

Discussion Paper #10  
June 2014

# PREVENTING FINANCIAL ABUSE

## OF PEOPLE WITH DEMENTIA

**TALKING ABOUT ALZHEIMER'S  
ACROSS AUSTRALIA**  
FIGHTDEMENTIA.ORG.AU

# ACKNOWLEDGEMENTS

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**If you have been a victim of financial abuse, Alzheimer's Australia NSW recommends contacting the NSW Elder Abuse Helpline on 1800 628 221. This is a confidential service offering information, advice and referrals for people who experience, witness or suspect the abuse of older people living in their homes in NSW.**

Alzheimer's Australia respectfully acknowledge the Traditional Owners of the land throughout Australia and their continuing connection to country. We pay respect to Elders both past and present and extend that respect to all Aboriginal and Torres Strait Islander people who have made a contribution to our organisation.

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# ACRONYMS

ABA	Australian Bankers' Association
ACAT	Aged Care Assessment Team
ACCC	Australian Competition and Consumer Commission
ACT	Australian Capital Territory
AlzNSW	Alzheimer's Australia NSW
CALD	Culturally and Linguistically Diverse
CORPD	Convention on the Rights of People with Disabilities
DCRC	Dementia Collaborative Research Centres
EPOA	Enduring Power of Attorney
NCAT	NSW Civil and Administrative Tribunal
NSW	New South Wales
OLSC	Office of the Legal Services Commissioner
OPG	Office of the Public Guardian
PIN	Personal Identification Number
POA	Power of Attorney
TARS	The Aged Care Rights Service
UK	United Kingdom
UN	United Nations
WHO	World Health Organisation



# EXAMPLES OF FINANCIAL ABUSE OF PEOPLE WITH DEMENTIA

(as reported by service providers)

*"A mother with dementia was moved from her home by her daughter, and without the knowledge of her son who lived in the UK. She was taken to live with the daughters' family and was locked in a bedroom. The mother executed a Power of Attorney at a time when she lacked capacity. Her house was sold without her knowledge and the funds were used to pay off the mortgage on the daughters' house and buy a four wheel drive. It was also used to buy a family holiday, pay for school fees and a trip to New York for one grandchild. The mother therefore lacked funds for a bond for a residential facility, which she would otherwise have been able to access. Instead she was locked away with no stimulation or independence until her son returned to Australia and discovered the abuse."*

*"An elderly widow (without immediate family) with dementia was befriended by a real estate agent. He was a friend of her gardener. She owned her own home. He charmed her and she took mortgages out over her home to lend him money and buy him a car. She is now in a nursing home. Two thirds of her assets have been taken. It was an aged care assessment team member who suspected the abuse but only after most of the funds had been taken."*

*"A nephew would present his aunt with a blank cheque and tell her he was going to purchase groceries. He would fill in the amount himself after she signed then make the cheque out for thousands of dollars. He was working towards having her discharged to his care and purchased a new four bedroom home where he purported he would look after his aunt. He also purchased a Mercedes Benz car!"*

*"An unemployed man moved in with his mother 'to care for her' but in fact he spent all her money on drugs and alcohol and she could not recognise it was happening. Neighbours suspected it was happening but were helpless to support this lady who refused to acknowledge her dementia or her sons' abuse."*

*"The daughter and her partner (who has Power of Attorney) moved in with mum who has dementia. They have four children and decided the house was too small so sold and purchased a new two storey home. Their mother is in small room downstairs with a bathroom in the family laundry but the home and all attached amenities are in her name. Often her accounts for care and services cannot be paid...but she is unwilling to go against her daughter as she says 'she will be put in a nursing home if she stops her daughter from using money'."*

*"A son and daughter, who were both solicitors, changed the title deeds on properties owned by their parents into their own names. They had systematically sold the parents' share portfolio and recouped the funds to themselves. Their parents are living in an inaccessible and very small rental property – effectively leaving them with no assets. Neither of the parents are aware as they both have cognitive decline and as they trusted their children they signed anything put in front of them."*

# EXECUTIVE SUMMARY

The financial abuse of people with dementia is a concern for Alzheimer's Australia NSW (AlzNSW). Over the years our staff have heard of numerous cases of financial abuse of people with dementia yet it is something that is rarely spoken about in the public domain. We hope this paper will generate public discussion about the issue and lead to changes in policy and practice to prevent people with dementia being financially abused.

Financial abuse is defined by the World Health Organisation (WHO) as "the illegal or improper exploitation or use of funds or resources of the older person". However this definition can be interpreted in different ways due to subjective understandings of what constitutes abuse. There are many risk factors for financial abuse, not just dementia. It is therefore important to consider family relationships and dynamics, social and cultural connections, physical and mental health and wellbeing and financial standing. Other forms of abuse, such as physical abuse and neglect or psychological and emotional abuse, may be occurring at the same time as financial abuse.

AlzNSW conducted research to examine how financial abuse of people with dementia occurs and what can be done to prevent or reduce the incidence of it. We held focus groups with our eight consumer advisory groups, surveyed service providers and professionals from a range of sectors, and interviewed family members of victims of financial abuse. Examples of financial abuse of people with dementia are included throughout the paper. Their stories highlight the ways in which financial abuse is perpetrated and the devastating effects it has for victims and their loved ones.

It is extremely difficult to calculate the prevalence of financial abuse of people with dementia as it occurs in a multitude of ways and much of it remains unreported to authorities. The percentage of cases that go unreported is likely to be high due to feelings of stigma, shame and embarrassment experienced by people who are victims of financial

abuse and their families. People with dementia may have diminished capacity to recall the financial abuse or lack insight to understand the abuse.

Much financial abuse is perpetrated within families. Some of this abuse would likely be considered 'inheritance impatience'. More than sixty-five percent of respondents to our survey indicated that children are most often identified as the perpetrators of abuse, and over ninety percent of respondents indicated someone known to the victim is most often the perpetrator.

Our research suggests that a considerable proportion of financial abuse of people with dementia is perpetrated by people appointed as an attorney under an Enduring Power of Attorney (EPOA) not acting in the interests of the person with dementia. Another enabler of financial abuse is the failure of some lawyers to assess the capacity of an individual to appoint a new EPOA.

Not all financial abuse of people with dementia is perpetrated by family members and those holding an EPOA though. People with dementia, particularly those who live alone, are susceptible to exploitation and abuse by neighbours and friends who prey on their vulnerability.

We found that people with dementia, family members and service providers are reluctant to report financial abuse. Victims are often in a relationship of dependence with the perpetrator and may fear repercussions if they report the abuse. There is also confusion at all levels in the community about who to report abuse to. When financial abuse is reported there are challenges in investigating cases. Financial abuse can be difficult to substantiate and prove, especially when the victim has dementia.

A number of possible strategies to reduce the incidence of financial abuse of people with dementia and to resolve cases satisfactorily emerged from the research. These include reporting of financial abuse of people with dementia, and registration and monitoring of

EPOAs. These measures are not universally supported and the surrounding debates are examined in this paper.

Our research findings have implications for many stakeholders including lawyers, police, banks and community services. Many agencies have a role to play in reducing the incidence and impact of financial abuse of people with dementia. Based on the findings of our research, AlzNSW recommends the following:

### NSW Government

1. The NSW Attorney General:
  - a. Introduce a Public Advocate whose role includes the investigation of reports of financial abuse;
  - b. Refer the examination of a register for Enduring Powers of Attorney to the NSW Law Reform Commission;
  - c. Refer the investigation of how to appropriately respond to financial abuse of people with dementia to the NSW Law Reform Commission;
  - d. Refer the investigation of the adequacy of current law covering financial abuse in the *Powers of Attorney Act 2003* to the NSW Law Reform Commission;
  - e. Amend the *NSW Interagency Protocol for Responding to Abuse of Older People* to reflect any changes to legislation and practice.
2. The NSW Police Force establish *Vulnerable Communities Officer* positions in each Local Area Command to assist in the identification of those at risk of financial abuse and to support victims.
3. The NSW Government ensure that education is provided to people who are appointed as attorneys under Enduring Power of Attorneys to ensure they understand their responsibilities.
4. The NSW Government provide broad public education about financial abuse and planning ahead

tools. This should include information in culturally and linguistically appropriate formats for Aboriginal and Culturally and Linguistically Diverse (CALD) communities.

### Australian Government

5. Australian Prudential and Regulatory Authority require banking and financial services institutions to develop internal systems and processes to prevent financial abuse and establish protocols to report suspected financial abuse of customers to state Public Advocates.

### Banking and financial services institutions

6. Staff receive mandatory training on identifying financial abuse using the education modules and resources developed by Capacity Australia.
  7. Staff receive mandatory training about dementia using the *'Is it Dementia?'* training resource developed by Alzheimer's Australia.
  8. Banking and financial services institutions provide information to their customers about how to protect themselves from financial abuse and steps they can take to plan ahead.
- ### Legal profession
9. The NSW Law Society provides training about financial abuse to lawyers and includes this as part of continuing legal education requirements.
  10. The NSW Law Society provides training about dementia to lawyers using the *'Is it Dementia?'* training resource developed by Alzheimer's Australia.

### Community service providers

11. All funded aged care organisations in NSW be required to make staff aware of their responsibilities and obligations under the *NSW Interagency Protocol for Responding to Abuse of Older People*.

# BACKGROUND AND AIMS

Financial abuse is a concern for people with dementia and their carers. Over the years Alzheimer's Australia NSW (AlzNSW) has heard of numerous cases of financial abuse of people with dementia yet it is something that is rarely spoken about in the public domain.

In response to this AlzNSW conducted a research project that aimed to:

1. Understand how financial abuse of people with dementia occurs and identify gaps in law and policy that enable it to occur;
2. Identify what will reduce the likelihood of financial abuse occurring and influence law and policy makers to initiate these changes; and
3. Educate service providers, people with dementia and carers about how to prevent financial abuse.

This discussion paper presents the findings of the research. It examines how financial abuse of people with dementia occurs, how financial abuse is reported and investigated, and what could be done to prevent abuse. Recommendations are provided for the NSW and Australian Governments, the financial and legal sectors, and providers of community services to help safeguard people with dementia from financial abuse and to reduce the incidence and magnitude of financial abuse of people with dementia. This project was conducted in the NSW context however its findings and recommendations have implications for Governments and service providers in other Australian States and Territories.



