LIVING WITH DEMENTIA IN PRISON

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Signed:

Date: 8th October 2016
ACKNOWLEDGEMENTS

- First and foremost I would like to thank the Churchill Trust for believing this issue was worthy of investigation and enabling me to pursue further knowledge overseas to feed developments in Australia as our prison population ages.
- My thanks and appreciation to the Hon. John Watkins AM, CEO of Alzheimer’s Australia NSW as well as staff and consumers who saw the important need to: investigate the care requirements of this most vulnerable population, ensure the scope of our organisational research and advocacy includes all people with dementia no matter where they live and, encourage Alzheimer’s Australia NSW staff members to enhance their professional development beyond our own front door.
- I owe enormous debt and gratitude to Mr David Huskins, Director, Corrective Services NSW who first introduced me to Corrective Services staff and enabled me to visit Long Bay gaol on more than one occasion to see and learn firsthand about the care of frail aged people in prison.
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EXECUTIVE SUMMARY

To investigate effective care programs for people living with dementia in prison
Jo-Ann Brown, Consumer Engagement Manager – Alzheimer’s Australia NSW. 120 Cox’s Road North Ryde, 2113. 0409922750

As Australia’s prison population ages at an increasing rate the needs of ageing prisoners will have to be addressed in specific ways to ensure that each prisoner receives the care he or she is entitled to as individuals under the state’s guardianship. As age is the greatest risk factor for the development of dementia the Australian prison system needs to be prepared for the challenges that dementia brings to the individual, the custodial and health care staff and other inmates with whom prisoners live.

This project aims to investigate effective care programs for people living with dementia in prison. It describes ways in which the Australian prison system can learn from systems in New Zealand and the United States of America (U.S.) to ensure optimum health and wellbeing for people living with dementia in prison.

The U.S. has over 1.5million convicted prisoners as at year end 2014. Of these 10% (151,000) are over the age of 55 and 2% (34,000) over the age of 65\(^1\).

Due to longer sentences, historic sentencing and the three strikes rule the U.S. is experiencing an unprecedented number of people ageing in prison. Naturally there is growing awareness of the costs and specific needs of the ageing prison population including the care and accommodation requirements of those with dementia and cognitive impairment. Consequently some institutions are confronting the challenges this crisis brings and developing some innovative programs of care.

As part of my fellowship I travelled to the U.S. and visited prisons in San Luis Obispo, California; Jefferson, Missouri; Beacon, New York and a nursing home for former prisoners in Rocky Hill, Connecticut.

I also visited New Zealand which has similar increases in its ageing prison population and is also dealing with issues relating to dementia and cognitive impairment. I visited Rimutaka Prison in Wellington where a High Dependency Unit is providing quality health care for its ageing prison population and those requiring assistance with their activities of daily living (ADLs).

In both countries I spoke with experts in the field who advocate for the human rights of prisoners to be upheld through quality healthcare and compassion.

\(^1\) US Department of Justice. Bureau of Justice Statistics 2015
http://www.bjs.gov/content/pub/press/p14pr.cfm
Key Learnings and Conclusions

- Lack of awareness of the early signs of dementia mean many inmates with dementia go unnoticed until their changed behaviours give rise for concern
- A person-centred care approach is imperative for the inmate-patient due to the diverse range of causes of cognitive impairment and dementia amongst their cohort including Alzheimer’s disease, intellectual disability, drug and alcohol abuse, Traumatic Brain Injury (TBI) and age-related causes
- Risk management is key to quality health care to ensure the safety of the person with dementia, the custodial and health staff, the other inmates and the community at large
- Inmate-peer assistance provides quality, cost-effective care to those with dementia and benefits all stakeholders
- Dementia-specific training for all health and custodial staff as well as inmate-peer assistants is vital to the delivery of good health care for, and the wellbeing of, the inmate-patient
- Social and physical stimulation is vital for the wellbeing of all inmates before and after a diagnosis of dementia
- Collaborative, holistic and integrated care from assessment to death ensures the human rights of the inmate-patient are met
- Safe and compassionate release of ageing, dying prisoners into community care has human, social and economic benefits for all stakeholders.

These findings shall be disseminated via:

- My own professional networks across the aged care and correctional health care sector
- Promotion at conferences and fora
- Promotion in journals and newsletters pertaining to dementia care and correctional health care
- Promotion and information to state and federal government departments who oversee the health care of prisoners and aged care generally, particularly residential aged care.
THE PROGRAM

Site visits:

1. Rimutaka Prison, Wellington, New Zealand
   - Ms Bronwyn Donaldson
   - Ms Jenny Strand
   - Dr Nikki Reynolds

2. California Men’s Colony – San Luis Obispo, California, USA
   - Dr Cheryl Steed
   - Ms Teresa Macias
   - Prof Bettina Hodel
   - Dr Hereberto Sanchez
   - Dr Mary Comperini

3. Jefferson County Correctional Center, Missouri, USA
   - Ms Angela Umstattd-Schmutz

4. Fishkill Correctional Facility, Beacon, NY, USA
   - Dr Joseph Avanzato
   - Dr Paul Kleinman

5. ‘60 West’ Nursing Home Rocky Hill Connecticut, USA
   - Mr Mike Landi
   - Ms Jessica Dering
   - Mr Robert Bourke

Interviews:

6. Dr Linda Roberts, Kansas University Medical Unit, Kansas, USA

7. Dr Brent Gibson, National Commission for Corrective Health Care, Chicago, USA

8. Prof. Tina Maschi, Fordham University, New York, USA
BACKGROUND

In 2015 the number of prisoners in adult corrective services custody in Australia was 36,134, an increase by 7% from 33,789 prisoners in 2014. The number of older (over 50) prisoners in Australia is approximately 4,000 and accounts for 12% of the prison population. There are 1300 prisoners over 60 years and 708 over 65. These figures indicate a rise in the number and proportion of older prisoners in Australia and highlight the need to address the concerns this growth will bring. For example:

- the cost of care and accommodation for inmates with health issues associated with age related functional decline
- the need for appropriate and meaningful programs for older inmates and
- the need to streamline the transfer of ageing and dying inmates within the prison system or to community or residential care.

Naturally with an increasing ageing prison population there is the consequent potential for a rise in the number of people with dementia living in prison. The risks for developing dementia are evident in prison populations before and during incarceration.

Preceding their entry to prison many inmates have a history of dementia risk factors such as emotional trauma, drug and alcohol abuse, head injury, low socio-economic status, low levels of education and inadequate access to good health care.

Also the deinstitutionalisation of mental health patients has meant increasing numbers of people, who might have previously been hospitalized when they first exhibited evidence of serious mental illness, live in the community until they commit a crime and are then sent to prison instead of alternative accommodation that can meet their health needs.

Once inside the prison setting other risk factors can hasten the onset of dementia such as: depression, TBI, HIV AIDS, and lack of intellectual, social and physical stimulation.

