

FIGHT ALZHEIMER'S
SAVE AUSTRALIA
FIGHTDEMENTIA.ORG.AU

**SUBMISSION TO THE AUSTRALIAN LAW
REFORM COMMISSION (ALRC)**

**RESPONSE TO THE ALRC ISSUES PAPER:
ELDER ABUSE**

AUGUST 2016

EXECUTIVE SUMMARY

Alzheimer's Australia welcomes the opportunity to provide a submission in response to the Australian Law Reform Commission (ALRC) June 2016 Issues Paper, *Elder Abuse*.

Dementia is a significant and rapidly growing health and social issue in Australia. People living with dementia and other forms of cognitive impairment have a heightened risk of abuse, as they may find it difficult or impossible to fully comprehend, recall, or report the abuse. Even if reported, these reports are sometimes dismissed as being unreliable. With the growing prevalence of dementia, it is imperative that there are national safeguards in place to protect people with dementia from all forms of abuse, be that financial abuse, physical abuse or neglect, sexual abuse, or emotional and psychological abuse.

This submission from Alzheimer's Australia takes a broad approach to the issue of elder abuse, as it impacts on people with dementia. Elder abuse encompasses not only the most obvious and more widely acknowledged forms of abuse such as deliberate financial exploitation by families and carers, or intentional physical assault by staff of residential aged care facilities but also more subtle forms of human rights abuses, such as chronic neglect by families and carers, or inappropriate use of physical and chemical restraint of residents in aged care.

Our submission, which starts with twenty-four recommendations, outlines the factors that enable such abuses to happen, discusses a number of case studies involving people with dementia, and proposes means to prevent and address abuse of people with dementia in Australia.

Alzheimer's Australia believes that a multi-faceted response to elder abuse is needed, which addresses not only the legal context and response, but also addresses the systemic factors which lead to the abuse of the human rights of people with dementia. We argue that broad measures are needed which improve the capacity of family carers and of residential aged care facility staff, to help ensure they can provide adequate care for people with dementia. We argue that measures are needed to improve the performance and quality of aged care services and health services in caring for people with dementia. We put forward a range of proposals for legislative and legal system reforms to prevent and address elder abuse. Finally, we emphasise the importance of consumers having good information on the legal rights of people with dementia, and about how these rights can be enforced; and the importance of the whole community having an improved understanding and awareness of elder abuse.

Our submission includes several case studies and consumer comments in relation to elder abuse, which have been provided to Alzheimer's Australia by people with dementia and their carers, and in some cases by service providers. They have been de-identified but are provided in the consumers' words, and represent the lived experience of people with dementia and their carers with regards to elder abuse.

We trust that this submission is of assistance to the ALRC in developing recommendations to prevent and address elder abuse in Australia.

RECOMMENDATIONS

Recommendation 1: Adopt a broad definition and approach to elder abuse

The ALRC should adopt a broad approach to the Inquiry, encompassing all forms of abuse of human rights of older people, across all circumstances and settings. The WHO definition of elder abuse should be adopted, with an amendment to remove the reference to trust to ensure that it is inclusive of any abuse experienced by an older person.

Recommendation 2: Take measures to prevent and address financial abuse

To prevent and address financial abuse, older people require targeted, consumer-friendly information to support their financial literacy. A strong regulatory framework is needed, including legislative mechanisms such as the Future of Financial Advice reform package, the national regulatory regime for consumer credit, and simple, easily accessible dispute resolution mechanisms for clients dealing with financial institutions; as well as non-legislative codes of conduct. Banks and other financial services institutions should have policies and procedures in place to prevent and address financial abuse, including staff education and training on financial abuse and the vulnerability of people with dementia, mandatory reporting of financial abuse, and information for customers on financial abuse.

Recommendation 3: Provide better support for carers of people with dementia

A capacity-building approach is needed to support carers of people with dementia, and prevent situations developing where the unmitigated impact of caring can lead to abuse and neglect. Carers of people with dementia need specialised support services, which are specific to caring for a person with dementia. Alzheimer's Australia is supportive of the Government's plan to establish an Integrated Carer Support Service. This service should offer specialised, evidence-based multi-faceted interventions combining information, education, skills training, and psychosocial therapies, led by qualified professionals, delivered over a sustained period of time, with active participation by carers. Access to well-funded, flexible respite care and peer support is also critical for carers of people with dementia. This should include emergency respite and support, for example in situations where a carer is experiencing challenging or aggressive behaviours by the person with dementia.

Recommendation 4: Address physical and sexual assault in residential aged care

To help prevent and address physical, psychological and sexual abuse of residents of aged care facilities, all direct care workers in both residential and community aged care should be required to undertake more extensive background checks analogous to Working with Children Checks; and mandatory reporting of physical and sexual abuse should apply to all aged care services, whether in receipt of Commonwealth funding or otherwise.

Recommendation 5: Report on performance and quality of aged care services

Data on performance and quality of aged care services should be routinely collected, analysed, and made publicly available, to assist consumers in making informed choices in regard to the services they receive. The public availability of such data will also help to drive service competition and quality improvement.

Recommendation 6: Ensure adequate and skilled staffing in residential aged care

To ensure quality and safety in residential aged care, mandated minimum ratios of staff to residents, and mandated minimum levels of qualified nursing staff, are required. Funding arrangements for aged care should support appropriate staff ratios and skill mix.

Appropriate education and training is also critical. A cohesive, structured and integrated national approach to dementia education and training is needed, including minimum standards for education and training for those working with people with dementia, covering among other things education on pain management and end-of-life care for people with dementia.

Recommendation 7: Address inappropriate use of physical and chemical restraint in aged care

All staff in residential aged care facilities should receive high quality training in dementia care, including a social model of care and alternatives to physical and chemical restraint. In particular, staff should be equipped to identify and address environmental, physical health, and psychosocial factors that may be the cause of behavioural and psychological symptoms. Quality standards and assessment processes for aged care services should aim to end inappropriate use of physical and chemical restraint and provide information to consumers about their use; and the aged care complaints scheme should escalate complaints which relate to use of restraint or assault.

Recommendation 8: Address abuse by appointed decision-makers

Older people and particularly those with a diagnosis of dementia should be encouraged to appoint legally-authorized substitute decision-makers to help ensure their wishes are respected in the event they lose capacity. All persons appointed under financial Enduring Power of Attorney agreements and under Enduring Guardianship/Enduring Power of Attorney for health arrangements should be required to undertake education regarding their legal and ethical responsibilities. All financial Enduring Power of Attorney agreements should be registered; and the feasibility of subsequent monitoring and audit of actions taken under the agreements should be examined. Centrelink should also be required to check with the relevant Guardianship Tribunal/Board if they receive a claim or notice to change a nominee for purposes of payment of entitlements to ensure that the change of nominee is genuine.

Recommendation 9: Ensure people with dementia have access to their diagnosis

Medical practitioners should be made aware of their legal and ethical responsibilities in relation to the need to inform a person with dementia of their diagnosis unless they have indicated they do not wish to be told, in accordance with the *Australian Clinical Practice Guidelines and Principles of Care for People with Dementia*. Other persons should not be told of the diagnosis without the consent of the person with dementia, if they still have capacity.

Recommendation 10: Improve dementia care for people in hospitals

To improve dementia care in acute hospitals and prevent human rights abuses, Version 2 of the National Quality and Safety Health Service Standards which embed care for people with cognitive impairment throughout the standards, should be implemented as early as practicable. In line with these revised standards, dementia should be identified and managed at hospital admission, and discharge should be planned for from the outset.

Families and carers should be enabled to be actively involved in the care and support of the person with dementia if they so wish. Staff should be trained to more effectively communicate with and care for the person with dementia. Physical environments should be made more dementia-friendly, and alternatives to psychotropic medications should be used wherever possible. The Dementia Care in Hospitals Program, which has been shown to improve care, should be adopted widely in acute care hospitals across Australia.

Recommendation 11: Improve end-of-life care for people with dementia

Health professionals should encourage individuals to discuss and document their end-of-life care preferences when services commence, and provide increased information and support around planning for end-of-life care during the early stages of dementia.

Nationally consistent advance care planning legislation is required to reduce confusion and provide protection to health professionals and community members. Advance care directives should be linked to electronic health records to allow access by all professionals. The expressed preferences of the individual with regard to their end-of-life care should be respected where they meet legally available options. Training and protocols for health professionals should be provided so that they know when and how to implement advance care plans.

Recommendation 12: Expand the role of Public Advocates in elder abuse

The role of Public Advocates should be expanded to include investigating and responding to elder abuse for all vulnerable older people, whether or not there has been a diagnosis of cognitive impairment, and whether the vulnerable person is in an institution or in the community. The Public Advocate should report on findings of such investigations, and should make immediate support referrals as soon as investigations commence, working collaboratively with other relevant agencies. All states and territories should have a Public Advocate, and legislation covering Public Advocates should be harmonised across states and territories to enable a nationally consistent approach.

Recommendation 13: Improve access by older people to courts and tribunals

Modifications should be undertaken to the procedures and environments of courts and tribunals to improve access by older people, including people with dementia. Relevant recommendations and models include the 2004 review of senior access to the Magistrates Court of Tasmania; the Eleazer Courtroom in the USA; and the Dementia Enabling Environments Project in Australia.

Recommendation 14: Improve access to quality elder mediation services

Current local elder mediation services and pilots in Australia should be evaluated and international models considered, so that the value of a nationally consistent approach to elder mediation can be assessed. Parties should be informed about available elder mediation services, to encourage consideration of these options where appropriate. Further work is needed to develop mechanisms to ensure that the rights of a person with cognitive impairment are not compromised in mediation processes.

Recommendation 15: Consider amending state and territory criminal law

Consideration should be given to amending state and territory criminal law to address specific criminal offences against older people, including expanding police powers in cases of suspected elder abuse.

Recommendation 16: Harmonise state and territory domestic violence legislation

Harmonisation of state and territory domestic violence legislation is needed, to provide a consistent and comprehensive framework for use of protection orders, including in cases of elder abuse.

Recommendation 17: Consider mandatory reporting of abuse

General practitioners and their multidisciplinary teams, Aged Care Assessment Teams, and community care workers should be considered as candidates for mandatory reporting of abuse and neglect of older people. Staff of banks and other financial institutions should also be mandated to report financial abuse. Such reporting should take place with the consent of the person who has been abused if the person has capacity. It is essential that robust protocols are developed for this purpose and that those mandated to report receive adequate training regarding their use. Whether or not they are mandated to report, these frontline service providers require education and support more generally in relation to dementia and abuse.

Recommendation 18: Increase capacity of police and prosecutors

Education and training for police and prosecutors is required to improve understanding of elder abuse. Police and prosecutors should develop policies and protocols to address elder abuse, and should work in collaboration with community agencies and other relevant parties. Responses by police and prosecutors should be grounded in a human rights approach which respects the rights of the vulnerable older person.

Recommendation 19: Improve services for victims of elder abuse

Elder abuse helplines should exist in all jurisdictions and be expanded to meet demand. Emergency housing services specifically for victims of elder abuse are needed. An expansion of free legal services is also required across jurisdictions, to ensure victims of elder abuse have access to the legal system. All jurisdictions should consider the appointment of Commissioners acting for senior members of their communities, to highlight issues such as elder abuse, and support and advocate for action.

Recommendation 20: Improve prosecution and sentencing practice

Policies and resources should be developed in Australia with reference to established overseas models, to improve prosecution and sentencing practice in Australia in relation to elder abuse.

Recommendation 21: Develop appropriate restorative justice approaches

Restorative justice approaches based on successful overseas models should be developed as an option for responding to cases of elder abuse in Australia, to be utilised in cases where restorative justice is appropriate to the situation and meets the preferences of the victim.

Recommendation 22: Distinguish between civil breaches and criminal conduct

Civil penalties should be considered as an appropriate response in less severe cases of elder abuse, where there is not a clear criminal intent: for example, minor breaches of financial Power of Attorney legislation. In cases of potential criminal conduct, criminal prosecutions should be pursued.

Recommendation 23: Improve consumer information about legal rights

People with dementia and their carers, as well as the broader community, need ready access to information about the legal rights of the person with dementia, and about mechanisms to ensure these rights are upheld. Information about elder abuse and services available for victims is also required.

Recommendation 24: Improve community awareness about elder abuse

Community awareness and education campaigns on elder abuse are needed, to promote prevention and early reporting of elder abuse.

BACKGROUND: DEMENTIA IN AUSTRALIA

Dementia is a complex chronic condition caused by one or more of a number of illnesses affecting the brain. It is a terminal condition that impacts on cognitive functioning, with effects on a range of areas including memory, language, and thinking.¹ It is often met with stigma and misunderstanding,² isolates people and their carers from social networks,³ and carries significant social and economic consequences.⁴

The care and support of people with dementia is one of the largest healthcare challenges facing Australia. It is estimated that there are now more than 353,800 Australians living with dementia and over a million people involved in their care; and that by 2050 there will be nearly 900,000 people with dementia.⁵ Each week there are 1,800 new cases of dementia in Australia, and this is expected to increase to 7,400 new cases each week by 2050.⁶

While the onset of dementia is correlated with advancing age, the condition also affects some younger people. An estimated 25,100 Australians with dementia are under the age of 65. This number is expected to increase to 36,800 by 2050.⁷

Dementia has an enormous impact on the health and aged care system, with the cost of dementia to these sectors calculated to be at least \$4.9 billion per annum.⁸ Dementia also has a profound social impact. People with dementia experience stigma and social isolation,⁹ and family carers often find it difficult to balance work, life and caring responsibilities.¹⁰

As our population ages, and as more of us survive the diseases of mid-life, more of us – both in terms of raw numbers, and as a proportion of the population – will experience dementia. The Framingham Study has found that for those of us who reach the age of 65 without having developed dementia, the risk we have of developing dementia in our remaining lifespan is 20% for women and 17% for men.¹¹ The higher lifetime risk for women is mainly due to women's longer life expectancy.

Given the high and ever-increasing prevalence of dementia, its correlation with age, and the extreme vulnerability of people with dementia, it is critical that issues affecting people with dementia have a high priority in the current ALRC inquiry into elder abuse.

¹ Mitchell, S. et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, 361, 1529.

² George, D. (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet*, 376, 586-7

³ Blay, S., & Peluso, E. (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2), 163-71.

⁴ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁵ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁶ Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050*. Report for Alzheimer's Australia.

⁷ Australian Institute of Health and Welfare (2012). *Dementia in Australia*.

⁸ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁹ Alzheimer's Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*

¹⁰ Brooks D, Ross C, Beattie E (2015). *Caring for Someone with Dementia: the economic, social and health impacts of caring and evidence-based support for carers*. Report for Alzheimer's Australia.

¹¹ Sehadri S, Belser A, Kelly-Hayes M, Kase CS, Au R, Kannel WB et al, (2006). The lifetime risk of stroke: Estimates from the Framingham Study. *Stroke*; 37 (2):345-50; cited in Alzheimer's Association (USA) 2013 *Alzheimer's Disease Facts and Figures* p 19. www.alz.org/downloads/facts_figures_2013.pdf

ABUSE OF PEOPLE WITH DEMENTIA

This section of our submission focuses on the first section of the ALRC Issues Paper, “What is Elder Abuse?”

A recent report from the Australian Institute of Family Studies notes that although evidence about the prevalence of elder abuse in Australia is lacking, it is likely that between 2% and 10% of older Australians experience elder abuse in any given year, and the prevalence of neglect may be higher. The available evidence suggests that most elder abuse is intra-familial and intergenerational, with mothers most often being the subject of abuse by sons, although abuse by daughters is also common, and fathers are also victims. The study found that financial abuse appears to be the most common form of abuse experienced by elderly people, and this is often accompanied by psychological abuse, which is also a very common form of abuse.¹²

The very nature of dementia, as a degenerative disease that affects cognitive skills and decision-making ability, makes people with dementia vulnerable to human rights abuses, particularly as their cognitive impairment makes it difficult or impossible for people experiencing abuse to report their experiences through the appropriate channels and to be in a position to provide irrefutable evidence of abuse. People with dementia may also be reluctant to report abuse because they are often highly dependent for their care on those perpetrating the abuse, whether this be family members, or staff of aged care facilities.

