



Discussion Paper #9
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DEMENTIA IN PRISON

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

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EXECUTIVE SUMMARY

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

This paper examines literature, both local and international, and reports on the status quo for people living with dementia in prison. It addresses the needs of this group and the risk factors for dementia for people living in prison. The paper acknowledges efforts being made internationally and in Australian and NSW settings to meet the needs of prisoners with dementia and advocate for better outcomes for this vulnerable group. Just as prisoners have a right to good health care for a range of health concerns such as diabetes, hypertension and asthma, so too do those prisoners with a diagnosis of dementia. To that end Alzheimer's Australia NSW has made the following recommendations to enhance and enable optimum care for prisoners with dementia.

That corrective service authorities across Australia:

- Adopt the models of best practice at Long Bay gaol highlighted in this paper more widely across prison systems in Australia
- Corrective service authorities ensure assessment for cognitive impairment is included in health checks for prisoners aged over 50 and ensure prisoners diagnosed with dementia are given adequate support to contribute to their future care plan while they still have capacity
- Corrective service authorities provide dementia-specific staff training across all aspects of the prison system, including health professionals and corrective officers, so as to increase knowledge of symptoms of dementia and appropriate dementia care in the prison environment
- Corrective service authorities across Australia make changes to the physical, social and structural environment of prison settings, where there are significant numbers of prisoners with dementia, to reduce the behaviours of dementia and accommodate the needs of ageing prisoners with dementia
- Corrective service authorities across Australia collaborate with a cross section of allied health, aged care and specialist services to provide dementia-specific advice, training and support to meet the complex needs of inmates with dementia
- Corrective service authorities across Australia develop referral pathways to the Alzheimer's Australia Younger Onset Dementia Key Worker Program to support parolees in accessing the support they need to live independently
- Corrective service authorities implement a risk reduction program, such as Alzheimer's Australia's *Your Brain Matters*, to delay the onset of dementia in all prison settings
- The NSW Government accept and enact the recommendations of the 2013 Law Reform Commission report *People with Cognitive and Mental Health Impairments in the Criminal Justice System: criminal responsibility and consequences*

BACKGROUND & PURPOSE

No problems – old and quiet¹

The ageing population in Australia’s prisons is rising at a rate faster than the general ageing population of Australia². Between 2000-2012 the number of older prisoners in Australia grew by approximately 95% with the over 65 age group growing by 166%. The ageing prison population constitutes approximately 12% of the total prison population³.

Longer incarceration periods, mandatory prison sentences and an increase in the number of older first offenders contribute to the ageing prison population. Furthermore a disproportionate percentage of older prisoners are sex offenders who are not always candidates for alternative accommodation such as transfer to residential aged care facilities.

Table 1. Prisoners in Australia by age and year from 2000-2012

| Age (yrs) | Australian prisoners in 2000 | Australian prisoners in 2012 | Increase |
|-----------|------------------------------|------------------------------|------------|
| 50-54 | 848 | 1473 | 627 (74%) |
| 55-59 | 459 | 909 | 447 (97%) |
| 60-64 | 281 | 568 | 289 (102%) |
| 65+ | 218 | 579 | 363 (166%) |
| Total | 1806 | 3529 | 1726 (95%) |

Source: Prisoners in Australia (ABS cat.no. 4517, 2000 and 2012)

Alongside Australia’s ageing population in and out of the prison environment is the increasing number of people with dementia in Australia. 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. It is a fatal disease. Currently there are 332,000⁴ Australians living with dementia and 112,000 of those live in NSW. Without a cure the number of Australians with dementia is expected to increase to 900,000 by 2050⁵.

A person with dementia in prison will, as they

would in the community, struggle with gradual loss of: memory; functioning; coordination; health; and retaining their sense of identity. Behavioural and psychological symptoms of dementia such as agitation, aggression, paranoia, delusions, self-neglect and incontinence can commonly occur at some point in the course of dementia and provide challenges for their carers. In older age groups it is not uncommon for individuals to have additional physical and mental health co-morbidities which can further complicate their treatment.

