

**FIGHT ALZHEIMER'S**  
**SAVE AUSTRALIA**  
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**SUBMISSION TO THE**  
**AUSTRALIAN HUMAN RIGHTS**  
**COMMISSION**

**OPTIONAL PROTOCOL TO**  
**THE CONVENTION AGAINST**  
**TORTURE AND OTHER**  
**CRUEL, INHUMAN OR**  
**DEGRADING TREATMENT OR**  
**PUNISHMENT (OPCAT) IN**  
**AUSTRALIA- DISCUSSION**  
**PAPER**

**JULY 2017**

## EXECUTIVE SUMMARY

Alzheimer's Australia welcomes the opportunity to provide a submission to the Australian Human Rights Commissions' Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT) Discussion Paper (the Paper).

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. There are currently more than 410,000 Australians living with dementia. Dementia is the second leading cause of death in Australia and will have an increasing impact on the health system due to population ageing.<sup>1</sup>

We note the aims of OPCAT to prevent ill treatment in places of detention through the establishment of a preventive-based inspection mechanism, and, as such, have made recommendations relating to the monitoring mechanisms noted in the discussion paper, namely:

- the National Preventive Mechanism (NPM), the domestic Australian entity or network responsible for inspections; and
- the UN Sub-committee on the Prevention of Torture (SPT), the UN body of independent experts responsible for conducting visits to places of detention in jurisdictions that have ratified OPCAT and provide guidance to NPMs to assist in the performance of their duties.

Our submission draws on the needs of individuals with dementia in relation to OPCAT and provides comment on two distinct population cohorts: issues relating to people with dementia who are imprisoned; and issues relating to restraints used on people with dementia in the aged care system, particularly in residential aged care facilities. In relation to the latter, Alzheimer's Australia wishes to be clear that we do not define residential aged care services as 'places of detention'; however, the current reviews of aged care quality regulatory processes highlights the fact that there are still some instances of inappropriate restraints being used in a residential aged care setting. It is in this context that we offer our comments.

### **People with dementia who are imprisoned**

Although there is limited data, it is likely that the numbers of people with dementia who are imprisoned are increasing and that many cases are undiagnosed. This population includes both people who have aged in the prison system and older first-time offenders whose offending may be related to dementia, particularly frontotemporal dementia. We need to ensure that people with dementia in prison are properly diagnosed, supported and cared for and that appropriate arrangements are made on their release (if applicable).

Alzheimer's Australia makes the following recommendations for the NPM in relation to the imprisonment of people with dementia and cognitive impairment:

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<sup>1</sup> The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017). *Economic Cost of Dementia in Australia 2016-2056*.

- All detainees aged over 55, and any others who exhibit signs of cognitive impairment, receive appropriate cognitive assessment as part of a comprehensive health assessment.
- When a person with dementia has committed an offence which requires a custodial sentence, alternatives to prison be considered. Such alternatives should ensure appropriate care and support for the person with dementia, as well as ensuring community safety.
- Programs are needed to provide access to appropriate treatment and support for people with dementia who are detained in prison. Dementia-specific prison units should be implemented where possible, based on successful models in operation both in Australia and overseas. When this specialised support is not available, appropriate support and protections must be in place for people with dementia living in mainstream prisons.
- Prison staff need to be appropriately trained about dementia and the needs of people with dementia.
- People with dementia exiting the prison system need referral into appropriate accommodation and support programs and support in accessing these programs upon release.

### **People with dementia in residential aged care facilities**

Alzheimer's Australia recognises that the aged care system does not clearly fall within the definition and scope of OPCAT, nor do we posit that residential aged care services be classified as 'places of detention'. However, as noted by stakeholders at the HRC workshops, some concerns have been raised by consumers about the use of restraint in this setting and that the underpinning principles of human rights equally apply in this environment. There is evidence that both physical and chemical restraints are used to respond to the behavioural and psychological symptoms of dementia, despite clinical evidence suggesting that psychosocial responses should be the first line approach. Behavioural and psychological symptoms are often an indication of unmet needs, such as untreated pain, hunger or thirst, or boredom.

