



**dementia  
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## **Proposed response to elder abuse in the ACT**

**A response from Dementia Australia**

**January 2020**

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## About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 459,000 Australians living with dementia and the estimated 1.6 million Australians involved in their care.

Dementia Australia works with people impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with individuals and communities means that we are an important advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.

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## Introduction

Dementia Australia welcomes the opportunity to provide a submission in response to the ACT Government's discussion paper on a proposed response to elder abuse in the ACT.

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning, including loss of memory, intellect, rationality, social skills and physical functioning.

Dementia is one of the largest health and social challenges facing Australia and the world. Dementia is not a natural part of ageing. It is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, the second leading cause of death in this country, and is predicted to become the leading cause of death within the next five years.<sup>1</sup>

In the ACT alone, over 6,000 people have a diagnosis of dementia. Without a significant medical breakthrough, there will be almost 19,000 people living with dementia in the ACT, by 2058.<sup>2</sup>

Dementia, and other forms of cognitive impairment, increases a person's vulnerability and risk of elder abuse.<sup>3</sup> In particular, the degenerative nature of dementia – which impacts on individual's cognitive skills and decision making – can make people with dementia more vulnerable to human rights abuses.

As their cognitive abilities decline, people with dementia can find it increasingly difficult to report their experiences of abuse and may not be in a position to provide evidence of abuse to the relevant authorities. In some cases, people with dementia may be considered an unreliable witness, even if they feel able to present their evidence. People with dementia may also be reluctant to report abuse because of fear of retaliation by the individual or concern for losing support – especially if the perpetrator is a family member or informal carer.<sup>4</sup> As dementia progresses, many individuals will come to depend on their families and carers for support across all aspects of their daily living and medical care. The thought of losing this support can therefore be particularly daunting. Detecting abuse amongst people with dementia can also be difficult, as many common signs of and reactions to abuse, such as withdrawal or increased dependence, may be difficult to distinguish from dementia symptoms.<sup>5</sup>

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<sup>1</sup> Australian Bureau of Statistics (2018) Causes of Death, Australia, 2017 (cat. No. 3303.0)

<sup>2</sup> Dementia Australia. Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra. 2018

<sup>3</sup> 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>

<sup>4</sup> Burgess AW, Phillips SL. Sexual abuse, trauma, and dementia in the elderly: a retrospective study of 284 cases. *Vict Offender*. 2006; 1 (2): 193 – 204

<sup>5</sup> Paris BE, Meier DE, Goldstein T, Weiss M, Fein ED. Elder abuse and neglect: how to recognize warning signs and intervene. *Geriatrics*. 1995; 50 (4): 47 – 51

With the prevalence of dementia rising exponentially, the risk of being impacted by elder abuse is an increasing concern. It is critical that effective safeguards are in place, across all states and territories, to protect people with dementia from elder abuse. Dementia Australia supports the ACT's efforts to raise community awareness and drive cultural change to address elder abuse. We particularly support the delivery of foundation training for public servants, which provides education on elder abuse and highlights the barriers that might inhibit older people from disclosing abuse.

To address the legal response to elder abuse in the ACT, Dementia Australia supports the two recommendations proposed in the discussion paper, which include:

- Increasing the legal response to incidents of elder abuse, so offences are captured in criminal law, and;
- To enable the ACT Civil and Tribunal service (ACAT) the authority to remedy cases of elder abuse.

In the implementation of these, we encourage the ACT Government to consider the following recommendations:

## Recommendations

**Recommendation 1:** *Future criminal legislation should take a collaborative approach, whereby the criminal, health, disability and aged care legal systems work together to implement a clear legal response to elder abuse.*

**Recommendation 2:** *Any legislative or systemic change regarding elder abuse must be clearly articulated to the community. Simple information, targeted towards people with a cognitive impairment, should be distributed through multiple channels including through residential aged care homes, local community groups and health settings.*

**Recommendation 3:** *Legislation should be accompanied by the appropriate level of supports for individuals impacted by abuse. Psychosocial supports, targeted towards people with dementia, should also be accessible for individuals who may require support to report and overcome their experiences.*

**Recommendation 4:** *ACAT employee education should include dementia awareness training to improve their capacity to investigate incidents of abuse involving a person living with dementia.*

**Recommendation 5:** *The ACT elder abuse community awareness initiatives should include information about ACAT services, and the importance of planning for the future. For example, how to prepare a Will, appointing a substitute decision maker and writing an advanced care plan for people with a cognitive impairment.*

**Recommendation 6:** *Additional supports and resources to be provided to carers and family members to help improve carer capacity and enable them to provide adequate and safe care for people with dementia.*

**Recommendation 7:** *Dementia-specific training, which incorporates identifying and supporting people impacted by elder abuse, should be made available for all front-line health*

and care staff throughout the ACT.

