available in the family. A common solution was for the older person to move in with an adult child and their family.⁴⁹

⁴⁴ Herd B, The Family Agreement – a Collision Between Love and Law? *Reform: Older People and the Law Issues* 81 2002 p23-28 (p24)

⁴⁵ Skousgaard T. *Promoting Family Provided Elder Care*. Presented at the Canadian Conference on Elder Law October 2006 (p3) http://www.ccels.ca/conferences/2006_CCEL_Program/index.htm

⁴⁶ Lewis R, *Elder Law in Australia*. Lexis Nexis Butterworths. Sydney. 2004 p260

⁴⁷ Herd 2002 p23

⁴⁸ This can include younger people who have early onset dementia.

⁴⁹ Herd 2002

Life expectancy was then lower and female adult children were mostly traditional homemakers, not part of the fulltime workforce, and were expected to care for their elderly parents. From the 1950s on, the Church and Charitable sectors introduced institutional care in 'convalescent homes' and females started to return to the fulltime workforce. As a result, the family's caring role diminished and the development of aged care facilities increased. In the new millennium, however, Government policies are encouraging people to stay at home as they age, creating new pressures for families and the expectation that the caring role will once again be within the family. Many families do provide care for their elderly family member rather than rely on Government funded services.⁵⁰

There are many different cultural expectations within the Australian community about caring for ageing parents which range from caring for parents at home to, 'its not my responsibility'. An increasing number of families are choosing to enter into family agreements.

Benefits versus risks

Caring for older parents at home has many benefits for both the older person and the family. Benefits include social, individual and economic benefits as well as intangible rewards such as quality and choice of care, quality of life, independence, proper functioning of society and cost containment.⁵¹

However, there is the risk for arrangement to "go wrong" leaving the vulnerable older person at risk economically, socially, physically and emotionally. When this happens there is usually a negative impact on the family providing the care as well. The negative impact on both the older person and their family can include both economic and non economic factors. The family's economic income may be limited because the caregiver is unavailable for outside employment, the caregiver's role may not be adequately remunerated and there are often additional 'out of pocket' expenses.⁵²

There can also be a negative impact on the quality of life of both the caregiver and the older person. The burden of care can lead to frustration and even physical abuse. It is well documented that the carer's health and well being is often diminished the longer the caring role continues. This is particularly relevant for carers of people with advanced dementia, where there is often increased psychological stress, loss of independence and difficulty in maintaining social relationships.⁵³

⁵⁰ Herd 2002

⁵¹ Skousgaard 2006

⁵² Ibid

⁵³ Cahill SM, Shapiro MM. "The only one you neglect is yourself": Health outcomes for carers of spouses or parents with dementia. Do wives and daughter carers differ? *J Family Studies*, 1998; 4 (1): 87-101.

Skousgaard argues that the majority of care agreements are not formalised in writing, let alone engaged with the legal system. Even when these agreements are written down or a lawyer assists, the finer and more practical points may not be addressed. “Failure to consider the finer points can result in differing expectations or understandings about the range of services to be provided, value of services that are provided, the length of time for which services will be provided and the circumstances in which the services will be provided.”⁵⁴ Rarely do they take into consideration the possible changes in the health and circumstance of either the caregiver or the older person, including their increasing frailty and their dying.

In many families one family member (often a daughter or daughter-in-law) will provide most of the care for a frail parent, which can entail having to give up their own paid work and chance of promotion or the chance to accumulate adequate superannuation to ensure financial security in their own old age. Then, when the parent’s estate is settled, they either receive only the same as those family members who did not provide care or, in extreme cases, even less, due to tensions that have arisen between themselves and the person being cared for, because of the demands of the caring role. Such inequity can, at least potentially, be addressed by completing a legal family agreement.