Alzheimer's Australia recommends that the NPM takes note of the comments offered in the context of residential aged care and that the aged care sector, in return, has the potential to benefit from learnings of OPCAT's implementation across other areas of indefinite detention. Alzheimer's Australia therefore highlights the following issues and suggestions in relation to restraint of people with dementia in the aged care system for the NPM's consideration:

- Staff in residential and community aged care need to be educated and trained 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 increase the likelihood of the person with dementia experiencing behavioural and psychological symptoms.
- Consumers and carers of people with dementia need information about best practice in dementia care, and about the legal rights of the person with dementia, including in relation to physical and chemical restraint.

- Quality standards and assessment processes for aged care services should aim to negate inappropriate use of physical and chemical restraint. All residential aged care facilities should incorporate benchmarking and audits 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. This consent would include the use of appropriate substitute decision makers. The Quality Indicator program in residential aged care should be expanded to include public reporting of the use of antipsychotic medications.
- The Aged Care Complaints Commissioner should escalate complaints which relate to use of restraint or assault to a manager within set timeframes to ensure the safety and protection of human rights of residents.

## BACKGROUND: DEMENTIA IN AUSTRALIA

Dementia is a complex chronic condition caused by one or more of a large number of illnesses affecting the brain. It is a terminal condition that robs people of their abilities and memories.<sup>2</sup> It is cloaked in stigma and misunderstanding,<sup>3</sup> isolates people with dementia and their carers from social networks,<sup>4</sup> and carries significant social and economic consequences.<sup>5</sup>

The care and support of people with dementia is one of the largest healthcare challenges facing Australia. There are more than 410,000 Australians living with dementia. By 2025, the number of people with dementia is expected to increase to more than 530,000. Without a medical breakthrough, the number of people with dementia is expected to be 1.1 million by 2056.<sup>6</sup> Dementia is the second leading cause of death of Australians<sup>2</sup> contributing to 5.4% of all deaths in males and 10.6% of all deaths in females each year.

Dementia has an enormous impact on the health and aged care systems, with the cost of dementia to these sectors calculated to be at least \$4.9 billion per annum<sup>7</sup>. Currently around 237 join the population of people living with dementia each day. The number of new cases of dementia will increase to 318 people per day by 2025 and over 650 people by 2056. Dementia also has a profound social impact. People with dementia experience stigma and social isolation<sup>8</sup>, and family carers often find it difficult to balance work, life and caring responsibilities<sup>9</sup>.

Many of us will be diagnosed with dementia over the years ahead, or will have loved ones faced with the diagnosis. As our population ages, and as increasing numbers of Australians 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 people who reach the age of 65 without having developed dementia, the risk of developing dementia in their remaining lifespan is 20% for women and 17% for men<sup>10</sup>. The higher lifetime risk for women is mainly due to women's longer life expectancy.

Estimates by the Australian Institute of Health and Welfare (AIHW) indicate that 30% of people with dementia lived in residential aged care in 2011, while 70% lived in the community.<sup>11</sup> Provision of dementia specialist and comprehensive community based support, and appropriate, high quality residential care are therefore critical to meeting the needs of people living with dementia.

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<sup>2</sup> Mitchell, S. et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, 361, 1529-38.

<sup>3</sup> George, D. (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet*, 376, 586-87.

<sup>4</sup> Blay, S., & Peluso, E. (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2), 163-71.

<sup>5</sup> Access Economics (2003). *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*. Report for Alzheimer's Australia. Available: [www.fightdementia.org.au/research-publications/access-economics-reports.aspx](http://www.fightdementia.org.au/research-publications/access-economics-reports.aspx)

<sup>6</sup> The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017). *Economic Cost of Dementia in Australia 2016-2056*.

<sup>7</sup> Australian Institute of Health and Welfare (2012). *Dementia in Australia*.

<sup>8</sup> Alzheimer's Australia (2014). *Living with Dementia in the Community: Challenges and Opportunities*

<sup>9</sup> 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.

<sup>10</sup> 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](http://www.alz.org/downloads/facts_figures_2013.pdf)

<sup>11</sup> Australian Institute of Health and Welfare (2012). *Dementia in Australia*.

## PEOPLE WITH DEMENTIA IN THE CRIMINAL JUSTICE SYSTEM

People with dementia in Australia's criminal justice system will very clearly fall within the OPCAT's mandate, in both the setting and the treatment of this cohort.