The onset of dementia and cognitive impairment can be masked by those living the structured day-to-day routine of prison life. However once there are changes in a person’s behaviour, or changes in their capacity to cope on an intellectual level, they can easily become victims to bullying by other inmates and reprimanded by custodial staff.

In 2014 as a social researcher with Alzheimer’s Australia NSW I wrote a discussion paper Dementia in Prison to raise awareness of the experiences and needs of people living with dementia in prison and to alert authorities to the challenges that lie ahead as Australia’s ageing prison population increases.

At the same time others wrote of their concerns and the need for change. They called for more attention toward planning for an expected increase in dementia in prison, better assessment programs, and further research on the care of the inmate with dementia. All agreed the complex interaction of physical, emotional and environmental risk factors associated with dementia requires an equally complex and specific response.

Amidst the growing concern within Australia international literature increasingly called for the needs of people with dementia in prison to be met. Tina Maschi’s seminal work used
a human rights lens to highlight the need to work with diverse disciplines and professionals to conduct cognitive assessments regularly, provide suitable care plans that include appropriate accommodation, ensure specific training for custodial and health staff and extend and refine the inmate peer programs used by some prisons to support people with dementia. Maschi reports this ageing, mental health and criminal justice crisis is too large to ignore. She refers to dementia and states:

*We need to make sure that we take care of all of its ‘victims’, wherever they reside, including in prison (Maschi et al, 2012)*
METHOD

As outlined in the Program section I visited four prisons and one nursing home. The sites selected are highlighted in much of the literature\textsuperscript{x} and in my own report, written for Alzheimer’s Australia NSW\textsuperscript{xi}. All the sites I visited incorporate the care of people with dementia and cognitive impairment into their management strategy.

I conducted interviews with experts in the field of correctional health care, in person and via email. I also conducted a focus group discussion with a group of inmate carers in one facility.

In all facilities I observed the day-to-day routine of prison and nursing home life and was able to question my hosts during the observation. Unfortunately, as most of the field work was conducted within the prison setting, I was not permitted, with the exception of two facilities, to use my digital recording device.

DEFINITIONS

Dementia and cognitive impairment

The original premise of this project was to investigate effective care programs for people living with dementia only. However numerous sites I visited accommodated people with ‘cognitive impairment’ and dementia together under the same general mode of care.

‘Dementia’ describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. It affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person’s normal social or working life\textsuperscript{2}. On the other hand an individual with ‘cognitive impairment’, particularly mild cognitive impairment, can usually perform everyday tasks without assistance but may have problems with memory loss or the capacity to make decisions.

Old Age

When ‘old age’ is described in the prison setting both in Australia and internationally, the functional definition of ‘old age’ is generally 50 years and older. This is based on research findings that identify a 10-year differential between the overall health of prisoners and that of the general population. This is generally due to a combination of the inmate’s lifestyle pre-incarceration and the capacity for the prison environment to escalate the ageing process and age-related illnesses.\textsuperscript{xii} Within this report, unless stipulated this will be the definition used.

Prison v gaol

The terms ‘prison’ and ‘gaol’ are interspersed in the Australian vernacular however in the U.S. gaols (jails) are most often run by sheriffs and/or local governments and are designed to hold individuals awaiting trial or a serving short sentences. Prisons on the other hand are mostly operated by state governments and the Federal Bureau of Prisons (BOP) and are designed to hold convicted individuals for longer periods of time.

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\textsuperscript{2} Alzheimer’s Australia webpage https://www.fightdementia.org.au/about-dementia/what-is-dementia
SITE VISITS

In this section I report on visits to various facilities that accommodate current and former prisoners with dementia and cognitive impairment.

RIMUTAKA PRISON, WELLINGTON, N.Z.

Personnel:
Ms Bronwyn Donaldson, Director Offender Health, Department of Corrections, NZ
Ms Jenny Shand, Health Centre Manager, High Dependency Unit, Rimutaka Prison, Wellington, NZ

New Zealand has a prison population of 9,800 which in a country of only four and half million is a high incarceration rate. While New Zealand’s prison population is growing its ageing prison population is also on the rise, especially in recent times due to an increase in historical sentencing for sex offences. In 2011 there were 51 inmates over the age of 70 and by late 2015 that number had risen to 118.

In response to the increasing health needs of ageing inmates Rimutaka Prison opened New Zealand’s first High Dependency Unit (HDU) in 2012. This was a joint collaborative project with the Ministry of Health and the Department of Corrections.

The HDU provides highly dependent inmates with single rooms similar to hospital rooms. Originally the HDU opened with 20 beds but has since expanded to include another 10 beds. All inmate-patients have their own health file, including an advance care directive and treatment plan (Attachment 1). A registered nurse is on duty from 8am-5pm and health care assistants are available around the clock. Palliative care is available for inmates not released for hospice care. Jenny Shand, the Health
Centre Manager, reported that some inmates request not to be released and stay in the unit to spend their last days with ‘family’. Hospice staff are often brought in to the unit from Te Omanga hospice\(^3\) and they oversee the care of the dying person.

**The residents**

HDU currently accommodates males only and most of the patients are in their seventies and eighties, with serious medical conditions that require assistance and support for their ADLs\(^{\text{xiii}}\) While only two have been formally diagnosed with dementia there were indications that others had various degrees of cognitive impairment. Some other diagnoses included cancer and Acquired Brain Injuries (ABI).

**Assessment and care**

Most patients with dementia or cognitive impairment first come to the notice of health staff when other inmates or staff notice changes in an individual’s behaviour. Screening takes place and a health professional uses the Montreal Cognitive Assessment (MOCA)\(^{\text{xiv}}\) to determine the individual’s cognitive capacity and, according to the results a care plan is set up. Inmates in the mainstream prison community are not given cognitive assessments as part of their regular health checks unless they exhibit changed behaviours. Occasionally if an inmate has a psycho-social test for another issue the psychologist might pick up signs of cognitive impairment.

When a person has been identified as having behaviours that are disruptive or unusual they are often isolated from mainstream before being placed in the HDU for monitoring and for staff to understand the cause of their behaviours and their mode of communication. This is important for health staff to ensure person-centred care is being delivered and the behaviours are reduced.

Care plans are reviewed regularly and a Needs Assessment and Service Coordination (NASC) assessment is conducted if the patient’s needs change or if a transfer to residential care is recommended. This is completed by the District Health Board.

**Activities**

Activities available to patients in the HDU include: bingo; craft; TV; chess; cards; board games; gym work and the local Society for the Prevention of Cruelty to Animals (SPCA) provides animal therapy on a regular basis. While Rimutaka is a working prison with inmates learning skills such as horticulture; fence building and barista work, with opportunities open to all ages, the patients in HDU do not participate in this aspect of prison life.