Cognitive impairment and other forms of disability are established in the research literature as having a strong association with being vulnerable to elder abuse.¹³ While overt examples of elder abuse such as deliberate assault are highlighted in the media, abuse of people with dementia is highly varied and often subtle. In addition to assault and financial exploitation, which are widely recognized and discussed, more subtle and varied abuses of the human rights of people with dementia occur across a range of circumstances and settings including in interactions with employers, the healthcare system, residential care, financial services, and the criminal justice system.

This submission focuses particularly on some key settings and circumstances where abuse of people with dementia commonly occurs:

- Abuse by families and carers: While most families are caring and supportive, there have been well documented cases where people with dementia have been inadequately cared for, restrained against their will, physically abused, emotionally abused, or financially exploited by family members. This is often a result of carers being under tremendous stress and not having access to the supports they require. In some cases it is the result of longstanding family turmoil or an ongoing history of domestic violence, which can be exacerbated by the issue of dementia.

¹² Kaspiew R, Carson R, Rhoades H (February 2016). *Elder abuse: Understanding issues, frameworks, and responses*. Research report No 35, Chapter 3. <https://aifs.gov.au/publications/elder-abuse>

¹³ Kaspiew R, Carson R, Rhoades H (February 2016). *Elder abuse: Understanding issues, frameworks, and responses*. Research report No 35, p.8.

- Abuse in the residential aged care setting: While many aged care facilities are striving to provide the best possible care, there are concerns about some facilities where the human rights and dignity of vulnerable people with dementia have not been upheld and the inappropriate use of physical and chemical restraint is widespread. There are also cases of deliberate assault of residents by some staff members.
- Abuse in the health system: Examples include doctors not telling a person of their diagnosis, hospitals using inappropriate methods of restraint, or the will and preferences of the person with dementia with regard to their end-of-life care (expressed by the person themselves if they have capacity, or through an Advance Care Directive, or by their legally-authorized substitute decision-maker, if they have lost capacity), not being respected and followed.

Human rights abuses of people with dementia also occur in other settings and circumstances, which are not explored in depth in this submission, but which should be acknowledged. For example, abuse can occur in the workplace, where a person diagnosed with dementia may be discriminated against or lose their job. Abuse can also occur in the criminal justice system: there are high rates of cognitive impairment amongst prisoners, and these people are very vulnerable to abuse and are rarely offered adequate treatment and support.¹⁴

Alzheimer’s Australia notes that the ALRC has adopted the WHO definition of elder abuse as the starting point for this inquiry:

“Elder abuse can be defined as ‘a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person’. Elder abuse can take various forms such as physical, psychological or emotional, sexual and financial abuse. It can also be the result of intentional or unintentional neglect.”¹⁵

Alzheimer’s Australia supports this definition but notes that the concept of “expectation of trust” may be problematic as it will exclude abuse that occurs outside of trusting relationships, such as in the case of a sales person or telemarketer who does not necessarily have a relationship of trust with the vulnerable individual. We recommend that for the purposes of the Inquiry, the definition be amended to remove the reference to an expectation of trust. Alzheimer’s Australia also argues for the adoption of a broad approach by the ALRC when considering what aspects of elder abuse should be included in the Inquiry, to be inclusive of the many forms that elder abuse can take, as outlined above.

Recommendation 1

The ALRC should adopt a broad approach to the Inquiry, encompassing all forms of abuse of human rights of older people, across all circumstances and settings. The WHO definition of elder abuse should be adopted, with an amendment to remove the reference to trust to ensure that it is inclusive of any abuse experienced by an older person

¹⁴ Alzheimer’s Australia NSW (March 2014). *Discussion Paper 9: Dementia in Prisons*.

¹⁵ Cited in Australian Law Reform Commission (June 2016). *Elder abuse: Issues Paper*, p.13.

ABUSE BY FAMILY MEMBERS/CARERS

This section of our submission particularly addresses Question 3 of the ALRC Issues Paper, which asks for examples of elder abuse to provide illustrative case studies. Further examples and case studies are also provided throughout the submission.

Abuse of people with dementia by family members and carers is not uncommon, and ranges from inadequate care and neglect, through to intentional assault, unlawful restraint of the person, and financial and psychological abuse.

Financial abuse is the most reported and analysed form of elder abuse. An Australian study found that between one-third and two-thirds of those experiencing financial abuse in the study sample had dementia. Financial abuse was carried out through means including misuse of powers of attorney, coerced changes to wills, unethical trading in title to property, and the coercion of people without capacity into signing documents in relation to assets that would result in financial gain for the perpetrator.¹⁶

The strongest risk factors that have been identified for older people being financially abused are: a family member having a strong sense of entitlement to an older person's property or possessions; the older person having diminished capacity; and the older person being dependent on a family member for care.¹⁷ Many older people with dementia are likely to experience a number of these risk factors.

In 2014, Alzheimer's Australia NSW undertook research to examine how financial abuse of people with dementia occurs, and how it can be prevented or reduced. The study found that it is very difficult to estimate the prevalence of financial abuse of people with dementia, particularly as it is often unreported, due to shame, fear of/dependence on the perpetrator, lack of knowledge of who to report to, and difficulties in understanding and recalling the abuse. However it is clear that much of this financial abuse occurs within families, with children of older people with dementia often reported to be the perpetrators. The research found that a considerable proportion of financial abuse is perpetrated by people appointed as an attorney under Enduring Power of Attorney arrangements, though this was not always the case. Most perpetrators were known to the victims, with neighbours and friends also featuring as perpetrators.¹⁸

Financial abuse can be psychologically as well as economically devastating, as illustrated by the following case study.

¹⁶ Cited in Kaspiew R, Carson R, Rhoades H (February 2016). *Elder abuse: Understanding issues, frameworks, and responses*. Research report No 35, pp 10-11.

¹⁷ Cited in Kaspiew R, Carson R, Rhoades H (February 2016). *Elder abuse: Understanding issues, frameworks, and responses*. Research report No 35, p 11.

¹⁸ Alzheimer's Australia NSW (June 2014). *Preventing financial abuse of people with dementia*. Discussion paper No. 10.

Case study: Financial abuse

“Our dad was manipulated into taking a loan against his house for our youngest sister’s debts. Initially he said no and she screamed and abused him until he called and relented after a period of silent treatment from her. The agreement was she was to make repayment and she never made one. When dad realised he'd been conned he made payments himself and then paid out loan in lump sum. Advised by his older brother and also a lawyer, dad pursued court proceedings but case dismissed due to lack of evidence substantiating the loan.”

The following comment comes from a man with dementia who has reported being financially abused by his own children.

Consumer comment: Financial abuse

“After being a victim of elder abuse, I can now speak out with authority on the effects it has on us and what we can do to protect ourselves from letting this happen. We are in a state of disbelief and unable to understand what is happening to us and it is necessary to report it so someone that is not emotionally connected can deal with it and help us. Elder abuse comes in so many different forms and we tend to only think about physical abuse but emotional abuse is much worse and a crime. Emotional abuse will strip you of your dignity, inner peace and could drive you so deep into depression that suicide may seem to be the only solution. This is the main reason why it needs to be reported so help can be provided.”

The Alzheimer’s Australia NSW project identified a number of potential strategies to address financial abuse of people with dementia. These included reporting of financial abuse of people with dementia; and registration and monitoring of Enduring Power of Attorney agreements.¹⁹ These matters, and relevant recommendations, are discussed further in the section of this submission covering abuse by substitute decision-makers.

Financial literacy is an important means of making older people less vulnerable to financial abuse, and the Australian Securities and Investments Commission (ASIC) provides significant information to assist older people with their financial literacy. Alzheimer’s Australia supports this approach, but notes that for people with progressive cognitive impairment, consumer information needs to be supported by legislation and regulation to protect older people from financial abuse. Indeed, ASIC itself has stated that “financial literacy is not a panacea” and has emphasised that a strong, regulatory framework is required to protect against financial abuse, including legislative mechanisms such as the Future of Financial Advice reform package, the national regulatory regime for consumer credit, and dispute resolution mechanisms for clients dealing with financial institutions, as well as non-legislative codes of conduct.²⁰ Alzheimer’s Australia supports this multi-faceted approach.

¹⁹ Alzheimer’s Australia NSW (June 2014). *Preventing financial abuse of people with dementia*. Discussion paper No. 10.

²⁰ Cited in Kaspiew R, Carson R, Rhoades H (February 2016). *Elder abuse: Understanding issues, frameworks, and responses*. Research report No 35, p 35.

Alzheimer's Australia also calls for banks and other financial services institutions to have measures in place to prevent and address financial abuse of people with dementia, including staff education and training, mandatory reporting of financial abuse, and information for customers on financial abuse.

Recommendation 2

To prevent and address financial abuse, older people require targeted, consumer-friendly information to support their financial literacy. A strong regulatory framework is needed, including legislative mechanisms such as the Future of Financial Advice reform package, the national regulatory regime for consumer credit, and simple, easily accessible dispute resolution mechanisms for clients dealing with financial institutions; as well as non-legislative codes of conduct. Banks and other financial services institutions should have policies and procedures in place to prevent and address financial abuse, including staff education and training on financial abuse and the vulnerability of people with dementia, mandatory reporting of financial abuse, and information for customers on financial abuse.

Turning to other forms of abuse: inadequate care and neglect of people with dementia is a largely hidden problem, which can be exacerbated when there is a long standing history of domestic violence or family breakdown, as the following case study illustrates.

Case study: Inadequate care/neglect

"Mrs K is a 69 year-old woman living with dementia who was being cared for by her live-in male friend who has a long history of excessive alcohol usage. Mrs K had been estranged from all family members for many years and their whereabouts were unknown. Both Mrs K and her carer had frequent contact with emergency services and domestic violence services. Mrs K has been a client of a community service since 2009 and received in-home respite for nine hours each week. She was unable to prepare her own meals and required support and direction for most aspects of daily living.

In early 2014 the service received a phone call from the police to report that Mrs K had been found wandering in the neighbourhood at night and when they returned her home, her carer was intoxicated and aggressive. The carer was transported to hospital for a psychiatric assessment and short term in-home respite was sought for Mrs K. On the following day the service was contacted by a Family and Domestic Violence Response Worker who reported that an Initial Domestic Violence report had been issued. The home was reported as "filthy and in total disarray" and the police reported that Mrs K was seen as "a person in need of protection". A second Incident Report was received from the Ambulance service reporting that the carer had stated to them that he had planned to put medication into Mrs K's food to kill her and then himself. The carer had stated that he had not wanted Mrs K to be removed from his care. Mrs K was the owner of the house and the carer had lived there for a number of years and could not afford to pay rent elsewhere.

On the following day the carer was released from hospital and returned to Mrs K's home reported to be "fit and healthy". An urgent application for Guardianship was lodged with the State Administrative Tribunal (SAT). A Medical Report could not be submitted with the application as Mrs K had only seen a GP irregularly and as she had not been seen by a GP within the past 12 months the

State Administrative Tribunal advised the service that it would be difficult to proceed without one. Mrs K was admitted to short term residential respite and during this time a GP was nominated who was able to provide a Medical Report to assist the Guardianship process.

Following discharge from residential respite, community service workers continued to visit the home and provide meals for Mrs K as there had been evidence that there was no food in the house. Mrs K was frequently found outside by neighbours wandering at night. We were advised by hospital social workers that without a guardianship order Mrs K could not be removed from her home and placed in alternative permanent accommodation and that the carer would not allow domestic services to be provided in the home.

Until the application for Guardianship was approved four months later and Mrs K was admitted permanently to a residential facility, the police continued to be actively involved when neighbours phoned to report that Mrs K was either found wandering alone outside her house or that there was no food within the house.”

Neglect and inadequate care may be accompanied by other forms of abuse, as in the following case study.

Case study: Inadequate care/financial abuse

“My father’s “carer” was my step-mother before he was moved to an aged care facility... My step-mother sold personal property (a valuable family heirloom) of my father’s when there was no necessity and the proceeds of the sale were not used for his benefit or care. My step-mother limited our access to my father while he was in her care and tried to limit our access when he was in the care facility. My step-mother significantly delayed replacing teeth and glasses lost by the care facility. They would not have been replaced had I not eventually filed formal complaint. My father was put on medications which the doctor specifically told me were being administered for the benefit of the care facility, to which he had a bad reaction, they would not have been discontinued had I not filed formal complaint. Non-replacement of worn out clothing, inappropriate clothing (eg too tight socks) and seriously inadequate foot care.”

Recommendations relating to the protection of older people from such abuse are outlined later in this submission, in the sections dealing with legislative and legal system reforms.

Another issue of concern is restraint of people with dementia living in the community by their carers. The legal framework in relation to regulating and monitoring the use of restraint is under-developed in Australia.²¹ However, all persons essentially have the right to live in a “restraint-free” environment, with restraint only to be used if other strategies or interventions have failed. Restraint should only be used as a last resort, to prevent a person from harming themselves or someone else. Restraint can only be used lawfully without consent of a Guardian or Attorney with legal authority for this decision, in situations of immediate high risk or emergency.

²¹ The discussion on the legal rights of the person with dementia in relation to restraint in this submission is drawn from Alzheimer’s Australia (March 2016). *Dementia and your legal rights*. <https://fightdementia.org.au/sites/default/files/NATIONAL/documents/Dementia-and-your-legal-rights.pdf>

If a person with dementia is living at home, anyone, including family members or carers can only restrain the person in the case of an emergency, and only for as long as the emergency lasts. Then the family member or carer needs to seek an assessment of the person's health and service needs, to ensure the person's safe care in the community. Often unsettled behaviour is an indicator of other health needs, such as an underlying infection or untreated pain, which requires assessment and treatment. Even if the family member or carer is also the legal decision-maker it does not mean that they can indefinitely restrain the person or lock the person in. Yet there are reports of people with dementia being unlawfully restrained by families and other carers, and in the absence of systematic external scrutiny, restraint and other forms of abuse can continue unchecked.

Inadequate care, restraint, and other forms of abuse may in some cases result from carers of people with dementia lacking coping skills and/or being unable to access adequate support to help them deal with the impact of caring.

Most people with dementia prefer that the person with dementia remain living at home for as long as possible, and carer support is a critical factor which currently enables 70% of people with dementia to live in the community. People with dementia need access to quality formal care in the community, but the "informal" care provided by family members and other carers is critical in enabling people with dementia to live well in the community for longer.

The vast majority of people with dementia living in the community (91%) rely on an informal carer to support them, and more than one in five (22%) rely solely on informal care. There are a significant number of Australians providing informal unpaid care to people with dementia, and most of these are the spouse or adult child of the person with dementia.²² The increasing focus on home care, while aligned with consumer preferences, is likely to lead to increased demand for support in the community. The highest level home care packages provide an average of 14 hours per week of direct care. This is insufficient for many people with dementia as their condition advances, and additional informal care will be needed.

While there may be some positive impacts from the caring role, in many cases the impacts of caring can be challenging. Caring for a person with dementia can lead to increased rates of stress, depression, and anxiety, as well as having a negative impact on physical health. Caring can have a profound emotional impact, with carers reporting feelings of guilt, sadness, anger, lack of control, worry, and even grief. Caring for a person with dementia can also put carers at risk of social isolation; and often has significant negative financial impacts. The overall impact is greatest for carers who live with the person with dementia, as these people provide more hours of care on a day-to-day basis, and may experience disruption of their sleep due to night-time disturbances.²³

²² Brooks D, Ross C, Beattie D for Alzheimer's Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer's Australia Numbered Publication 42, pp 7-8.