The ageing population in Australian prisons has grown at a faster rate than the general population, with about 12% of the prison population now aged over 65. There is likely to be a growth in the number of people with dementia in prisons.<sup>12</sup> There were nearly 30,000 people in Australian prisons in 2012, and given rates of dementia in the general community, along with high risk factors and premature ageing of prisoners, Alzheimer's Australia estimates that dementia potentially affects at least 5% of prisoners over the age of 55.<sup>13</sup> Other estimates put the prevalence of dementia amongst prisoners as a whole at anywhere from 1% to 30%, and it is highly likely that dementia in prisons is underdiagnosed.<sup>14</sup>

### ISSUES FOR CONSIDERATION

Amongst this population are long-term offenders, including prisoners who have aged in the prison system and developed dementia; older first-time offenders, often people with fronto-temporal dementia who have disinhibition, loss of empathy, compulsive behaviours, and poor impulse control; and people with younger onset dementia.<sup>15</sup> Health assessments for older first-time offenders in particular should include assessments for cognitive impairment.<sup>16</sup>

People with dementia in prison, like people with dementia in other settings, may struggle with a gradual loss of memory, functioning, co-ordination, health, and retaining their sense of identity.<sup>17</sup> Research indicates that more than one in five prisoners aged over 55 need help with daily tasks. They often have multiple chronic diseases, and rates of depression are high. The physical environment – stairs, bunks, long walks to cafeterias, etc. – are often unsuitable for older prisoners, and prison staff may not be not trained and/or willing to provide care and support to older prisoners with higher needs.<sup>18</sup>

While specialist units for prisoners with dementia are costly, there are some advantages for providing specialised support. Units such as the Kevin Walker Unit for older prisoners in Long Bay can protect these prisoners from victimisation and facilitate access to specialist resources and care, as well as assist with eventual reintegration into society.<sup>19</sup> Overseas, specific geriatric and special needs facilities have been designated within prisons such as Laurel Highlands in Central Pennsylvania and Singen, Germany. These facilities have demonstrated benefits in reducing victimisation of prisoners with dementia and in containing costs by concentrating specialist staff in one unit.<sup>20</sup>

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<sup>12</sup> Alzheimer's Australia NSW (2014). *Discussion Paper 9: Dementia in Prisons*, p.5.

<sup>13</sup> Alzheimer's Australia NSW (2014). *Discussion Paper 9: Dementia in Prisons*, p.6.

<sup>14</sup> Cations M, Withall A, Ninaus N, Brown J, Butler T, Schofield P, Brodaty H; University of NSW (2016). *Dementia and the Ageing Prisoner*. Webinar presentation.

<sup>15</sup> Cations M, Withall A, Ninaus N, Brown J, Butler T, Schofield P, Brodaty H; University of NSW (2016). *Dementia and the Ageing Prisoner*. Webinar presentation.

<sup>16</sup> Alzheimer's Australia NSW (2014). *Discussion Paper 9: Dementia in Prisons*, p.10.

<sup>17</sup> Alzheimer's Australia NSW (2014). *Discussion Paper 9: Dementia in Prisons*, p.5.

<sup>18</sup> Cations M, Withall A, Ninaus N, Brown J, Butler T, Schofield P, Brodaty H; University of NSW (2016). *Dementia and the Ageing Prisoner*. Webinar presentation.

<sup>19</sup> Alzheimer's Australia NSW (2014). *Discussion Paper 9: Dementia in Prisons*, p.15; Cations M, Withall A, Ninaus N, Brown J, Butler T, Schofield P, Brodaty H; University of NSW (2016). *Dementia and the Ageing Prisoner*. Webinar presentation.

<sup>20</sup> Alzheimer's Australia NSW (2014). *Discussion Paper 9: Dementia in Prisons*, p.11.

Mainstreaming, if it includes amending facilities, training staff and educating other prisoners about dementia, also has potential to be beneficial. A positive example from the United States of America is the Special Needs Program for Inmate-Patients with Dementia – California Men’s Colony. In this model, staff receive training, and cognitively healthy offenders look after those with dementia, with an underlying philosophy that “socially inappropriate behaviour in dementia can be avoided and/or reduced by changes in both physical and social environments and activities.”<sup>21</sup>

The needs of prisoners with dementia from special needs groups, including the disproportionately high numbers of Aboriginal and Torres Strait Islander prisoners, as well as female prisoners, and people with younger onset dementia, require special consideration.<sup>22</sup>

Alzheimer’s Australia believes that alternatives to prison should be considered, taking into account the needs of the person with dementia, and the need to manage risks to the community.