**Staff**

All staff of the HDU apply to work there and are carefully vetted for suitability. Health Care Assistants (HCAs) often come from the aged care sector in the community and internal training is provided on topics such as diabetes and CPR but no specific training about dementia care. Once staff are in the HDU they are taught that there is no place for aggression or punishment. HCAs support the patients with recreational and every day

\(^3\) [http://www.teomanga.org.nz](http://www.teomanga.org.nz)
activities however there is no evidence or plan to incorporate the use of other inmates to provide care as in many prisons in the U.S. In light of the aforementioned working prison ideal it was reported that upskilling inmates in aged care assistance would not be worthwhile as they would not be able to access work in that particular field once released. Indeed, the current number of patients with cognitive impairment or dementia in Rimutaka, unlike the numbers in U.S. prisons, probably doesn’t warrant the use of inmates to support the level of staffing required at this point in time.

Environment
The unit, which is clinical in appearance, is age care friendly with level flooring and easily accessible rooms and showers. The bedrooms are generally kept open and all have height-adjustable beds. The recreational area is light and bright and easily navigated. A large date clock has recently been installed in the room.

On the day I visited all patients in the HDU appeared to be happy and those that were conversing with staff and amongst themselves were obviously benefitting from social interaction in a safe environment. Unless the patient cannot leave their room all meals are served in the recreational area. There are garden beds in the outdoor area for gardening and space to move around for those who are more mobile.

The High Dependency Unit at Rimutaka is ensuring their ageing prisoners are well-cared for, living in a safe environment and being given opportunities for intellectual and social stimulation.

On the same day I also spoke with Dr Nikki Reynolds, Chief Psychologist for the NZ Department of Corrections. She confirmed that early stage dementia usually does go
unnoticed longer due to the routine regularity of prison life, and even in the HDU due to patient apathy and compliance. Reynolds claims that while staff do a good job, often under difficult conditions, the number of diagnoses of dementia would increase if all staff were trained to conduct screening. She acknowledged that many prisoners (the world over) have a low health history and this would contribute to the development of cognitive impairment and dementia.

Ironically Reynolds reports: *If someone is doing a short sentence and gets a health test then it is picked up more readily than others who have been there for a while.* Also, child sex offenders are diagnosed more often as they are tested regularly by psychiatrists, particularly if they are going before the parole board, when their tests will often include cognition testing.

Reynolds also expressed concerns that first time offenders in mid-life often show signs of dementia. She knew of a man who was in a nursing home when he started accessing child pornography. He was sentenced and imprisoned, but from her reckoning, had obvious signs of dementia.

Reynolds suggested further investigation of supported accommodation options for inmates with dementia and those with mental health concerns, particularly once they are released into the community and in need of palliative care. She suggested a not for profit organisation could work with government to accommodate this cohort or provide staff to meet the needs of these people in government funded housing.

As Reynolds stated:

*They may be offenders but they are citizens and entitled to health care in the same way everyone else is.*

**Key Learnings and Conclusions**

- The High Dependency Unit is a good example of collaboration between the government departments of Health and Corrections
- Screening and assessment is essential for timely delivery of health care for inmates
- A well planned safe environment is conducive to social engagement and the wellbeing of ageing prisoners
- Behaviours that challenge staff and other inmates can be reduced by different management styles that include psycho social means.
California Men’s Colony (CMC) is one of 34 institutions that comprise California’s Department of Corrections and Rehabilitation (CDCR) and the California Correctional Health Care Services (CCHCS). Each institution has developed specialized programs addressing particular needs and accordingly inmates can be transferred from one institution to another for a variety of reasons that could include safety, medical treatment or access to particular programs.

The CEO of CMC, Teresa Macias, reported that in recognition of the growing ageing inmate population CDCR/CCHCS has developed special programs and renovated or constructed new facilities such as the California Health Care Facility (CHCF), a state of the art facility in Stockton, California. To cope with the demand of care the Gold Coat Program, while developed independently at CMC has been incorporated into the work of CDCR.

The CHCF at Stockton houses the largest number of inmates living with late stage dementia in CDCR. These patients are usually only partially mobile by the time they are transferred to Stockton and have often been transferred due to challenging behaviours of dementia. Palliative care is provided at this facility for those who cannot be released on compassionate
grounds or transferred to nursing home care. Staff here receive dementia training as part of their professional development and are supported by the state to further their dementia education outside their workplace training⁴.

The California Men’s Colony (CMC) sits on 356 acres and is divided into two facilities known as East and West. The West facility is minimum security with housing in open dormitories. Here inmates are rehabilitated and prepared for re-entry into the community. They can undertake training activities such as the option to become part of the Camp Cuesta firefighting team which assists government and local agents to clear grassland and tackle fires in the area.

The medium-security East facility has individual cells, fenced and armed perimeters, and its housing divided into four quadrangles (A, B, C, and D). Each quadrangle has its own dining hall and recreational area.

CMC also includes a hospital and inpatient mental health crisis treatment facility. At the time of my visit the facility’s total population was 4095. CEO Teresa Macias⁵ estimated: Approximately 25% of our inmate patients are mental health patients in the Enhanced Outpatient Program (EOP), the Correctional Clinical Case Management System (CCCMS) and or the Developmental Disability Program (DDP).

**Assessment**

Inmates are screened for cognitive disorders within 21 days of admission to all California prisons and if diagnosed they are transferred to a prison that has programs to suit their needs, assist them in their ADLs and protect them from victimisation. Alternatively psychologists and doctors can be alerted by another inmate or staff member if an inmate appears to have lost executive functioning or is displaying memory loss issues. Then they are tested again and the process of care begins.

**Developmental Disability Program**

The Developmental Disability Program (DDP) serves inmates with cognitive impairments – includes developmentally disabled, head injury, stroke, substance induced cognitive impairment, and dementia.

The DDP was developed after a major lawsuit was filed in 1997 in California on behalf of inmate-patients with developmental disabilities demanding better care. Hodel and Sanchez⁶ report that since then the Californian prison system has been obliged to provide safe housing, supportive services and special handling for rule violations for inmates with developmental disabilities as well as those with dementia and other types of cognitive impairment.

**D Facility**

I visited D Facility, which houses patients in the EOP and DDP programs. Patients are housed in single cells and often require assistance and guidance with their ADLs. Originally amongst this cohort there were 36 patients identified as exhibiting severe cognitive impairment,

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⁴ Email communication with Dr Comperini
⁵ Email communication with CEO Teresa Macias
most with some sort of dementia, but since the new California Health Care Facility has opened in Stockton, 27 of the patients with high needs have been moved there, leaving nine patients identified as exhibiting severe cognitive impairment, most with dementia.

**Model of care**

Clinical and custodial staff, as well as trained inmate-caregivers called Gold Coats, all work together to support the patients living in D Facility. All staff I spoke with understood symptoms of dementia such as confusion, forgetfulness, reduced comprehension and misinterpretation of boundaries. Psychologist Dr Cheryl Steed reported some with cognitive impairment will forget they are not permitted to touch staff or use inappropriate language or affection.

**Case study**

Recently in the music group a man with advanced dementia wanted Dr Steed to dance with him but she was able to gently dissuade him without escalating any problematic responses from him or custodial staff.