Although these agreements can amount to a contract, there are barriers under common law that prevent enforcement and thus protection for the partners. Skousgaard argues that there are two distinct yet interdependent reasons for these barriers. First, the common law of contract contends that the ‘family’ and their arrangements should not be interfered with and second, the common law of contract focuses primarily on “the economic aspects of the relationship and almost always subordinates the non-economic aspects of the relationship”⁵⁵

The common law of contract still has the perception that the ‘family’ is based on early twentieth century notions of a family when there were much clearer expectations of the role of each member and no expectations of compensation. This, together with respect for privacy and non-interference, means that there is a “hands off approach to families and their arrangements in all but extreme cases”⁵⁶

Skousgaard argues that the way to move forward is for the common law of contract to become responsive to current needs and practices. One of the most important functions of the common law of contract is to mirror and support accepted social norms. This is essential for a more effective and efficient method of regulating family agreements. Munro agrees that the domestic contract principle fails to have relevance as “it does not address the inherent power differential between parties to domestic agreements such as informal family accommodation agreements.”⁵⁷

The impression that the common law does not either enforce family arrangements as contracts, or will not interfere with them is not entirely accurate. There is, at least in theory, no reason why a “family agreement” cannot be enforced as a contract if all the relevant requirements of a contract are met, (for example, the intention to create legal relations, capacity, offer and acceptance, consideration, and certainty).

⁵⁴ Skousgaard 2006 p15

⁵⁵ Ibid p17

⁵⁶ Ibid p29

⁵⁷ Munro R. Family Agreements: All with the BEST of Intentions. *Alternative Law Journal* 2002. 27 (2):68-72 (p72)

The confusion has arisen because there is a presumption that where family or social arrangements are concerned, the law presumes that there is no intention to create legal relations, thus one crucial requirement for a contract is missing (see eg Balfour v Balfour [1919] 2 KB 571; Cohen v Cohen (1929) 42 CLR 91). However, if the family or social arrangement is clearly intended to create a legal relationship (and assuming that the other requirements of a contract are present), then that social or family arrangements are binding and can be enforced as a contract (see eg Raffaele v Raffaele [1962] WAR 29).

Having said this, there is always the potential for an issue of whether or not there is sufficient evidence to show there was an intention to create a legal relationship, especially where one of the parties suffers from dementia, so any legislative reform in this area is to be supported.

Another alternative would be to have family arrangements in writing and in the form of a contract under seal. Such contracts are technical and formal in nature, needing as they do to be “signed, sealed and delivered”. Ideally they would have to be prepared by an appropriately qualified legal practitioner.

There is scope for legislative reform and even consolidation in this area in the interests of the community. However, there is the Constitutional issue of whether the Commonwealth has power to pass legislation of general application in this area, falling within the competence of the States.⁵⁸

Alzheimer’s Australia urges the Committee to consider the relevance of family agreements for the increasing number of older people particularly those who have lost and will lose their decision-making capacity. These vulnerable older people (and those with early onset dementia) need to be protected by a legislative framework that prevents exploitation and guarantees that they will be cared for with dignity and compassion.

Recommendations

1. Alzheimer’s Australia recommends that the Federal Government commission a Discussion Paper on Family Agreements to commence the development of this emerging area of Elder Law.
2. Alzheimer’s Australia recommends that Commonwealth legislation be enacted to govern exhaustively the area of family agreements, with agreed complementary legislation passed by State/Territory jurisdictions as necessary. Any such arrangements should be consistent with Centrelink requirements for gifting and reporting.

⁵⁸ Advice from an Alzheimer’s Australia Consumer.