If people with dementia are detained in prison, however, measures need to be in place to ensure they receive appropriate cognitive assessment, and access to appropriate treatment and support. Staff need to be trained, and other prisoners educated, about dementia and the needs of people with dementia; and people with dementia exiting the prison system need to be referred into appropriate accommodation and support programs.

The NSW Law Reform Commission has completed a review of the criminal law and procedure applying to people with cognitive and mental health impairments in the NSW criminal justice system, including the issue of criminal responsibility and consequences.<sup>23</sup> The report makes extensive recommendations which largely relate to amending NSW legislation and practice; however, the work completed in NSW is likely to provide a good model for reforms across other jurisdictions and nationally.

## **RECOMMENDATIONS FOR CONSIDERATION**

While we continue to have people with dementia incarcerated in prisons, we need to ensure that they are properly diagnosed, supported and cared for in prison and that appropriate arrangements are made on their release. Alzheimer’s Australia makes the following recommendations for the NPM to consider in relation to imprisonment of people with cognitive impairment:

- All detainees aged over 55, and any others who exhibit signs of cognitive impairment, should receive appropriate cognitive assessment as part of a comprehensive health assessment.
- When a person with dementia has committed an offence which requires a custodial sentence, alternatives to prison should be considered. Such alternatives should

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<sup>21</sup> Cations M, Withall A, Ninaus N, Brown J, Butler T, Schofield P, Brodaty H; University of NSW (2016). *Dementia and the Ageing Prisoner*. Webinar presentation.

<sup>22</sup> Alzheimer’s Australia NSW (2014). *Discussion Paper 9: Dementia in Prisons*, p.9.

<sup>23</sup> New South Wales Law Reform Commission (2013). *People with cognitive and mental health impairments in the criminal justice system: Criminal responsibility and consequences*. Report 138.

[http://www.lawreform.justice.nsw.gov.au/Pages/lrc/lrc\\_completed\\_projects/lrc\\_peoplewithcognitiveandmentalhealthimpairmentsinthecriminaljusticesystem/lrc\\_peoplewithcognitiveandmentalhealthimpairmentsinthecriminaljusticesystem.aspx](http://www.lawreform.justice.nsw.gov.au/Pages/lrc/lrc_completed_projects/lrc_peoplewithcognitiveandmentalhealthimpairmentsinthecriminaljusticesystem/lrc_peoplewithcognitiveandmentalhealthimpairmentsinthecriminaljusticesystem.aspx)

ensure appropriate care and support for the person with dementia, as well as ensuring community safety.

- For people with dementia who are detained in prison, programs are needed to provide access to appropriate treatment and support. Dementia-specific prison units should be implemented where possible, based on successful models in operation both in Australia and overseas. When this specialised support is not available appropriate support and protections must be in place for people with dementia living in main-stream prisons.
- Prison staff need to be appropriately trained about dementia and the needs of the person with dementia.
- People with dementia exiting the prison system need referral into appropriate accommodation and support programs and support in accessing these programs upon release.

## **PEOPLE WITH DEMENTIA AND RESIDENTIAL AGED CARE FACILITIES**

As referenced in our introductory comments, Alzheimer's Australia recognises that the aged care system does not clearly fall within the definition and scope of OPCAT; nor do we posit that residential aged care facilities be defined as 'places of detention'. However, the use of restraints in this setting is often raised by consumers as a concern and the importance of this issue is reflected in current federal reviews, with both an independent ministerial review<sup>24</sup> and a Senate inquiry underway.<sup>25</sup>

As such, Alzheimer's Australia recommends that the NPM takes note of the comments offered in the context of residential aged care and that the aged care sector, in return, has the potential to benefit from learnings of OPCAT's implementation across other areas of indefinite detention.

### **ISSUES FOR CONSIDERATION**

Restraint of people in aged care has been defined as follows:

"Stopping a resident without their consent from doing what they appear to want to do, or are doing, is restraint. Any device that may stop a resident from getting out of a bed or a chair and/or stops their free movements is restraint. Restraint is any aversive practice, device, or action that interferes with any person's ability to make a decision or which restricts their free movement."<sup>26</sup>

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<sup>24</sup> Review of National Aged Care Quality Regulatory Processes 2017.