In recent times significant developments have taken place to identify and treat dementia. Biomarkers and psychosocial factors have been identified, programs to provide care and support to people living with dementia and their families have been developed, and a greater understanding of the impact of dementia is growing due to health promotion and community awareness campaigns. However, there is little research that examines the increasing numbers of ageing prisoners in custody alongside the consequent projected rise of people with dementia living in the prison environment. Maschi et al (2012)⁶ assert this special subgroup of older adults is the most vulnerable and neglected in our efforts to improve quality of life and care for people with dementia.

Purpose

The purpose of this discussion paper is to raise awareness of the experiences and needs of people with dementia in prison. It will describe the increasing ageing prison population and the high risk factors for dementia that exist for prisoners. The paper will acknowledge efforts being made on international, Australian and NSW specific terms to meet the needs of prisoners with dementia and advocate for better outcomes for this vulnerable group of often forgotten people. The scope of the paper’s focus will be confined to prisoners living within the prison environment and will not explore options that could include ageing prisoners residing in the community.

LIVING WITH DEMENTIA IN PRISON

What is an 'old' prisoner?

While definitions for an 'old' prisoner are variable, overall many researchers have defined older prisoners to be those over the age of 50. This definition is based on findings that there is a 10-year differential between the overall health of prisoners and that of the general population which is reflected in prisoners' premature experience of ageing disease and disability^{7,8}.

On a global scale the number of people with dementia in prison has gone largely unrecorded until very recently. Yet if we combine rates of dementia in the community with the theory of accelerated ageing in prison it would seem that there is potential for dementia to affect at least five percent of prisoners over the age of 55⁹.

Prison Population in Australia and NSW

At 30 June 2012 there were 29,383 prisoners in Australia. NSW had the highest number of all the states and territories at 9,645¹⁰. The extensive reach of Justice Health & Forensic Mental Health Network locations across the state is depicted in Figure 1.

Life for people with dementia in prison

The structured, routine operation of day-to-day life in prison can mean a person with dementia will often go unnoticed for a considerable period as there is little requirement to make decisions, act independently or coordinate their daily lives. A prisoner with dementia is not always noticed until their behaviours of dementia reduce their capacity to cope with every day activities. Consequently a late diagnosis denies them the opportunity for appropriate care and treatment to relieve the symptoms of dementia early in its progression.

The sad thing is that there are many prisoners with mild dementia who go unnoticed in the prison system. They develop coping mechanisms which provide the correct answers to people exposed to them for a short time. It usually isn't until they can no longer cope that we realize the problem exists¹¹.

As the symptoms of dementia increase, a person with dementia in prison will have difficulty following rules, socialising appropriately and performing activities of daily living for themselves such as eating, dressing and bathing. If the person with dementia has not been diagnosed they can run the risk of reprimand or punishment due to lack of understanding of their behaviours which in turn can compromise their physical and mental wellbeing.

Due to the often frightening culture that exists in a prison setting people with dementia are also vulnerable to bullying and victimisation by other prisoners or alternatively they may become aggressive to other staff and prisoners¹².

The issue of safety, for the prisoners with dementia, the staff and other prisoners, is a significant consideration when addressing the needs of the prisoner with dementia.