²³ Brooks D, Ross C, Beattie D for Alzheimer's Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer's Australia Numbered Publication 42, pp 9-12.

Consumers have also raised the issue of aggression by the person with dementia themselves, towards their carer. Aggression is not always an outcome of dementia, but can be exhibited in up to 30% of people with the disease and is more common in people with dementia than those without.²⁴ In many cases aggression is a symptom of unmet needs or other medical issues. Dementia can bring about profound psychological and behavioural changes which in some cases can expose carers and others to aggressive behaviour, or to sexual assault resulting from sexual inhibition. The following consumer comment relates to the issue of aggression by the person with dementia.

Case study: Aggression by the person with dementia

“I want to share examples of elderly carers of people with dementia being physically and emotionally abused by the person with dementia. This can result in serious harm to the carer, which in turn impacts on the care they can offer to the person who is hurting them. I know someone who has twice experienced the person with dementia trying to kill them. I know someone else who is constantly being yelled at for supposedly trying to confuse and torment the person they care for. These are not isolated examples. They are indicative of the levels of fear and lack of predictability experienced by many older people who care for a person with dementia. These carers often feel isolated by their experiences as they wish to remain loyal to the person they care for and also are encouraged by the government, service agencies and family to keep caring for the person at home.”

While in some cases there may be a long history of domestic violence which is exacerbated by the onset of dementia, in other cases the person with dementia may have no history of violence and the aggressive behaviour may be purely symptomatic of the disease or of another underlying condition or unmet need.

It is critical that effective supports are in place to provide carers with strategies and resources to cope with the demands of caring, as well as practical support regarding responding to behavioural symptoms and respite. Such supports will help to mitigate the negative impacts of caring, and increase carer well-being and the sustainability of the caring role. Indeed, the National Framework for Action on Dementia 2015-2019, agreed to by all governments across Australia, states that: “Carers should have access to support tailored to their needs in order to effectively respond to and manage the pressures associated with the physical, mental and emotional demands of their caring role.”²⁵

To enable people with dementia to live at home for as long as possible – which meets their preferences, and is also cost-effective for the health and aged care systems – it is critical that their carers are well supported. Research to date suggests that structured interventions that combine information, education, skills training, and psychosocial therapies, led by qualified professionals, delivered over a period of time, and with active participation by carers, tend to show the most positive improvements in carer outcomes. Carers also highly value access to respite care and peer support.

²⁴ NSW Nurses and Midwives' Association (February 2016). *Who will keep me safe? Elder abuse in residential aged care*, p.6.

²⁵ National Framework for Action on Dementia, 2015-2019, p 14.

Recommendation 3

A capacity-building approach is needed to support carers of people with dementia, and prevent situations developing where the unmitigated impact of caring can lead to abuse and neglect. Carers of people with dementia need specialised support services, which are specific to caring for a person with dementia. Alzheimer's Australia is supportive of the Government's plan to establish an Integrated Carer Support Service. This service should offer specialised, evidence-based multi-faceted interventions combining information, education, skills training, and psychosocial therapies, led by qualified professionals, delivered over a sustained period of time, with active participation by carers. Access to well-funded, flexible respite care and peer support is also critical for carers of people with dementia. This should include emergency respite and support, for example in situations where a carer is experiencing challenging or aggressive behaviours by the person with dementia.

ABUSE OF PEOPLE WITH DEMENTIA IN AGED CARE FACILITIES

This section of our submission responds to the Aged Care section of the ALRC Issues paper, and Questions 11 to 21 in relation to elder abuse in aged care settings.

More than 50% of people in Commonwealth-funded residential aged care setting have dementia.²⁶ Although many people with dementia may receive good care in residential aged care settings, unfortunately there are also many instances where this is not the case. Alzheimer's Australia receives reports from consumers about physical, psychological, and sexual abuse, inappropriate use of restraints, unreported assaults, and people in extreme pain at end-of-life not having access to palliative care.²⁷

While there are some obvious situations of elder abuse, for example where a resident is physically attacked, there are also more subtle forms of human rights abuses which are often unrecognised as such, and which overlap with broader issues relating to the quality of care provided by some facilities. Lack of dignity and respect for the resident, over-medication, physical restraint, and failure to address pain are some examples of this.

Stories shared by consumers paint a disturbing picture of an aged care system under strain which in some cases is failing to meet the basic human rights of our most vulnerable citizens. In Australia, there are some measures in place to protect the rights of consumers such as the National Aged Care Advocacy Program and the Aged Care Complaints Scheme; but serious issues remain, as evidenced in this section of our submission.

There have been a number of recent media reports highlighting issues of abuse within residential aged care, including the appalling footage of elder abuse caught on hidden cameras and reported on the *ABC 7:30 Report* on 25 July 2016. Aged care providers usually dismiss these issues as uncommon and the result of the criminal actions of rogue staff members. The abuse that is reported and captured on film is just the tip of the iceberg.

²⁶ Australian Institute of Health and Welfare (2012) *Residential aged care in Australia 2010-11: A statistical overview*. Cat. no. AGE 68. Canberra

²⁷ Alzheimer's Australia (2013). Paper 37: *Quality of residential aged care: The consumer perspective* p 4. https://fightdementia.org.au/sites/default/files/20131112_Paper_37_Quality_of_Residential_Aged_Care.pdf

Most abuse happens without a camera in the room and the person with dementia is usually unable to report it.

In preparing our submission, Alzheimer's Australia has received a number of stories and examples of physical abuse happening within aged care. Aged care staff members as well as family members have provided these examples.

Case study: Assault in residential aged care

"When working as a PCA [personal care assistant] in 2 high care units, I witnessed multiple, daily examples of residents who were unable to communicate being abused including: PCA telling resident to 'die you f---ing old bitch! because she resisted being bed bathed.

Hoist lifting was always done by one PCA on their own not 2 as per guidelines and time pressures meant PCAs often using considerable physical force to get resistive people into hoists; resident not secured in hoist dropped through and broke arm - died soon after; residents being slapped, forcibly restrained and force-fed or not fed at all; resident with no relatives never moved out of bed, frequently left alone for hours without attention; residents belongings being stolen and food brought in by relatives eaten by PCAs..."

Case study: Assault in residential aged care

"Abuse occurs on a much more regular basis than the public realise. A colleague took a pair of scissors into a resident's room (a lady with dementia) and hacked her hair off. Another colleague flicks and pinches residents' noses (who have dementia). Another resident with dementia is tied to a chair with a restraint for hours on end, soiling herself whilst in that chair for lengthy periods and screaming out incessantly every waking hour whilst in that chair. Another resident with dementia attacks staff every time they touch her so management told staff to leave this woman lying in her own faeces/urine rather than get into a physical battle with this woman..."

Case study: Assault in residential aged care

"Carer at a nursing home kicked my mother in the shin then claimed that mum was 'confused'. There was no other explanation for her injury, I had seen her 10 minutes beforehand and she was fine. I went back to her room and she was upset and told me what happened. Fresh bruise spreading on her leg as we looked."

Case study: Assault in residential aged care

"Mother who has since passed away had several incidents in her central Victorian aged care home where she and other residents were verbally abused and physically abused by night staff but unfortunately they were too intimidated and couldn't provide evidence to prove it. We were finally able after staff broke her shoulder and failed to seek medical treatment for over 8 hours despite being asked by my sister if there was something wrong with her shoulder approximately 1 hour after

it happened. Local hospital advised that she shouldn't be returned to [the aged care home]. We fought authorities to change aged care home... 2 staff sacked and Aged Care Complaints notified by family and a staff member of home who had seen too much abuse by staff to residents over long period which led to massive residents leaving [the aged care home] within a short period including several residents who had resided there for multiple years.”

Questions have been raised about implementing 24/7 monitoring within aged care facilities. It is the view of Alzheimer's Australia that we need to address the fundamental issues in the aged care system, rather than simply creating a system of compliance and monitoring which could violate the privacy of residents.

Australian research has identified a lack of mechanisms to ensure that professionals such as personal care workers are fit for the responsibilities of working with the aged, and has suggested a need for licensing of these workers and a way of conducting background checks analogous to the Working with Children Checks that are required for people who work with children. The research also highlighted the fact that no statutory reporting obligations apply in aged care services that do not receive Commonwealth government funding.²⁸ Alzheimer's Australia supports action to address these matters. While workers in aged care are currently required to undergo police checks, we believe more extensive background checks are required, and that these should apply to workers in both residential and community aged care.

Recommendation 4

To help prevent and address physical, psychological and sexual abuse of residents of aged care facilities, all direct care workers in both residential and community aged care should be required to undertake more extensive background checks analogous to Working with Children Checks; and mandatory reporting of physical and sexual abuse should apply to all aged care services, whether in receipt of Commonwealth funding or otherwise.

Currently the funding model and accreditation standards within aged care are focused on clinical inputs, processes, and documentation which has created a medical model of care without a focus on quality of life for residents. There is a need for a cultural shift within aged care to move from “looking after residents” to providing “support for residents to achieve quality of life”. In the current system, providers are rewarded for the amount of clinical care they provide rather than being rewarded for measures that are important to the individual and in maintaining quality of life.

Alzheimer's Australia has long been advocating for publicly reported quality indicators in aged care as currently there is not a single publicly reported measure of quality in place for aged care in Australia. A voluntary quality-indicator program has commenced as part of the aged care reforms but data is not yet being made publicly available. The initial indicators included as part of this program are clinically focused and do not capture consumer experience and quality of life within aged care services.

²⁸ Cited in Kaspiew R, Carson R, Rhoades H (February 2016). *Elder abuse: Understanding issues, frameworks, and responses*. Research report No 35, pp 11-12.

The lack of quality measures within residential aged care is in stark contrast to the health system which has successfully implemented a range of quality measures as part of its accreditation program, through the excellent work of the Australian Commission on Safety and Quality in Healthcare.

Recommendation 5

Data on performance and quality of aged care services should be routinely collected, analysed, and made publicly available, to assist consumers in making informed choices in regard to the services they receive. The public availability of such data will also help to drive service competition and quality improvement.

While physical and sexual assault of residents is clearly a criminal matter, it is symptomatic of a system that is not working. Even where blatant abuse may not be occurring, there are often issues relating to quality of care which arguably constitute abuse. Poor quality residential care which does not offer dignity, comfort, and meaning, can equate to psychological abuse of residents, as illustrated by the following case study.

Case study: Inadequate care in residential aged care

“My mother was diagnosed with Alzheimer’s around 50. Family members placed her in a ... complex for geriatrics; the youngest resident. Mum remained a resident of the complex for 9 years until her death in 2014. Mum’s first ward was a lock-in facility for dementia, with no stimulation or meaningful activities. The place smelt like shit and had a vibe of death; dingy and dim. She wandered the hallways all day, bored out of her brain. Mum was soon put into a wheel-chair and moved to a palliative care unit where she remained in bed for the next 5 or 6 years, in a dark room with the curtains permanently drawn and an old arm-chair covered in black mildew, which no-one ever dared sit on.

If Hell exists, this was it. The hallways echoed with moans and outcries from patients, begging nurses to come change them, crying from the humiliation of having to sit in their own muck and faeces for hours on end: “Help me! Please! Can anyone hear me? Please! This is no way to be!” It was horrifying. My mother’s hygiene was not attended to by staff and nurses treated her like an inconvenience and a lifeless corpse. They had no respect for her well-being and treated her without dignity.

On many occasions, staff spoke about my mother as if she were already dead. One nurse had the audacity to discuss DNR options with others, in front of my mother, as tears rolled down mum’s face – ignoring my mother’s stress and trauma at hearing this. Another time, when my mum was suffering terribly from aspiration pneumonia, a nurse took no regard when suctioning mum’s throat and said to me, “She’s got no fight left in her. It won’t be long now. When MY husband died...” and proceeded to tell me about her husband’s death, as my mother moaned and groaned in pain, coughing, spluttering and crying out in pain. I was so over-come by grief and trauma that I had no response but to bow my head and cry a waterfall of tears, silently with a deep pain in my chest. The undignifying and inhumane way that my mother was treated within this ‘care’ facility will last with me forever.”

The family member who provided the case study above has suggested the need for more vigilant spot checks of residential aged care facilities, including on weekends (including Sundays). It is suggested by this family member that the spot checks should include reading the resident's case notes, and inspecting the resident closely: for example, checking for hygiene, scabies, dermatitis, decaying teeth, neglected cleanliness, and so on, with penalties including closure for repeated breaches.

A lack of appropriate care to meet the needs of people from diverse priority groups is a related area of concern. The following examples of inadequate care for people from culturally and linguistically diverse (CALD) backgrounds have been provided by a person who has experience both as a family carer and as a service provider to people with dementia.

Case study: Inadequate care for residents from CALD backgrounds

"M had been in a residential care facility... for 3 weeks before I was called in to help the facility establish his cultural background (no one could communicate with him). It must have been a total nightmare for him for these 3 weeks as he had forgotten how to speak English, did not have family (neighbour brought him into the facility).

H was a lady I worked for, in my capacity of bi-cultural social support worker; her personal care worker used to refuse to be with her and talk to her if H was not showered and had an incontinence problem... With appropriate attitude, I was always able to encourage H to shower and change, use perfume and come for a drive with me."

Another issue of concern in residential aged care is inadequate management of pain. An Alzheimer's Australia survey found that 41% of care professionals reported having received no training on assessment of pain in people with dementia.²⁹ Often when people with dementia are in pain they are unable to tell anyone; however, pain may trigger behavioural changes and any such changes should be investigated. Good pain management reduces confusion and distress, and reduces the need for psychotropic medications. Aged care staff should have skills in pain assessment and management, including for people with dementia; and staff should acknowledge and utilise the insights of families and carers in this area.

Lack of respect for residents' expressed preferences in regard to their end-of-life care is commonplace in aged care facilities as well as in the health care system. Residents are frequently transferred to hospital towards end-of-life, which may be against their wishes and not in their interests; but may, in part, reflect the facility's inability to provide appropriate end-of-life care due to lack of qualified nursing staff, as discussed below. Many family carers report experiencing difficulties in securing care in line with the wishes of the person with dementia, and there is a clear need for more training for care staff on palliative care and legal end-of-life care options.³⁰

²⁹ Alzheimer's Australia (February 2014). *End of life care for people with dementia: Survey report.* https://www.fightdementia.org.au/files/EOI_ExecSummary_Web_Version.pdf

³⁰ Alzheimer's Australia (February 2014). *End of life care for people with dementia: Survey report.* https://www.fightdementia.org.au/files/EOI_ExecSummary_Web_Version.pdf

An adequate and appropriately skilled workforce is a key element of ensuring quality in aged care. The case study of assault exposed on the 7.30 Report in July 2016 was linked by the victim's family member to declining staff ratios and declining standards of care generally in the aged care facility in question.

Aged care services should have a skilled, experienced and adequate staff contingent to work effectively with people with dementia. Alzheimer's Australia notes with concern that over the past decade and more, there has been a significant shift in the aged care workforce. There is a trend towards employing less skilled (and lower cost) staff in residential settings in the delivery of direct care services. At the same time as the acuity of care required has been increasing, there has been a substantial decrease in the proportion of qualified nursing staff in the aged care workforce, and an increase in the proportion of unlicensed and unregulated personal carers.³¹ These trends can only be expected to continue as Australia moves further into a market-based model of residential aged care, with pressures to reduce staff costs in order to increase profitability.