# WHAT IS FINANCIAL ABUSE?

The World Health Organisation (WHO) defines elder financial abuse as “the illegal or improper exploitation or use of funds or resources of the older person”<sup>i</sup>. Financial abuse can be interpreted differently and difficult to detect due to subjective understandings of what constitutes abuse. For example, some cultural groups and families have particular attitudes and different norms with regard to the sharing of money and property. Family-mingled funds and resources lead to different understandings of what constitutes improper use<sup>ii</sup>.

The Australia Human Rights Commission defines financial abuse as “when a person you trust uses that relationship of trust to gain access to your money or property” and identifies the varied forms financial abuse can take, including:

- Pressure to act as guarantor for a loan;
- Pressure to transfer or sell property;
- Pressure to give away money;
- Loans not being repaid; or
- Persons authorised to manage your money not acting in your best interest, or using your money for themselves<sup>iii</sup>.

The advocacy organisation Seniors Rights Victoria suggests that “financial abuse tends to exist in the grey area between thoughtless practice and outright theft”, noting that it is “usually not a single event but a process that develops over time and so it is difficult to assess at what point a well-intentioned but ill-considered financial act tips over into abuse, or when borrowing money becomes misappropriation”<sup>iv</sup>.

Planned financial abuse is deliberately targeted and may include the ‘grooming’ of a vulnerable person to develop a relationship of trust. Loneliness and social isolation may play a part in marking a vulnerable person as a potential target for predatory abusers. Opportunistic abuse is more likely to emerge over time and

be perpetrated by someone with a Power of Attorney who may initially act legitimately but take liberties because they can or because they find themselves in difficult circumstances such as debt<sup>v</sup>.

Interpretational differences lead to varied reporting of prevalence statistics of elder financial abuse<sup>vi</sup>. The WHO definition is broad; it encompasses financial abuse perpetrated by people known to the victim as well as abuse perpetrated by strangers and institutions, by way of scams and fraud. For the purposes of this project we defined financial abuse as abuse perpetrated by people in a position of trust. Scammers may approach people in many different ways, including through phone calls, emails, letters and door-knocking. People who fall victim to scams should report the scam to the Australian Competition and Consumer Commission (ACCC). Although people with dementia are at an increased risk of falling victim to scams and being defrauded, this type of exploitation was outside the scope of investigation for this project.

# THE PREVALENCE OF FINANCIAL ABUSE OF PEOPLE WITH DEMENTIA

It is very difficult to quantify the prevalence of financial abuse of people with dementia. Lowndes *et al.* (2009) provide a thorough overview of the challenges of collecting prevalence data for elder financial abuse, outlining the international and Australian studies that have attempted to quantify the extent of elder financial abuse. Although it is difficult to determine the prevalence, it is estimated that financial abuse affects up to five percent of older Australians<sup>vii</sup>. This is likely to be an underestimate as financial abuse occurs in multitude of ways and much of it remains unreported to authorities<sup>1</sup>.

The percentage of cases that go unreported is likely to be high due to feelings of stigma, shame and embarrassment experienced by people who are victims of financial abuse and their families. People with dementia may have diminished capacity to recall the financial abuse or lack insight to understand the instance/s of abuse. Even in cases where they do detect and report abuse they may be dismissed as being an unreliable witness who is confused and lacks credibility<sup>viii</sup>. In addition, as will be discussed in this paper, much financial abuse is perpetrated within families and therefore remains hidden. Victims are often in a relationship of dependence with the perpetrator of abuse and may fear there will be repercussions if they report the abuse.

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<sup>1</sup> The AlzNSW project team attempted to determine the reported incidence of financial abuse of people with dementia in NSW. Statistical data was requested from a number of organisations including the National Dementia Helpline, the NSW Guardianship Tribunal, the Financial Ombudsman, the NSW Elder Abuse Helpline and The Aged Care Rights Services (TARS). Although data is collected on financial abuse and/or cognitive impairment, systems are not in place to link the data fields.

# WHY ARE PEOPLE WITH DEMENTIA VULNERABLE TO FINANCIAL ABUSE?

The term dementia describes the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning. It encompasses the progressive loss of memory, intellect, rationality, social skills and physical functioning. A person may have symptoms for several years before dementia is diagnosed.

A diagnosis of dementia does not necessarily mean that a person can no longer make decisions for themselves. Legislation throughout Australia is informed by the United Nations (UN) Conventions on the Rights of People with a Disability (CORPD) and the Common Law presumption of capacity where it is assumed a person has capacity unless it can be proven that they do not. It is usually the responsibility of the treating health professional to determine whether or not someone has capacity to manage their financial affairs and other matters<sup>ix</sup>.

As symptoms progress, a person with dementia will lose the ability to make financial decisions and manage their finances. The gradual loss of capacity and decline in cognitive abilities increases the vulnerability of people with dementia and their risk of falling victim to financial abuse and exploitation.

Financial abuse does not include financial mismanagement of their own funds by a person with dementia. The lack of cognitive capacity to manage their finances makes people much more vulnerable and increases their risk of being financially abused, exploited and defrauded. Rapid advances in technology and the changing nature of banking, including the rise of online transactions and the declining use of cheques, can increase the vulnerability of people with dementia as these changes are difficult to understand and navigate yet they can also offer some protections as it can be easier to detect abuse.



# THE 'RED FLAGS': SIGNS OF FINANCIAL ABUSE

There are many risk factors for financial abuse, not just dementia. It is therefore important to consider family relationships and dynamics, social and cultural connections, physical and mental health and wellbeing and financial standing. Other forms of abuse may also be occurring at the same time as financial abuse, including neglect and physical abuse, psychological or emotional abuse. Social isolation is also a risk factor for financial abuse. Research indicates that adult children, grandchildren and other relatives are the most likely perpetrators of financial abuse<sup>x</sup>.

Signs of financial abuse include<sup>xi</sup>:

- Fear, stress and anxiety expressed by a person with dementia
- Unfamiliar or new signatures on cheques and documents of a person with dementia
- The inability of a person with dementia to access bank accounts or statements
- Bank, credit and debit cards and accompanying Personal Identification Numbers (PINs) of a person with dementia handed over to another person
- Significant withdrawals from accounts of a person with dementia
- The accounts of a person with dementia suddenly moved to another financial institution
- Significant changes to a will of a person with dementia
- Isolation and control of a person with dementia by carer
- Evidence of undue influence e.g. coercive behaviour by another person
- Lack of concern for the welfare of a person with dementia (signs of neglect)
- No money to pay for aged care when there should be sufficient funds.

# THE IMPORTANCE OF PLANNING AHEAD

AlzNSW encourages people, especially those who have received a diagnosis of dementia, to plan ahead for their future. This includes appointing an attorney under an Enduring Power of Attorney (EPOA) to manage their financial and legal affairs, as well as an enduring guardian to make lifestyle, care and accommodation decisions on their behalf, updating their Will and making an Advance Care Directive to ensure their end of life wishes are carried out. This empowers people, extends their decision-making autonomy and allows them to plan for when they no longer have capacity to articulate their wishes<sup>2</sup>.

With regard to financial affairs, it is important that people appoint an attorney to support them in their decision-making and act as their authority when they lack capacity. The attorney should include the person with dementia in decision-making processes for as long as possible until they no longer have capacity. An EPOA is a legal document that allows a person (the principal) to nominate one or more persons (the attorney/s) to act on their behalf. It gives the attorney authority to manage legal and financial affairs including buying and selling real estate, shares and other assets, operating bank accounts and spending money on the principal's behalf. An attorney has the same powers as the principal to deal with the person's financial affairs and has a legal obligation to act in their best interests. Unfortunately, financial abuse can be committed by people appointed as an attorney who fail to act in the interests of the person with dementia.

The Power of Attorney document has to be stored in a safe place and the attorney must have a copy. A copy should also be provided to anyone else who needs to know its contents, such as a solicitor or an accountant. If the attorney is to deal with real estate owned by the principal in NSW, then the Power of Attorney document must be registered with Land and Property Information Division of the NSW Department of Lands. Otherwise, there is no requirement for a Power of Attorney to be registered in NSW<sup>xii</sup>.

<sup>2</sup> In relation to the topic of this paper, Wills, Enduring Guardian and Advance Care Directives are not relevant. More information about these planning ahead instruments is provided in the glossary appendix. For more information about planning ahead in NSW, refer to the Planning Ahead Tools website - <http://www.planningaheadtools.com.au/>. For information about planning ahead in other Australian States and Territories, refer to the Start2Talk website - <http://www.start2talk.org.au/>

When appointing an EPOA, it is imperative that people consider who they trust most to make future decisions in their best interests. This may or may not be a spouse, child or other family member. In instances where there are many children, it is important that the principal discuss their choice of attorney with their family so that there are no misunderstandings and/or recriminations in the future. Where the principal is estranged from family or does not hold the view that their family members would act in their best interest, consideration needs to be given to appropriateness of appointing a friend, the NSW Trustee and Guardian or a solicitor.

When an EPOA document is made the attorney's power continues even if the principal loses the mental capacity to manage their own affairs. An EPOA can be specified to commence when a person lacks capacity to manage their financial affairs as determined by a GP in consultation with a geriatrician. A medical certificate should be attached to the power of attorney document with evidence of the principal's lack of capacity.

Once mental capacity is lost the principal cannot revoke an EPOA. If a person lacks capacity to make an EPOA appointment the Guardianship Division of the NSW Civil and Administrative Tribunal (NCAT)<sup>3</sup> can appoint a financial manager where that person lacks the ability to manage their financial affairs<sup>4</sup>.

If an attorney mismanages the affairs of a principal, who lacks capacity, any person with an interest in the welfare of the principal can apply to NCAT to have the appointment reviewed. NCAT have the power to remove the attorney and replace the attorney with another or to make a financial management order.

<sup>3</sup> This was previously known as the Guardianship Tribunal. From 1 January 2014, the Guardianship Tribunal and the Administrative Decisions Tribunal, along with more than twenty other existing State tribunals, were integrated into the NSW Civil and Administrative Tribunal (NCAT). NCAT is a government initiative that provides a single, accessible gateway to tribunal services.

<sup>4</sup> The legal test to determine whether a person can manage their financial affairs requires consideration as to whether:

- The person can deal in a reasonably competent fashion with the ordinary daily activities in relation to his or her financial affairs
- The person is at risk because he or she may be disadvantaged in the conduct of his or her financial affairs
- Money or property that he or she possesses shall be dissipated or lost
- The current situation will continue into the foreseeable future
- The person is able to pay bills and set a budget so that his or her income meets his or her expenses
- The person need not have the capacity to be able to undertake a complicated financial transaction that most people would require a assistance with (such as a conveyancer)

As stated in the case PY v RJS [1982] 2 NSWLR 700.