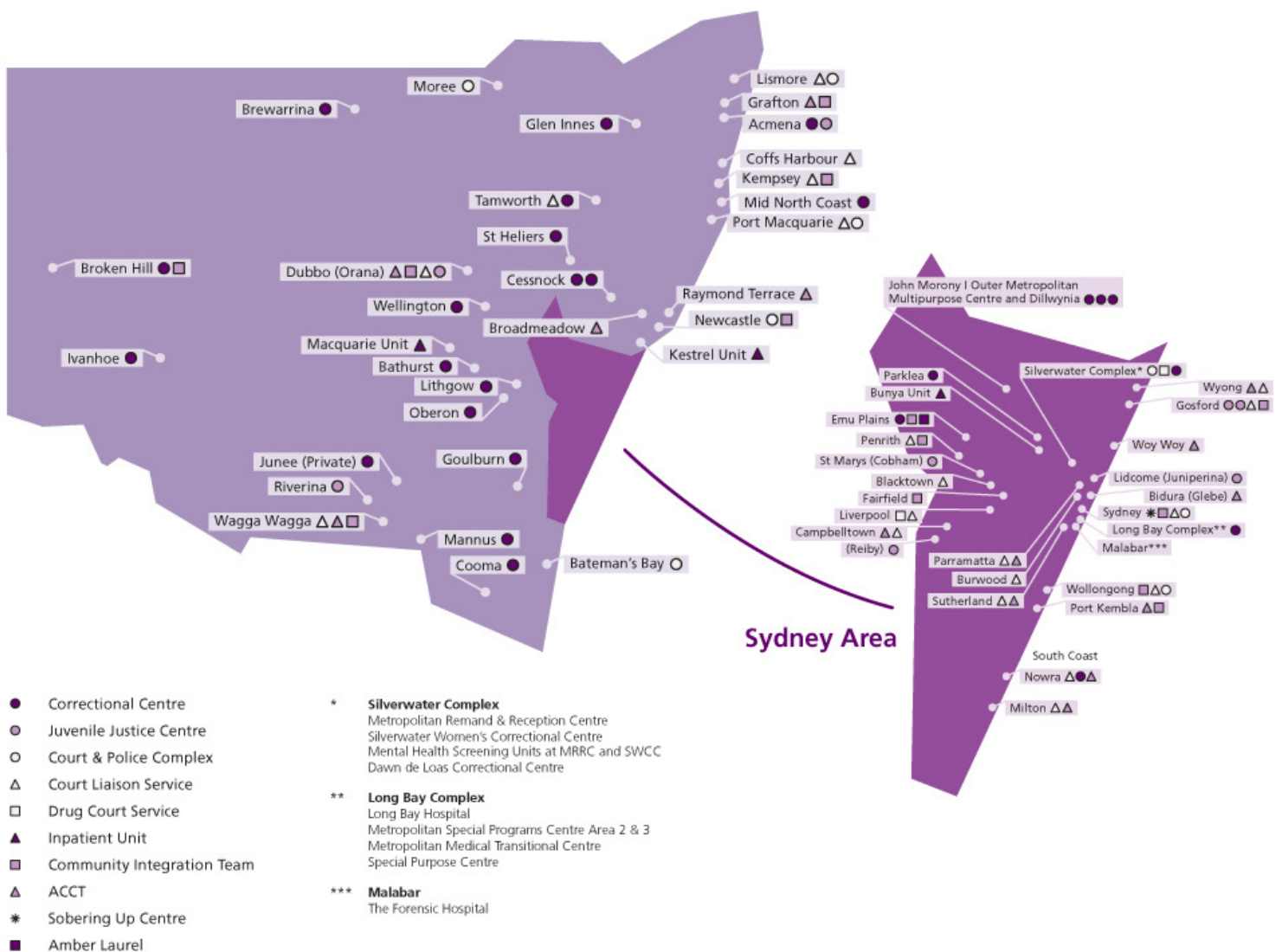
While some correction facilities would like to transfer many older prisoners with dementia to residential aged care facilities, the facilities are often unwilling to take them. This can be due to factors such as the serious convictions of some older prisoners, concerns for residents or in deference to the rights of victims and their families.

Risk factors for dementia in prison

The risk of prisoners developing dementia is not solely because of their age. They are also at risk due to other factors before and after incarceration.

Preceding their entry to the prison system many prisoners have a history of dementia risk factors

Figure 1. Justice Health & Forensic Mental Health Network locations



Source: Justice Health & Forensic Mental Health Network 2012/13 Year in Review

which can include post-traumatic stress disorder, drug and alcohol abuse, low socio-economic status, low levels of education and inadequate access to health care.

Once living within the prison environment other risk factors can hasten the development of dementia such as:

- Depression
- Traumatic Brain Injury (TBI)
- Smoking
- HIV AIDs
- Lack of intellectual stimulation
- Lack of social stimulation

It is interesting to note the high prevalence rate of some health conditions in the NSW custodial population compared to the Australian population. See Table 2.