The trend towards lower staff to resident ratios along with lower proportions of qualified nurses on staff, driven primarily by commercial considerations, is highly likely to have negative impacts on the quality of residential care:

“More and more, older Australians are remaining in their own homes for longer, and are entering nursing homes only when their care needs are too complex to be managed in the community. That complexity of care means that more than ever, we need qualified nursing staff whose skills are valued, whose professionalism is acknowledged and who feel they can care for their residents properly.”³²

Although clinical care is only one component of quality, the reduction in direct nursing care to a residential care population with increasingly high needs militates against achieving high quality care and avoiding unnecessary hospitalisations. Ensuring overall adequate staffing levels is also important to ensure that staff have sufficient time to interact with residents and assist them in meeting their physical and social needs.

Recommendation 6

To ensure quality and safety in residential aged care, mandated minimum ratios of staff to residents, and mandated minimum levels of qualified nursing staff, are required. Funding arrangements for aged care should support appropriate staff ratios and skill mix. Appropriate education and training is also critical. A cohesive, structured and integrated national approach to dementia education and training is needed, including minimum standards for education and training for those working with people with dementia, which includes among other things education on pain management and end-of-life care for people with dementia.

³¹ King D, Mavromaras K, Wei Z, He B, Healy J, Macaitis K, Moskos M, Smith L; National Institute of Labour Studies, Flinders University (2013). *The aged care workforce 2012: Final report*.

³² Australian Nursing and Midwifery Federation (2015). *Fact sheet 4: A snapshot of residential aged care*.

The inappropriate use of physical and chemical restraint in residential aged care settings is a significant issue of concern for people with dementia and their families. Physical restraint may include methods such as bed boundary markers, deep chairs, lap belts, hand mitts, seat belts, or leg, wrist or ankle restraints; removal of mobility aids; or restriction of the person to a locked area/secure ward. Chemical restraint refers to the use of psychotropic medications to modify the person's behaviour.³³

The presence of physical restraint in aged care facilities varies, and the evidence suggests prevalence rates from 12% to 49%. Physical restraint can cause a range of adverse psychological and physical effects, and research has shown that overall physical restraints do not prevent falls, and may in some cases cause death. Clinical guidelines indicate that physical restraints should be an intervention of last resort. Environmental, strength-promoting, surveillance, and activity-based alternatives should be considered first; and consultation with the carer and/or legally-authorized representative should occur wherever possible prior to restraint being applied.³⁴

It is estimated that about half of people in aged care and about 80% of those with dementia are receiving psychotropic medications, although this varies between facilities. There is evidence to suggest that in some cases these medications have been prescribed inappropriately. The evidence supporting the use of antipsychotic medications is modest at best, with international data suggesting that only 20% of people with dementia derive any benefit from antipsychotic medications. These medicines have a range of serious side effects and are associated with increased mortality for people with dementia, and expert consensus guidelines recommend psychosocial interventions as a first line approach to behavioural symptoms of dementia. Psychotropics are best used only where there is severe and complex risk of harm, where psychosocial interventions have been exhausted, or where there are co-morbid pre-existing mental health conditions; and the principle behind their use should be "start low, go slowly". Informed consent for their use must be obtained where possible from the person or their legally-authorized representative.³⁵

Case study

"My dad was over medicated with strong medical drugs that were not being monitored by staff at the nursing home or the doctor. This went on for years across two different nursing homes, no matter how much I tried getting my voice heard no one ever listened - they said they would address things but when I'd leave and come back things were never changing only worsening."

As noted above, under existing Australian legal frameworks, restraint should only be used if other strategies or interventions have failed, as a last resort, to prevent a person from harming themselves or someone else. Restraint can only be used lawfully without consent of a legally-authorized representative for this decision, in situations of immediate high risk or emergency. In other cases, aged care facilities require consent from the individual, or the

³³ Peisah C, Skladzien E (March 2014), *Alzheimer's Australia Paper 38: The use of restraints and psychotropic medications in people with dementia*.

³⁴ Peisah C, Skladzien E (March 2014), *Alzheimer's Australia Paper 38: The use of restraints and psychotropic medications in people with dementia*, p 7.

³⁵ Peisah C, Skladzien E (March 2014), *Alzheimer's Australia Paper 38: The use of restraints and psychotropic medications in people with dementia*, p 8.

legally appointed or nominated person or agency, to make accommodation and restraint decisions, such as placing a person in a locked ward, or administering psychotropic medication. While this decision can be made against the person's will, it still must have legal authority, so the Attorney or Guardian needs to consent on the person's behalf.

Despite these legal protections, consumers have told Alzheimer's Australia that it is often the case that, in practice, informed consent is not obtained for restraint, particularly with regard to the use of antipsychotic medications. This should be considered as elder abuse. Where families do provide consent, often no alternatives to restraint are offered, and the family may feel obliged to provide consent as they may be concerned that the person with dementia may otherwise be asked to leave the facility.

The Commonwealth Government has produced a booklet on the use of restraint in residential aged care facilities, which provides useful guidance on this matter. This guidance includes:

"A person-centred approach is a restraint free approach – a way of thinking that preserves the human rights of any person... With a restraint free approach, the use of any restraint must always be the last resort after exhausting all reasonable alternative management options... The application of restraint, for ANY reason, is an imposition on an individual's rights and dignity and, in some cases, may subject the person to an increased risk of physical and/or psychological harm. The inappropriate use of restraint may constitute assault, battery, false imprisonment or negligence. Staff need to identify, in a proactive approach with management, how to prevent situations that may lead to a perceived need for restraint."³⁶

A new study from the University of NSW Dementia Collaborative Research Centre has found that three out of four nursing home residents who are prescribed anti-psychotic drugs may not need them for a medically-appropriate reason. The project tested whether behavioural symptoms could be reduced without the use of anti-psychotic medications. As part of the project, nurses and residential care facility managers were given expert training in identifying and preventing the causes of aggression, by understanding more about the person and identifying triggers. They then passed the training on to other residential care staff and collaborated with families and other health professionals. Of the 140 patients who underwent the trial, 75 per cent were able to cease taking anti-psychotic drugs and remained drug free for six months after the change in treatment.³⁷ The study illustrates the significant potential of person-centred care in reducing reliance on chemical restraint.

To address the issue of inappropriate restraint of people with dementia in the aged care system, staff need effective education and training on person-centred care and on alternatives to restraint. Consumers and carers need to understand and be able to advocate for the legal rights of the person with dementia. In addition, quality standards and

³⁶ Department of Health and Ageing (2012). *Decision Making Tool: Supporting a Restraint Free Environment in Residential Aged Care*.

https://www.dss.gov.au/sites/default/files/documents/09_2014/residential_aged_care_internals_fa3-web.pdf

³⁷ Reported at: <http://mobile.abc.net.au/news/2016-07-26/most-dementia-sufferers-in-nursing-homes-dont-need-drugs-study/7654188>

assessment processes for aged care services should aim to end inappropriate use of physical and chemical restraint. All residential aged care facilities should participate in benchmarking and audit on the use of restraints and antipsychotic medications to ensure that these are used appropriately, with consent and only when all other options have been exhausted. It is also important that the aged care complaints scheme escalates complaints which relate to use of restraint or assault to a manager within set timeframes to ensure the safety of residents³⁸.

Recommendation 7

All staff in residential aged care facilities need to receive high quality training in dementia care, including a social model of care and alternatives to physical and chemical restraint. In particular, staff should be equipped to identify and address environmental, physical health, and psychosocial factors that may be the cause of behavioural and psychological symptoms. Quality standards and assessment processes for aged care services should aim to end inappropriate use of physical and chemical restraint and provide information to consumers about their use; and the aged care complaints scheme should escalate complaints which relate to use of restraint or assault.

As with community settings, there have also been concerns raised about aggression by people with dementia towards staff and other residents in aged care facilities.

Case study: Assault by another resident

“My mother-in-law [who has dementia] has been assaulted four times at a residential care facility... One of those occasions required stitches. It appears to be the same person (another resident) who is the offender. My husband is now writing letters but whilst there is correspondence, there isn't much action in preventing these episodes from reoccurring... “

A 2015 member survey by the NSW Nurses and Midwives' Association (NSWNMA) found that aggression towards other residents and staff by people with dementia is common, and poses a serious dilemma:

“It would be inappropriate to criminalise people with cognitive impairment for committing acts of physical or verbal violence as they are essentially 'blameless' being affected by a brain disease rather than carrying out intentional ill will. However, there must be an effective system in place to keep both aged care residents and staff protected from physical or verbal attack.”³⁹

Alzheimer's Australia agrees that aggression exhibited by people with dementia does not constitute criminal abuse; but the challenges posed by these situations are acknowledged.

³⁸ Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 6.

³⁹ NSW Nurses and Midwives' Association (February 2016). *Who will keep me safe? Elder abuse in residential aged care*, p.8.

ABUSE BY APPOINTED DECISION-MAKERS

This section of our submission responds to Question 29 in the ALRC Issues Paper:

Question 29 What evidence is there of elder abuse committed by people acting as appointed decision-makers under instruments such as powers of attorney? How might this type of abuse be prevented and redressed?

It should not be assumed that all or indeed most financial abuse of people with dementia occurs under Power of Attorney arrangements: the uptake of such arrangements is not high, and financial abuse commonly occurs in the absence of such arrangements. Properly monitored, appointed decision-maker arrangements can provide safeguards against financial and other forms of abuse, and their wider uptake should be promoted.

Nevertheless, the survey undertaken by Alzheimer's Australia NSW cited earlier indicated that a substantial amount of financial abuse of people with dementia is occurring under Enduring Power of Attorney arrangements; and that another enabler of financial abuse is the failure of some lawyers to assess the capacity of an individual to appoint a new attorney pursuant to an Enduring Power of Attorney.⁴⁰

When a person with dementia appoints an Attorney to manage their finances, the legislation requires the Attorney to act diligently, keep financial records, and not undertake financial transactions between the person with dementia and themselves (these are known as "conflict" transactions). However, there is usually no formal oversight or auditing of these arrangements. In fact, it is not until someone notices that the Attorney is not acting in the best interests of the person with dementia that something can be done about the situation. As a concerned third-party it can be very difficult to confirm your suspicions of abuse, as you do not usually have access to the relevant bank records (often it is the staff at the aged care facility who notice that something is wrong, because the fees are no longer being paid). If no-one notices that something is going wrong, or if no-one makes an application to the Board or Tribunal for a review of the power of Attorney arrangements, the Attorney could continue to misuse the power – to the obvious detriment of the person with dementia.⁴¹

In many cases there are disagreements between family members of the person with dementia. In such cases the situation can be very fraught, and it can be difficult to uncover the truth, as the following case studies indicate.

Case study: Appointed decision-makers

"Mother has dementia. Had [Power of Attorney] set up prior to diagnosis with daughter who lived close by. Older son, who has substance abuse problems, got new [Power of Attorney] and drained mum's funds for his personal gain. Impersonated her to take over dormant credit cards in her name. Left her destitute and in debt at 93. Mum was evicted from quality care facility. With little funds had to move into less than desirable board and care home with no dementia care. Subjected to wilful

⁴⁰ Alzheimer's Australia NSW (June 2014). *Preventing financial abuse of people with dementia*. Discussion paper No. 10.

⁴¹ Alzheimer's Australia (March 2016). *Dementia and your legal rights*.

neglect and was deliberately dehydrated and kept in a cold room at night with no covers. Hospitalized for severe hypothermia. Very sick and transferred to a skilled nursing facility. Had to move to another less than desirable board and care. Shortly after, mum suffered a severe broken hip from a fall as diagnosed by a specialist. Caregivers did not notify daughter right away. Daughter was visiting 2 days later and got medical help. Mum died within a month. The financial exploitation had life threatening consequences for mom. Very sad. Angry police and other agencies did nothing to support mum [as] a victim of elder abuse.”

Case study: Appointed decision-makers

“An elderly gentleman with Alzheimer's, who is classed as vulnerable as his mind is easily manipulated, has been coerced by certain family members to place a bogus VRO [violence restraining order] application on another family member, who was his full time carer for 2 years and was responsible for getting him diagnosed and helped when the rest of the family had no contact with him. They only took an interest when the carer appraised them of his deteriorating health. This VRO was conspired by the family members to keep the carer from preventing them from placing themselves into a position of power over the elderly gentleman as they had also, at the same time, convinced him to make a new Will and EPA [enduring power of attorney] with them as sole beneficiaries and his sole attorneys. The elderly gentleman has no knowledge of doing this. He has been lied to, manipulated and caused to travel hundreds of kilometres to court to fulfil these family members’ agendas. He not only has Alzheimer's but also cancer as well as arthritis in his back and two hip replacements, making traveling painful. He can no longer take care of himself in his own home, which is what the caring family member was doing for him. The carer had no option but to make an urgent application to SAT [the State Administrative Tribunal] to protect the elderly gentleman and was told there were orders for the Public Advocate (who became his guardian) to place restraining orders on these other family members while these claims were being investigated - the PA refused to do so... the PA instead is allowing the other family members to dictate the elderly gentleman's care. This [in the consumer’s view] is a shocking case of elder abuse where the perpetrators are being encouraged rather than prevented by the PA... “

Consumer comment: Appointed decision-makers

“I wonder how someone with Alzheimer’s and trouble communicating their true wishes can sign a piece of paper and have all their rights and assets transferred to someone else. Surely that should be a process overseen by independent people, who take many appointments to assess the true wishes of someone that needs assistance. A signature on a form obtained by a family member then given to Centrelink can't take into consideration the true feelings of someone that has dementia.”

The above case study is in relation to a nominee process through Centrelink. Centrelink does not often recognise the substitute decision-making framework and would not link the fact that someone is under guardianship and not capable of changing the decision-maker. The state and territory based guardianship systems should notify Centrelink of when a substitute decision-maker is appointed so that Centrelink can check that there is a genuine change of nominee and not a fraudulent one.

Action is required to address financial abuse of people with dementia occurring under Enduring Power of Attorney agreements. The Alzheimer's Australia NSW project recommended that education be provided to people who are appointed as Attorneys to ensure they understand their responsibilities; and also noted the importance of banks and other financial services institutions having policies and procedures in place to prevent and address financial abuse, including staff education and training, mandatory reporting, and information for customers on financial abuse.

The report also noted that many survey respondents in the study supported mandatory registration of Enduring Power of Attorney agreements, as is the case in several overseas jurisdictions; and subsequent monitoring or auditing of the use of the powers by the Attorney, though it was noted that this could be an imposition for Attorneys.⁴²

Alzheimer's Australia supports action to address the financial abuse of people with dementia through Enduring Power of Attorney arrangements. We also note that failure by people appointed as Enduring Guardians/Enduring Powers of Attorney for health to follow the instructions of the person who has appointed them could constitute abuse, and measures are needed to address this. Failure by service providers to follow the instructions of the legally authorised representative, particularly in end-of-life care situations, can also constitute abuse, and these issues are discussed further below.

Recommendation 8

Older people and particularly those with a diagnosis of dementia should be encouraged to appoint legally authorised substitute decision-makers to help ensure their wishes are respected in the event that they lose capacity. All persons appointed under financial Enduring Power of Attorney agreements and under Enduring Guardianship/Enduring Power of Attorney for health arrangements should be required to undertake education regarding their legal and ethical responsibilities. All financial Enduring Power of Attorney agreements should be registered; and the feasibility of subsequent monitoring and audit of actions taken under the agreements should be examined. Centrelink should also be required to check with the relevant Guardianship Tribunal/Board if they receive a claim or notice to change a nominee for purposes of payment of entitlements to ensure that the change of nominee is genuine.

⁴² Alzheimer's Australia NSW (June 2014). *Preventing financial abuse of people with dementia*. Discussion paper No. 10.

HEALTH SERVICES AND ELDER ABUSE

This section of our submission responds to the section in the ALRC Issues Paper dealing with health services.