# PREVIOUS RESEARCH

A review of Australian and international literature revealed that scarce research has been conducted about financial abuse of people with dementia. Previous research<sup>xiii</sup> has focused on elder financial abuse generally and, although it acknowledges that people with cognitive impairment are often victims, it does not focus on the specific vulnerabilities and particular experiences of people with dementia.

The 'Protecting Elders' Assets Study'<sup>xiv</sup> undertaken by researchers at Monash University in partnership with the Victorian State Trustees is the most comprehensive Australian study on financial elder abuse to date. One of the aims of this project was to identify existing data about financial elder abuse in Victoria. From the data available they found that the majority of older people coming to the attention of organisations from financial abuse are women, and that the people most likely to be perpetrating the abuse are sons, and to a lesser extent, daughters. They also found evidence that powers of attorney are being used to commit financial abuse<sup>xv</sup>.

There is a lack of knowledge about financial abuse in Aboriginal and Culturally and Linguistically Diverse (CALD) communities in Australia. The 'Protecting Elders' Assets Study' noted that culture is an important determinant of both elders' perceptions of what constitutes abuse and the sense of entitlement felt by family members which explained differences in reporting and prevalence of abuse amongst different cultural groups. Further research is needed on different cultural understandings of financial abuse however this was outside the scope of this AlzNSW research project.

Research<sup>xvi</sup> conducted by The Alzheimer's Society in the UK in 2011 found that fifteen percent of carers surveyed report that the person they care for had been subject to some kind of financial abuse<sup>5</sup> and identified that people living alone without any kind of support are most at risk from exploitation. The Alzheimer's Society made recommendations for helping people with dementia and carers manage

their money while minimising the risks of financial abuse, including:

- Improve knowledge and awareness about financial management and planning among people with dementia, carers and professionals
- Improve community support services for people with dementia to manage their money
- Ensure that banking systems are better equipped to support people with dementia and carers to manage money safely
- Increase access to independent advocacy for people with dementia
- Improve data sharing between agencies and local areas and ensure that multi-agency policies are consistently implemented to prevent and respond to financial abuse.

5 Note that scams were included as financial abuse in the Alzheimer's Society study.

# ALZHEIMER'S AUSTRALIA NSW RESEARCH PROJECT

To examine the issue of financial abuse of people with dementia in NSW, AlzNSW conducted a mixed-method research project<sup>6</sup>. Following a review of the literature, the following methods were used to collect data from people with dementia, carers, service providers and professionals.

## **Focus groups with AlzNSW consumers (people with dementia and carers)**

Focus groups were conducted with members of the eight AlzNSW Consumer Advisory Groups in Sydney, Wollongong, Orange, Wagga Wagga, Port Macquarie, Newcastle, Cooma and Armidale. The focus groups were designed to gain insight into community understanding and perception of financial abuse.

## **Interviews with carers of victims of financial abuse**

Interviews<sup>7</sup> were conducted with four carers of people with dementia who have been victims of financial abuse to gain insight into how financial abuse occurs and what can be done to prevent it.

## **Survey of professionals**

Eighty-nine responses were received to an online survey<sup>8</sup> for service staff and professionals<sup>9</sup>

about their experiences of supporting people with dementia who have been financially abused and about their suggestions for reducing the incidence and impact of financial abuse.

## **Consultations with key stakeholders**

The project team consulted with key stakeholders including the NSW Police, NSW Guardianship Tribunal, Financial Ombudsman Service, NSW Trustee and Guardian, and the NSW Public Guardian.

## **Expert review**

The project was guided by an expert advisory committee consisting of representatives from The Aged Care Rights Service (TARS), the NSW Elder Abuse Helpline, NSW Legal Aid, and the legal and financial sectors. The committee reviewed research findings and assisted in the development of recommendations.

<sup>6</sup> This project received ethics approval from the Macquarie University Human Research Ethics Committee.

<sup>7</sup> Challenges were faced in recruiting victims of financial abuse and their family members to participate in interviews. This was anticipated; we know financial abuse of people with dementia is taking place but it is a sensitive and highly emotional issue that many people do not want to admit to or talk about. In addition, given that it is often a relative who has perpetrated the abuse other family members do not want to talk about it due to family conflict and shame.

<sup>8</sup> The survey was available online from October 2013 to February 2014 and distributed via a number of channels.

<sup>9</sup> The majority of respondents (37%) work in community aged care, followed by legal services (21%) and community and allied health (12.4%). Respondents also work in residential aged care, acute health, financial services and advocacy organisations.



# ALZHEIMER'S AUSTRALIA NSW RESEARCH FINDINGS

This section discusses the findings of the AlzNSW research project in four key areas: public awareness of financial abuse; how financial abuse occurs; reporting of financial abuse, and; investigation and resolution for victims. Case studies<sup>10</sup> are included throughout to highlight the ways in which financial abuse occurs and the practical and emotional impact on victims of abuse and families.

## Public awareness of financial abuse

The focus groups with AlzNSW consumer advisory group members examined public awareness, understanding and perceptions of financial abuse. The members believe financial abuse of people with dementia is not an issue that many people are aware of until they are living with dementia and it was not something they had considered prior to the dementia diagnosis.

Survey and focus group data indicates that increased awareness of the potential for people with dementia to be financially abused is required. This would require broader public awareness campaigns to educate people about what constitutes financial abuse and how to safeguard against abuse.

*“Better education about financial abuse and the need for power of attorney and guardianship arrangements. Better education of aged care professionals in the community and residential care. Better education for staff of financial institutions re: elder abuse and dementia. Better publicity of cases of financial abuse, including convictions.”* (survey respondent – residential aged care)

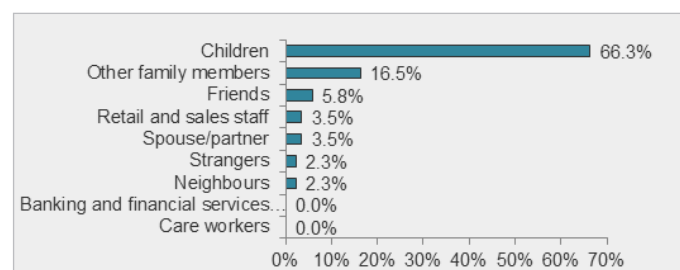
Some AlzNSW consumers believe that there is a role for the media to play in highlighting cases of financial abuse of people with dementia, raising awareness and drawing attention to the issue. On

the flip side, there is a risk that this could increase the vulnerability of people with dementia as more people become aware of how financial abuse can be perpetrated and take advantage of situations.

## How financial abuse occurs

Survey respondents were asked to report who is more often identified as the perpetrator of financial abuse in the cases they come across. Graphs 1 and 2 demonstrate that overwhelmingly people with dementia are abused by family members and others who are known to them. More than sixty-five percent of respondents reported that children are most often identified as the perpetrators. Over ninety percent of respondents indicated that a person known to the victim is more often identified as the perpetrator of financial abuse. Care workers and banking and financial services staff were not identified as perpetrators of financial abuse. This is an interesting finding as it is these types of cases that are most commonly described in media reports about elder financial abuse.

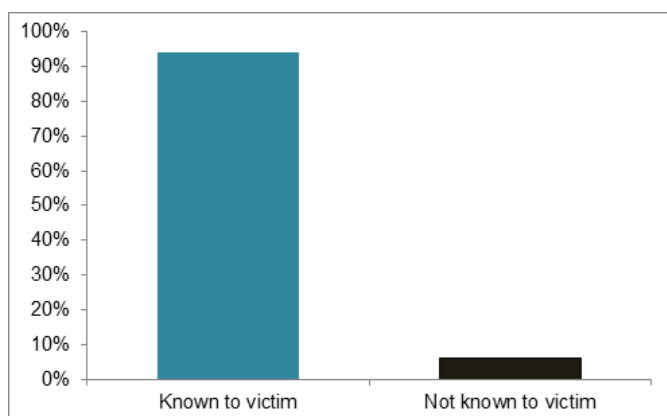
**Graph 1:** Who is more often identified as the perpetrator of financial abuse of people with dementia?



Source: AlzNSW survey

<sup>10</sup> These case studies are drawn from the interviews conducted with family members of victims of financial abuse. To protect the confidentiality of those involved pseudonyms are used and no identifying details are included.

**Graph 2:** Relationship of perpetrator to victim of financial abuse



Source: AlzNSW survey

During the focus group discussions, the AlzNSW consumers raised significant concerns about telemarketers and charities targeting people with dementia, and financial abuse perpetrated by strangers and by scams. However, as noted earlier, scams are different to financial abuse by a person of trust. If a person has a history of donating to a charity, then the charity will continue to contact them unless notified not to.

The majority of instances of financial abuse are perpetrated by someone well known to the victim – family members and friends. Like other forms of abuse, victims are more likely to be financially abused by people they know than by strangers.

*“I’m convinced money is thicker than blood, and I think more and more people will take advantage of people with dementia in family situations.” (AlzNSW consumer)*

*“The abusers are often family members and may not view it as abuse but rather as their right to an inheritance.” (survey respondent – primary health)*

A culture of inheritance leads to a sense of entitlement and expectation that children will inherit from their parents. It appears that a considerable proportion of financial abuse perpetrated by

family members could be viewed as ‘inheritance impatience’. With increases in life expectancy for both men and women, children are waiting longer to inherit from their parents. The term ‘inheritance impatience’ is used to describe a situation where family members deliberately or recklessly prematurely acquire their ageing relatives’ assets that they believe will, or should, be theirs one day<sup>xvii</sup>.

### “Irene”

*Irene is in her late 80s and, although she began showing signs of cognitive impairment several years ago, she was not formally diagnosed with dementia until 2011. Irene still lives at home on her own, with support from services and family members.*

*Irene was financially abused by two of her five children, one of whom holds her enduring power of attorney. In 2007 they convinced Irene to sign documents which placed a reverse mortgage on her property. The money was used to pay for a family holiday. They also used the frequent flyer points from her credit card to pay for airfares. Irene does not know that there is a reverse mortgage on her home; she did not comprehend what she signed and did not receive independent legal or financial advice.*

*This situation has caused considerable conflict amongst Irene’s children. One of Irene’s daughters, Peta, who is her enduring guardian and responsible for her mothers’ care, lifestyle and accommodation decisions, has been advised by lawyers that she could apply to the Guardianship Tribunal for financial management or to have the Trustee appointed as Irene’s financial manager. However Peta does not want to place unnecessary stress on Irene and wants to try to keep the peace amongst conflicting family members.*



## Abuse of EPOA

The survey data indicates that a substantial amount of financial abuse of people with dementia is occurring through abuses of EPOAs.