Table 2. Comparison of Prevalence for Health Conditions

| Health Condition | NSW Custodial population | | Australian Population | |
|--|--------------------------|----------|-----------------------|---------|
| | Male % | Female % | Male% | Female% |
| Current tobacco smoker | 75% | 80% | 18% | 15% |
| Hepatitis B | 28% | 34% | Less than 1% | |
| Hepatitis C | 28% | 45% | 1% | |
| Head injury resulting in consciousness | 52% | 35% | 2% | |
| Depression | 33% | 51% | 5% | 7% |
| Attempted suicide | 19% | 27% | 2% | 4% |
| Obesity | 55% | 58% | 70% | 56% |
| Heart Disease | 19% | 24% | 5% | 4% |
| Asthma | 25% | 40% | 10% | 11% |

Source: Justice Health & Forensic Mental Health Network 2012/13 Year in Review¹³

Moreover, the psychological strain of prison life, fear of victimisation and separation from family can also exacerbate the ageing process and the risk of dementia¹⁴.

The complex interaction of physical, emotional and environmental risk factors associated with dementia requires an equally complex and specific response. Extra support and resources are required throughout the continuum of care for prisoners with dementia, as would be given to those with diagnoses such as diabetes, hypertension or Parkinson’s disease.

Indeed implementing a health and wellbeing program, such as Alzheimer’s Australia’s *Your Brain Matters*, to reduce the risk of dementia for all prisoners, would assist in tackling the onset of dementia across the board.

SPECIAL NEEDS GROUPS

Aboriginal and Torres Strait Islander prison population

Dementia affects Aboriginal and Torres Strait Islanders at an earlier age than the general population. They are three times more likely to develop dementia, particularly in the 45-69 age group¹⁵.

Aboriginal prisoners also have a higher risk of dementia when considering lifestyle factors such as traumatic brain injury, low socio-economic status, drug and alcohol abuse and low levels of education.

Aboriginal and Torres Strait Islander prisoners make up a high proportion of the prison population. In 2012 Aboriginal and Torres Strait Islander prisoners comprised just over a quarter (27% or 7982) of the total prisoner population and yet comprise only two and a half percent of the total Australian population¹⁶. The imprisonment rate for Aboriginal and Torres Strait Islander prisoners is 15 times higher than non-Indigenous prisoners¹⁷. NSW has the highest number (2025) of Aboriginal prisoners in Australia while the Northern Territory has the highest percentage (83%) of Aboriginal prisoners per total population of prisoners in the Territory¹⁸. Aboriginal prisoners are mostly young offenders but their projected lifespan is increasing and therefore the potential for an older cohort to emerge over time is stronger alongside the risk for dementia.

Aboriginal people in the community are considered to be ageing from age 50. Therefore it is reasonable to expect that Aboriginal people living in the prison environment would be considered to be ageing at a younger age than the adjusted 'old' age of 50 years for mainstream prisoners, and so, would be at greater risk of developing the symptoms of dementia at a very early age. This special needs group requires specific consideration when developing care plans and treatment for ageing prisoners with symptoms of, or the potential to develop, dementia.

Ageing females in prison

Currently there are very small numbers of females ageing in custody; however the increase in the whole female prison population over the decade 2000-2010 exceeds the increase in the whole male prison population for that time (61% compared with 35%)¹⁹.

Furthermore, the increasing numbers of females ageing in prison exceeds the increase in numbers of females in prison under 50 years (53% in the same time span)²⁰. This growth is consistent with that of the overall growth in ageing prisoners and, as mentioned, overtakes the increasing growth in Australia's ageing population.

While research has indicated that studies of male and female prisoners are not always comparable due to particular differences in criminal histories and their lived experiences in prison, there is a need to be aware of the greater number of females diagnosed with dementia in the mainstream population due mostly to their longer life span²². There is, therefore, a need to recognise the potential for ageing female prisoners to develop dementia when considering programs and support for their health care.

Younger Onset Dementia

While people over the age of 50 are considered 'old' by prison standards, in the general community people who exhibit the symptoms of dementia under the age of 65 are said to have younger onset dementia. People with younger onset dementia are often more physically active, have dementia related to lifestyle factors such as alcohol and drug abuse and can develop dementia due to a mental health condition.

A younger cohort of prisoners with a diagnosis of dementia will require particular care and treatment that is quite different from the care and treatment plans designed for older, often less mobile prisoners.