Barriers to older Australians accessing legal services

Indirectly, barriers for people on limited means to afford the cost of Power Of Attorney and other legal services that may have a fee. Legal Aid often difficult to access except in metropolitan areas National Dementia Helpline

There are many barriers that prevent older people from accessing legal services. This is a significant issue when encouraging older people to appoint a substitute decision maker, to make a will or to seek legal advice for other reasons. The barriers often tend to increase when a person is diagnosed with dementia.⁵⁹

Many people do not go to lawyers, some cannot afford to and others do not understand the need to. Seeking legal advice is more readily acceptable to those who are well educated, financially secure, and confident enough to proceed with finding a suitable lawyer. Bottomly and Parker point out “the relationship between poverty and inequality in access to and use of legal service”.⁶⁰

Many people are unaware of their legal rights or how to access information when in need. Government funded legal aid is accessible to some people but others are not aware of the service. State Public Trustees offer services that may assist many older people. For many people from culturally and linguistically diverse (CALD) backgrounds, accessing legal advice is difficult and may also be culturally inappropriate.

In 2004, Edwards and Fontana compiled a report for The Law and Justice Foundation of NSW on *The Legal Information Needs of Older People*.⁶¹ This report reviewed the relevant literature and identified the legal information needs of older people and the barriers that prevent them from accessing the necessary information.

This work is particularly relevant for this Inquiry into Older People and the Law as all the issues identified relate to people living with dementia

Major areas which were identified in the report as needing attention included:

1. The legal information needs of older people:

- Accommodation and housing e.g. nature of tenancy, rights of renters
- Health related issues e.g. advance[d] health care directives
- Financial and consumer related legal issues e.g. eligibility for services
- Discrimination related issues e.g., employment, provision of services
- Elder Abuse issues e.g. psychological and financial abuse and neglect
- Grandparenting issues
- Substitute decision making and end of life issues e.g. wills and probate

⁵⁹ These barriers are also relevant for younger people who develop early onset dementia.

⁶⁰ Bottomly S, Parker S. *Access to Justice*, Ch 5 in *Law in Context*, Federation Press, Annandale NSW, 1997. P 74.

⁶¹ Edwards S, Fontana A, *Legal Information Needs of Older People*. Law and Justice Foundation of NSW 2004. Available on the web: www.lawfoundation.net.au/ljf/chapter/038FD4CA228EA732CA257060007D140 Accessed 2/11/2006

Older people also need information on where and how to make a complaint when dealing with issues related to the above topics.

The authors also noted that older people from CALD backgrounds, Aboriginal older people, those who are socially isolated and those living in remote areas need information on similar topics but their priorities may differ and their needs may be even greater.

2. Awareness and knowledge of services and information

- Many older people are unaware that they have information needs. They have a low awareness of services and the sources of information available to them. In particular, there is a low awareness of and knowledge about legal issues and legal services and information services.
- Older people are unaware of their legal rights or the increasing amount of legislation which has been enacted to strengthen these rights.
- Their knowledge of enduring powers or attorney and advance[d] health directives is low.

3. Awareness and knowledge is lower among the following groups of older people:

- The ‘decisional dependent’, that is older people who are willing to give control of their affairs to other people
- Those with lower incomes and wealth
- Aboriginal people
- Older people with disabilities
- Those from CALD backgrounds
- Some who live in rural and remote areas.

4. Barriers to information acquisition

Edwards and Fontana found that barriers to information acquisition can arise from either the characteristics of older people or from the characteristics of the information providers.

Barriers associated with the characteristics of older people include:

- reluctance to think about death and disability-associated issues
- low literacy level among both English speakers and those from a non- English speaking background
- lack of confidence in enforcing their rights
- perceptions that the law is disempowering and cannot solve their problems
- fears that lawyers may act against their interests

Barriers can also result from the characteristics of information providers. These may include:

- high costs
- stereotypes about older people
- a lack of interest by legal practitioners in older clients

- lack of knowledge about older people or the legal issues they face
- lack of legal aid services

Barriers that limit older people's use of available complaint procedures include:

- reluctance to complain
- lack of awareness of how to make a complaint
- fear of retributions from service providers

5. Information provision strategies

The report proposed a number of information provision strategies:

- As many older people do not realise they have legal information needs, it is necessary to take a **proactive** approach when promoting services. Providers should help to make older people aware of their needs, for example, the importance of making arrangements for end-of-life contingencies.
- In addition, the diversity of older people means that it is important to select specific target groups/segments and develop different messages and strategies for each group.
- There is general agreement on which information provision strategies are most effective: face-to-face methods are recommended by both older people and by providers. These should be supplemented by printed information. In addition, local newspapers, presentations, radio (particularly talkback radio), telephone information services and television are recommended.