*"The POA (Power of Attorney) has too much power in that they can steal everything and not suffer any punishment except to belatedly have the POA taken off them before they take the last ten dollars! Banks state that due to privacy laws they are unable to alert anyone other than the person to problems with their accounts. If the person has dementia and it's the POA abusing them, then what's the point?"* (survey respondent – community/allied health)

Where an attorney acts outside the scope of the power and the principal (person with dementia) lacks capacity, this is theft by the attorney against the principal. An attorney cannot give gifts to themselves or to third parties, or gain a benefit, where a principal lacks capacity unless such a gift or benefit is expressly authorised in the EPOA document. AlzNSW recommends education for people who are appointed attorneys to ensure they understand their responsibilities and obligations to the principal.

There is no registration or subsequent monitoring of EPOAs in NSW. Many survey respondents noted that this is a substantial loophole that enables financial abuse of people with dementia to occur.

*"People who are appointed as power of attorney need to be educated in the responsibilities and restrictions that go along with holding someone's power of attorney. There needs to be an accountability reporting for the use of those monies on a regular basis, possibly submit reports on an annual basis that outline the use of the persons monies."* (survey respondent – community/allied health sector)

*"Mandatory registering of POA's – with numbered allocation – attorneys to be required to register when activating the POA. Spot*

*checks on POAs to make sure they were being used appropriately."* (survey respondent – legal sector)

Some respondents suggested that registration and monitoring requirements are necessary in order to ensure some level of accountability of attorneys. A register would enable solicitors to make enquiries of the attorney if it was suspected that the principal was being neglected. It would also allow any person who wished to lodge an application to review the appointment of a power of attorney on the basis of neglect and breach of their obligations to do a search of the register to identify who to lodge the application against in the Guardianship Division of NCAT. Powers of Attorney are registered in other jurisdictions including England, Wales and Singapore. For example, in the UK Office of the Public Guardian maintains a register and individuals can apply to search the register to see if someone has another person acting on their behalf.

Beyond a register, some have suggested that there be a monitoring or auditing process to increase the accountability of attorneys and enable financial abuse committed by attorneys to be identified. However implementing such a process would make them similar to financial managers appointed by the Tribunal and be a significant imposition on those who are correctly fulfilling their obligations. Some stakeholders have concerns that a registration and monitoring process would deter people from completing EPOAs. AlzNSW recommends that the NSW Law Reform Commission examine the feasibility of a register of EPOAs.

## **"Anna"**

*Anna was diagnosed with dementia in 2002 in her late seventies. Prior to her diagnosis, Anna updated her will, appointed one of her four children as her attorney through an EPOA and another as her enduring guardian. From 2009 to 2013 Anna was financially abused by one of her four children, Carol.*

*Carol moved closer to her mother, claiming that she wasn't happy with how she was being cared for. Carol took Anna to her solicitor and had her EPOA revoked and changed to Carol. The family was not consulted.*

*In 2010, Carol placed her mother in residential care without consulting other family members. Later that year, Carol took Anna to yet another solicitor and had Anna's enduring guardian document and will changed. Carol did not tell the solicitor that Anna lived in a nursing home or that she had dementia; and the solicitor did not assess Anna's capacity.*

*Carol transferred significant amounts of money out of Anna's bank account into her own account. She then set up another account at a different bank and transferred all of the money into it. Carol also sold Anna's property without consulting the family. Carol's sister, Heather, estimates that over time Carol stole in excess of \$300,000 from Anna's account.*

*One day Anna called Heather very distressed and upset about what Carol was doing. Heather went to the bank to try to find out how much money Anna had. The bank staff could not tell her much because she did not hold the EPOA but they did tell her that there was only \$1200 left in Anna's account.*

*Heather also spoke to the solicitor who said they weren't aware that Anna had dementia, were told by Carol that she was caring for Anna at home and that they believed Anna had capacity. Heather was denied access to Anna's file because she was not Anna's attorney. This solicitor, also Carol's solicitor, had not declared a conflict of interest nor offered Anna independent legal advice. Heather told AlzNSW:*

*"There needs to be more education for solicitors. How do they assess capacity? Appointing someone EPOA is easy. Getting it taken off them is a real issue."*

*Carol threatened her siblings with violence when they uncovered what she had done. Heather praises the staff at Anna's residential aged care facility who supported an anxious and fearful Anna.*

*Assistance from the Police was limited and Heather told AlzNSW:*

*"The police said if you'd walked in here and someone else had done this without an EPOA we'd have them up for embezzlement and fraud. But once there's an EPOA our hands are tied and the worst thing is because your mother has dementia, that person has the ability to turn around and say well she gave me permission and she's forgotten."*

*Anna's three other children lodged an application with the then Guardianship Tribunal<sup>11</sup> and one was granted a financial management order. However there was no recourse to reclaim the money stolen from Anna by Carol. A few months after this ordeal, Anna suffered a heart attack and passed away in 2013. Carol remained the executor of Anna's will which stated that her estate would be split between her four children – but there is nothing left to distribute. Over the years, Carol gained access to almost all of Anna's estate. She remains estranged from her siblings.*

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<sup>11</sup> Now called the Guardianship Division of NCAT

## Assessment of capacity by solicitors

Another issue raised by survey respondents is the failure of some solicitors to assess the capacity of an individual when a new EPOA or updated Will is sought by a person with dementia or their family members.

*“...the test of capacity made by solicitors is not necessarily completed appropriately or thorough enough to capture the extent of the person’s disability. When someone has dementia they can be easily swayed to make a POA not in their best interests or to change one that is also not in their best interests.”* (survey respondent – legal sector)

*“Legal representatives appear to be willing to change POAs etc. without seeking more specialist advice about capacity, especially when the person with the cognitive impairment has a known diagnosis.”* (survey respondent – community/allied health)

Interview participants also raised this as a major concern with significant levels of financial abuse occurring due to changes to EPOA documents when the person with dementia lacked capacity and did not understand what was taking place.

Solicitors should conduct thorough interviews with clients and ask open-ended questions to test the principals’ understanding of the powers that the attorney will have under the EPOA. Solicitors have an obligation to confirm that the principal understands the EPOA document and trusts the attorney to act in their best interests. Where a solicitor is uncertain as to the principals’ full understanding of the nature and scope of the EPOA the solicitor should brief a medical practitioner on the legal test for capacity for making the EPOA and obtain an expert report. This procedure is set out in the *Law Society of NSW Guidelines for Making Enduring Powers of Attorney*. People who believe that a solicitor has failed to act in the best interests of a client who lacks capacity can make a complaint to the Law Society of NSW or the NSW Office of

the Legal Services Commissioner (OLSC). AlzNSW recommends that the NSW Law Society provides training about financial abuse and dementia to all lawyers as part of continuing legal education requirements.

## Abuse by ‘friends’

Not all financial abuse of people with dementia is perpetrated by family members and those holding an EPOA. People with dementia, particularly those who live alone, are susceptible to exploitation and abuse by neighbours and existing or new found friends who prey on the vulnerability of the person due to their declining cognitive capacity.

Several members of the AlzNSW consumer groups told of cases of new ‘friends’ who come on to the scene when dementia became apparent. For example, one consumer knew of a woman at a local church who befriended a person with dementia and was subsequently investigated for theft. Another consumer spoke of women trying to take advantage of their father following his diagnosis of dementia. The women made a point of befriending him and then asked him for gifts and money. The family changed their fathers’ telephone number so the women could not call him.

## **"Tom"**

*Tom, at almost 80 years of age, has lived in the same country town his whole life. He has lived on his own since his wife died several years ago and has been quite lonely as none of his five children live close by. In recent years Tom's family were concerned about some memory loss and confusion but thought it was just old age.*

*Two years ago a woman in her early forties moved to the town and befriended Tom. Tom's daughter Linda describes this woman, Melanie, as charming, cunning and manipulative. Tom's family were concerned about his new friend as he was not calling them as much and when he did he constantly talked about Melanie.*

*Linda would often make the seven hour trip to visit her father and during one of her visits, Melanie came over for dinner. Linda told AlzNSW:*

*"I felt sick the whole time she was there; she was touching dad's hand and calling him 'dear'. And she knew the house so well. I couldn't believe she knew where everything was."*

*A few months later, Tom told Linda that Melanie wanted to buy a house and was asking him to go to auctions with her. Not long after that Tom seemed depressed when his children spoke to him and he stopped talking about Melanie. When Linda asked about Melanie, Tom told her that Melanie would get angry at him for visiting and yell at him. The family then found out that Tom had bought a house for Melanie to rent from him. Tom had also paid for paint, carpet, curtains, air conditioning, and a kitchen refurbishment. Linda estimates that he may have spent up to \$20,000 fixing the house up for Melanie.*

*Six months after Tom purchased this house, he was diagnosed with dementia. Around this time Linda found out that Tom's regular solicitor was not used in the purchase of the house. She contacted the new solicitor who was so relieved that Linda called because Melanie was demanding that the title deeds of the property be transferred to her. Fortunately the solicitor refused to do this. Linda also found out that Melanie convinced Tom to sign a handwritten agreement reducing her rent to \$50 a week. Tom did not realise what Melanie had done; he told Linda:*

*"she just told me that I had to sign it so I just signed it."*

*Following these events, Linda activated the EPOA that she had for her father and asked Melanie to vacate the house. Eventually Melanie did move out and they now have new tenants living there and are trying to sell the property.*

*Linda has no idea how much money Melanie may have acquired from Tom, who would take large amounts of money out of his account and store it in a home safe. Linda has since found out that Tom's friends and neighbours, as well as the solicitor and real estate agent, were all concerned about Tom's relationship with Melanie but did not want to interfere. They are now all aware of Tom's dementia diagnosis and watch out for him in between frequent visits from his children. Of this experience Linda says:*

*"I never thought about reporting it to police because she's really scary...she frightens me and she's threatened other people in town...but she's clever and charming as well...and I don't know how much money she got and I don't want to put us through that."*

## Reporting of financial abuse

### Service providers

Survey respondents were asked about the reporting requirements they follow when they come across instances of financial abuse of clients with dementia. Responses to this question varied; some respondents have processes within their organisation which they are required to follow, while others are not aware of any reporting requirements. Within different sectors and different roles, reporting policies and processes, where they do exist, do not seem to be consistent or understood consistently. Many respondents do not know how or where to report suspected and actual financial abuse of people with dementia. There did not appear to be a clear reporting process or protocol.