As mentioned above, if someone is reported showing signs of dementia and not coping in the mainstream CMC population they are evaluated by Dr Steed and their ‘adaptive functioning’ is assessed. If this deems them to be cognitively impaired to some degree she prescribes specific care supports for staff to address and deliver according to the person’s need. The medical clinic might do more formal testing, or prescribe an MRI, but generally if the staff feel someone needs assistance they start the process of support as soon as possible. An assessment is made focussing on their level of functioning within the prison in several areas related to their ADLs including: self-care, self-direction, self-advocacy, socialization, and use of leisure time.

The person is then admitted to the DD (Developmental Disability) Program. The DD Program has three levels of support:

- **DD1** – lowest need and can usually manage most ADLs themselves
- **DD2** – moderate need when Gold Coats usually start to assist
- **DD3** – requires more support and automatically gets Gold Coat assistance

Patients progress through the levels via reassessments and reviews conducted by the Inter Disciplinary Support Team (IDST) made up of custodial and clinical staff. The reviews take place once a year for DD1s, twice yearly for DD2s and quarterly for DD3s. In between times if staff suggest changes Dr Steed will change their ‘prescription’ to increase their support such as: “prompts for shower”.

Those diagnosed with dementia at CMC can have a variety of causes such as Alzheimer’s disease, vascular disease, Lewy body, hydrocephalus dementia, TBI, alcohol and drug abuse and stroke related dementia.

Dr Steed explained that disclosure of a diagnosis to the patient depends on whether or not the patient has been formally diagnosed and whether they have the capacity to cope with being told they have dementia. For the more psychologically fragile patients she is inclined to work with them on coping mechanisms for their memory problems, rather than discuss
the specific diagnosis and possibly devastating prognosis. However there have been other patients, who want her to speak openly and directly with them about their diagnosis, which she does.\(^6\) If the patient still has good insight and cognitive capacity clinical staff are encouraged to obtain release of information from the patients so that staff have the legal authority to contact the patient’s family members about their health status.

I asked Dr Steed if questions ever arise about the role dementia may have played in the crime committed, particularly amongst older first offenders. She reported that she is frequently asked why someone with dementia is still in prison and why the presence of dementia in an older offender isn’t being used as a defence more often. She reasoned “if people can be found not guilty ‘by reason of insanity’ why not ‘by reason of dementia’?” Parole based on medical grounds, known as compassionate release, rarely occurs and requires that an inmate be terminally ill, and essentially bed-bound. Until the very late stages, many of the inmates with dementia won’t meet these criteria for compassionate release.

**Environment**

En route to the housing unit I was able to observe the very large, although grassless, due to the current drought, exercise yard. Inmates mingle in this yard and undertake a range of activities. Some alone, walking and exercising, while others talked in groups or played ball together.

The housing unit accommodated the less able at the ground floor level and others on levels above. All cells are single cells. Signs above the sink remind patients how to wash their hands and a distinct red arrow on the wall beside the toilet bowl reminds patients the direction in which they need to be pointing to urinate.

The occupants all have a key to their own cell and can come and go as they please during the day. This not only allows them to display responsibility but also gives them some privacy if and when they want it. This feature of CMC is quite unique in the prison system.

Unfortunately there are stairs to navigate at CMC and the dining hall, that meets their social and dietary needs, is located upstairs. Consequently, if a person is immobile or becomes immobile, meals are brought to their cells on trays until such time they can be transferred to an institution that can better accommodate their needs. This may seem harsh but if an area such as the dining hall is inaccessible, not being able to get there is a personal violation of their right to food and nutrition.

**Case Study**

One patient who had had a stroke participated in rehabilitation and was cleared for stair climbing to the dining hall. However after information was reported to Dr Steed by the Gold Coats that he needed two of them to assist him, and was a falls risk, he was transferred to better more suitable accommodation

\(^6\) Dr Cheryl Steed email communication
The Gold Coat Program

The Gold Coat Program was the main reason for my visit to this prison. This innovative and cost effective program was developed at CMC in the early 1990s using long serving well-behaved inmates to assist staff care for patients with mental health conditions and varying degrees of cognitive impairment, including dementia.

The Program was set up by a recreation therapist named Katherine Evans who recognised the need to assist severely mentally ill prisoners with their ADLs. At the same time she recognised a need for mainstream prisoners to have opportunities to do meaningful work in their prison community. Dr Sanchez reported that Evans felt there were prisoners who wanted to make amends to society and this was an opportunity to fulfil that need.

Initially the Gold Coat Program was set up to assist those with mental health problems at CMC and required a major change in culture for correctional staff. Fortunately, at the time custodial authorities saw the social and economic benefits and agreed to work with clinical staff to facilitate the Program.

In 2009 Dr Bettina Hodel encouraged and enabled the Program to include inmates with cognitive disorders and dementia who needed assistance. Currently at CMC there are six Gold Coats working with the cognitively impaired and six working with mental health patients. Some Gold Coats have been in the Program for lengthy periods of time while others are in their first year.

The inmates who participate in the Program wear yellow (gold) jackets over their regular prison garb and are trained to assist patients, mostly by guiding and prompting, with daily tasks such as dressing, showering, and other personal hygiene issues, including cleaning up toileting accidents. They tidy the cells and make beds for those who can’t while others help patients write letters and attend to documents for parole application.

They escort patients to the dining hall and to medical appointments within the prison. Gold Coats act as companions keeping a watchful eye out for bullies and alerting staff of any victimization concerns and ensuring the inmate-patients get food at meal time. The Gold Coats also assist with exercise classes and activities designed to stimulate memory. Generally the role is one of ‘guidance’. If a patient requires any ‘hands on’ assistance such as someone in late stage dementia then the person will be transferred to hospital or hospice care at Stockton.

Recruitment and training for the Program

Inmates at CMC can apply for a position in the Program or may be referred by a staff member as suitable. When the Program first began at CMC custody administrators expressed concern about Gold Coats taking advantage of the mentally ill patients and so custody and health staff worked together on the selection process.

Applicants must have a clean disciplinary record for at least five years with no disciplinary write ups. A history of predatory behaviours, sexually violent crimes or any crime against a

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7 Email communication with Dr Heriberto Sanchez 23 August 2016
prison supervisor would eliminate them from acceptance to the Program. They must demonstrate a good work history in prison with a good referral from work supervisors and custody staff. Each new Gold Coat is on probation for about 3-6 months and is shadowed by another for a period of time. Dr Steed explained ‘they have to take it slowly and can’t be seen to be jumping in’ … trying to effect change immediately.

Naturally, the role of a Gold Coat does not suit everyone. A suitable personality needs to be cooperative with good communication skills. They need to be able to communicate with staff, and at the same time, in Dr Steed’s words:

….. be willing to be called a ‘snitch’ occasionally by the other inmates.

Gold Coat team members have typically been incarcerated for a long time. All of the Gold Coats are serving life sentences with the possibility for parole, the shortest time the Gold Coat has been incarcerated is 21 years and the longest 40 years. Due to their long sentences many of the Gold Coats are older, more mature, more familiar with the system and, the investment in training is worthwhile because they will be in prison longer.