Additional strategies for dissemination of information to older people about legal issues include:

- formal talks from experts
- pamphlets and brochures
- a public education campaign to raise awareness of issues such as enduring powers of attorney and legal rights
- a specialist legal service for older people

Regardless of the dissemination method selected, it should ensure:

- confidentiality
- reasonable costs which are known ahead of time
- lawyers who demonstrate friendliness, warmth, ability to communicate and a respectful attitude
- lawyers from different cultural backgrounds.

Information Acquisition

Many older people, like the population as a whole, do relatively little information seeking when they are facing a problem or a critical situation. Often only one source is approached.

In addition, many do not seek information 'until the time comes'. For example, many think there is no need to worry about enduring powers of attorney or an advance[d] health directive until later in life, or they believe their family will take care of issues such as substitute decision-making.

In retrospect, however, older people often wished they had sought more information before 'the time came'.

The report concludes:

Providing information to older people is complex because of the diversity of the group and many older people's low perception of their needs. Many different pathways to information need to be provided. There has, however, been limited empirical evidence on the effectiveness of different methods and strategies. Further research is needed in this area and on when older people need legal information, how they acquire it and what they do with the information when it is provided.⁶²

Alzheimer's Australia would like to emphasise the importance of Edwards and Fontana's findings and reiterate that the barriers identified in this report can be accentuated when people are living with dementia.

Specialist Legal-Advocacy Service

As this Submission has identified, navigating a way through the complex array of legal issues can be difficult particularly for people as they age. These difficulties are then compounded when decision-making capacity is declining.

In most States and Territories, there is no obvious place for older people to go to access the information and the support when they want to attend to their affairs including appointing their enduring powers, discussing wealth transfer, family agreements and attending to their wills. People cannot always access lawyers, Legal Aid or the Public Trustees, download information off the Internet or telephone a 'helpline' for advice. Many are reluctant to be referred to a Guardianship Tribunal.

Callers to Helpline note that some disagreement has occurred especially when there are a number of family members. However these families are often reluctant to talk to Tribunal. Some callers to the Helpline also report Tribunal attendance was an experience that was distressing. National Dementia Helpline

⁶² Edwards & Fontana 2004 p15

Research in South Australia⁶³ found that when people are first diagnosed with memory loss, attending to the process of appointing enduring powers and making advance directives is a bit too hard for them to do alone.

Some of the participants went to lawyers to execute these powers and others used *Do it Yourself Kits*. Some had not got around to it even though the decision-making capacity of one of the partners was already declining. All agreed that the law and practice associated with enduring powers and advance directives is a complex area for the individuals and families to understand.

Not all lawyers were familiar with the loss and disruption associated with a diagnosis of dementia. Discussing end of life decisions with a lawyer was not appropriate nor is the discussion of the dilemmas that many people confronted with difficult family relationships.

One woman who had appointed an enduring power of guardianships with a *Do it Yourself Kit* had misunderstood the extent of the powers that she was delegating to her guardians. All four people involved in this case had University degrees. This is an example of the potential for mistakes when people proceed without well informed assistance.

Recommendations from this research included providing people with dementia with reliable opportunities for accessing the information about enduring powers and advance directives, including assistance with the process. Other research supports this need for assistance in completing the documents as people age or become very ill. They require assistance especially when there is conflict in the family or there is no obvious person to appoint or they are bewildered by the legal documentation.⁶⁴

Establishing specialist legal-advocacy services for older people with trained legal, paralegal and counselling services would address this current gap in service provision for older people.