*"[I] call the Elder Abuse Helpline and the Aged Care Rights Service (TARS). Ensure that treating doctor is aware. If assessment by an Aged Care Assessment Team (ACAT) is necessary, ensure that ACAT is aware of my suspicions. If appropriate, get the Guardianship Tribunal and Public Trustee involved."* (survey respondent – acute health)

*"We refer people to the police and then to the Guardianship Tribunal to apply for a financial management as a way of avoiding abuse, particularly by family members, or people who had been appointed Power of Attorney by the person."* (survey respondent – advocacy service)

Some respondents who work for NSW Government agencies reported that they follow the guidelines outlined in the *NSW Interagency Protocol of Responding to Abuse of Older People (2007)*. This protocol aims to ensure that NSW Government agencies, and partner agencies in the non-government sector, who are involved in supporting older people are able to respond appropriately to abuse of older people living in community settings. It outlines the lead roles of NSW Police, NSW Health, ACAT, acute care staff, sexual assault

and mental health services, and the Guardianship Tribunal and the expectations of workers in these organisations. AlzNSW recommends that all community aged care organisations ensure that their staff are aware of their responsibilities and obligations as outlined in the protocol.

Respondents were asked to state whether elder financial abuse reporting requirements vary if the victim has dementia. For the majority of respondents the reporting requirements were not different, however several noted that they were more likely to make an application to the Guardianship Division of the NCAT if the victim had dementia and that there would be a greater level of advocacy and support required due to the lack of capacity.



## **"Henry"**

*Henry was financially abused by his partner, Edith, and Edith's children. Henry and Edith lived together for ten years. Edith, two years older than Henry, initially moved in as his housekeeper but over the years their relationship developed.*

*Through an EPOA Henry had appointed his only son, John, as his attorney. Henry's family describe him as a dominant personality who was stubborn and strong willed. However Edith was able to manipulate and control Henry and isolated him from his relatives. Henry and Edith were married by a clerk of the court in mid-2010. John told AlzNSW:*

*"Dad wasn't good on the day he got married. He was blank, he was non-communicative. We actually thought he was drugged. Now we realise it was part of the dementia."*

*It took his family quite a while to realise that Henry's behaviours and personality changes were symptoms of dementia. Henry was diagnosed with dementia in 2011 in his mid-eighties. Following his diagnosis, Edith moved out and refused to play any part in caring for Henry. When she left she told Henry's family that she was "going to take him for every penny".*

*John assumed responsibility for organising care services for Henry, and as his dementia progressed, eventually moved him to a dementia-specific nursing home. After investigating Henry's finances, John and his wife uncovered the extent of the financial abuse perpetrated by Edith and her family. They estimate that Edith and her children stole in excess of one million dollars from Henry's estate. They also discovered that on the day of Henry and Edith's marriage, Henry had signed a new Will which would benefit Edith and her family immensely.*

*The abuse began in 2009 with Edith's sons borrowing \$50,000 from Henry which he never paid back. When confronted about this unpaid debt, they changed their story, telling John:*

*"He's got dementia. It was all a gift. Prove it wasn't."*

*Henry had owned several properties. Over time these were sold, with the funds deposited into Henry's bank accounts. Following their marriage, Edith gained joint one-sign access to Henry's accounts. In April 2011 when John became aware of what had occurred he spoke to Henry's bank and his account was frozen. However they were not able to provide details of the transactions because, although John was Henry's attorney, Edith was still an account holder. Edith withdrew \$2000 out of the account when she realised that the family had figured out something was happening. She then went to the branch to try to withdraw all of the money but the account was frozen by that time.*

*When Henry died in 2013, the bank allowed Edith to remove over \$500,000 from the joint account as the account was unfrozen following Henry's death. Edith did not have Henry's death certificate and the bank stated that they released the funds based on survivorship. Bank staff told John they wanted to tell him that the account was unfrozen but that legally they couldn't because John was not Henry's attorney after death.*

*John and his wife have spent close to \$200,000 in legal fees to get justice for Henry and the ordeal took a considerable toll on their health. Henry's three grandchildren, who were supposed to receive twenty percent of his estate each, have inherited almost nothing.*

## People with dementia and their families

As expected, survey respondents reported that their clients with dementia do not understand their rights when they are victims of financial abuse. Ninety-five percent of respondents agreed that victims of financial abuse do not pursue resolution because they do not know how to take action and they do not have the capacity to do so.

An important consideration is that people with dementia who have been financially abused may not have the cognitive capacity or insight to know that they have been a victim of financial abuse. The onus to report is therefore on family members, advocates or service providers who become aware of what has happened. Some members of the AlzNSW consumer advisory groups indicated that they would not know who to report abuse to if it did occur to themselves or the person they care for. The family members of victims of financial abuse interviewed for this project struggled to report the instances of financial abuse. They either did not report the abuse or faced barriers in cases being investigated and resolved.

*“There are other factors that need to be considered also such as fear of social isolation. Clients with or without dementia are often aware of the financial exploitation but would prefer this went on and the abuser remained as their carer/friend/companion rather than address it and become further socially isolated or left without a carer.”* (survey respondent – community/allied health)

Instances of financial abuse of people with dementia also go unreported because victims are often dependent upon the perpetrators of abuse. People with dementia may not be willing to report the abuse because they do not want a member of their family in trouble with the law and fear that there will be repercussions if they speak out. Seventy-one percent of survey respondents believe that fear of retribution prevents people reporting financial abuse, and ninety-five percent

of respondents agreed that victims of abuse do not pursue resolution because they do not want a member of their family charged.

## Mandatory reporting

The desire for mandatory reporting of financial abuse or suspected abuse of people with dementia was evident in the survey response. A number of respondents indicated that there should be mandatory reporting of financial abuse similar to what occurs in instances of suspected child abuse, where a service provider has a duty of care and professional obligation to report their concerns.

*“[The process should be] streamlined like in child protection where a formal report is made, investigated by an appropriate body and then followed up in the community and case managed if needed.”* (survey respondent – acute health sector)

Although this idea has some merit, questions remain about where and to whom people would report their concerns, and, if financial abuse was reported, whose role it would be to investigate the allegation and confirm whether or not financial abuse had occurred. There are also concerns about mandatory reporting hindering the autonomy of an individual – what if a victim does not want the abuse reported? There would also need to be examination of what measures could be put in place to redress the abuse, and mediate a resolution and/or punish the perpetrators. There is currently no body to undertake such tasks. AlzNSW was unable to find any evidence to suggest that mandatory reporting of financial abuse has a deterrence effect. Further investigation of the capacity of mandatory reporting to reduce the incidence and increase investigation and resolution of financial abuse is needed to create an effective policy response.

The issue of mandatory reporting of financial abuse of older people was raised in a 2007 Australian Government *Inquiry into Older People and the*

Law. After reviewing the case for and against, the Committee did not support the introduction of mandatory reporting of suspected financial abuse, supporting instead the voluntary reporting of suspected financial abuse. This Committee acknowledged the need for a mechanism for those wishing to report abuse<sup>xviii</sup>. AlzNSW believes that it is timely to re-open this discussion and recommends that the NSW Law Reform Commission investigate how to appropriately respond to financial abuse of people with dementia.

## Investigation and resolution for victims

AlzNSW found that if instances of financial abuse of people with dementia are reported they are challenging to investigate. People with dementia are often regarded as unreliable witnesses and it can be difficult to prove abuse has occurred. Some survey respondents suggested that there needs to be a dedicated investigative team for financial abuse.

*"There needs to be an elder abuse investigation team set up in NSW and all of Australia. A hotline number to call is not good enough because the people answering the calls can only refer them to the same people we already do and it goes nowhere. There needs to be an investigative team set up."* (survey respondent – community aged care)

Respondents reported that it is difficult for organisations to share information to aid in the investigation of financial abuse cases.

*"[We] need a memorandum of understanding between key agencies to enable information to be shared in these cases. Would be amazing if banks could report fraud activity to identified social care services who are in a position to undertake further investigation. In domestic violence cases when financial abuse, as well as other types of abuse are reported to the police, the case is assessed as a whole... The overall picture of abuse is being missed."* (survey

respondent – community/allied health sector)

Respondents also reported they have found police reluctant to investigate cases of financial abuse of people with dementia. Financial abuse can be difficult to substantiate and prove, especially when the victim has dementia. The police are able to intervene more easily if other forms of abuse, such as physical abuse, are also occurring.

AlzNSW understands that physical abuse and neglect are easier to investigate and prosecute as they are covered under the *Crimes (Domestic and Personal Violence) Act 2007* and there is no need for a victim or witnesses to make a statement because there is physical evidence of the abuse. Whereas instances of financial abuse are covered under the *Crimes Act 1900* and consequently a different pathway of investigation and prosecution is followed. Financial abuse requires a victim to report the abuse, make a statement, and be prepared to go to court. It is also difficult to investigate because the police need to apply to a magistrate for a warrant to access bank records and other documents. If the case does progress to judicial processes, it has to be proven beyond a reasonable doubt to a magistrate and this is complicated by dementia and questions of capacity.

*"It is extremely difficult to get the money back after the fact. Most often the money has been spent and the legal costs and time and effort in seeking to have it repaid make it just too hard."* (survey respondent – legal sector)

When abuse occurs through the misuse of an EPOA, it is difficult to pursue because the attorney was given the legal authority to act. If they have failed to act in the best interest of the principal, or outside the scope of the EPOA, there may be a criminal offence and certainly grounds for civil action. To clarify that such actions are in fact a crime by the attorney against the principal, TARS suggests that it would assist the police and prosecutors if the *Power of Attorney Act 2003* set out a list of criminal offences describing breaches

of attorney's obligations to a principal who lacks capacity<sup>xix</sup>. However, others argue against such criminal resolution as it does not return funds or assets to victims. A victim or their representative need to pursue civil action to reclaim what has been stolen or misappropriated. This is a time-consuming and stressful process to undertake and the chances of success are limited. AlzNSW recommends that the NSW Law Reform Commission investigate the adequacy of current law covering financial abuse in the Act.