<https://agedcare.health.gov.au/quality/review-of-national-aged-care-quality-regulatory-processes>

<sup>25</sup> Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised.

[http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/AgedCareQuality](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/AgedCareQuality)

<sup>26</sup> 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](https://www.dss.gov.au/sites/default/files/documents/09_2014/residential_aged_care_internals_fa3-web.pdf)

The inappropriate use of physical and chemical restraint, particularly in residential aged care, but also in community 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.<sup>27</sup>

The presence of physical restraint in aged care facilities varies, with evidence suggesting 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 legal representative should occur wherever possible prior to restraint being applied<sup>28</sup>.

It is estimated that about 50% of people in residential aged care and about 80% of people 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 indicating 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 carer/substitute decision-maker.<sup>29</sup>

The legal framework in relation to regulating and monitoring the use of restraint is under-developed in Australia.<sup>30</sup> 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.

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

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<sup>27</sup> Peisah C, Skladzien E (2014), Alzheimer's Australia Paper 38: *The use of restraints and psychotropic medications in people with dementia*.

<sup>28</sup> Peisah C, Skladzien E (2014), Alzheimer's Australia Paper 38: *The use of restraints and psychotropic medications in people with dementia*, p 7.

<sup>29</sup> Peisah C, Skladzien E (2014), Alzheimer's Australia Paper 38: *The use of restraints and psychotropic medications in people with dementia*, p 8.

<sup>30</sup> The discussion on the legal rights of the person with dementia in relation to restraint is drawn from Alzheimer's Australia (2016). *Dementia and your legal rights*. <https://fightdementia.org.au/sites/default/files/NATIONAL/documents/Dementia-and-your-legal-rights.pdf>

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. Sometimes, 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.

Similarly, aged care facilities require consent from the individual, or the legally appointed or nominated person or agency, to make accommodation and restraint decisions, such as placing a person in a locked ward. 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.

The use of medication to treat behavioural disturbance should be consented to either by the individual, if they still have capacity to make healthcare decisions, or by the substitute healthcare decision-maker, except in an emergency situation.

Despite these legal protections, anecdotal evidence from Alzheimer's Australia consumers shows 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. 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 Australian 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.”<sup>31</sup>

To address the issue of inappropriate restraint of people with dementia in the aged care system, staff need 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 people with dementia.

In addition, quality standards and assessment processes for aged care services should aim to end inappropriate use of physical and chemical restraint. All residential aged care facilities should incorporate benchmarking and audits on the use of restraints and

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<sup>31</sup> 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](https://www.dss.gov.au/sites/default/files/documents/09_2014/residential_aged_care_internals_fa3-web.pdf)

antipsychotic medications to ensure that these are used appropriately, with consent and only when all other options have been exhausted.<sup>32</sup> Reporting of the use of physical restraint has been included in the Voluntary Quality Indicator Program in Residential Aged Care, but this should be extended to also include the use of antipsychotic medications as a form of restraint.

It is also important that the Aged Care Complaints Commissioner is informed so that they are able to escalate complaints which relate to use of restraint or assault to a manager within set timeframes to ensure the safety of residents.<sup>33</sup>

Consumers have also raised concerns regarding the placement of people with dementia in secure units, often without due process, including a lack of alternatives and lack of informed consent. Placement in secure units generally occurs in response to behaviours being exhibited by the person, such as agitation, aggression, or wandering behaviours. As noted previously, in many cases such behaviours may indicate that the needs of the person are not being met – for example, they may be in pain, hungry, thirsty, or bored; or they may simply feel a need to move about, which in itself can be a positive in terms of maintaining the person's physical health and fitness. The needs of the person should be explored and alternative approaches to restraint should be exhausted, to ensure placement in secure units is undertaken only as a last resort.

In some cases, placement in a secure unit may be required for duty of care reasons and may be in the best interests of the person, and indeed may even reflect their will and preferences if they were in a position to express these. Where placement in secure units is unavoidable, informed consent should be obtained, and measures should be taken to ensure the welfare of the person who is being detained. For example, confining a person to a secure area is likely to be more acceptable where the area is of sufficient size, comfort, and quality to make it a relatively pleasant place to be – for example, a wing of a building including some outside space, rather than simply a solitary locked ward. Safe walking areas to accommodate wandering can also be extremely beneficial.<sup>34</sup> Further consideration is required of how to protect the rights and ensure the welfare of people with dementia who are placed in secure units.