Communication of a diagnosis of dementia

Consumers have reported concerns that some medical practitioners decide in some cases not to inform a person they have been diagnosed with dementia. In fact, this is an abuse of the person's rights, as the failure to communicate the diagnosis early in the disease process means the person may lose the opportunity to plan for the future and put arrangements in place while they still have capacity, including documents such as advance care plans, enduring guardianship, enduring power of attorney, and Wills.

The vast majority of people prefer to be informed about a diagnosis of dementia, for reasons relating to autonomy and the opportunity to plan for the future,⁴³ and most are accepting of such a diagnosis.⁴⁴ The reluctance of some doctors to disclose a diagnosis of dementia can be due to the doctor's lack of confidence in having a correct diagnosis, concern to act in patients' best interests, stigma associated with the label of dementia, and reluctance to have a difficult discussion.⁴⁵ While sharing the diagnosis is advocated in guidelines as an important component of good clinical care,⁴⁶ non-disclosure is common, and is more likely in cases of early dementia, and in cases where the diagnosis needs to be disclosed to the patient rather than to a carer.⁴⁷

⁴³ Van den Dungen P, van Kuijk L, van Marwijk H, van der Wouden J, Moll van Charante E, van der Horst H, van Hout H (2014). Preferences regarding disclosure of a diagnosis of dementia: a systematic review. *Int Psychogeriatr*, Oct; 26(10):1603-18; Grossberg GT, Christensen DD, Griffith PA, Kerwin DR, Hunt G, Hall EJ (2010). The art of sharing the diagnosis and management of Alzheimer's disease with patients and caregivers: recommendations of an expert consensus panel. *Prim Care Companion J Clinical Psychiatry*, 12(1):PCC.09cs00833.

⁴⁴ Millard F, Baune B (2009). Dementia – who cares?: a comparison of community needs and primary care services. *Aust Fam Physician*, Aug; 38(8):642-9; Dodd E, Cheston R, Fear T, Brown E, Fox C, Morley C, Jefferies R, Gray R (2014). An evaluation of primary care led dementia diagnostic services in Bristol. *BMC Health Serv Res*, Nov 29; 14:592; Luck T, Lupp M, Sieber J, Schomerus G, Werner P, König HH, Riedel-Heller SG (2012). Attitudes of the German general population towards early diagnosis of dementia – results of a representative telephone survey. *PLoS One*, 7(11):e50792.

⁴⁵ Phillips J, Pond CD, Paterson NE, Howell C, Shell A, Stocks NP, Goode SM, Marley JE (2012). Difficulties in disclosing the diagnosis of dementia: a qualitative study in general practice. *Br J Gen Pract*, Aug; 62(601):e546-53; Pond, D (2012). Dementia – an update on management. *Aust Fam Physician*, Dec; 41(12):936-9; Caruana-Pulpan O, Scerri C (2014). Practices in diagnosis, disclosure and pharmacotherapeutic management of dementia by general practitioners – a national survey. *Aging Mental Health*, Mar; 18(2):179-86.

⁴⁶ Grossberg GT, Christensen DD, Griffith PA, Kerwin DR, Hunt G, Hall EJ (2010). The art of sharing the diagnosis and management of Alzheimer's disease with patients and caregivers: recommendations of an expert consensus panel. *Prim Care Companion J Clinical Psychiatry*, 12(1):PCC.09cs00833; Ngo J, Holroyd-Leduc JM (2015). Systematic review of recent dementia practice guidelines. *Age Ageing*, Jan; 44(1):25-33; National Health and Medical Research Council (NHMRC) Cognitive Decline Partnership Centre, Guideline Adaptation Committee (February 2016). *Clinical practice guidelines and principles of care for people with dementia*.

⁴⁷ Phillips J, Pond CD, Paterson NE, Howell C, Shell A, Stocks NP, Goode SM, Marley JE (2012). Difficulties in disclosing the diagnosis of dementia: a qualitative study in general practice. *Br J Gen Pract*, Aug; 62(601):e546-53; Pond, D (2012). Dementia – an update on management. *Aust Fam Physician*, Dec; 41(12):936-9; Van Hout HP, Vernooij-Dassen MJ, Jansen DA, Stalman WA (2006). Do general practitioners disclose correct information

Case study: Non-communication of the diagnosis of dementia

“One of the most crucial things this inquiry needs to address is WHAT IS REAL ABUSE? Because in my opinion, when a GP or Geriatrician does not give out the correct diagnosis, either because it is a misdiagnosis (like in my mother’s case), or the GP is a family doctor and does not want to “hurt” the poor old lady (like in my friend’s case), this is actually abuse. The person is being deprived of the possibility to plan their present and future, put a Care Plan in place, a Will, etc.”

The new Australian clinical practice guidelines for people with dementia recommend that the diagnosis of dementia should be communicated to the person with dementia by a medical practitioner. The medical practitioner should be honest and respectful and use a gradual and individualised approach when communicating the diagnosis to the person with dementia, their carers and family. The guidelines also note that while people have a right to know their diagnosis, they also have a right not to know if that is their choice. In the rare cases where the person with dementia does not wish to be told their diagnosis, this wish should be respected, and carers and family members need to be supported to manage the situation and the consequences of this decision.⁴⁸

Recommendation 9

Medical practitioners should be made aware of their legal and ethical responsibilities in relation to the need to inform a person with dementia of their diagnosis unless they have indicated they do not wish to be told, in accordance with the *Australian Clinical Practice Guidelines and Principles of Care for People with Dementia*. Other persons should not be told of the diagnosis without the consent of the person with dementia, if they still have capacity.

Care in the hospital system

People with dementia who are hospitalised experience unacceptably worse clinical outcomes and longer lengths of stay as well as a higher likelihood of readmission compared to people without dementia. Not only is this detrimental to the person with dementia but it also results in a high cost to the health care system. Many people with dementia are not identified as having dementia on admission to hospital, and even where they are, hospital staff often lack education and training on dementia and the care of people with dementia. There may also be a failure to involve and listen to carers. The result is that people with dementia may be labelled as “difficult” and have their human rights abused in the hospital setting: for example, being over-medicated with anti-psychotic drugs, or being physically restrained by being tied to a bed.⁴⁹ There have also been reports of advance care plans made by people with dementia not being respected and followed in the acute hospital setting, as discussed below.

to their patients suspected of dementia and their caregivers? A prospective observational study. *Aging Ment Health*, Mar; 10(2):151-5.

⁴⁸National Health and Medical Research Council (NHMRC) Cognitive Decline Partnership Centre, Guideline Adaptation Committee (February 2016). *Clinical practice guidelines and principles of care for people with dementia*.

⁴⁹ Alzheimer’s Australia (2014). *Dementia care in the acute hospital setting: Issues and strategies*. Paper 40. <https://fightdementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-40.pdf>

The following consumer case study was reported in the proceedings of a 2014 Alzheimer's Australia symposium on dementia care in the acute hospital setting.⁵⁰

Case study: Hospital care

'On his third night at the hospital, [my husband] tried to climb over the bed-rails to follow us when we left. Someone on duty made the judgement to give him five times his dose of the antipsychotic, Risperidone, to 'quieten him down'. He was rendered unconscious for the next five days. After five weeks, he was finally discharged from the aged care acute unit with noticeably diminished capacities and incontinent... A second admission... involved a resection of his prostate gland. He was nursed postoperatively in the urology ward with both wrists and ankles tied to the bed-rails for 48 hours, so he would not 'pull his tubes out'. This occurred in the absence of consultation with myself and our family.'

Alzheimer's Australia supports moves at system level to improve care for people with dementia in the hospital system. Alzheimer's Australia has been actively providing input into the development of Version 2 of the National Safety and Quality Health Service Standards which are the basis for hospital accreditation, and we are very pleased that safety and quality of care for people with cognitive impairment will be embedded throughout the revised Standards. Better screening, detection, and care for people with cognitive impairment in the health care system can make a real difference.

There are also some very positive "on-the-ground" initiatives to improve dementia care in hospitals. The Dementia Care in Hospitals Project is a national project based on a model of care developed by Ballarat Health Services in conjunction with Alzheimer's Australia Victoria and people with dementia and their families. This approach is based on staff education and cultural change linked with an overbed alert – a visual Cognitive Impairment Identifier – which alerts staff to memory and thinking difficulties such as dementia, delirium and cognitive impairment experienced by the patient. Hospitals which use the approach undertake extensive hospital-wide training on use of the identifier, and on the associated philosophy of care. The approach has been shown to improve staff and carer satisfaction with the care provided to people with dementia in acute care facilities. It has been implemented in over 20 hospitals across Victoria, and is now being rolled out and further evaluated in four states across Australia.^{51 52}

Another example of a positive initiative in the hospital system is the TOP 5 model developed in NSW which recognizes the value of carers in informing the provision of appropriate health care for a person with dementia or other cognitive impairment. The model aims to encourage health professionals to better engage with carers, to obtain valuable non-clinical

⁵⁰ Alzheimer's Australia (2014). *Dementia care in the acute hospital setting: Issues and strategies*. Paper 40.

<https://fightdementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-40.pdf>

⁵¹https://fightdementia.org.au/sites/default/files/08_Mark_Yates_The_Ballarat_Approach_The_Dementia_Care_in_Hospitals_Program.pdf

⁵² Alzheimer's Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, p 13.

information to better personalize care. The information is documented on a TOP 5 form made available to every member of the care team, which aims to improve communication between the team, the patient, and the carer. Up to 5 personal tips from carers to inform strategies for providing good care for the person may be documented on the form. The approach has shown great promise in its first phase of implementation, including ease of uptake, high acceptability to staff and carers, a decrease in the need for intensive staffing, a reduction in falls, and a reduction in the use of anti-psychotic medication. The approach is now being more broadly piloted in a Phase 2 study.⁵³

The following recommendation is based on strategies developed at an Alzheimer's Australia symposium on dementia care in hospitals, held in 2014,⁵⁴ and on work undertaken to date through the Dementia Care in Hospitals Program.

Recommendation 10

To improve dementia care in acute hospitals and prevent human rights abuses, Version 2 of the National Quality and Safety Health Service Standards which embed care for people with cognitive impairment throughout the standards, should be implemented as early as practicable. In line with these revised standards, dementia should be identified and managed at hospital admission, and discharge should be planned for from the outset. Families and carers should be enabled to be actively involved in the care and support of the person with dementia, if they so wish. Staff should be trained to more effectively communicate with and care for the person with dementia. Physical environments should be made more dementia-friendly, and alternatives to psychotropic medications should be used wherever possible. The Dementia Care in Hospitals Program, which has been shown to improve care, should be adopted widely in acute care hospitals across Australia.

End-of-life care

Being able to access appropriate care at the end-of-life is a critical factor in a more dignified death. This requires early planning and documentation of wishes, as well as end-of-life care discussions with clinicians and family members, particularly for people who have progressive neurological diseases such as dementia.

A survey of care professionals and family carers undertaken by Alzheimer's Australia found that consumers struggle to get access to appropriate end-of-life care for people with dementia. One in five family carers reported experiencing difficulties in securing care in line with the wishes of the person with dementia, and the majority lacked access to palliative care, hospice care, or care in the community.⁵⁵

⁵³ <http://www.cec.health.nsw.gov.au/programs/partnering-with-patients/top5>

⁵⁴ Alzheimer's Australia (2014). *Dementia care in the acute hospital setting: Issues and strategies*. Paper 40. <https://fightdementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-40.pdf>

⁵⁵ Alzheimer's Australia (February 2014). *End of life care for people with dementia: Survey report*. https://www.fightdementia.org.au/files/EOI_ExecSummary_Web_Version.pdf

A number of factors contribute to poor access to quality end-of-life care for people with dementia including:

- A lack of understanding that dementia is a terminal illness, which leads to delays or inability to access palliative care services.
- Poor understanding of the legal rights of people living in aged care by both health professionals and family members.
- A relatively low rate of advance care planning by people with dementia and their families which means that there may be uncertainty about the person's wishes for end-of-life care.
- Care providers not adhering to end-of-life care wishes due to staffing issues or concerns about legal implications.
- A lack of assessment and appropriate treatment of pain for people who have difficulty communicating their discomfort.

Alzheimer's Australia and Palliative Care Australia have developed a joint position statement on palliative care and dementia. The statement highlights the challenges around access to end-of-life care for people with dementia and makes recommendations to improve access to care.⁵⁶ The following recommendation is based on this position statement.

Recommendation 11

Health professionals should encourage individuals to discuss and document their end-of-life care preferences when services commence, and provide increased information and support around planning for end-of-life care during the early stages of dementia. Nationally consistent advance care planning legislation is required to reduce confusion and provide protection to health professionals and community members. Advance care directives should be linked to electronic health records to allow access by all professionals. The expressed preferences of the individual with regard to their end-of-life care should be respected where they meet legally available options. Training and protocols for health professionals should be provided so that they know when and how to implement advance care plans.

⁵⁶ Palliative Care Australia and Alzheimer's Australia *Palliative Care and Dementia: Position Statement*. https://fightdementia.org.au/sites/default/files/18122013_PCA_Alzheimer_position_statement.pdf

LEGISLATIVE AND LEGAL SYSTEMS RESPONSES TO ELDER ABUSE IN RELATION TO PEOPLE WITH DEMENTIA

Alzheimer's Australia has developed the following sections of our submission with the assistance of expert legal input.⁵⁷

The role of public advocates

This section of our submission specifically addresses Questions 33 and 34 in the ALRC Issues Paper.

Question 33 What role should public advocates play in investigating and responding to elder abuse?

Alzheimer's Australia notes that while Public Advocates are statutory appointments at a state or territory level, not all jurisdictions appoint a Public Advocate,⁵⁸ and in some jurisdictions the role is combined with another statutory appointment.⁵⁹

In the jurisdictions where there is a "discrete" Public Advocate the role itself varies considerably. In some states the functions of the Public Advocate are confined to systemic advocacy.⁶⁰ In other jurisdictions the Public Advocate, when appointed by a Tribunal can act as a guardian for a person whose mental capacity is impaired.⁶¹ A common theme in much of the legislation in the various jurisdictions is that only those with impaired capacity fall under the mandate of the Public Advocate.⁶² This somewhat narrow definition therefore limits who the Public Advocate can actually advocate for. Also, some guardians see themselves as "decision-makers" only, not as actual advocates or case-managers for the people for whom they are appointed for. However, in Victoria the term used is "disability"⁶³ which in relation to a person is defined as "...intellectual impairment, mental disorder, brain injury, physical disability or dementia,"⁶⁴ This more expansive definition allows for greater scope when addressing the issue of who the Public Advocate can advocate for.

The fact that there are so many disparities between the states/territories is not conducive to a co-ordinated national approach when addressing the issue of elder abuse. It is also problematic that these protective measures for older people fall within the domain of states and territories, whilst overall responsibility for aged care and many relevant services are

⁵⁷ Legal input was provided to Alzheimer's Australia by Sue Field and colleagues.

⁵⁸ Notably New South Wales, Tasmania and the Northern Territory.

⁵⁹ See <https://www.ptg.act.gov.au/>

⁶⁰ See for example s209 *Guardianship and Administration Act 2000* (Qld).

⁶¹ See for example s16 *Guardianship and Administration Act 1986* (Vic).

⁶² See for example s21(1)(a) *Guardianship and Administration Act 1993* (SA); s97(d) *Guardianship and Administration Act 1990* (WA); s209 (1)(a) *Guardianship and Administration Act 2000* (Qld).

⁶³ See s15 *Guardianship and Administration Act 1986* (Vic)

⁶⁴ S3 *Guardianship and Administration Act 1986* (Vic)

under the control of the Commonwealth.⁶⁵ Harmonisation of the legislation at state/territory level should be considered in the first instance.