*"In many cases when financial abuse is substantiated and there is hard evidence a financial manager may be appointed to prevent further abuse but there are no powers to take action against the perpetrator and no means to have the money that was stolen repaid to the victim. Or if there are powers, no one is interested in undertaking this work. Need legislation to prosecute abuse of vulnerable adults." (survey respondent – community/allied health worker)*

During our consultations with key stakeholders, the idea of a public advocate model for NSW was proposed. Public advocate positions exist in Victoria, South Australia, Queensland, Western Australia and the Australian Capital Territory (ACT). Their role is to promote and protect the rights of adults with decision-making disabilities to reduce their risk of neglect, exploitation and abuse. In some jurisdictions the public advocate has the power to investigate abuse.

AlzNSW recommends the introduction of a public advocate for NSW. In relation to financial abuse, a NSW public advocate could be developed with the statutory authority to receive reports and investigate instances of financial abuse of people with dementia and other vulnerable adults. The role could also extend to facilitating resolution of the abuse and providing understanding and clarification of the responsibilities and obligations of attorneys.

# IMPLICATIONS

The research findings have important implications for a number of stakeholders as outlined below.

## Legal profession

The research findings highlight the importance of the legal profession in preventing financial abuse of people with dementia. Lawyers can assist their clients in protecting themselves against current and future abuse. It is suggested that lawyers develop relationships with other professionals and relevant community agencies to refer their clients to for support<sup>xx</sup>.

Lawyers must ensure that their clients understand EPOAs and have the capacity to enter into them. *The Law Society of NSW's Guidelines for Making an Enduring Power of Attorney*<sup>xxi</sup> and capacity guidelines *When a Client's Capacity is in Doubt: A practical guide for solicitors*<sup>xxii</sup> must be adhered to.

Lawyers can be found to be negligent in cases where they have not properly advised clients<sup>xxiii</sup>. Family lawyers who identify a conflict of interest must ensure that they advise individual family members to seek independent legal advice.

## Banking and financial institutions

The research findings highlight the key role of bank staff, who may unwittingly enable financial abuse to occur, and of institutions in responding to suspected financial abuse of their clients. The banking sector has created initiatives to protect their customers from financial abuse. The Australian Bankers' Association (ABA) has developed an industry guideline - *Protecting Vulnerable Customers from Potential Financial Abuse*. However, this guideline does not have any legal force or prescribe binding obligations on individual banks. The ABA industry guidelines are voluntary and it is up to ABA members to incorporate guidelines into their internal processes, procedures and policies. Australian banking and financial institutions are not

statutorily required to report suspicions of financial abuse<sup>xxiv</sup>. AlzNSW recommends that banking and financial services institutions be required to develop systems and processes to prevent financial abuse of their customers and to establish protocols to report suspected financial abuse.

Further training is required for banking staff to recognise dementia and the signs of financial abuse. Clear protocols and processes need to be put in place for staff to record and report instances of financial abuse of clients with dementia. In 2014, Capacity Australia, funded by the Dementia Collaborative Research Centre, engaged and consulted the banking sector across Australia to develop a tailored education module based on the ABA's guidelines, supplemented by information related to financial capacity and supported decision-making. An online education tool using adaptive learning technology has been tested in the banking sector and demonstrated successful knowledge translation in this setting<sup>xxv</sup>. AlzNSW recommends that all banking staff receive mandatory training on financial abuse and dementia.

In the UK, the Alzheimer's Society has partnered with Lloyds Banking Group to develop the *Dementia-Friendly Financial Services Charter*. This is a commitment for organisations to work in "partnership with other relevant organisations and appropriate agencies to ensure that they develop and follow best practice when dealing with vulnerable customers, including reporting incidents of suspected financial abuse/harm...to ensure that customer facing staff have recourse to external expertise and advice and they are in a position to share information where it would help reduce the risk of financial abuse"<sup>xxvi</sup>.

## Police force

There are significant challenges for the police in investigating cases of financial abuse, especially when abuse has been perpetrated through the misuse of an EPOA. However the police force



does have an important role in recognising and responding to financial abuse of people with dementia.

The North Shore Local Area Command of NSW Police has a *Vulnerable Communities Officer* based at Chatswood Police Station. The role of this officer is to support vulnerable people including those from CALD backgrounds, people with disabilities, and older people, including those with dementia. This officer spends time assisting older people with cognitive impairment who have experienced abuse or neglect. AlzNSW recommends that this valuable position be established in other local area commands.

Police officers need to have a greater understanding of dementia and how to engage with people with dementia in their work. AlzNSW understands that there is a lack of dementia training for police and would suggest that this become a mandatory requirement as part of their training. As a first step, the use of the Alzheimer's Australia resource '*Is it Dementia?*' for emergency services would be useful.

## Community service providers

It is often staff such as dementia advisors, key workers, community carers and residential aged care workers who first suspect that a client may be being financially abused. Community workers are in a position to support clients who are vulnerable to abuse and to assist them if abuse occurs<sup>xxvii</sup>.

Service providers must ensure that their staff are trained and well equipped to report their suspicions. Protocols based on the *NSW Interagency Protocol for Responding to Abuse of Older People* should be adhered to and staff made aware of their responsibilities and duty of care obligations.

Service providers also have a role to play in discussing the importance of planning ahead with clients and encouraging them to make plans to protect themselves as much as possible from

financial abuse while they have the capacity to do so.

## People with dementia and carers

Any measures to protect or safeguard people with dementia from financial abuse should be consistent with international human rights frameworks. People with dementia should be supported to retain autonomy and control over their finances and remain involved in their decision making for as long as possible, while protecting them from undue influence and abuse. The key to achieving this is to assess the person's capacity to make the decisions and to encourage autonomy with those decisions, while also identifying the decisions they are either incapable of making or may be able to make with support, using proxy, and substitute decision-making.

A degree of personal responsibility also needs to be considered. Individuals need to plan ahead while they have capacity to do so and they need to make careful choices about who they appoint as their attorney. They need to decide who is most trustworthy and who will act in their best interests in the future – and this may not be a child or another family member. While no one can predict the future actions of another, due diligence must be taken to ensure that those who are appointed attorney are the most appropriate person. Attorneys also need to be aware of their responsibilities and obligations to act in the best interests of the principal. AlzNSW recommends further public education about financial abuse and about the importance of planning ahead to protect ones' own financial future.

# CONCLUSION

This discussion paper has highlighted the multiple ways in which financial abuse of people with dementia is able to occur and examined the cultural, legal and systemic challenges faced in preventing it. The financial abuse of people with dementia is a complex issue to address. This paper has identified possible measures which could address this multi-faceted problem. Based on the findings of our research, AlzNSW makes the following recommendations.

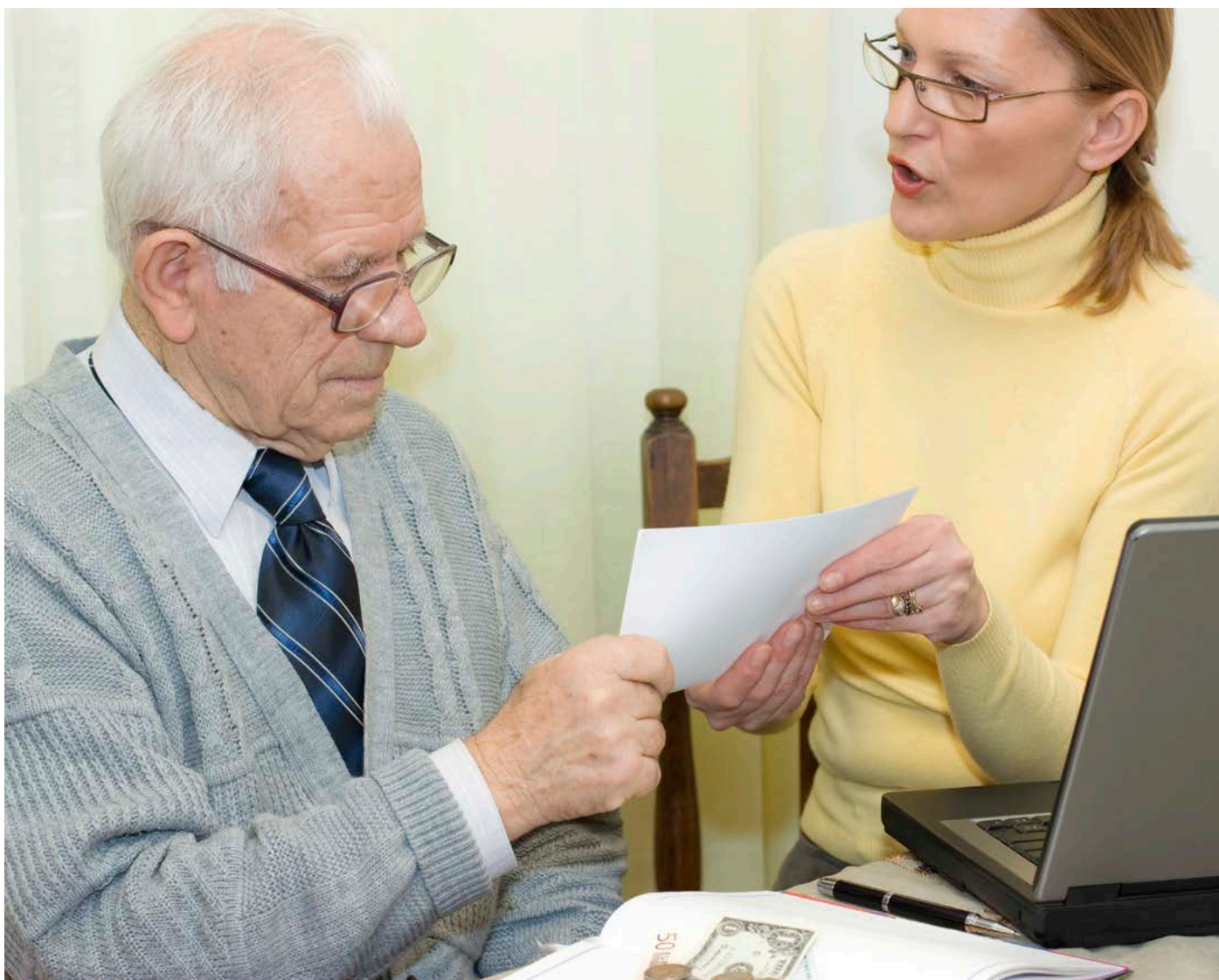
# RECOMMENDATIONS

## NSW Government

1. The NSW Attorney General:
  - a. Introduce a Public Advocate whose role includes the investigation of reports of financial abuse;
  - b. Refer the examination of a register for Enduring Powers of Attorney to the NSW Law Reform Commission;
  - c. Refer the investigation of how to appropriately respond to financial abuse of people with dementia to the NSW Law Reform Commission;
  - d. Refer the investigation of the adequacy of current law covering financial abuse in the *Powers of Attorney Act 2003* to the NSW Law Reform Commission;
  - e. Amend the *NSW Interagency Protocol for Responding to Abuse of Older People* to reflect any changes to legislation and practice.
2. The NSW Police Force establish *Vulnerable Communities Officer* positions in each Local Area Command to assist in the identification of those at risk of financial abuse and to support victims.
3. The NSW Government ensure that education is provided to people who are appointed as attorneys under Enduring Power of Attorneys to ensure they understand their responsibilities.
4. The NSW Government provide broad public education about financial abuse and planning ahead tools. This should include information in culturally and linguistically appropriate formats for Aboriginal and Culturally and Linguistically Diverse (CALD) communities.