A model of a specialist legal-advocacy centre already exists in Toronto, Canada:

The **Advocacy Centre for The Elderly (ACE)** is a community based legal clinic for low income senior citizens. It is managed by a volunteer board of directors at least half of whom are seniors. ACE is funded through Legal Aid, Ontario and is the first legal clinic in Canada to specialize in the legal problems of seniors. ACE provides direct legal services to low-income seniors, public legal education, and engages in law reform activities. ACE services and activities are in relation to areas of law of special importance to the seniors' population.⁶⁵

⁶³ **Brown M**, Jarrad S. Putting the Powers in Place: Planning for the Future. Final Report. Alzheimer's Australia SA Inc. 2005

⁶⁴ **Brown M**, Fisher JW, Brumley DJ, Ashby MA, Milliken J. Advance directives in action in a regional palliative care service: "Road testing" the provisions of the Medical Treatment Act 1998 (Vic) *Journal of Law and Medicine*. 2005.13: (2) 186-190

⁶⁵ <http://www.advocacycentreelderly.org/>

Alzheimer's Australia supports the idea of establishing such a Specialist Legal-Advocacy Service which would augment existing aged rights/advocacy services funded by the Federal Government and support the Public Advocates and Guardianship Tribunals. Federally funded State-based services will require more uniformity in both the legislative framework and policies throughout Australia.

Elder Law

To complement the development of specialist legal-advocacy services it would be advisable to establish 'Elder Law' as a specialty. This has already commenced at the University of Western Sydney⁶⁶ and in Canada⁶⁷. All States and Territories need access to this type of legal education to assist lawyers and other professionals in understanding the unique needs of vulnerable older people.

The range of legislation that impacts on older people is broad and complex ranging from Social Security to the *Aged Care Act 1997* and at the state level legislation such as enduring powers and Guardianship and Administration Acts. Supporting an Elder Law speciality would assist in knowledge sharing, research, an increased understanding and higher quality interventions on behalf of vulnerable older people.

Recommendations

1. Alzheimer's Australia endorses the recommendations of Edwards and Fontana's report on the barriers that prevent older people from accessing information and support for legal information acquisition.
2. Alzheimer's Australia recommends that the Federal Government establish and fund a **Specialist Legal-Advocacy Service** for older people in each State and Territory.
3. Alzheimer's Australia recommends that the Federal Government support the development of Elder Law as a specialty in specific Universities across Australia.

⁶⁶ <http://www.uws.edu.au/about/acadorg/clb/sl/research/elderlaw>

⁶⁷ <http://www.ccels.ca/>

Discrimination

People with dementia are often subjected to discrimination as their decision-making capacity deteriorates. Discrimination may occur across a number of areas such as employment, accommodation and insurance. Most employers have a legal responsibility to take reasonable steps to assist people find a way around their difficulties and not to unlawfully discriminate against individuals because of their disability, in this case, memory loss.

The Commonwealth *Disability Discrimination Act 1992* was introduced to ensure that Australians with disabilities have legal protection against discrimination.

Because people are being diagnosed with dementia earlier, there is now greater potential for the diagnostic label to lead to discrimination in the work place, even though the person maybe still capable at their job.

Recommendation

Alzheimer's Australia recommends that the Federal Government collect further evidence of discrimination in employment, relating to people living with dementia to assist in future policy development and increase public awareness of the legal issues associated with discrimination relevant to people living with dementia.

Other Issues:

Informal Decision-Making

The majority of decisions involving older people, particularly those with dementia, occur in the private domain and not in public Guardianship Tribunals. However, most families do not have the education and/or information to assist them to navigate through the complex processes involved.

Evidence from the many telephone enquiries at the Offices of the Public Advocate, Guardianship Tribunals, Aged Rights Advocacy Services and the National Dementia Helpline confirm the fact that many families struggle with decision-making especially when a family member loses decision-making capacity.