Older First Offenders

Currently efforts are being made within the NSW judicial system to address the need for recognition of cognitive impairment as a defence for some crimes²² and media reports have documented cases where a diagnosis of dementia has allowed an individual to avoid sentencing²³. If some crimes committed in old age are the manifestation of dementia, especially fronto-temporal dementia, which can reduce inhibitions and result in violent or deviant behaviour, it should be recognised that

there is the potential for detection of dementia to go unnoticed during the transition to prison and beyond for some time²⁴.

Health assessments for older first time offenders, made on entry to the correctional facility should include assessments for cognitive impairment. This would allow a better understanding of the person's health status by correctional staff and at the same time provide a baseline from which to assess as the person ages.



Photo: News Ltd

POLICY PERSPECTIVE AND COST

Policy Perspective

Dementia as a health condition has grown in importance on the political agenda.

In Australia:

- Dementia is now identified as a National Health Priority in Australia (2012)²⁵
- \$200m research funding has been promised by the Australian government
- A call for increased improvement in early diagnosis and early interventions/treatments has been made by lobby groups
- The NSW Dementia Services Framework Implementation Plan has been developed

And yet provision for prison reform is not high on the list of the electorate's demands. Consequently this neglect means correctional centres are less able to manage increasing problems that arise with an ageing population such as the incidence of dementia.

Cost

The cost of providing health services for ageing prisoners is high due to greater prevalence rates for health issues associated with ageing such as diabetes, arthritis and heart disease²⁶.

Meeting the needs of prisoners with dementia will exacerbate the cost of health provisions for older prisoners, as the condition often presents alongside other co-morbidities. Comprehensive healthcare programs must work to address the needs of as many health conditions as possible via good collaboration and coordination amongst prison staff and health providers.

Where specific geriatric and special needs facilities have been designated within prisons such as Laurel Highlands in Central Pennsylvania and in Singen, Germany, costs are reduced by housing a number of older prisoners who are cared for by the same specialist staff; as well as reducing incidences of victimisation of older prisoners²⁷.

GOOD PRACTICE

Assessment is imperative to start change

There are challenges to assessment and diagnosis of dementia that are specific to the prison environment. As previously outlined, regimentation can mask the symptoms of dementia in prisoners who are used to the daily routine of prison life and if they do not pose a threat to security or other prisoners the symptoms can go unnoticed. Other research states that symptoms of early stage dementia such as confusion or depression can present as 'quieter' behaviour that is often overlooked in favour of prisoners with more vocal disruptive behaviours²⁸.

It usually isn't until they can no longer cope that we realize the problem exists²⁹.

If early diagnosis of dementia can be made while the person still has capacity and insight, it allows the person with dementia to be informed of their diagnosis and make decisions about their future care and wellbeing via advance care planning.

Early diagnosis also ensures staff and other prisoners are aware of the health condition of the prisoner and appropriate responses to their behaviour are understood and acted upon accordingly.

Training for correctional staff

It is a balancing act for correctional staff to maintain prison management while also attending to prisoners with dementia special needs³⁰.

It is imperative that the needs of ageing prisoners are met via well trained staff. However, alongside training for aged care, dementia-specific training must also be implemented in correctional centres to ensure that all support staff have education and understanding about the nature of dementia, the psychological and behavioural symptoms of dementia and the effect the condition can have on those diagnosed and the people they live with. Dementia training for staff would allow the early symptoms of dementia to be detected, as well as

the changes in symptoms as dementia progresses, to guarantee appropriate, timely treatment and care.

Staff with high level communication skills, empathy and respect, are important for the effective care of people with dementia. If staff are aware of the historical identity and the cognitive capacity of the person with dementia it can enable them to use alternative interventions which can alleviate behavioural problems and provide effective support to the person.

Due to the separation of the person with dementia from their family or community support networks the prison staff become their default social support. Therefore it is suggested that prison staff be regularly debriefed to ensure their wellbeing is maintained as well³¹.

Adapting the prison environment

Behavioural and psychological symptoms of dementia can be challenging, disruptive and socially unacceptable, however changes can be made to the physical environment, social environment and activities for the person with dementia to avoid or reduce these behaviours³².