Grafton Aged Care Home in NSW provides a positive model of good practice in addressing residents' needs and protecting their rights.

### ***Grafton Aged Care Home (GACH)***

GACH is an aged care home constantly improving service delivery through innovative policies procedures and staff education programs. Following participating in the Alzheimer's Australia NSW project *Moving into Care*, GACH developed a strong focus on improving care for their residents with a diagnosis of dementia.

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<sup>32</sup> Alzheimer's Australia (2013), Paper 37: *Quality of residential aged care: The consumer perspective* p. 6.

<sup>33</sup> Alzheimer's Australia (2013), Paper 37: *Quality of residential aged care: The consumer perspective* p. 6.

<sup>34</sup> 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](https://www.dss.gov.au/sites/default/files/documents/09_2014/residential_aged_care_internals_fa3-web.pdf)

GACH ran a workshop in June 2015 to educate members of staff and equip them as leaders within the areas they work. The 6 hour workshop focuses on understanding dementia, the needs and wants of those with dementia, and how to best apply person centred care practices.

As a result, GACH has made the decision to maintain an 'open doors' policy in their secure dementia unit which led to the development and implementation of the afternoon café and friendship morning. The afternoon café provides an opportunity for residents to participate in meaningful activities while assisting staff workloads. Meaningful activities are provided in the café depending on the residents present. Consequently, staff members have witnessed a reduction in wandering and an increased appetite in residents when involved in the preparation of food.

Following the success of the afternoon café, the 'Friendship Morning' initiative was implemented. The 'Friendship Morning' provides 4 hour one-on-one meaningful activities for residents to participate in, run by recreational activities officers and assistants in nursing with a sound knowledge of dementia care. GACH has also shifted from using plastic cups and plates to china crockery for tea, coffee, and meals.

GACH also makes use of STAR charts as a tool designed to provide staff with important information about a resident's history in order to help staff better engage with the resident. As part of the 'Resident of the Day' initiative, staff regularly review and update STAR charts, which has proved to be helpful for staff and of benefit to the residents.

## **RECOMMENDATIONS FOR THE NPM'S CONSIDERATION**

In relation to the restraint of people with dementia in the aged care system, this submission has outlined evidence that people with dementia can be inappropriately restrained, both physically and through use of psychotropic medication. Often this restraint is in response to the exhibition of severe behavioural and psychological symptoms of dementia, which can be more effectively managed through other models of care.

Alzheimer's Australia makes the following recommendations for the NPM to consider as part of the approach to the OPCAT in relation to restraint of people with dementia in the aged care system:

- Staff in residential and community aged care need to be educated and trained 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 increase the likelihood of the person with dementia experiencing behavioural and psychological symptoms.
- Consumers and carers of people with dementia need information about best practice in dementia care, and about the legal rights of the person with dementia, including in relation to physical and chemical restraint.
- Quality standards and 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. This consent would include the use of appropriate substitute decision makers. The Quality Indicator program in residential aged care should be expanded to include public reporting of the use of antipsychotic medications

- The aged care commission should escalate complaints which relate to use of restraint or assault to a manager within set timeframes to ensure the safety of residents.

## 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, human rights issues in relation to people with dementia who are imprisoned, and those who are restrained within the aged care system, need to be considered and addressed.

We trust that the matters raised in this submission will be of assistance to the Australian Human Rights Commission in the implementation of the OPCAT and its ratification.

## 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.

Alzheimer's Australia represents and supports the more than 410,000 Australians living with dementia, and the more than one million family members and others involved in their care. 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.

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

Our organisation advocates on the basis of evidence-based policy, promotes awareness of dementia, delivers national projects and programs under contract from the Commonwealth, and provides research grants to emerging researchers. We are committed to a strong consumer focus and have a number of consumer advisory mechanisms, which actively seek and represent the voice of people with dementia themselves, as well as carers. We participate on many Ministerial and Departmental Committees, and contribute to consultation forums and advisory groups. We are also involved with key groups progressing aged care reforms including the Aged Care Sector Committee and the Aged Care Quality Advisory Council.

We are committed to achieving a dementia-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.