A Gold Coat helps another inmate put his boots on

Tenure as a Gold Coat is a maximum of five years but if the Gold Coat moves from one area to the other then this is considered starting their time on the Program afresh. If they stop participating in the Gold Coat Program, protocol would suggest they be transferred out to a prison matching their custody level. In addition, if disciplinary actions arise for a Gold Coat, the individual has his tenure in the Program ceased immediately.

Initially, the local branch of the Alzheimer’s Association conducted a training program with staff and the Gold Coats team and provided a customised manual on dementia. The training was recorded to enable staff, such as Dr Steed, to continue delivering the training sessions
for new members of the team or offer topics to other members for review such as:

- the effect of dementia on behaviour
- understanding the causes and clinical presentation of dementia
- how to communicate with low-functioning patients, and importantly
- awareness of carer burnout

The training sessions can take up to 16 weeks and are conducted once a year by Dr Steed with the opportunity for current Gold Coats to attend if they want to update their skills. Dr Steed reports there is a fair amount of kudos attached to completion of the Program and their notes are highlighted to confirm their good work, which can help their record when they go before the parole board. They are awarded a certificate on completion.

**Workload**

With assistance from Gold Coats the daily routine in D Facility usually begins early with breakfast and can continue till after dinner as inmates are allowed out in the yard until 8:30pm.

At the time of my visit showering was taking place and patients were moving briskly from their cells to the bathrooms and back again, often accompanied by a Gold Coat who was there to guide them and remind them of the bathing process, helping to pour shampoo onto their hair and holding their clothes/towel away from the water.

Each Gold Coat is paid $36 a month, roughly 22 cents an hour. While not substantial by any means, it is a tangible reward they can use for themselves to buy items such as food or hygiene products but sometimes they buy items for another inmate who may not have much, for instance, on their birthday. They are paid for work 40 hours a week but quite often volunteer out of these hours, and on the weekend.

Dr Hodel reported that getting payment for the Gold Coats was one of her biggest challenges. She fought for nearly a year for them to receive some sort of financial compensation as they work hard and often out of hours. Because they live in the same building as the patients they are often called upon in their down time to help others.

**Supervision**

Dr Steed meets with the team every week and they are free to discuss issues about the Program. For instance some patients have mental health issues as well as dementia so discussion might be centred on an inmate experiencing hallucinations and what the Gold Coat’s response should be.

Dr Steed and the facility place high importance on the health of each Gold Coat and encourage them to care for their own wellbeing. Some Gold Coats can ‘overly invest’ in the role and so are reminded they don’t have to do everything, there are always others who can help. Dr Steed is always available for emotional support for issues that may affect their role such as a death in the family or going through parole, and they are encouraged to take time out.
The future
While some of the Gold Coats move on and are paroled out of prison the skills they learn in prison can’t always be transferred into employment in the community due to strict employment criteria for aged and disability care work in the community. However Dr Steed did report that a small group are now working with a social worker who is developing a program at UCLA similar to a half-way house for prisoners transferring out.

At CMC the Program is implemented without any external funding and has proved to be a very successful and cost effective intervention. There are now eleven Gold Coat Programs across California and similar models being run in other parts of the U.S. with various adaptations. Some medical units, for instance, have inmates assisting in a role similar to a hospital warden and others sit bedside patients in hospice care providing support.

A conversation with the Gold Coats
During my visit I was invited to have an in-depth group conversation with seven of the Gold Coats. The meeting lasted for two hours and provided valuable insight into the lives of these men.

It’s a way of life now; I’ve been doing it for five years. It’s part of who I am

The men acknowledge the value of the training they receive and find the updates and regular supervision beneficial. All members were quite knowledgeable about cognitive impairment and the different causes of dementia, recognising for instance that not all dementias are caused by Alzheimer’s disease. They appeared to be aware of the symptoms of cognitive impairment and how to respond to them and all reflected on the importance of ‘de-stressing’ as caregivers and the need to care for themselves.
As they reflected on their participation in the Program the following quotes were offered:

_Patience and empathy are essential for the job_

_As I have grown older I know I have become more self-aware, more compassionate_

_I wake up in the morning and I know I have all my buddies downstairs waiting for me to help them_

_I had a relative who had a stroke and I had to help them re-learn things and help them, so I knew I had the aptitude to do this job_

_I took on the job because I just like helping people._

The men get to know the patients they assist. They agree the patients’ behaviours may scare others, or give the wrong impression to people that don’t know them, but they believe they are there to protect these patients and ensure other inmates understand their ways and give them sympathy.

_A Gold Coat helps a patient file his nails_

The Gold Coats accompany the patients to the gym, help them with artwork, encourage their participation at dances and make up skits for plays. Every day there is something to do to keep them engaged and active. The activities program is varied enough to keep the Gold Coats interested as well.

Gold Coats are also available to help patients make phone calls and write letters. As one man reported:

_This weekend I will be helping one of the guys with a package request to his mother. We get the catalogue and I help him choose what he wants. Then I help him write a letter to his mother with his request. It takes a couple of hours but it means he gets what he wants….when the package arrives we ask the guards not to tell anyone as there are a lot of_
predators out there waiting to attack (once they know a package has arrived).

The group explained to me that if you have a ‘code brown’ (faecal incontinence) or a ‘code red’ (an episode involving blood such as an attempted suicide) to clean up it can be distressing but when describing a recent ‘code brown’ experience they reported:

_We just went with it; got the guy undressed and got him in the shower...you can’t lose your cool at those times._

The men explained that the training they receive helps them in these situations. They also claim the training helps them ‘misdirect and distract’ the patients who may be confused or misunderstand what they are doing. One man explained that at first he was affronted when someone lashed out and yelled at him but he realised, through his training, that this was different.

_You have to be prepared for people to spit on you and hit you_

I asked if they find it hard not to favour some inmates. They reported they try to avoid it but they do form friendships with some. One man reported that you would never show overt favouritism toward one but you do get to know which people are more vulnerable than others and need ‘watching’. They explained you have to gain the trust of the patients so they will let you support them. Some of the patients with cognitive impairment have ‘episodes’ when they will ‘explode’ but the Gold Coats explained:

_If you know the person and you know the signs you can deal with it._

They all agreed that they know they have back up and resources to call on if things get difficult.

_Trust_

Trust is an important element in the success of the Program. Trust between the staff and the Gold Coats, trust between the Gold Coats and the patients and trust between the Gold Coats themselves. One of the men explained that if something disruptive occurs he always goes back to the patient at the end of the day to check he is ok. Another Gold Coat spoke of a patient who is aware when his mood is changing and so will come to a trusted Gold Coat and say ‘I need help’ before things escalate.

The Gold Coats help each other when things get too difficult for one of them, or if they need time off to rest or regroup. They discuss their concerns with each other and can confide in each other. If they don’t feel physically or emotionally well another will ‘cover’ for them. One reported:

_It can get overwhelming, we have to rely on each other and we have to communicate otherwise it wouldn’t work._

The Gold Coats explained that when they have their weekly meetings with Dr Steed they are also given the opportunity to share their concerns and they problem solve together. They
trust Dr Steed enough to be honest with her and let her know when they feel under pressure or need a rest.