People are often not clear when a substitute decision maker should be appointed, or who in a fraught family network should be appointed to make the decisions when the family member is no longer able to do so. Complex family relationships add further difficulty to this area.

Older people are very vulnerable to decisions made by family members often acquiescing because of dependency. Therefore we need to strengthen families ability and confidence in decision making in a way that maintains respect for the older person' rights and choices.

Strategies that would assist include:

- modules in carer education that include substitute decision-making
- a resource booklet to assist family members in the decision-making process
- extend the counselling support available eg. Through the National Dementia Helpline.

Recommendation

Alzheimer's Australia recommends that additional resources be developed to assist families in decision-making for vulnerable older people.

Capacity Assessment

The definition of capacity is a contentious issue that is only now receiving attention in Australia.⁶⁸

It is a construct that is based on the complexities of a person's abilities as they interact with their environment. It is also subject to fluctuation. A person's overall capacity to make decisions can be enhanced by personal strengths, good service provision, information and support. Personal limitations, poor service provision and lack of support can limit it.

In addition, the external environment will often influence or determine whether a person with an impairment makes decisions in areas where they are capable. For example, legislation which only provides for a finding of global incapacity automatically limits the opportunities for a person to make their own decisions in areas where they might otherwise be found to be capable.

Taken together, all these factors create major challenges for professionals and members of the community who are involved in capacity assessment.⁶⁹

The concept of capacity is fundamental to a person being able to make a legally enforceable decision relating to decisions about medical treatment, entering a contract or empowering others to be a guardian or an attorney.

A person can make decisions if they understand the nature and the consequences of their actions. The decision will depend on the circumstance in each case and the nature of the transactions. Currently there is no comprehensive approach to assessing capacity or addressing the support needs of a person whose capacity is in question.⁷⁰

There is a growing concern in Australia about the lack of appropriate tools for assessing capacity and who is responsible for the assessments. A survey of health professionals in South Australia in 2003 found that 60% considered that a standard assessment tool for capacity would help their work considerably.⁷¹

⁶⁸ Attorney General's Dept of NSW. Are the rights of people whose capacity is in question being adequately promoted and protected? Discussion Paper. March 2006 (P3) Available on the Web at <http://www.lawlink.nsw.gov.au/diversityservices>

⁶⁹ Ibid p3

⁷⁰ Ibid

⁷¹ Strachan M. *Shades of Grey*. Discussion Paper. Alzheimer's Australia SA 2003

The Discussion Paper *Shades of Grey* written as a result of this survey had 30 responses from individuals and organisations in which 85% stated that the absence of a formalised assessment process affected their work and the current ad hoc assessments were restrictive and inadequate. These respondents wanted an independent assessment process that could provide more certainty, consistency, independence and reliability.⁷²

At the moment capacity assessment is in the jurisdiction of mostly medical and legal professionals but the tools they use vary and as noted there is no consistency or reliability. Some jurisdictions overseas are addressing this problem, for example Ontario, Canada has created an independent system of capacity assessment with specialised training and accreditation.

Many of the legal issues addressed in this Submission hinge on appropriate capacity assessment of older people particularly those with dementia.

The Discussion Paper by the NSW Attorney General; *Are the rights of people whose capacity is in question being adequately promoted and protected?* is applicable to the issues experienced nationally. Alzheimer's Australia urges the Committee to consider how the Federal Government might extend the influence of this discussion paper across the nation.

Recommendation

Alzheimer's Australia recommends that the Federal Government endorse the approach of the NSW Attorney General Discussion Paper *Are the rights of people whose capacity is in question being adequately promoted and protected* and commend it to the other State and Territory governments for consideration.