## Criminal law reform to reduce elder abuse in the ACT

Although a legislative response is not a standalone solution to combatting elder abuse, we appreciate that legislation is critical to deterring future instances of abuse, and responding to incidents appropriately when they arise.

### Joint sector approach to tackling elder abuse

People with dementia have reported incidents of elder abuse across a number of settings including in the health system, in residential aged care and disability settings for people with younger onset dementia. However, most commonly elder abuse is reported to take place in the individual's home, by a 'trusted' family member, close friend or carer.<sup>6</sup>

As abuse can occur in multiple places, and is addressed by different codes of law, the response to abuse can often be inconsistent. Regardless of where abuse occurs, it is critical that all reports of abuse are responded to appropriately and consistently. Taking a joined up legal approach to abuse will help to develop a single, consistent and more effective response to all cases of elder abuse. A joined up response will also help to ensure individuals do not fall through the cracks of multiple codes of law – which is often the experience of people with dementia who have experienced elder abuse.

*Recommendation 1: Future criminal legislation should take a collaborative approach, whereby the criminal, health, disability and aged care legal systems develop a joint legal response to elder abuse.*

### Communicating legislative change

*'Support and education is needed for the general community, people with dementia and those who might perpetrate elder abuse.'*

#### Former carer of a person living with dementia

People with a cognitive impairment can find it hard to comprehend and engage with complex topics such as changes to legislation and legal processes. However, in order for abuse to be detected, it is critical that people with dementia, their carers and families, understand what abuse is and where or how they report it. Providing clear information on elder abuse, and using multiple channels to communicate information is critical to increasing community awareness to vulnerable groups, such as people living with dementia. For example, information could be distributed through residential aged care homes, local community groups and through key health channels, such as GP's and pharmacists - who are often the key contact points for older people and their families.

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<sup>6</sup> 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>

**Recommendation 2:** Any legislative or systemic change regarding elder abuse, must be clearly articulated to the community. Simple information, targeted towards people with a cognitive impairment, should be distributed through multiple channels including through residential aged care homes, local community groups and health settings.

### **Provision of supports for individuals impacted by abuse**

Individuals with a cognitive impairment may find it challenging to recognise when abuse is occurring to them, or to report their experiences of abuse. One of the barriers to reporting abuse is the fear of retaliation, or fear of losing supports which individuals with dementia may rely on.<sup>7</sup> Some individuals may also find it difficult to comprehend their experience, or have difficulty communicating it to the relevant authorities – this can be due to a lack of decision making capacity or impaired language and communication abilities.<sup>8</sup> Crucially, then, it is important that supports are in place to assist people with a cognitive impairment to report their experiences. That includes supports to individuals who may be suspected to be victims of abuse – but may not recognise that they are being abused.

Social and psychological supports, led by professionals with dementia training, are best placed to help people with dementia understand and report their experiences, in addition to supporting them after the abuse has been resolved.

**Recommendation 3:** Legislation should be accompanied by the appropriate level of support for individuals impacted by abuse. Psychosocial supports, targeted towards people with dementia should also be accessible for individuals who may require support to report and overcome their experiences.

## **Strengthening the powers of the ACT Civil and Administrative Tribunal (ACAT)**

The best way to safeguard against abuse is to encourage people with dementia to plan ahead, by appointing a trusted attorney or substitute decision maker who can act honestly on your behalf, developing a Will and preparing an advanced care plan that records personal wishes.

According to the most recent ACAT annual report, in 2018-19, 49% of ‘guardianship and management of property’ cases, were regarding a person living with dementia.<sup>9</sup> With such a high prevalence of dementia-related cases, it is essential that ACAT staff have the ability to investigate and respond to complex cases of abuse, which may involve persons living with dementia.

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<sup>7</sup> Burgess AW, Phillips SL. ‘Sexual abuse, trauma, and dementia in the elderly: a retrospective study of 284 cases’. *Vict Offender* 2006 ; 1( 2 ): 193-204

<sup>8</sup> Hansberry MR, Chen E, Gorbien MJ. ‘Dementia and elder abuse’. *Clinics in geriatric medicine*. 2005 1;21(2): 315-32.

<sup>9</sup> ACT Civil and Administrative Tribunal. Annual Review 2017-2018. Accessed at: [https://www.acat.act.gov.au/data/assets/pdf\\_file/0005/1362947/ACAT-Annual-Review-2017-18.pdf](https://www.acat.act.gov.au/data/assets/pdf_file/0005/1362947/ACAT-Annual-Review-2017-18.pdf)

As such, Dementia Australia strongly recommends the inclusion of specific dementia education for all ACAT staff who are involved in preparing and hearing guardianship cases. Education should address the signs of abuse in people with a cognitive impairment, the challenges of reporting information and how to engage with people with dementia, such as through the use of supported decision making techniques.