It was obvious after speaking with the Gold Coats team that the Program has built their confidence, self-worth, compassion and optimism. One described the interaction with the patients needing help as ‘uplifting’. They all agreed that the program has helped them as much as it has helped the patients.

One Gold Coat encapsulated the overwhelming benefit that can be gained from participation in the Program when he told me:

_I was helping an elderly gentleman rub lotion into his feet and legs and when I went to wash my hands the reality of the situation set in and I realised what I had been doing. I knew then that I was right for the job._

**Key Learnings and Conclusions**

- CMC offers extended periods of time in the exercise yard and freedom to wander around the unit which is beneficial to the health and wellbeing of the prisoner
- Use of inmates in the Gold Coat Program is a cost efficient intervention to care for inmates with cognitive impairment and dementia
- The Gold Coat Program provides extra support and risk management to custodial and healthcare staff
- The Gold Coat Program benefits its inmate members through training, a sense of purpose and increased self esteem
- Trust and responsibility are key to the success of the Gold Coat Program
- Effective champions such as Dr Steed and Dr Hodel are essential to the success of an inmate careworker program for people with dementia and cognitive impairment.
JEFFERSON CITY CORRECTIONAL CENTER, MISSOURI, U.S.A.

Personnel: Ms Angela Umstattd-Schmutz, Manager Enhanced Care Unit

Jefferson City Correctional Center (JCCC) is a moderate to maximum security prison operated by the Missouri Department of Corrections. It has 1930 inmates with over 600 staff. JCCC was opened in 2004 replacing the Missouri State Penitentiary, Jefferson City.

JCCC prides itself on its prison industry as part of the Missouri Vocational Enterprises program that provides a variety of opportunities for upskilling and job training to inmates. Inmates make goods for agencies and non-government organisations such as sewing quilts and bags and assembling educational kits for schools. JCCC also provides a number of educational and psychological programs for inmates such as anger management and the opportunity to gain a high school diploma.

I met staff and inmates working in various capacities and learnt about interventions such as:

- the Puppies for Parole program[^8], which provides inmates with the opportunity to train rescue dogs in obedience and socialisation before they are adopted out and
- the Intensive Therapeutic Community where difficult to treat offenders volunteer for an intensive six month program of social, psychological and spiritual adjustment; working towards a better, healthier lifestyle when they are released with greater

[^8]: http://doc.mo.gov/DAJ/P4P.php
resilience to avoid recidivism. It was reported to me that 83% of graduates of this program do not reoffend.

The Enhanced Care Unit

The Enhanced Care Unit (ECU), managed by Angela Umstattd-Schmutz, was however my main point of interest as this was where elderly inmates with high care needs are accommodated away from the general prison population.

The ECU opened in January 2011 in response to the increasing number of inmates over the age of 50 with health concerns. In the state of Missouri alone this inmate age group has nearly tripled from 6% of the prison population to 15% in the last two decades. JCCC currently has 30 prisoners over the age of 65.

As with many other states the increase has not been driven by an increase in crime but by state sentencing policies such as:

- 1979 capital murder statute that requires convicted murderers to serve 50 years before parole
- A 1984 first-degree murder statute that removed parole eligibility completely
- 1994 Truth in Sentencing Act which imposed greater mandatory sentencing overall

Case study

A 63 year old man has been in prison for over 25 years for killing a policeman while high on LSD. He recently underwent back surgery and will soon require further operations. He receives epidural steroid injections for pain every four months. He believes prisoners like him deserve a second chance after having ‘made a bad decision in life’. Ironically, drug and alcohol abuse are not only the cause of violent one-off crimes but also the reason for premature ageing and so a higher risk of developing dementia.

The ECU currently accommodates 72 patients of varying ages and health conditions including five with dementia. A large number of the patients have mobility issues and so the built environment has been modified to accommodate wheelchairs. Hand bars have been installed in the toilets and showers, and one toileting area can now accommodate an oxygen tank.

The unit is light and spacious. It is two storeyed with the more mobile patients residing in the upstairs cells. The day I visited some men were lying on their beds resting or watching TV while others were sitting around tables chatting or doing puzzles. There is a whiteboard at one end of the room that notifies the patients about the food for the day, the weather,

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doctors’ appointments that need to be attended and sometimes a saying or a trivia question to get the group talking and thinking.

Assessment and health reviews
The JCCC has a strong focus on mental health. A team of mental health workers meet regularly to discuss the behaviours and health concerns of prisoners. If cognitive impairment or dementia is identified care plans are created to ensure appropriate strategies are put in place to enable correctional staff to cope with behaviours of dementia and ensure safety for the person and those around them.

Daily Living Assistants
Like the Gold Coat Program in CMC, JCCC also employs trained inmates to assist the older inmate-patients. Called Daily Living Assistants (DLAs) these men undertake similar tasks to the Gold Coats, guiding and supporting the patients with their ADLs as well as recreational pursuits such as chess, cards, jigsaws and music therapy. The DLAs live upstairs in the unit, unless an older patient requires a DLA to be housed in the same cell on the ground floor, for assistance. Their responsibilities are shared amongst the patients so that one does not become burdened with a high need patient and it gives the DLAs the opportunity to learn about each individual’s needs.

The DLAs are trained by an external nursing educator and in Australian terms would be considered to have the skill level of a ‘personal care attendant’ with basic knowledge of dementia care. The DLAs provide cost effective, safe, quality care to ageing patients but also, as Ms Umstattd-Schmutz reported, the work provides the DLAs with ‘a sense of restorative justice – a way of making amends’. While most DLAs are volunteers some are paid a small wage.
Unfortunately I was not able to interview the DLAs at JCCC however from my observation they appeared to be younger than the men in the Gold Coat Program at CMC and their training not so intensive. Their gentleness and consideration for the older patients was evident however and the patients seemed happy to have them there to help.

If the older patients in the prison require more specialised nursing care they are transferred to the infirmary, which is not unlike a hospital with single rooms. The infirmary can accommodate 29 patients and also houses an outpatient clinic, x-ray and dental service and provides medical care for younger patients. It has two padded rooms for patients requiring seclusion to ensure their own safety and the safety of others.

When a person nears the end of their life they are moved to the hospice for specialised palliative care. DLAs can support the dying patients and family members are welcome to visit. The staff in the hospice informed me that getting the patient reconnected with family before they die is paramount and they ‘pull out all stops to find family’ as they are often disconnected due to their crime.

The staff I met at JCCC were kind, compassionate people who are trying to do the best for their patients with limited resources. The staff are proud of the work they do and the respect shown to them by patients and other inmates reflected the care inmates are given in the ECU and other areas of the prison.