⁷² Ibid

Guardianship Tribunals

The Guardianship Tribunals exist to protect vulnerable people with mental incapacity or illness from abuse, exploitation and neglect (including self neglect). The role of the Guardianship Tribunals is not well understood in the community. Once a person has lost decision-making capacity the Guardianship Tribunal is the only avenue to legally appoint a substitute decision-maker. It is the safety net for these vulnerable people. Therefore the Tribunals are very important in protecting the rights of people living with dementia.

Callers to the National Dementia Helpline note that disagreements are common in families where there are a large number of family members. However these families are often reluctant to talk to a Tribunal about these difficulties. Some callers to the Helpline also report that attending a Tribunal hearing was distressing.

Alzheimer's Australia emphasises the need for the process of applying for guardianship to be easy and accessible. Also families need to be well supported with mediation and advocacy services. These services are stretched in some states or non-existent. Development of **specialist legal and advocacy services** and resources for families, as previously mentioned, could enhance the states' Guardianship Tribunals.

The terminology and the legislative frameworks around Guardianship differ across the states and are not transferable between states creating difficulties for families who are mobile. Harmonisation of the Guardianship legislation is required in the same way as the advance care planning

Recommendations

1. Alzheimer's Australia recommends that the Federal Government develop **specialist legal and advocacy services** to assist families in the area of guardianship.
2. Alzheimer's Australia recommends that the Federal Government explores the possibility of harmonisation of Guardianship legislation with the National Guardianship Administration Network.

Table 1: Summary of Legislation Affecting End-of-Life Issues

| State | Advance Directive/ Refusal of Treatment | Proxy/ Agent* | Comments |
|-----------------------|--|------------------|---|
| New South Wales | No have guidelines only | Yes | AHDs made pursuant to the NSW Health document <i>Using Advance Care Directives</i> (2004) are a common law advance directive and legally binding. Individuals may also appoint Enduring Guardians. |
| Victoria | Yes | Yes | Patient can write a “refusal of treatment” certificate, but only for a <u>current</u> , illness which does not have to be terminal: <i>Medical Treatment Act 1988</i> . The legislation also allows appointment of proxy who can refuse treatment. |
| Queensland | Yes | Yes | <i>Powers of Attorney Act 1998</i> allows AHD refusing treatment. This Act and <i>Guardianship & Administration Act 2000</i> allow for others including an attorney under an EPA to consent to withdrawing/withholding life-sustaining treatment. |
| South Australia | Yes | Yes | <i>Consent to Medical Treatment and Palliative Care Act 1995</i> confirms that a person over 18 years can write an advance directive that refuses consent to medical treatment any time (i.e. anticipatory) but only for terminal illness. |
| Western Australia | No | No | <i>Acts Amendment (Advance Health Care Planning) Bill 2006</i> (not yet enacted) allows an advance health directive to be completed and no requirement for a current condition or terminal illness. |
| Tasmania | No | Yes | <i>Directions for Medical Treatment Bill 2005</i> (not yet enacted) allows an advance directive for a current condition, or if has terminal illness or in persistent vegetative state. Individuals may appoint Enduring Guardians. |
| Northern Territory | Yes | No | <i>Natural Death Act 1988</i> allows a person 18 years and over to make an advance directive to refuse extraordinary treatment in the event of a terminal illness. |
| A.C.T. | Yes | Yes | <i>Medical Treatment Act 1994</i> allows an adult to give a direction about the refusal or withdrawal of medical treatment. There is no requirement for the condition to be current or terminal. |

* All states/territories have guardianship legislation

The US, Canada and the Netherlands all have provision for Advance Directives and proxy decision-making; In the UK, a 1993 High Court decision (Re C -Adult: Refusal of Medical Treatment) said advance directives are legally binding and a House of Lords decision to withdraw tube feeding from a patient in a persistent vegetative state (Re: Bland) set an important precedent; Britain Passed a law in December 2004 allowing living wills or documents that set out what medical treatment they want if they become seriously ill and lose the capacity to make a decision.