**Recommendation 4:** ACAT employee education should include dementia awareness training to improve their capacity when investigating potential incidents of abuse towards a person living with dementia.

### **Encouraging the ACT to ‘plan for the future’**

Whilst evidence suggests that legally appointed substitute decision makers are most likely to commit certain forms of abuse – for example financial abuse - it should not be assumed that all, or even most, abuse of people with dementia occurs under Power of Attorney arrangements. Effective planning ahead remains the best way to safeguard against potential abuse.

Currently, the uptake of Enduring Power of Attorney and Guardianship arrangements is low, and abuse can occur in the absence of such arrangements. Therefore, properly monitored, appointed decision-maker arrangements can provide safeguards against financial and other forms of abuse, and their wider uptake should be promoted throughout the ACT. Encouraging ACT residents to engage in advanced care planning arrangements, and preparing for the future – by creating Wills and appointing substitute decision makers - helps to ensure that individuals personal views and preferences are recorded, and therefore harder to override if that individual loses their decision making capacity.

**Recommendation 5:** The ACT elder abuse community awareness initiatives should include information about ACAT services, and the importance of planning for the future. For example, how to prepare a Will, appointing a substitute decision maker and writing an advanced care plan for people with a cognitive impairment.

## **Addressing the systemic factors contributing to elder abuse**

Strategies to combat elder abuse need to address both the legal context of abuse, in addition to the social factors which may contribute to abuse. Whilst the following recommendations may not be in scope of this consultation – it is important that the ACT take into consideration two key contributing factors which may lead to cases of abuse:

- Carer capacity to provide safe and appropriate care for people with a cognitive impairment;
- Education of elder abuse and dementia for frontline staff.

### **Carer capacity**

Carers of people living with dementia take on a physically and emotionally demanding role – often without the support of paid carers or carer supports. In many cases, carers will have to juggle taking care of their loved one, with managing their own health concerns and needs.



Understandably, the impact of caring can take its toll, leading to carer burnout. In some cases, the increasing demands of caring for people with dementia, can also lead to carers experiencing abuse themselves<sup>10</sup> – as demonstrated by the following case study.

#### **Case study:**

*“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.”*

It is critical that capacity building supports are in place to provide carers with strategies and resources to cope with the demands of caring, as well as practical supports to help carers respond to behavioural symptoms of dementia. Such supports will help to mitigate the negative impacts of caring, and prevent situations developing where the demanding impacts of caring can lead to abuse and neglect.

Research to date suggests that structured interventions that combine information, education, skills training, and psychosocial therapies, led by qualified professionals, tend to show the most positive improvements in carer outcomes.<sup>11</sup> Carers also highly value access to respite care and peer support.<sup>12</sup>

**Recommendation 6:** *Additional supports and resources should be provided to carers and family members to help improve carer capacity, and enable them to provide adequate and safe care for people with dementia.*

#### **Dementia education and awareness**

The discussion paper notes the ACT’s plan to rollout foundation training on elder abuse for all ACT public servants. This initiative is a good opportunity to also educate ACT public servants and frontline workers about the specific complexities of dementia, and the relationship between elder abuse and people with a cognitive impairment. As set out in recommendation 4, education should address the signs of abuse in people with a cognitive impairment, the challenges with reporting information and how to engage with people with dementia, such as through the use of supported decision making techniques.

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<sup>10</sup> Hansberry MR, Chen E, Gorbien MJ. ‘Dementia and elder abuse’. *Clinics in geriatric medicine*. 2005 1;21(2): 315-32.

<sup>11</sup> Jackson D, Roberts G, Wu ML, Ford R, Doyle C. ‘A systematic review of the effect of telephone, internet or combined support for carers of people living with Alzheimer’s, vascular or mixed dementia in the community’. *Archives of gerontology and geriatrics*. 2016 1;66: 218-36.

<sup>12</sup> Smith R, Drennan V, Mackenzie A, Greenwood N. ‘The impact of befriending and peer support on family carers of people living with dementia: a mixed methods study’. *Archives of gerontology and geriatrics*. 2018 1;76: 188-95.



***Recommendation 7:** Dementia-specific training, which incorporates identifying and supporting people impacted by elder abuse, should be made available for all front-line health and care staff throughout the ACT.*

## **Conclusion**

Thank you for the opportunity to participate in this important consultation. Dementia Australia welcomes further discussions with the ACT Government as work progresses to ensure that the needs of people with dementia living in the ACT are appropriately considered in the development of any future legislation or initiatives to prevent and respond to elder abuse.