People with dementia respond to particular environmental features. Changes to the environment for people with dementia in prison can include: different colours for cell doors that correspond with that person's shower and toilet space, big print signage and pictures, calendars to indicate the date and routine events, handrails and non-slippery floors and the removal of mirrors.

Trained staff, and in some programs, trained prisoners, can provide social support for people with dementia in simple ways such as eating alongside them, walking with them and conversing.

Activities for people with dementia can include discussion and reminiscence about positive events in their lives, activities that involve music and activities that include the support of others such as gardening or simple games.



Photo: John Donegan ABC.net.au

Research³⁴ indicates that exercise can delay the progress of dementia and so enhance the wellbeing of the person diagnosed. Furthermore people diagnosed with younger onset dementia are often physically strong and energetic which enables them to continue an exercise regime that may be too arduous for their older counterparts. Consequently physical exercise, modified according to the person's capacity should be encouraged to promote health and wellbeing amongst those prisoners diagnosed with dementia.

Coordinating Services

Amongst the evidence of good practice reported, coordination of services and collaboration between agencies, internal and external to the prison system is paramount. A multi-disciplinary approach allows resources and expertise to be used so that program and service development is comprehensive and appropriate to the needs of people with dementia living in a prison environment.

Further research required

While information and research regarding ageing prison populations^{34,35,36}, has increased there is little research being undertaken regarding the specific needs of people with dementia living in a prison setting. It is important to begin an accurate collection of data to inform future clinical and service developments in this area. This could include studies to evaluate programs of assessment and diagnosis of people with dementia in prison and subsequent treatment options as well as the

barriers to accessing these processes³⁷.

Research needs to be undertaken around the issue of older or middle aged first offenders. Health assessments on entry to the prison system need to screen for cognitive impairment and address the possibility of dementia, regardless of age, which could, in turn, be related to the crime committed.

Finally, further investigation into alternative accommodation arrangements for the projected numbers of prisoners with dementia would provide a number of opportunities: to increase safety for the whole prison population; to reduce the behaviours of dementia that can impact on the cost of care and, to enhance the health and wellbeing of the prisoner with dementia.

EVIDENCE OF GOOD PRACTICE

Evidence of good practice

There have been significant developments to accommodate the needs of ageing prisoners with chronic health conditions in Australia and overseas.

Recent research carried out by Adam Moll for the Mental Health Foundation in UK³⁸ indicates that some prisons have implemented measures to meet the needs of older prisoners. Fourteen correction facilities took part in the research, with only two, Fishkill in New York and California Men's Colony, indicating they had a dementia-specific unit.

Fishkill, N.Y.

Fishkill prison in New York has created a dementia-specific, 30 bed unit within the prison's medical centre to accommodate and care for prisoners from around the state with dementia, often related to Alzheimer's disease or AIDs.

Workers, including nurses, corrections staff and cleaners all undergo a 40-hour training course, designed by the Alzheimer's Association, about dementia and cognitive impairment so that they are equipped to deal with the prisoners in the unit³⁹.

The training regime aims to minimise instances of confusion and anxiety for the prisoner with dementia and, combined with regular reporting of incidents involving physical contact with prisoners, builds an awareness around the notion that what may seem like irrational behaviours are actually symptoms of dementia and can be managed in alternative less threatening ways⁴⁰.

California Men's Colony

California Men's Colony (CMC) is a designated prison that accommodates prisoners with severe cognitive impairments such as dementia, to meet their specific needs and reduce incidents of victimisation against them. CMC offers a psychosocial program called Special Needs Program for Prisoners with Dementia (SNPID) that supports the needs of the prisoners with dementia via changes to the physical environment, the social environment and individual activities for the prisoner with dementia. The SNPID includes other prisoners, who have exemplary good behaviour records, to assist and support the prisoners with dementia on a regular basis. By changing the environment and

providing stimulation to the person with dementia the challenges arising from the behaviours of dementia can be reduced or avoided⁴¹.

Long Bay Correctional Complex, Sydney

Within NSW significant developments are being undertaken by Justice Health & Forensic Mental Health Network at Long Bay Correctional Complex in collaboration with other agencies to enable better care and treatment for prisoners with cognitive impairment and dementia. The following is an outline of the work that is underway.