## Australian Government

5. Australian Prudential and Regulatory Authority require banking and financial services institutions to develop internal systems and processes to prevent financial abuse and establish protocols to report suspected financial abuse of customers to state Public Advocates.



### Banking and financial services institutions

6. Staff receive mandatory training on identifying financial abuse using the education modules and resources developed by Capacity Australia.
7. Staff receive mandatory training about dementia using the 'Is it Dementia?' training resource developed by Alzheimer's Australia.
8. Banking and financial services institutions provide information to their customers about how to protect themselves from financial abuse and steps they can take to plan ahead.

### Legal profession

9. The NSW Law Society provides training about financial abuse to lawyers and includes this as part of continuing legal education requirements.
10. The NSW Law Society provides training about dementia to lawyers using the 'Is it Dementia?' training resource developed by Alzheimer's Australia.

### Community service providers

11. All funded aged care organisations in NSW be required to make staff aware of their responsibilities and obligations under the *NSW Interagency Protocol for Responding to Abuse of Older People*.

# APPENDIX: HELPFUL RESOURCES

- NSW Elder Abuse Helpline 1800 628 221 <http://www.elderabusehelpline.com.au/>
- The Aged Care Rights Service (TARS) (02) 9281 3600 or 1800 424 079 [NSW country callers] <http://www.tars.com.au/>
- LawAccess NSW 1300 888 529 <http://www.lawaccess.nsw.gov.au>
- Older persons legal and education program NSW Legal Older Persons Unit <http://www.legalaid.nsw.gov.au/what-we-do/civil-law/a-service-for-older-people>
- Planning Ahead Tools (NSW) 1300 887 529 <http://www.planningaheadtools.com.au/>
- NSW Guardianship Tribunal 1800 463 928 [http://www.gt.nsw.gov.au/gt/guardianshiptribunal\\_home.html](http://www.gt.nsw.gov.au/gt/guardianshiptribunal_home.html)
- NSW Trustee and Guardian 1300 364 103 <http://www.tag.nsw.gov.au/>
- NSW Office of the Public Guardian (02) 8688 6070 or 1800 451 510 [http://www.publicguardian.lawlink.nsw.gov.au/publicguardian/pg\\_index.html](http://www.publicguardian.lawlink.nsw.gov.au/publicguardian/pg_index.html)
- Find Legal Answers <http://www.legalanswers.sl.nsw.gov.au/>
- NSW Capacity Toolkit [http://www.diversityservices.lawlink.nsw.gov.au/divserv/ds\\_capacity\\_tool.html,c=y](http://www.diversityservices.lawlink.nsw.gov.au/divserv/ds_capacity_tool.html,c=y)
- Capacity Australia (02) 8987 1944 <http://capacityaustralia.org.au/>
- Start2Talk [www.start2talk.org.au](http://www.start2talk.org.au)
- Is it Dementia? <http://isitdementia.com.au/>
- Financial Abuse of the Vulnerable Older Person – Financial Ombudsman Service Banking & Finance - Bulletin 56 December 2007 [www.fos.org.au/custom/files/docs/fos-banking-finance-bulletin-56.pdf](http://www.fos.org.au/custom/files/docs/fos-banking-finance-bulletin-56.pdf)
- Australian Bankers' Association Inc. Protecting vulnerable customers from potential financial abuse – Industry guideline [www.bankers.asn.au/consumers/financial-abuse-prevention](http://www.bankers.asn.au/consumers/financial-abuse-prevention)
- Australian Network for the Prevention of Elder Abuse (ANPEA) <http://www.anpea.com.au/Home.aspx>
- Seniors Rights (Victoria) Online Elder Abuse Toolkit - 1300 368 821 <http://www.seniorsrights.org.au/toolkit/>
- Australian Human Rights Commission – Your Rights in Retirement <https://www.humanrights.gov.au/publications/your-rights-retirement>



# APPENDIX: GLOSSARY

## **Advance Care Directive**<sup>xxviii</sup>

An Advance Care Directive records your specific wishes about treatment that you would like to have in the event of life-threatening illness or injury, and any treatments you would refuse. There is no specific form to use for an Advance Care Directive. It is a good idea to discuss your wishes and treatment options with your treating doctor. You can request that your Enduring Guardian refer to your Advance Care Plan or Directive before making any medical or health decisions.

Your treating doctor will consider your Advance Care Directive to be valid if:

- You had capacity when you wrote it
- It has specific details about treatments that you would accept or refuse
- It is current (it was not written a long time ago and you have not changed your mind since writing it)
- You were not influenced or pressured by anyone else when you wrote it.

Doctors and health care professionals will only refer to your Advance Care Directive if you are unable to make your own decisions.

## **Capacity**<sup>xxix</sup>

The ability of an adult to make decisions for themselves. A person is said to have capacity if they can:

- Understand the facts and choices involved
- Weigh up the consequences
- Communicate the decision

There is no specific legal definition or test of capacity in NSW. Different tests of capacity are required when making a Will, appointing an Enduring Guardian or giving a power of attorney. For more information on capacity, refer to the Capacity Toolkit.

## **Enduring Guardian**<sup>xxx</sup>

The Guardianship Act 1987 (NSW) makes it possible for a person with capacity to appoint an Enduring Guardian. An Enduring Guardian can make decisions for you in areas such as accommodation, health and services, if you lose the capacity to make your own decisions at some time in the future. An Enduring Guardian cannot make decisions about your money or assets. The appointment of your Enduring Guardian takes effect only if you lose the capacity to make your own major personal decisions.

## **Enduring Power of Attorney (EPOA)**<sup>xxxi</sup>

You can make an Enduring Power of Attorney to appoint someone to manage your financial affairs. An Enduring Power of Attorney will continue to have effect after you have lost your capacity to self-manage. This is important for everyone, but particularly for elderly people.

A Power of Attorney does not relate to decisions about your lifestyle, medical treatment or welfare. Where you live, who you live with and what health care you receive are covered by Enduring Guardianship. A Power of Attorney ceases when you die. The executor named in your Will then takes over the responsibility of administering your estate.

## **Guardianship**<sup>xxxii</sup>

A guardian appointed by the Guardianship Division of NCAT has the authority to make lifestyle or personal decisions for someone who is incapable of making these decisions for themselves. Lifestyle or personal decisions may include decisions about medical or dental treatment, where someone lives and what services they need.

## **Guardianship Division of the NSW Civil and Administrative Tribunal (NCAT)**<sup>xxxiii</sup>

The Guardianship Division of NCAT is a specialist disability division within NCAT. The Division conducts hearings to determine applications about adults with a decision making disability who are incapable of making their own decisions and who



## APPENDIX: GLOSSARY (CONT.)

may require a legally appointed substitute decision maker.

Applications may be made to the Guardianship Division to:

- Make guardianship orders to appoint a private guardian (family member or friend) and/or the NSW Public Guardian
- Make financial management orders to appoint a private financial manager and/or the NSW Trustee & Guardian
- Provide consent for treatment by a doctor or dentist
- Review enduring powers of attorney
- Review an enduring guardianship appointment
- Approve a clinical trial so that people with decision-making disabilities can take part.

The Guardianship Division of NCAT considers applications about people who are in NSW or who have property or other financial assets in NSW. The Guardianship Act 1987 sets out the limits of its responsibilities and functions and the principles to be applied when making decisions.

### **Financial Manager**<sup>xxxiv</sup>

The Guardianship Division of NCAT can appoint a financial manager to manage the financial affairs of a person who is incapable of making their own decisions about their finances. Generally, the Tribunal only hears applications where there are no appropriate arrangements already in place or where an appropriate alternative to an application cannot be found.

A financial manager has the authority to make decisions about financial affairs for someone who is incapable of making these decisions for themselves. Financial affairs refers to things such as operating bank accounts, paying bills, investing money, selling or buying property and includes legal affairs such as instructing a solicitor to act in legal proceedings.

### **NSW Public Guardian**<sup>xxxv</sup>

The Public Guardian promotes the rights and interests of people with disabilities through the practice of guardianship, advocacy and education. The Public Guardian is a statutory official appointed by the Guardianship Division of the NSW Civil and Administrative Tribunal (NCAT) or the Supreme Court under the Guardianship Act 1987.

When the Public Guardian is appointed they are authorised to make health and welfare decisions on behalf of the people under their guardianship. The Public Guardian cannot make decisions about financial matters or the person's estate. The Public Guardian is only appointed when there is no private person who can be appointed as guardian.

### **NSW Trustee and Guardian**<sup>xxxvi</sup>

The role of the NSW Trustee and Guardian is to act as an independent and impartial Executor, Administrator and Trustee for the people of NSW and provide direct financial management services and authorisation and direction to private financial managers.

### **Power of Attorney**<sup>xxxvii</sup>

A Power of Attorney is a legal document appointing a person or trustee organisation of your choice, to manage your financial and legal affairs while you are alive. This person or organisation is then known as your attorney. In order to make a valid Power of Attorney you must be 18 years or over and have the capacity to understand the nature and effect of the appointment.