There is obvious scope for an expansion of the role of Public Advocates, for all vulnerable older people, whether or not there has been a diagnosis of cognitive impairment, and whether the vulnerable person is within an institution or in the community.

There have been previous recommendations in the Australian context that the powers of the Public Advocate should be broadened to include receiving and investigating complaints in relation to abuse, neglect, or exploitation of people with impaired decision-making ability.⁶⁶

There are precedents involving similar models overseas. For example, the *Adult Support and Protection Act (Scotland) 2007* requires local councils to make inquiries about a person's well-being, property or financial affairs if it knows or believes that the person is an adult at risk, and that it might need to intervene; and authorises the council officers to enter any place for the purpose of enabling or assisting a council conducting inquiries to decide whether it needs to do anything to protect an adult at risk from harm.⁶⁷

It has been recommended that should the investigative powers of the Public Advocate be expanded, the investigators would not only report on their findings but make immediate support referrals as soon as they begin investigating.⁶⁸ In order to make these referrals, they would need to have improved knowledge of health and mental health conditions, or work within tight collaborative networks, where information is shared and others are able to proactively volunteer to provide support. The Public Advocates would also need skills in determining criminal from civil offences and work closely with the Police to ensure criminal matters are referred to them expeditiously.

Should such an expansion of the role of Public Advocates occur this would require a collaborative approach with many other relevant agencies, such as Primary Health Networks, Commonwealth Aged Care and Police.

Recommendation 12

The role of Public Advocates should be expanded to include investigating and responding to elder abuse for all vulnerable older people, whether or not there has been a diagnosis of cognitive impairment, and whether the vulnerable person is in an institution or in the community. The Public Advocate should report on findings of such investigations, and should make immediate support referrals as soon as investigations commence, working collaboratively with other relevant agencies. All states and territories should have a Public Advocate, and legislation covering Public Advocates should be harmonised across states and territories to enable a nationally consistent approach.

⁶⁵ For a detailed discussion on this area, see Wendy Lacey's article: *Neglectful to the Point of Cruelty? Elder Abuse and the Rights of Older Persons in Australia*, 36 *Sydney L. Rev.* 99, 2014

⁶⁶ Chesterman J (2012) *Responding to violence, abuse, exploitation and neglect: Improving our protection of at-risk adults*. Report for the Winston Churchill Memorial Trust of Australia.
https://www.churchilltrust.com.au/media/fellows/Chesterman_John_2012_Report.pdf

⁶⁷ *ibid* p47.

⁶⁸ Chesterman *op cit* p 81.

Question 34 Should adult protection legislation be introduced to assist in identifying and responding to elder abuse?

Alzheimer's Australia notes that there is no specific adult protection legislation in place in Australia, though there are examples overseas of legislation specifically designed to protect vulnerable adults from abuse.⁶⁹

The question of whether it is necessary to introduce separate adult protection legislation in Australia is debateable. Protection of vulnerable older people may be better achieved through extended powers for Public Advocates as outlined above, as well as reforms to relevant Guardianship Tribunals and amendments to state and territory criminal legislation as outlined below.

Forums for redress

This section of our submission specifically addresses Questions 39 to 41 in the ALRC Issues Paper.

Question 39 Should civil and administrative tribunals have greater jurisdiction to hear and determine matters related to elder abuse?

Firstly, there needs to be consideration of classification of elder abuse into criminal and civil matters. Severe or extreme cases of elder abuse, including cases of physical assault, sexual assault, breaches of a domestic violence or protection orders, and some financial abuse (potential fraud cases), should be treated as criminal matters and referred to the police as a priority. These matters would be dealt with in the criminal jurisdiction, beginning with the Magistrates Courts. In many states, specialist courts have been established, such as Domestic Violence Courts⁷⁰ to ensure that there is a sophisticated response to the issues. Part of the sophisticated response is to have strong and coordinated links with key agencies, develop protocols and practice notes for conduct of the proceedings and guidelines for communicating with parties.⁷¹

By contrast, there will be other matters which should be dealt with through the civil system. Legal definitions and the resulting clarification of language will be important to educate police and other social service agencies on the distinction between criminal and civil matters.⁷²

Currently, the focus of civil and administrative tribunals is to make appointments of substitute decision-makers, when someone lacks capacity to make their own decisions, and when existing appointments (such as Enduring Powers of Attorney) are not sufficient.⁷³ Elder abuse is not limited to people who lack capacity to make their own decisions, as seen in some of the cases highlighted in the noted New South Wales Inquiry.⁷⁴

⁶⁹ Nova Scotia, Canada: *Adult Protection Act* R S c.2, s.1; *The Adult Support and Protection (Scotland) Act* 2007.

⁷⁰ See Queensland Department of Justice and Attorney General *Interim Evaluation of the Trial Specialist Domestic and Family Violence Court in Southport, 2016 – DJAG Interim Report*.

⁷¹ See DJAG Interim Report pp 3-4.

⁷² See Integrated Police Response for Abused Seniors – Practice Guidelines for Implementing the Model, Montreal Canada, Beaulieu and Cote, 2016.

⁷³ See *Elder Abuse in NSW*, Legislative Council, 2016, p14.

⁷⁴ See case studies in *Elder Abuse in NSW* p.78.

Before enlarging powers of Civil and Administrative Tribunals, powers of enforcement of an order need to be considered. For example, having to get an order from a Civil and Administrative Tribunal, and to then have it enforced in a Magistrates Court is unnecessarily complex. Either orders should be enforceable in the civil and administrative tribunal, or the matter should commence in the Magistrates Court. Whilst some administrative tribunals have power to enforce certain orders, they have rarely exercised that power.^{75 76}

The power of tribunals would need to be substantially upgraded (as they are not courts of general jurisdiction, but statute based) to address financial abuse by overturning unfair transactions, including property transactions⁷⁷ real estate transactions, motor vehicle transactions, and bank transfers, and to be able to enforce these decisions.

There is little value in expanding the powers of Tribunals when there may be little to no enforcement provisions within the overarching legislation that provides for the operational powers of each State and Territory Tribunal. It needs to be considered whether it would be more effective to place powers in courts that already have enforcement powers and accompanying resources, (for example following the model for establishing specialist magistrates courts)⁷⁸ or expanding Tribunals in relation to substantive responses to elder abuse as well as in relation to their ability to enforce orders.

Question 40 How can the physical design and procedural requirements of courts and tribunals be improved to provide better access to forums to respond to elder abuse?

The informality of tribunal hearings enable a greater degree of flexibility to respond to needs of clients. However, the “problem-solving” court approach can also provide for a more person-centred approach. Judicial and court officers apply a therapeutic jurisprudence approach, whereby the “law does things to help people” and as a response “it also results in more compliance with Judicial Orders.”⁷⁹

However, there is a requirement for greater flexibility and accommodation of need in courts and tribunals, so that more people can participate in person in matters that concern them. For example, providing for close proximity parking for people with a disability, and then ensuring wheelchair access into the building and into the hearing room (and placing this information on the relevant website).

The overwhelming majority of the community do not frequent Courts, be they Supreme, District or Magistrate. Courts are generally not user friendly. However, changing demographics resulting in an increased number of older people, combined with the increase in awareness of the issues surrounding elder abuse, makes it possible that there may well

⁷⁵ See SMD [2013] QCAT 350, as an overview of earlier decisions.

⁷⁶ see ODY (Guardianship) [2016] VCAT 804.

⁷⁷ for an overview of the complexity of overturning a property transaction see Case Study, *Elder Abuse in NSW* p78.

⁷⁸ See *Report on the Interim Evaluation of the Domestic and Family Violence Court in Southport*, Department of Justice and Attorney General, 2016.

⁷⁹ For an international overview of this approach, including an applied understanding of procedural fairness in this context refer to “Fundamentals of Drug Treatment Courts” paper presented 28-31 March, Queensland Australia, Hon. Judge Peggy Fulton Hora, Superior Court of California (Ret.).

be more older people who are victims of elder abuse appearing in the Courts. In fact, as early as 2004, the then Chief Magistrate of Tasmania noted an increase in the number of older people appearing in the Courts and commissioned research to ascertain whether the Tasmanian Courts were “user friendly” for older people. The subsequent Report⁸⁰ made several recommendations relating to simple, inexpensive, but very effective measures, to assist older people when attending Court. Some practical recommendations included:

- A designated Court for older people, during a quiet time of the day.
- Appointment of a specific contact person at the Courts.
- Staff training and the use of trained Court Volunteers; including allocating more tasks to Court Volunteers, so that they are made aware of the older person’s attendance on the day, and can take steps to meet the older person and make them feel as comfortable as possible.
- Increased font size for the Court Lists.
- Reviewing application and court forms, so that linguistic, cultural and disability needs are identified and acted upon.
- Making sure application forms are in large print.
- Providing for devices for people to hear proceedings (such as hearing loops) as people may be accused of lacking capacity to follow hearings, purely because they may not have been able to hear proceedings.
- Providing brochures and videos on court or tribunal layout and process so that people are more familiar, and less time is spent on basic information exchange in the hearing.
- Using a range of communication mediums, including whiteboards, to set an agenda, so that people who are unfamiliar to the environment can follow visually.
- Providing for breaks in proceedings, and ensuring that the person knows that they do not have to stay and that they have a support person to go with them if they no longer want to be present in proceedings.
- Court rooms are often harsh environments that echo, which does not assist people with hearing problems. Carpeted rooms provide for “softer acoustics”.
- Using technology such as filming an interview for the Tribunal, would be useful, as it is well known that people may have fluctuating capacity, and be more lucid at different times of the day. They could give evidence in a more comfortable setting, at a time of day that best suited them.
- Having hearings or mediation sessions within the person’s hospital or care facility may also be beneficial.

Many of the above ideas have been implemented in a functioning courtroom in the USA, and are publicly displayed in a website to reduce anxiety for participants in court processes. The Eleazer Courtroom is the first courtroom in the USA designed specifically with the needs of elderly people in mind. Features include:

- Carpeting designed to give visual clues for those with visual impairments -- a border along the edge in a color different from the carpet, with diamond insets marking each row to give a visual clue regarding seats.
- Rounded corners on all tables and desks.
- Sturdy chairs with locking wheels and firm arms.

⁸⁰ Sue Field “Access to Justice – Seniors and the Courts (A Study of the Magistrates Court of Tasmania), Elder Law at UWS, September, 2004.

- Easily accessible witness box at floor level with no steps.
- Ramp to judge's bench inside judge's chambers, so judge in wheelchair can ascend bench without being observed.
- Podium that is electronically height-adjustable, with electronic side shelves or wings for those in a wheelchair and with limited upper body mobility.
- Use of technology to enhance accessibility of participants -- including flat panels in gallery and hearing amplification devices.
- Non-glare, non-buzz lighting.
- Color picked to enhance vision of elders.
- Courtroom participants are able to move about the courtroom without highlighting physical limitations.⁸¹

Significant work has also been undertaken in Australia on design principles to make buildings and environments more enabling for people with dementia.⁸² These design principles could be adopted by courts and tribunals as one means of improving access for people with dementia.

Recommendation 13

Modifications should be undertaken to the procedures and environments of courts and tribunals, to improve access by older people, including people with dementia. Relevant recommendations and models include the 2004 review of senior access to the Magistrates Court of Tasmania; the Eleazer Courtroom in the USA; and the Dementia Enabling Environments Project in Australia.

Question 41 What alternative dispute resolution mechanisms are available to respond to elder abuse? How should they be improved? Is there a need for additional services, and where should they be located?

In Australia, there are few alternative dispute resolution mechanisms available to respond to elder abuse. Relationships Australia has commenced a pilot project in 2016 of Elder Relationship Services, a counselling and mediation services to support families to negotiate issues in relation to ageing.⁸³ Other local services exist, and an Elder Mediation Australasian Network has recently been established in Australia to promote understanding of and referrals to elder mediation, and establish and maintain professional standards of mediators.⁸⁴

Tribunals may have the ability to provide conferencing or alternative dispute resolution, but are not necessarily skilled to proceed in a format that is not an actual hearing.

In other jurisdictions, alternative dispute resolution is viewed as most useful when tied to a legal process, and court cases are often resolved a day before, or on the day of a hearing. The Canadian Centre for Elder Law⁸⁵ defines elder mediation as:

⁸¹ See <http://www.stetson.edu/law/academics/elder/home/eleazer-courtroom.php>

⁸² See <http://www.enablingenvironments.com.au/>

⁸³ <http://www.relationships.org.au/media/media-releases/media-release-elder-services-launch/view>

⁸⁴ see <http://elder-mediation.com.au>

⁸⁵ Canadian Centre for Elder Law, "Elder and Guardianship Mediation" 2012.

“...the mediation of disputes arising in the context of aging. One or more of the parties will be an older adult or the issues in dispute will be ones of particular significance to older adults: e.g., estate planning, powers of attorney, caregivers (who, when, where, how much care, respite care, etc.), lifestyle choices, independence and self-determination vs. safety concerns. The issues and parties are often intra-familial, but can involve third parties such as housing providers. Elder mediation tends to be multipartite and involve family and intergenerational dynamics. It requires a particular degree of sensitivity and skill on the part of mediators.”⁸⁶

When elder mediation is considered the issue of “capacity” is often raised as a barrier to the consideration of mediation.

“The issue of mental capacity itself is generally regarded as not suitable for mediation because it is a legal determination. Numerous other issues arise in connection with an application for adult guardianship, however. For example, there can be a dispute over who among several family members is to be the guardian, or over the extent of the powers the guardian should have. Issues of this kind are amenable to negotiation and agreement among interested parties, and leave room for mediated solutions. These other issues are often closely intertwined with the question of capacity, however. The involvement of a party with diminished cognitive powers or other physical or economic vulnerabilities means that guardianship mediation is often fraught with complex legal and ethical concerns for the mediator.”⁸⁷

Mediation services are often seen as a way to “tailor” solutions to an individual’s circumstances. Overall, the Canadian experience is that of growing mediation that is connected with a court process.

“The development of elder mediation in particular builds on the general trend in Canada for increased use of legislated and court-connected (mandatory or voluntary), private, and community-based mediation. Mediation in Canada is rapidly expanding and research suggests its broad efficacy and value. Mediation is becoming a common stage in conflict resolution and is often integrated directly in civil court rules or into governing statutes... the evolution of “guardianship mediation” builds upon a trend in Canada to modernize adult guardianship regimes.”⁸⁸

Parties need to be informed about mediation options, including through civil and administrative tribunal application forms, as a means of educating people about least restrictive options. Further work is needed to develop mechanisms to ensure that the rights of a person with cognitive impairment are not compromised in such processes, as a level of equality may be assumed in the approach to mediation.

⁸⁶ pxiii.

⁸⁷ *idem*

⁸⁸ *Ibid* p4

Recommendation 14

Current local elder mediation services and pilots in Australia should be evaluated and international models considered, so that the value of a nationally consistent approach to elder mediation can be assessed. Parties should be informed about available elder mediation services, to encourage consideration of these options where appropriate. Further work is needed to develop mechanisms to ensure that the rights of a person with cognitive impairment are not compromised in mediation processes.

The role of criminal law

This section of our submission specifically addresses Questions 42 to 50 in the ALRC Issues Paper.

Question 42 In what ways should criminal laws be improved to respond to elder abuse? For example, should there be offences specifically concerning elder abuse?

As the situation currently stands in Australia there are no specific criminal laws that address the issue of elder abuse. Although in the states and territories there are laws which address assault,⁸⁹ murder⁹⁰ and fraud⁹¹ for example, none of these pertain only to older persons.⁹² In some jurisdictions there is domestic violence legislation that could or does capture some forms of elder abuse, but nevertheless is still not specific to older people. For example pursuant to section 5 of the *Family Violence Protection Act 2008* Victorian Police are able to protect vulnerable family members in certain situations.⁹³ Another example can be found in the jurisdiction of Queensland where under the *Domestic and Family Violence Protection Act 2012* section 5(d) specifically refers to “elderly people” as an example of “...people who may be particularly vulnerable to domestic violence.”