Justice Health & Forensic Mental Health Network and addressing the needs of persons with dementia in NSW prisons

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The healthcare needs of older offenders in New South Wales (NSW) are addressed by Justice Health & Forensic Mental Health Network (JH&FMHN). Justice Health & Forensic Mental Health Network is a statewide service providing healthcare for those who come into contact with the criminal justice and forensic mental health systems in NSW¹.

Service provision for incarcerated persons with dementia has been an ongoing area of development for JH&FMHN and Correctional Services New South Wales (CSNSW). Health services for patients with dementia in JH&FMHN are currently provided by physiotherapists, geriatricians, psychogeriatricians, general practitioners, podiatrists, optometrists, dentists, psychologists, occupational therapists, audiologists, and specialised aged-care nurses. Existing services include an inpatient facility in Long Bay Hospital for older offenders requiring long-term supported care and a CSNSW operated unit (Kevin Waller Unit) offering aged-care offenders independent living in segregation from the mainstream prison population with support from a disability service provided by CSNSW.

Recent advances in clinical services in this area include the introduction of a state-wide Aged Care Bed Model to facilitate appropriate placement of prisoners with dementia, identification of specific areas allocated for aged care patients in rural correctional centres, and a Memorandum of Understanding with Calvary Healthcare for the provision of Occupational Therapy services within the inpatient facility and the Kevin Waller Unit in the Long Bay Correctional Complex.

In addition to a commitment to ongoing service development, JH&FMHN are also collaborating with universities in NSW to conduct research related to improving service provision for patients with dementia. A recent research initiative saw the development of tools and procedures related to the identification, assessment and management of patients with dementia in NSW prisons. Future direction for research lead by JH&FMHN include the development and evaluation of an aged-care health service model to ensure appropriate placement of and care provision for older offenders in the correctional environment.

¹ JH&FMHN provides health care in a complex environment to people in the adult correctional environment, to those in courts and police cells, to juvenile detainees and to those within the NSW forensic mental health system and in the community. In all contexts, JH&FMHN works closely with a variety of other organisations, including NSW Ministry of Health, Corrective Services NSW, Juvenile Justice, Local Health Districts, community groups and advocacy groups

CONCLUSION AND RECOMMENDATIONS

Conclusion

While it is difficult to determine how many people in prison have a diagnosis, or the onset, of dementia the projected increase in the ageing prison population indicates the figure will continue to rise significantly.

The need to address the healthcare requirements of people with dementia in prison is an urgent one. Governments must acknowledge this important issue, through legislative change, and protect people with dementia in prison in a timely and appropriate way. Change will require interdisciplinary, collaborative action to develop practice, policy and research initiatives. This will ensure the health and care entitlements of this vulnerable group of people are delivered, just as they would in the community.

Recommendations

That corrective service authorities across Australia:

- Adopt the models of best practice at Long Bay Correctional Complex highlighted in this paper more widely across prison systems in Australia.
- Ensure assessment for cognitive impairment is included in health checks for prisoners aged over 50 and ensure prisoners diagnosed with dementia are given adequate support to contribute to their advance care plan while they still have capacity
- Provide dementia-specific staff training across all aspects of the corrections system including health professionals and wardens to increase knowledge of symptoms of dementia and appropriate dementia care in the prison environment
- Corrective service agencies across Australia make changes to the physical, social and structural environment of prisons to reduce the behaviours of dementia and accommodate the needs of ageing prisoners with dementia
- Corrective service agencies across Australia collaborate with a cross section of allied health, aged care and specialist services to provide dementia-specific advice, training and support to meet the complex needs of inmates with dementia
- Corrective service agencies across Australia develop referral pathways to the Alzheimer's Australia Younger Onset Dementia Key Worker Program to support parolees in accessing the supports they need to live independently.
- Corrective service authorities implement a risk reduction program, such as Alzheimer's Australia *Your Brain Matters*, to delay the onset of dementia in all prison settings
- The NSW Government accept and enact the recommendations of the 2013 Law Reform Commission report *People with Cognitive and Mental Health Impairments in the Criminal Justice System: criminal responsibility and consequences*