Making a Power of Attorney does not mean that you will lose control over your financial affairs. It simply gives your attorney formal authority to manage your financial affairs according to your instructions. Your Power of Attorney can be cancelled (revoked) at any time provided you have the capacity to do so.

An ordinary Power of Attorney is only legal while you have capacity. If you want to make sure your

attorney can still operate if you lose capacity, you will need to appoint an Enduring Power of Attorney.

### **Person Responsible**<sup>xxxviii</sup>

If you are sick or injured and cannot make decisions about your medical or dental treatment, your doctor can ask someone else to make a decision for you.

This person is known as the Person Responsible.

The Person Responsible is:

- Your guardian, if they have the authority to consent to your medical or dental treatment. Or, if you don't have a guardian;
- Your spouse, de-facto or same-sex partner. If you don't have a partner;
- A person who provides care for you (but not a paid carer). If you don't have a carer;
- A close friend or relative.

There are some things your Person Responsible cannot do:

- They cannot make decisions about your finances, accommodation or support.
- They cannot consent to treatment if you object.
- They cannot consent to certain treatments, including sterilisation or experimental treatments.

### **Will**<sup>xxxix</sup>

A Will is a legal document that sets out who you want to receive your assets (including jewellery or sentimental items), money and property when you die. Making a Will is the only way you can ensure your assets will be distributed according to your wishes when you die.

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# OTHER ALzNSW RESEARCH PUBLICATIONS

## Dementia in Prison

### Discussion Paper #9 March 2013

The ageing population in Australia's prisons has grown at a rate faster than the general ageing population and so there is the consequent potential for a rise in the number of people with dementia living in a prison setting. As the peak body advocating for all people living with dementia in New South Wales (NSW), no matter their domicile, Alzheimer's Australia NSW seeks to raise awareness about this group.

<http://www.fightdementia.org.au/common/files/NSW/20140423-NSW-REP-DementiaInPrison.pdf>

## Living with dementia in regional NSW

### Discussion Paper #8 November 2013

The age profile of rural populations is older than in urban areas, with the average age increasing at a more rapid rate. Risk factors for dementia are more prevalent in regional and rural areas. An increase in the proportion of people with dementia living in rural areas is expected over the next few decades. However, there is a lack of clarity around the current and predicted prevalence rates in regional and rural areas.

[http://www.fightdementia.org.au/common/files/NSW/20131113-NSW-PUB-Dementia\\_in\\_regional\\_NSW.pdf](http://www.fightdementia.org.au/common/files/NSW/20131113-NSW-PUB-Dementia_in_regional_NSW.pdf)

## Living alone with dementia

### Discussion Paper #7 June 2013

It is estimated there may be up to 65,000 Australians with dementia who live alone. However research shows that people living alone with dementia have a higher risk of economic insecurity and abuse, loneliness and depression, poorer health outcomes due to self-neglect and increased vulnerability to malnutrition, falls, accidents and hygiene problems. There is often an underlying

assumption in dementia and aged care policy that there is a spouse, relative or friend who lives with and cares for the person, and this is reflected in the way services are delivered. This discussion paper examines the implications of this for social policy and service provision.

<http://www.fightdementia.org.au/common/files/NSW/20130619-NSW-PUB-LivingAlone.pdf>

## Football, head injuries and the risk of dementia.

### Discussion Paper #6 March 2013

Alzheimer's Australia NSW hopes to raise public awareness of the potential risks of later-life cognitive impairment and dementia for football players who suffer multiple concussive and subconcussive injuries throughout their playing career. This paper examines the research emerging from the USA, reports of memory loss in current and retired football players in Australia, and the possible implications for the football codes.

[http://www.fightdementia.org.au/common/files/NSW/AlzNSW\\_Football\\_head\\_injuries\\_\\_the\\_risk\\_of\\_dementia\\_final\\_130313\\_web.pdf](http://www.fightdementia.org.au/common/files/NSW/AlzNSW_Football_head_injuries__the_risk_of_dementia_final_130313_web.pdf)

## The most difficult decision - Dementia and the move into residential aged care

### Discussion Paper #5, October 2012

Adjustment to residential care is more than just a discrete event. It begins well before placement actually occurs and continues beyond. While policy direction and the wishes of the person with dementia and their carer can dictate that people with dementia may stay living at home for as long as possible, the impacts of the symptoms and behaviours of dementia mean that ultimately a large number of people with dementia will move into residential aged care.



[http://www.fightdementia.org.au/common/files/NSW/20121016-NSW-PUB-Moving\\_To\\_Res\\_Care.pdf](http://www.fightdementia.org.au/common/files/NSW/20121016-NSW-PUB-Moving_To_Res_Care.pdf)

### **What prevents people with dementia making plans for their future?**

#### **Discussion Paper # 4, March 2012**

Planning ahead is important for the whole population. We all need to make sure if we get to a point where we can no longer make our own decisions that our wishes about our health care and financial plans have been set out in legally binding documents. Failure to do this can lead to added stress on our family and carers who will not have the legal ability to make sure our wishes are followed or who could be unsure of our wishes. People with dementia have the right to make decisions about their future while they still have the capacity to do so. It is therefore imperative in the early stages of the disease that people with dementia are provided with opportunities to plan for their future and record their wishes, while they still have capacity.

<http://www.fightdementia.org.au/common/files/NSW/20120328-REP-DiscussionPaper4.pdf>

### **Building Dementia and Age-Friendly Neighbourhoods**

#### **Discussion Paper # 3, July 2011**

The needs of people with dementia and other types of cognitive impairment have helped shape the design of residential facilities, but the issue of accessibility to public places and spaces for people with dementia and their carers has been almost completely neglected. In a series of focus group consultations we asked members of the eight Alzheimer's Australia NSW regional consumer committees to describe how they experienced their surrounding neighbourhoods once they stepped outside the safety and familiarity of their front gate and made their

way to the local shopping centre, park, doctor's surgery or club.

<http://www.fightdementia.org.au/common/files/NSW/20110803-NSW-PUB-DementiaFriendlyNeighbourhoods.pdf>

### **Addressing the stigma associated with dementia**

#### **Discussion Paper # 2, September 2010**

Dementia is a condition that carries a heavy burden of stigma. People's attitudes, perceptions and understanding of the nature of dementia can determine how a person diagnosed with dementia, their carer and family accept and learn to live with the condition. The stigma associated with dementia can often lead to social exclusion, discrimination and disempowerment.

<http://www.fightdementia.org.au/common/files/NSW/2010NSWAddressingStigmaDiscussionPaper2.pdf>

### **Driving and dementia in New South Wales**

#### **Discussion Paper #1, April 2010**

The issue of driving for a person with dementia, their family and their friends is often a contentious and emotional one. For any individual a licence to drive provides access to mobility and represents independence, freedom and, in some cases, status. The loss of a driving licence due to dementia can be traumatic but necessary.

[http://www.fightdementia.org.au/common/files/NSW/2010NSWDriving\\_andDementiaNSWDiscussionPaper.pdf](http://www.fightdementia.org.au/common/files/NSW/2010NSWDriving_andDementiaNSWDiscussionPaper.pdf)

# OTHER ALzNSW RESEARCH PUBLICATIONS

## Quality Support Groups Research Project

There is little knowledge of the way support groups in New South Wales are currently functioning, or how effectively they are providing support to their participants. The purpose of the Quality Support Groups Research Project is to understand the operation and structure of dementia support groups in New South Wales; ascertain what constitutes a quality support group; and determine how a quality support group can be achieved.

Quality Support Groups Research Project - Phase 3 The purpose of Phase 3 is to analyse findings from Phase 1 and Phase 2 of the Project. The Quality Support Groups Research Project provides a comprehensive understanding of quality in a support group and formulates best practice guidelines to enhance the delivery of quality service to carers of people with dementia. This research upholds the mission of Alzheimer's Australia NSW to minimise the impact of dementia through leadership, innovation and partnerships. This is the third and final report into a research project that spanned 5 years and looked at what comprises a quality support group. This is the first comprehensive state-wide Australian study of ongoing support groups for carers of people with dementia. Over the five years of the project more than 350 people took part, including leaders of the groups and carers who had at some time attended a support group.

Significant findings of the report are:

- Huge benefits of supports groups for people who attend on a regular basis
- The uncelebrated capacity of mutual aid amongst group members to assist each other

- The unexpected finding of the profound impact of grief and loss on the health and well-being of a carer of a person with dementia
- Some carers reported the grief and loss felt at the time of diagnosis was equal to or even greater than the grief felt when the person with dementia dies

[http://www.fightdementia.org.au/common/files/NSW/20110610-NSW-RPT-Executive-Summary-QSGRP-Phase\\_III.pdf](http://www.fightdementia.org.au/common/files/NSW/20110610-NSW-RPT-Executive-Summary-QSGRP-Phase_III.pdf)

The full Phase 3 report is available to purchase from Alzheimer's Australia Online Bookshop.

<http://www.fightdementia.org.au/common/files/NSW/2010NSWSupportGroupResrchPhase2.pdf>

This report presents the second phase of the Quality Support Groups Research Project, which acknowledges the voices of past and present members of dementia carer support groups.

[http://www.fightdementia.org.au/common/files/NSW/2010NSWSupportGroupResrchPhase1\(1\).pdf](http://www.fightdementia.org.au/common/files/NSW/2010NSWSupportGroupResrchPhase1(1).pdf)

The focus of phase one of the Quality Support Groups Research Project is a literature review of research conducted into dementia support groups and a survey of existing support groups in New South Wales to investigate the views of support group leaders.

## Notes

## Notes

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Forster:	02 6554 5097
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Central Coast <sup>#</sup>	02 9805 0100

### SYDNEY REGION

North Ryde:	02 9888 4268
St George/Sutherland:	02 9531 1928
Blacktown*:	02 9805 0100

**NATIONAL  
DEMENTIA  
HELPLINE**  
**1800 100 500**

This is an initiative of the Australian Government

### SOUTHERN NSW

Bega Shire:	02 6492 6158
Eurobodalla Shire:	02 4474 3843
Bateman's Bay:	02 6492 6158
Cooma, Bombala & Snowy Mountains Shires:	02 6452 3961
Yass, Young, Goulburn, Queanbeyan, Harden, Upper Lachlan and Palerang Shires:	02 6241 0881
Moss Vale:	02 4869 5651
Wagga Wagga:	02 6932 3095
Wollongong*:	02 9805 0100

### WESTERN NSW

Orange:	02 6369 7164
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