On the other hand, should a resident of a Commonwealth-funded Residential Aged Care Facility be subject to what is termed a “reportable assault”⁹⁴ then the Approved Provider is required to report the allegation or suspicion of a “reportable assault” within twenty four hours to the appropriate police and the Secretary.⁹⁵ However, this only captures a small percentage of older people, noting that only 30% of people with dementia live in residential aged care facilities; and even then the definition of a “reportable assault” is very limited. It is well known that the most common forms of elder abuse are financial and psychological and that up to 80% of abuse is perpetrated by family members.⁹⁶ The legislation cited earlier does not provide an avenue of redress for victims of such forms of elder abuse.

⁸⁹ s61 *Crimes Act 1900* (NSW).

⁹⁰ s18 *Crimes Act 1900* (NSW).

⁹¹ s192C *Crimes Act 1900* (NSW).

⁹² It should be noted though that in New South Wales there is specific provision for “Assaults at schools”, see Division 8B of the *Crimes Act 1900* (NSW). Perhaps a separate Division could be introduced for crimes against older persons.

⁹³ For detailed discussion on this topic see Chapter 2 John Chesterman, ‘Responding to violence, abuse, exploitation and neglect: Improving our protection of at-risk adults’ Report for the Winston Churchill Memorial Trust of Australia @ https://www.churchilltrust.com.au/media/fellows/Chesterman_John_2012_Report.pdf

⁹⁴ ss(9) s63 – 1AA *Aged Care Act 1997* (Cth) defines a “reportable assault” as “unlawful sexual contact, unreasonable use of force, or assault specified in the Accountability Principles and constituting an offence against a law of the Commonwealth or a State or Territory.”

⁹⁵ ss(2) s63 – 1AA *Aged Care Act 1997* (Cth).

⁹⁶ As cited in Wendy Lacey “Neglectful to the Point of Cruelty? Elder Abuse and the Rights of Older Persons in Australia”, 36 *Sydney L. Rev.* 99, 2014, p120.

If the victim of elder abuse is cognitively impaired then an application can be made to the relevant Guardianship Tribunal,⁹⁷ but the powers of these Tribunals are extremely limited in the orders that they can make in respect to elder abuse.⁹⁸ Furthermore, they cannot address issues concerning older persons who do possess mental capacity, irrespective of how vulnerable they may be.

If state and territory criminal legislation were to be amended to specifically include offences relating to elder abuse, the definition and age cut-off for applicability would need to be considered, as would the definition of vulnerability, and the definition of elder abuse.

It has to be acknowledged that under the current legislative regimes, both Commonwealth and State/Territory, the laws do not protect vulnerable older people. It is argued that there is scope for amendments to the state and territory criminal legislation to address specific criminal offences against older people. Such amendments could include specific divisions within the legislation to expand police powers in cases of suspected elder abuse and specifically address crimes when committed against older persons, such as fraud and assault. However, any changes to the legislation should take into account the definitional issues mentioned above.

Recommendation 15

Consideration should be given to amending state and territory criminal law to address specific criminal offences against older people, including expanding police powers in cases of suspected elder abuse.

Question 43 Do state and territory criminal laws regarding neglect offer an appropriate response to elder abuse? How might this response be improved?

Many state and territory criminal laws have provisions relating to “failure to provide necessities” or similar provisions, which would be broad enough to respond to many situations of elder abuse, for example, in New South Wales s44 *Crimes Act*⁹⁹ “Failure of persons to provide the necessities of Life” and s285 *Criminal Code Queensland*¹⁰⁰ “Failure to provide necessities”. These provisions are rarely utilised in Australia for the purpose of elder abuse. They tend to be utilized more for cases of child neglect by parents or guardians. This lack of prosecution of potential criminal neglect has occurred although cases of severe neglect have been the subject of coronial inquests.¹⁰¹

⁹⁷ Usually now a Division of one of the larger tribunals such as Victorian Civil and Administrative Tribunal, New South Wales Civil and Administrative Tribunal or the Queensland Civil and Administrative Tribunal, to mention but a few.

⁹⁸ For example they may revoke a power of attorney or enduring guardianship, but they do not, for example, have the power to make Orders for compensation.

⁹⁹ *Crimes Act 1900* (NSW).

¹⁰⁰ *Criminal Code Act 1899* (Qld).

¹⁰¹ Please see Wendy Lacey “Neglectful to the Point of Cruelty? Elder Abuse and the Rights of Older Persons in Australia”, 36 *Sydney L. Rev.* 99, 2014, pp 110-111 for the discussion on the inquest of Cynthia Thoresen and subsequent lack of prosecution.

One potential issue in relation to neglect cases may be a lack of understanding of appropriate care, including under- and over- medicating. This would require public prosecution bodies to access medical or nursing experts to determine basic standards.

Legal complexity in our federated model of government can present a barrier to uptake of legal protections. A project undertaken by the Canadian Centre for Elder Law based on analysis of elder abuse cases,¹⁰² has led to the production of fact sheets and legislative tables, which could provide a valuable model for Australian practitioners.

Overall, it seems that the current criminal law provisions could be utilized in Australia, but there would have to be improved knowledge with Police and Department of Public Prosecutions on elder abuse and on acceptable standards of care, including with regard to medication administration. This is dealt with under Recommendation 18 below.

Question 44 Are protection orders being used to protect people from elder abuse? What changes should be made to make them a better safeguard against elder abuse?

It is difficult to establish whether protection orders are being used currently to protect people from elder abuse. Many States have broad enough definitions of domestic violence and subsequent protection orders that would provide an adequate response to the broad range of elder abuse issues.

Magistrate's Courts are accessible across the country and these Courts are quite familiar with the operation of domestic violence applications and subsequent orders.

A useful comparative table of state and territory domestic violence legislation has already been completed by the Australian Law Reform Commission.¹⁰³ By combining elements of the states and territories existing laws, a more consistent and comprehensive framework could be established. For example, if deprivation of liberty and/ or kidnapping was included in all state and territory definitions, along with economic and /or financial abuse, this would increase the safeguards.

There is already an increasing understanding and reporting of domestic violence in our community. Increased community understanding that elder abuse is often a hidden form of domestic violence, is also required. Media and public relations strategies that are currently working for domestic violence could be analysed and implemented appropriately for elder abuse. The need for community awareness and education about elder abuse is addressed later in this submission.

Recommendation 16

Harmonisation of state and territory domestic violence legislation is needed, to provide a consistent and comprehensive framework for use of protection orders including in cases of elder abuse.

¹⁰² see http://www.bcli.org/sites/default/files/Counterpoint_Project_discussion_paper.pdf

¹⁰³ <http://www.alrc.gov.au/publications/5.%20A%20Common%20Interpretative%20Framework%20—%20Definitions%20in%20Family%20Violence%20Legislation/curre>.

Question 45: Who should be required to report suspected elder abuse, in what circumstances, and to whom?

Mandatory reporting is currently not part of our community response in relation to elder abuse. It is, however, our response in relation to child abuse. One of the fundamental differences is that children are viewed as being in need of protection, and only some older persons, because of a range of personal vulnerabilities, would be in need of protection.

If reporting of suspected abuse becomes mandated, the agencies and professionals who would have the greatest connection with older people would be the most effective notifiers of suspected abuse. Two such bodies would be General Practice teams¹⁰⁴ and to a lesser extent, Aged Care Assessment Teams (who are able to assess in a person's home and in a hospital setting, and are the "gate-keepers" for Commonwealth funded aged care services). The NSW Elder Abuse Inquiry had further discussions on this point, and the evidence of Professor Kurrle¹⁰⁵ is most helpful. Existing multi-disciplinary teams could be enhanced by a lawyer as team member.

Community care workers are another group who may be the first to detect signs of potential abuse in the community, and who could be considered for inclusion in mandatory reporting requirements.

Extensive education of these groups would be necessary to assist in their ability to identify elder abuse. Notification protocols would need to be developed in order to address real or perceived privacy issues (this has already occurred in many health settings in relation to notifications of child abuse). Areas that would need to be reported include neglect (including self-neglect), financial abuse and physical (including sexual) abuse. Solid grounding in a rights-based environment is required to ensure older people are treated with dignity and respect in response to concerns and abuse:

"...any system must be framed from a rights perspective to ensure that ageist and paternalistic approaches are not adopted, thereby avoiding the erosion of the rights and freedoms of vulnerable adults under the guise of safeguarding or protecting those people."¹⁰⁶

Without a solid and practical rights-based approach, one form of abuse may be swapped for "paternalistic protection", which many will also find to also contain abusive elements.

Recommendation 17

General practitioners and their multidisciplinary teams, Aged Care Assessment Teams, and community care workers should be considered as candidates for mandatory reporting of abuse and neglect of older people. Staff of banks and other financial institutions should also be mandated to report financial abuse. Such reporting should take place with the consent of the person who has been abused if the person has capacity. It is essential that robust protocols are developed for this purpose and that those mandated to report receive adequate training regarding their use. Whether or not they are mandated to report, these frontline service providers require education and support more generally in relation to dementia and abuse.

¹⁰⁴ According to the recent NSW Upper House Inquiry 97% of older people in NSW would visit their GP.

¹⁰⁵ See pp61-62 and pp66-67 of the Report.

¹⁰⁶ Lacey, *ibid* p130.

Question 46 How should the police and prosecution responses to reports of elder abuse be improved? What are best practice police and prosecution responses to elder abuse?

Police involvement in elder abuse situations is a state/territory matter. Both Queensland and New South Wales have designated police officers working in this area – one in each state. Although elder abuse itself is certainly not a new phenomenon, the realization by some governments of the vital role that police play is heartening. However, there is much more to be done.

The recently released Report on Elder Abuse in New South Wales¹⁰⁷ recommended:

“That the NSW Police Force establish a Vulnerable Community Support Officer in each Regional Command in New South Wales, with the position entailing training and support to front line officers, police response, liaison with local service providers and other government agencies, community education, awareness and engagement.” (Recommendation 10)

Should this recommendation be acted upon, New South Wales would be leading the other states and territories in police involvement in elder abuse.

However, before any improvements are suggested, consideration should be given to what underlying principles should form the basis of any policy, legal or operational changes. The following are suggested as a starting point:

- The rights of all older persons should be enshrined to ensure that they live in safety and with dignity;
- All older persons should have the right to determine their own life style and to make decisions and choices as to their living and financial arrangements;
- All older persons should have access to the same legal protections as everyone else in the community;
- All vulnerable older persons should have a valid safety regime akin to that set out in s8 of the *Children and Young Persons (Care and Protection) Act 1998* (NSW).¹⁰⁸

It should be noted that age *per se* does not automatically mean that a person is vulnerable or diminish their rights to make their own decisions, including whether or not to report abuse.

A comprehensive guide on policing in relation to elder abuse notes the importance of improving police understanding of elder abuse; developing policies and protocols that communicate the importance of addressing elder abuse; promoting collaborative efforts to respond to elder abuse; customising police responses to the special needs of elderly victims;

¹⁰⁷ New South Wales Legislative Council, General Purpose Standing Committee No. 2 “Elder Abuse in New South Wales” June 24th, 2016 @ <https://www.parliament.nsw.gov.au/committees/DBAssets/InquiryReport/ReportAcrobat/6063/Report%2044%20-%20Elder%20abuse%20in%20New%20South%20Wales.pdf>

¹⁰⁸ This is not advocating adult protection legislation, but rather setting out the basic rights associated with a “safe and nurturing environment”.

and reducing general community and cultural risk factors. The guide also recommends training for police, including how to work with other relevant agencies; and tools to assist police to apply best practices. It is noted that approaches such as enacting elder abuse laws and policies in isolation from other effective practices and strategies, adopting mandatory arrest and prosecution policies, and punishing older offenders who have Alzheimer's/dementia, are unlikely to be effective.¹⁰⁹

It is clear, then, that best practice models include, collaboration, training, resources and an underlying respect for the rights of vulnerable older persons.

Recommendation 18

Education and training for police and prosecutors is required to improve understanding of elder abuse. Police and prosecutors should develop policies and protocols to address elder abuse, and should work in collaboration with community agencies and other relevant parties. Responses by police and prosecutors should be grounded in a human rights approach which respects the rights of the vulnerable older person.

Question 47 How should victims' services and court processes be improved to support victims of elder abuse?

There is scant evidence of specific services for victims of elder abuse in Australia. Whilst there are support services for the victims of domestic violence (for women and children) the same cannot be said for older people.

Although there is emergency housing available for women and their children, these refuges are not designed for older women. Anecdotally, many older women are unable to cope with the noise, or the facilities (stairs, location etc). Lack of support from women their own age is also a factor and these older women often return (when they can) to the familiar environment where they were abused. Tailored emergency accommodation for victims of elder abuse, staffed by support teams who understand the issues surrounding elder abuse, should be a priority.

Although some states¹¹⁰ have Elder Abuse Helplines¹¹¹ which provide information, support and referral services¹¹² they are not funded to be a "one stop shop". Older people, particularly when victims of elder abuse, should only have to make one call which would provide them not only with the services mentioned above, but also free legal assistance, and through partnership arrangements, access to emergency accommodation.

Any such services for older people require not only social workers but lawyers experienced in dealing with older people, and in particular older people who are traumatized by their situation and may be impecunious. Furthermore, elder abuse does not just occur between the hours of 9 to 5, it occurs 24 hours a day. Helplines should therefore be staffed 24 hours a day to provide this much needed support.

¹⁰⁹ Payne B. "Physical and Emotional Abuse of the Elderly" Guide No. 71, Centre for Problem-Oriented Policing.

http://www.popcenter.org/problems/elderly_abuse/print/

¹¹⁰ Notably Queensland and New South Wales

¹¹¹ See <http://www.elderabusehelpline.com.au/about>, and <http://www.eapu.com.au/>

¹¹² They are also an excellent point for data collection on the statistics of elder abuse.

The importance of helpline services was noted in the recently released Report on Elder Abuse:¹¹³

“That the NSW Government expand the role of the NSW Elder Abuse Helpline and Resource Unit to include:

- Provision of case management and co-ordination
 - Consideration of Helpline operating hours, based on an assessment of demand
 - Adequate provision for culturally and linguistically diverse and Aboriginal clients”.
- (Recommendation 6)

Whilst police do provide their services 24 hours a day, extra resources are required to assist the victims of elder abuse. Designated police should be trained and available to meet the increasing demands associated with elder abuse.

There are currently very limited free legal services available to older people. While some jurisdictions, most notably Victoria and Queensland, have expanded pro bono legal services which incorporate the professional expertise of social workers, this model is not widespread, to the detriment of the victims of elder abuse.

However, Victoria has taken the issue of the needs of older people one step further with the appointment of a Commissioner for Senior Victorians.¹¹⁴ Positions such as this can further highlight and support issues such as elder abuse.

All older people deserve, as their right, access to justice, in particular those who are the victims of elder abuse. Courts should be made more enabling for older people, including those with dementia, as outlined in our response to Question 40 above.

Recommendation 19

Elder abuse helplines should exist in all jurisdictions and be expanded to meet demand. Emergency housing services specifically for victims of elder abuse are needed. An expansion of free legal services is also required across jurisdictions, to ensure victims of elder abuse have access to the legal system. All jurisdictions should consider the appointment of Commissioners acting for senior members of their communities, to highlight issues such as elder abuse, and support and advocate for action.

Question 48 How should sentencing laws and practices relating to elder abuse be improved?

There has been very limited opportunity to observe the practice of sentencing laws in relation to elder abuse. The absence of prosecutions and resulting sentences seems to convey an attitude of ageism and failure to care about criminal acts and their impact on an elderly person.