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OTHER ALzNSW RESEARCH PUBLICATIONS

Living with dementia in regional NSW Discussion Paper #8 November 2013

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

http://www.fightdementia.org.au/common/files/NSW/20131113-NSW-PUB-Dementia_in_regional_NSW.pdf

Living alone with dementia - Discussion Paper #7 June 2013

It is estimated there may be up to 65,000 Australians with dementia who live alone. However research shows that people living alone with dementia have a higher risk of economic insecurity and abuse, loneliness and depression, poorer health outcomes due to self-neglect and increased vulnerability to malnutrition, falls, accidents and hygiene problems. There is often an underlying assumption in dementia and aged care policy that there is a spouse, relative or friend who lives with and cares for the person, and this is reflected in the way services are delivered. This discussion paper examines the implications of this for social policy and service provision.

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

Football, head injuries and the risk of dementia. Discussion Paper #6 Mar 2013

Alzheimer's Australia NSW hopes to raise public awareness of the potential risks of later-life

cognitive impairment and dementia for football players who suffer multiple concussive and subconcussive injuries throughout their playing career. This paper examines the research emerging from the USA, reports of memory loss in current and retired football players in Australia, and the possible implications for the football codes.

http://www.fightdementia.org.au/common/files/NSW/AlzNSW_Football_head_injuries__the_risk_of_dementia_final_130313_web.pdf

The most difficult decision - Dementia and the move into residential aged care - Discussion Paper #5, Oct 2012

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

http://www.fightdementia.org.au/common/files/NSW/20121016-NSW-PUB-Moving_To_Res_Care.pdf

What prevents people with dementia making plans for their future? - Discussion Paper # 4, Mar 2012

Planning ahead is important for the whole population. We all need to make sure if we get to a point where we can no longer make our own decisions that our wishes about our health care and financial plans have been set out in legally binding documents. Failure to do this can lead to added stress on our family and carers who will not have the legal ability to make sure our wishes are followed or who could be unsure of our wishes.

People with dementia have the right to make decisions about their future while they still have the capacity to do so. It is therefore imperative in the early stages of the disease that people with dementia are provided with opportunities to plan for their future and record their wishes, while they still have capacity.

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

Building Dementia and Age-Friendly Neighbourhoods - Discussion Paper # 3, July 2011

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

[Building Dementia and Age-Friendly Neighbourhoods - Discussion Paper 3 July 2011\(PDF\)](#)

Addressing the stigma associated with dementia - Discussion Paper # 2, Sep 2010

The purpose of this paper is to raise public awareness about the effects of stigma associated with dementia, to address the need to change the way we, as a society, approach dementia, and to make recommendations for further action.

[Addressing the Stigma associated with Dementia Discussion Paper 2 \(PDF\)](#)

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

[Alzheimer's Australia NSW – Addressing the Stigma associated with Dementia - Executive Summary \(PDF\)](#)

Driving and dementia in New South Wales - Discussion Paper #1, Apr 2010

A new discussion paper, Driving and Dementia in NSW, indicates there is little clear, accessible information about the rights and responsibilities of a driver after a diagnosis of dementia.

[Driving and Dementia in New South Wales Discussion Paper 1 \(PDF\)](#)

Issues raised include:

- Driver testing for people with dementia must be im http://media.cirrusmedia.com.au/AD_Media_Library/AD_WEB_IMAGES/General/Prison_cell.jpg proved
- Legal obligations for a driver with dementia are unclear
- Call for improved transport alternatives for a person with dementia
- Need for better support for transition from driver to non-driver in NSW

[NSW Discussion Paper Key Recommendations \(PDF\)](#)

OTHER ALZNSW RESEARCH PUBLICATIONS

Quality Support Groups Research Project

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

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

Significant findings of the report are:

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

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

[Quality Support Groups Research Project - Phase 3 Executive Summary \(pdf 45 KB\)](#)

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

[Quality Support Groups Research Project - Phase 2 \(pdf 1.92 MB\)](#)

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

[Quality Support Groups Research Project - Phase 1 \(pdf 764\)](#)

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

Notes

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