Key Learnings and Conclusions

- The light and space in the ECU is a good example of an environment that accommodates the living requirements of frail aged inmates
- Health care training for staff and inmates covered a range of topics and included specific work around dementia care particularly management of behaviours
- Younger healthy inmates can assist ageing prisoners to provide cost effective care and at the same time be undertaking redemptive work which increases their skill level and sense of self
- While rehabilitation and re-entry to the community is a focus of the prison, for those ageing patients that will not have that option there is good compassionate care.
FISHKILL CORRECTIONAL FACILITY, BEACON, NY, U.S.A.

**Personnel:**  Dr Joseph Avanzato  
Dr Paul Kleinman

*People who need health care should have the care they need*

Dr Lester Wright (former Chief Medical Officer)

New York State has a prison population of 50,000 and Fishkill Correctional Facility in Beacon houses 1700 of these inmates at all levels of security. The facility has two housing units, the main unit with 26 dormitory style medium security units. All inmates at the prison are required to ‘work’ unless deemed medically unfit and programs exist for those who are under 65 without a high school diploma to attend ‘school’ and increase their standard of literacy.

The other unit at Fishkill is the Regional Medical Unit (RMU), which is designated a Mental Health Level 1 Facility and is one of five RMUs in the state of New York. Fishkill RMU serves the health needs of 10 prisons in southern New York State.

Fishkill’s RMU was built in 2006 and provides comprehensive health care for temporary and permanent patients. Services include rehabilitation, post-operative care and residential care. The RMU houses a full service pharmacy filling approximately 6000 prescriptions/month, a dental unit, X-ray unit, dialysis unit, emergency care (including telemedicine), a physical therapy and rehab room. Medical specialists and allied health professionals visit the RMU and a doctor is on call 24/7. There is an infirmary consisting of 20 beds.

The environment at RMU is not dissimilar to a hospital with a calm, safe atmosphere and rooms painted in light colours. It is very well maintained and spotlessly clean. Rooms are double and single with some four bed rooms for very short-stay patients. The hallways and doorways are wide to enable wheelchair/walker access.

The average age of permanent inmates in the RMU is around 60 years, much older than the average age in most prisons in the state.
The Long Term Care Unit

This 30 bed unit is on the 2nd floor of the RMU and is considered a ‘resource for the state’ as it houses patients from other prisons who require long term care and those who cannot stay in the infirmary. Patients can be any age and have a range of diagnoses including cancer, emphysema and heart disease. Staff include a physician, nurses at all levels and a dietitian. There is also counselling, ministerial and recreational support. Hospice care is provided in this unit.

The Unit for the Cognitively Impaired

The Unit for Cognitive Impairment (UCI) was the focus of my visit to Fishkill. It houses those with dementia and other mental health conditions. It is the only UCI in the state so transfers in from other prisons are common.

The UCI is on the 3rd floor of the RMU and currently houses 24 patients with a variety of health conditions that contribute to cognitive decline and dementia including Alzheimer’s disease, HIV AIDS, TBI, Huntington’s disease and mental health illnesses such as schizophrenia. Currently 21 of the 24 patients have dementia. The unit has capacity to house up to 30 patients and has had 71 admissions over the last 10 years.

Environment

The UCI is spotlessly neat and clean in the mode of a quality hospital setting. All rooms have an open door policy 24/7 unless the patient is under special supervision. Some rooms are labelled with a photo and name to identify their occupants and all have their own bathroom.

There is little colour in the décor although I was told the unit is decorated for holidays. All patients eat communally unless they are too sick and need to stay in their room. There is a recreation room and on the day of my visit it was occupied all day by people engaging with one another.

Staff

The Unit employs one doctor, two psychiatrists who work a combined 20 hours a week, a full time social worker, a full time psychologist, trained registered nurses, nursing assistants, corrections staff and a recreational officer. The recreational officer also liaises with community agents through the parole process to ensure a seamless transition for the patient back to their family.

Training for dementia care and cognitive impairment

In the UCI there is a strong emphasis on training and security and civilian staff train together with clinical staff to understand the needs of the patients.

Initially 40 hours of training was delivered by the local chapter of the Alzheimer’s Association to all staff at all levels. The organisation developed a power point presentation for prison use and now nursing educators provide the training to new staff and refresher courses to current staff.

Peer assistance

Inmate assistance via similar programs to the Gold Coat program in California is not allowed in New York State due to the risk of litigation for using untrained personnel. However
inmates are allowed to be trained to sit and comfort those in palliative care. The training is done within the prison and the inmates are entitled to sit with the dying person 24/7 if they want.

**Screening and assessment of patients**

Often a patient, from any of the ten feeder prisons, with cognitive impairment or dementia has been assisted by peers in the mainstream prison and gone unnoticed due to the slow progression of some dementias and also denial on the part of the patient.

However peers often report their concerns, sometimes anonymously, to the doctor or a nurse. A report is then sent to the medical team to assess the person in question.

Referrals from other prisons are taken based on information discussed during the referral process but if a prisoner is assessed and found not to be cognitively impaired they must return to their referral prison.

A medical diagnosis of dementia or other irreversible cognitive disorder must be established. If not, two or more of the following must be established:

- Walking without purpose or attempting to leave the assigned area
- Unusual behaviour which is not dangerous to self or others
- Verbally inappropriate behaviour (yelling, foul language)
- Disturbed sleep pattern
- Disoriented requiring assistance with ADLs ¹⁰

The patient must require treatment at an inpatient level and may need specific nursing care. The protocol stipulates the following inmates will not be admitted the UCI:

- Inmates who are predatory or physically strong and aggressive
- Inmates with severe physical limitations
- Inmates who need total care (bathing, ambulation, dressing, eating) ¹¹

The referring prison will provide documentation such as clinical test results, Mini Mental State Exam (MMSE) or GPCOG Patient Examination results, Comprehensive Medical Summary (CMS) and disciplinary record. During my visit I had the opportunity to witness a new patient take the MMSE with psychologist Dr Paul Kleinman. The care and understanding shown to the elderly man was commendable.

On arrival the inmate is held as an inpatient while Admission protocol (Attachment 2) is carried out including medical evaluation, psychiatric evaluation, psychological evaluation and a neurological evaluation for diagnosis if required. Once it has been determined that the person is cognitively impaired they are admitted to the Unit

Once a patient is admitted their CMS is updated regularly to assess their needs and amendments are made accordingly as their health changes. Further cognitive testing is not mandatory and only conducted if requested by the Chief Medical Officer.

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¹⁰ Fishkill Correctional Facility Unit for the Cognitively Impaired Admission Protocol

¹¹ Fishkill Correctional Facility Unit for the Cognitively Impaired Admission Protocol
The RMU holds a Patient Care Conference (PCC) every quarter for each patient and includes medical staff, a dietitian, the chaplain, a pharmacist and nursing staff. Smaller reviews are conducted weekly for specific cases.

**Exercise and Activities**
There are a variety of activities for the UCI patients including music, poetry, and pet therapy. However, due to the high level of security and regulation in this unit simple board games and puzzles are difficult to bring in to the unit. Unfortunately there is little outside activity in the small outdoor area provided. However some do go to the physical therapy room for exercise.