¹¹³ New South Wales Legislative Council, General Purpose Standing Committee No. 2 “Elder Abuse in New South Wales” June 24th, 2016 @ <https://www.parliament.nsw.gov.au/committees/DBAssets/InquiryReport/ReportAcrobat/6063/Report%2044%20-%20Elder%20abuse%20in%20New%20South%20Wales.pdf>

¹¹⁴ <https://www.seniorsonline.vic.gov.au/services-information/commissioner-for-senior-victorians>

However, there have been relevant developments overseas which may provide positive models for the improvement of sentencing laws and practices in Australia. In order to progress this area of law, guidance for law enforcement agencies has been developed in some of the USA states, in the form of prosecution handbooks. These handbooks give practical interviewing tips for vulnerable complainants and witnesses.¹¹⁵

The United Kingdom's Crown Prosecution Service has developed policy in response to needs of elderly people.¹¹⁶ This policy includes the Code for Crown Prosecutors, the role of the Police and helping older persons give their best evidence in court. This latter aspect of the policy outlines the role of witness care units for vulnerable witnesses and requests for special measures in giving evidence before the courts (such as playing pre-recorded witness and victim statements).¹¹⁷

The United States Centre for States Courts has developed a guide entitled "Prosecuting elder abuse cases: Basic tools and strategies".¹¹⁸ Besides outlining several strategies, including addressing issues of competency and capacity and building effective community networks, this guide also addresses common issues, including developing relationships with older people and extensive evidence check lists. One very useful aspect of this guide, is a comprehensive list of potential experts, their basic defined purpose (from a prosecution perspective) and whereabouts they can be located (or sourced).

Recommendation 20

Policies and resources should be developed in Australia, with reference to established overseas models, to improve prosecution and sentencing practice in Australia in relation to elder abuse.

Question 49 What role might restorative justice processes play in responding to elder abuse?

Restorative justice approaches can be a valid option in a range of responses to elder abuse. However, they may not be suitable in every case. In seeking justice, older people are not necessarily seeking punishment. They may instead wish to recover their property or reach an amicable agreement with their children, for example, in which case, approaches such as mediation may be more appropriate.

This approach can capture the complexity of the contributing factors to Elder Abuse, along with ensuring that people receive support during the process of confronting their alleged perpetrator. Restorative justice approaches should aim to decrease the fears of older people following on from incidents of abuse, including fear of loss of relationship and fear of not being believed by professionals and law enforcement agencies.

The guiding principles of the restorative justice approach are:

- Safety: to live in safety and security.
- Dignity and respect: to have personal values and preferences respected.

¹¹⁵ See <https://www.bja.gov/Publications/NCSC-Prosecuting-Elder-Abuse-Cases-Basic-Tools-and-Strategies.pdf>

¹¹⁶ See https://www.cps.gov.uk/publications/docs/caop_policy.pdf.

¹¹⁷ See p30 of the policy noted in footnote 24.

¹¹⁸ See <https://www.bja.gov/Publications/NCSC-Prosecuting-Elder-Abuse-Cases-Basic-Tools-and-Strategies.pdf>

- Autonomy: to determine and control their own affairs.
- Access to information: to receive all the available information they need in order to make meaningful and informed decisions.
- Confidentiality: to determine for themselves what personal information may be shared with others.
- The least restrictive interventions. Least restrictive of the individual's rights, abilities and personal liberties and least disruptive of life-style.¹¹⁹

These principles are underpinned by a collaborative approach between older people, support services, health professionals, legal professionals and law enforcement. An example is a restorative justice project in Ontario, which receives referrals from an Elder Abuse Response Team, consisting of a Police Officer and a Community Care Nurse.¹²⁰

Recommendation 21

Restorative justice approaches based on successful overseas models should be developed as an option for responding to cases of elder abuse in Australia, to be utilised in cases where restorative justice is appropriate to the situation and meets the preferences of the victim.

Question 50 What role might civil penalties play in responding to elder abuse?

Criminal law will only be applicable in more severe or extreme cases of abuse. Just as domestic violence law straddles both civil and criminal elements (the latter for breaches of orders), such a sophisticated response is also required for elder abuse.

Civil penalties would definitely apply in cases of economic losses. This would be most appropriate when there have been offences involving attorneys and other substitute decision makers. For example, minor penalties could apply when there have been breaches of the various financial Powers of Attorney Acts, such as not keeping property separate and not keeping appropriate records. These would be easier to establish (once an education system that is aligned with the acceptance of the attorney's powers has been instituted) from a basic investigation and strict liability would apply. Prolonged intermingling or conversion of moneys or assets by an attorney would attract a harsher penalty. This might be the final civil penalty, up until all criminal elements of fraud can be made out (including dishonesty).

Victoria has introduced provisions that allow for applications to be made for compensation orders, against attorneys who are in breach of their legal obligations. A recent VCAT decision¹²¹ demonstrates the difficulty in bringing a successful application against attorneys who may have been in breach of their obligations prior to 1 September 2015. This decision has the effect of greatly narrowing the scope of the application of the legislative changes.

Orders voiding under-value transactions could be a civil penalty. Unlike complex proof requirements in the general law, where the person with impaired capacity needs to prove that they lacked capacity to contract and the vendor knew of their incapacity, this provision only requires proof of an under-value transaction, combined with incapacity of the buyer.

¹¹⁹ Arlene Groh, 'Restorative Justice: A healing approach to Elder Abuse'.

<http://www.aaaceus.com/courses/NL1008/Article10.pdf>

¹²⁰ <http://www.wrps.on.ca/stay-safe/seniors-safety/elder-abuse>

¹²¹ YDM (Guardianship) [2016] VCAT 758

Essentially, the lower level Courts could hear these matters, similar to Child Protection and Domestic Violence matters now. Therapeutic jurisprudence guidelines would apply, to promote a fair and problem-solving approach.

Recommendation 22

Civil penalties should be considered as an appropriate response in less severe cases of elder abuse, where there is not a clear criminal intent: for example, minor breaches of financial Power of Attorney legislation. In cases of potential criminal conduct, criminal prosecutions should be pursued.

EDUCATION AND AWARENESS

One obvious way to begin to prevent and address abuse of people with dementia is to help ensure that people with dementia are informed about their legal rights.

Alzheimer's Australia has recently published a booklet on the legal rights of people with dementia.¹²² This booklet is a consumer-driven initiative, and was developed by Adjunct Fellow in Elder Law Sue Field and Professor Colleen Cartwright, with guidance from Alzheimer's Australia's consumer advisory groups, made up of people living with dementia and their carers. It is a much-needed tool for people with dementia and their families, to assist them in understanding their rights, and the actions they can take to ensure their rights are protected.

This consumer-friendly booklet is available on the Alzheimer's Australia website. It provides consumers with information and advice on issues including:

- Mental capacity and decision-making, and the role of substitute decision makers when people lack capacity to make their own decisions
- Legal rights and decision-making with regard to finances, including the appointment of an Attorney
- Legal rights and decision-making with regard to health care and other personal matters, including Enduring Guardianship (or equivalent term in some states/territories) and Advance Care Directives
- The legal rights and responsibilities of a person with dementia with regard to other issues such as employment, superannuation, driving, voting, and making wills.

The booklet also points consumers to a range of other resources that can help to ensure their legal rights are protected. Alzheimer's Australia hopes this resource will help people with dementia and their carers, particularly those who have been newly diagnosed, to understand their legal rights and put measures in place to ensure their rights are protected over time.

¹²² Alzheimer's Australia (March 2016). *Dementia and your legal rights*.

Some of the key information and advice we provide to people diagnosed with dementia in our Legal Rights booklet includes:

- While you still have capacity, it is important to plan ahead, discuss your wishes with family members or close friends and consider appointing someone, or more than one person, to make decisions for you if you do not have capacity.
- Appointing an Attorney as your substitute decision-maker for financial matters, and an Enduring Guardian as your substitute decision-maker for health and personal matters (or equivalent term in some states/territories), will help to ensure you can have peace of mind that your wishes will be legally respected.
- Substitute decision-making gives the decision-maker complete legal authority to act in relation to particular types of decisions about you, to the extent specified in their appointment by you or by a Guardianship Tribunal. The substitute decision-maker should act in consultation with you to the extent that your remaining capacity makes this possible. Once you have lost capacity, they must follow your written instructions if you have provided these, or follow your verbal wishes if you have discussed your wishes with them.
- While you have capacity (including after a diagnosis of dementia) you have the legal right to accept or refuse any treatment, including treatment for the dementia or for other health conditions, even life-saving treatment. Even after you have lost capacity, these views and wishes remain legally binding, and must be taken into account by your decision-maker.
- Preparing documents such as Powers of Attorney, Enduring Guardianship or equivalent, Advance Care Directives and Wills and updating them as required can ensure that your choices will be respected even if you are no longer able to express your views. It is also important that you seek professional advice where appropriate - medical, legal and financial - when preparing these documents.

To complement this information, consumers also require information about elder abuse, and what services and recourse are available for those who experience abuse.

Recommendation 23

People with dementia and their carers, as well as the broader community, need ready access to information about the legal rights of the person with dementia, and about mechanisms to ensure these rights are upheld. Information about elder abuse and services available for victims, is also required.

There is also an argument for broad community education and awareness-raising about elder abuse, both to prevent abuse and to encourage reporting. The Australian Institute of Family Studies Report notes that prevention and early intervention approaches in relation to elder abuse are in the early phases locally and internationally. The Institute notes one example of a local initiative, an elder abuse awareness campaign conducted in 2010 by the Queensland Elder Abuse Prevention Unit. The campaign was based on the theme: “Is it Happening to Someone You Know?” It involved posters displayed in shopping centres and cinemas, advertising on television and the supply of announcements for community services

slots on radio stations, together with press releases and media interviews. The campaign was targeted at the family and friends of older people and was intended to encourage greater awareness of elder abuse and reports to the Elder Abuse Helpline. An evaluation of the campaign found that notifications of elder abuse to the helpline rose by 64%, with an increase of 6% in notifications from family and friends.¹²³ Alzheimer's Australia supports increased community education and awareness campaigns in relation to elder abuse.

Recommendation 24

Community awareness and education campaigns on elder abuse are needed, to promote prevention and early reporting of elder abuse.

CONCLUSION

Dementia is one of the major chronic diseases of this century. With the continued ageing of the population and the growing numbers of people with dementia, strategies are needed to prevent and address abuse of older people with dementia.

This submission has discussed some of the key circumstances in which abuse is perpetrated on people with dementia, focusing on abuse by family members and other carers, including through substitute decision-making arrangements; abuse in the residential aged care system; and abuse in the health care system. We have argued for a broad definition of abuse, which encompasses not only the most blatant and intentional abuses, but also includes more subtle and systemic abuses, which impact on the human rights of people with dementia.

We have noted that financial abuse of people with dementia by family members and others close to them is quite common, and we have recommended that older people need targeted, consumer-friendly information to support their financial literacy, along with a strong regulatory framework to protect their rights. Measures to address abuse by appointed decision-makers, including registration of Power of Attorney agreements are also needed.

It is clear that physical and psychological abuse and neglect of people with dementia by family members and carers also occurs, and that this often coexists with endemic issues within the family. We recommend that a capacity-building approach is needed to support carers of people with dementia, and practical support services are needed to prevent situations developing where the unmitigated impact of caring can lead to abuse and neglect.

Physical and sexual assault of residents in aged care facilities is an issue which has been highlighted in the media. We propose immediate measures including more extensive background checks for workers, and mandatory reporting of physical and sexual abuse in all aged care services. However, these immediate measures need to be accompanied by broader approaches to improve performance and quality in residential aged care and address situations where issues such as poor quality care, over-medication and physical

¹²³ Cited in Kaspiew R, Carson R, Rhoades H (February 2016). *Elder abuse: Understanding issues, frameworks, and responses*. Research report No 35, p 38.

restraint, and a lack of pain management impact on the human rights of people with dementia and other residents in aged care facilities. Publicly available data on quality and performance is needed to assist consumers in making informed choices when they are selecting a residential aged care facility for themselves or others, and to drive service competition and quality improvement.

Adequate and skilled staffing in residential aged care is critical to safety and quality, and we have noted our concern about the trend to reduced staffing ratios and reduction in qualified nursing staff in aged care, in a context of increasing privatisation. These trends must be urgently addressed. Appropriate education and training for aged care staff is also critical. Specific measures are also needed to address physical and chemical restraint in the aged care system.

We have noted that subtle forms of human rights abuses of people with dementia also occur reasonably commonly in the health care system. Some of these abuses are generally not intentional, but are a result of deficits in knowledge and awareness of appropriate care for people with dementia. We have proposed that medical practitioners should be made aware of their legal and ethical responsibilities in relation to the need to inform a person with dementia of their diagnosis; that measures be taken to improve dementia care in hospitals; and that measures be taken to improve end-of-life care for people with dementia.

Our submission makes a number of recommendations in relation to legislative and legal system reforms to prevent and address elder abuse. We propose that the role of Public Advocates should be expanded to include investigating and responding to elder abuse for all vulnerable older people. We refer to a number of potential changes that could be made to improve access by older people to courts and tribunals. We also argue for improved access to quality elder mediation services.

In relation to the legal response, we suggest that consideration should be given to amending state and territory criminal law to address specific criminal offences against older people, including expanding police powers in cases of suspected elder abuse. We also propose harmonisation of state and territory domestic violence legislation, to provide a consistent and comprehensive framework for use of protection orders including in cases of elder abuse.

We recommend that general practitioners and their multidisciplinary teams, and Aged Care Assessment Teams, should be mandated to report all forms of abuse and neglect of older people. We also argue for increased capacity of police and prosecutors to act on elder abuse, through improved education and training, improved policies and protocols, and greater collaboration with community agencies and other relevant parties. Responses by police and prosecutors should be grounded in a human rights approach which respects the rights of the vulnerable older person.

Improved services for victims of elder abuse are needed. There are currently major gaps in the provision of services such as helplines to report abuse, emergency housing services that meet the specific needs of victims of elder abuse, and free legal services. We further suggest that all jurisdictions should consider the appointment of Commissioners acting for senior members of their communities, to highlight issues such as elder abuse, and support and advocate for action.

Prosecution and sentencing practices also require improvement; and Australia should develop appropriate restorative justice approaches based on successful overseas models, as an option for responding to cases of elder abuse in Australia, where restorative justice is appropriate to the situation and meets the preferences of the victim. We note the importance of distinguishing between civil and criminal cases, and recommend that civil penalties should be considered as an appropriate response in less severe cases of elder abuse, where there is not a clear criminal intent: for example, minor breaches of Power of Attorney legislation. In cases of potential criminal conduct, criminal prosecutions should be pursued.

Finally, we note the importance of good consumer information, and improved community awareness about elder abuse. People with dementia and their carers need ready access to information about the legal rights of the person with dementia, and about mechanisms to ensure these rights are upheld. Information about elder abuse and services available for victims is also required. In addition, community awareness and education campaigns on elder abuse are needed, to promote prevention and early reporting of elder abuse.

We trust that the matters raised in this submission will be of assistance to the Australian Law Reform Commission in the development of recommendations to prevent and address elder abuse, particularly in relation to people with dementia.

ABOUT ALZHEIMER'S AUSTRALIA

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. Dementia is the second leading cause of death in Australia, and there is no cure.¹²⁴

Alzheimer's Australia represents and supports the more than 353,800 Australians living with dementia, and the more than one million family members and others involved in their care.¹²⁵ Our organisation advocates for the needs of people living with all types of dementia, and for their families and carers; and provides support services, education, and information. We are committed to achieving a dementia-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.

¹²⁴ Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2013*: Cat no. 3303.0

¹²⁵ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.