**Disclosure of Diagnosis**
Patients are not always told they have a diagnosis of dementia, unless they ask.

Family visits are allowed and can be 24/7 if the person is in hospice care. Family is not told about a diagnosis of dementia unless the person with dementia gives permission for disclosure. However all patients are given autopsies after death which are then made public so the family eventually has the opportunity to be informed.

During my visit I was told that compliance with the HIPAA Privacy Rule\(^\text{12}\), which establishes national standards to protect individuals’ medical records and other personal health information can, in some instances, interfere with transfer of knowledge outside the medical realm and so negate opportunities for better health and wellbeing for the patient.

When the patient is transferred to the RMU they are given the option to make and appoint a Health Care Proxy \(^\text{13}\) and make an Advance Care Directive. Patients are also given the option to have ‘Do Not Resuscitate’ on their records but, I was told, very few do.

Records may indicate that the person has dementia but the actual causal illness such as Alzheimer’s disease is not always noted. However ‘needs assistance with ADLs’ is commonly noted.

**Transferring out of the UCI**
When transferring patients from Fishkill the risk of recidivism is always considered and particular patients with convictions, such as child sex abuse, are rated on the likelihood of relapse.

If the patient requires urgent medical attention and the state body will not assist UCI will send them to Emergency Care and have them admitted to hospital. If a patient is paroled on medical grounds, records will often state ‘medical complications’ rather than dementia.

Patients requiring hospice and palliative care who cannot be paroled out on medical grounds are transferred to the Long Term Care Unit or sent to another prison with care for ageing which is why most patients in the UCI have mild to moderate impairment.

There is only one state run nursing home in the state of New York and they will not take older patients with dementia preferring they stay in the long term care at RMU. The other

\(^{12}\) [http://www.hhs.gov/hipaa/for-professionals/privacy/]

\(^{13}\) [https://www.health.ny.gov/professionals/patients/health_care_proxy/]

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privately run nursing homes are equally reluctant to take former prisoners as residents. However if the patient can be transferred via a hospital or is wheel-chair bound they are more likely to be accepted.

When I asked if cognitive impairment is ever considered the cause of a crime I was told that sometimes prisoners with cognitive impairment are sent from court straight to the RMU.

**Case Study**
In 2006 a 26 year old who had spent the first 12 years of his life in foster care, has an IQ of around 50 and physical signs of drug abuse was arrested for rape. He suffers from PTSD thinking gangs are chasing him and was sent to the Special Needs Unit in NY State but is now at Fishkill.

**Case Study**
A man in his 60s without any criminal history test drove a new car and ‘forgot’ to come back with the car. He was charged with grand theft auto and is now in prison without any assessment being undertaken for cognitive impairment.

Avanzato believes there are many more inmates in prisons whose symptoms are not being picked up. He explained: if there are 55,000 prisoners in the state of New York, and there is a skew of 2.5% at one end of the population considered to be high functioning, then it is easy to assume that the 2.5% at the other end would be cognitively impaired. But, referrals are very low for this cohort with ICU seeing only one or two a month.

It is a pity more patients with cognitive impairment or dementia are not being referred to Fishkill’s RMU to take advantage of this well-run and well-equipped medical unit.

**Key Learnings and Conclusions**
- Skilled, coordinated, well trained staff can meet the needs of people with dementia in a prison setting
- Dementia and cognitive impairment need to be an important consideration in sentencing to ensure appropriate placement
- A more concerted screening mechanism is required for other mainstream prison populations to assess those who are not being identified with cognitive impairment or dementia
- The expertise that exists at RMU at Fishkill could be used to collaborate with a residential care agency in the community to enable the transfer of people with dementia who need long term or hospice care.
60 WEST NURSING HOME, ROCKY HILL, CONNECTICUT, U.S.A.

Personnel:  Mr Mike Landi, VP Operations
Ms Jess Dering Administrator
Mr Robert Bourke VP Psychosocial Services

Not all prisoners with dementia and cognitive impairment who require ongoing specialised care have family who can care for them upon release. Moreover, finding an appropriate aged care placement is difficult when victims’ rights are a priority consideration, as well as the safety of other residents in the facility and the community. However ‘60 West’ in Connecticut seems to have found a solution.

60 West is a nursing home in Rocky Hill, Connecticut providing care for individuals who are difficult to place. Referrals come from the Department of Mental Health and Addictions Services (DMHAS) and the Department of Corrections (DOC).

The Mission statement of this nursing home is to provide enrichment of patients’ lives through specialised care, dignity and acceptance.

The core values of 60 West are:
- Cultivate a diverse team with positive relationships
- Constant vigilance to maximize safety
- Be passionate about learning
- Be open-minded and never judge
- Engage the individual
- Encourage originality, embrace change
60 West was established in 2013 amidst much protest by the Rocky Hill Community. Graffiti was left on the property before it opened, the postman wouldn’t come up the driveway and neighbours created a website depicting young convicts in orange jumpsuits! However the State supported the establishment of the nursing home in recognition of the care and accommodation needs of these particular residents and the privately run iCare’s capacity to provide a quality, cost effective nursing home.

The State could see employment opportunities for the town and no extra drain on community services than the site’s previous occupant who also ran a nursing home. As the facility runs Federal programs the Federal Government will match funds issued by the state thus reducing costs for the state.

Residents
Most of the former prisoners have transitioned from inpatient level of care or infirmaries run by the Department of Corrections and all have been legally released from prison, even though some are on parole. I was told if a place like this didn’t exist many of them would have been dropped off at a hospital Emergency Ward.

Many of the ageing residents have co-morbidities such as brain injury, cerebrovascular diseases, Parkinson’s disease, cardiovascular disease, Huntington’s disease and the effects of drug and alcohol abuse, dementia and mobility issues.

Screening
Each patient is comprehensively evaluated before admission to 60 West and not accepted if seen to pose a risk to the public. Consequently the staff report there are very few ‘incidents’ due to the thorough screening process.

The Preadmission Screening and Resident Review (PASRR) tool is used during the admission process. This tool determines whether individuals require long term residential care and cannot be cared for in the community. The nursing home must ensure that the individual’s psychological, psychiatric, and functional needs are considered alongside their personal goals and preferences. As 60 West is Medicaid certified it can fulfil the requirements of long term nursing home care for the ‘difficult to place’ residents. Many of whom have mental health issues.

I was told that those who did not commit premeditated crimes are often the easiest to care for. They usually do not have mental health issues, have served long sentences and are used to a regulated way of life.

14 https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Preadmission-Screening-and-Resident-Review-PASRR.html
The environment
On the day I visited 60 West it had the environment of a quality nursing home. The residence is clean, welcoming and well maintained. The entry leads directly into a foyer where some of the residents, who were seated, greeted me on arrival.

The facility can accommodate up to 95 residents but as it currently only houses 70 people (both males and females) the rooms are spacious with room to move about. All of the large bedrooms are double rooms and each has an ensuite.

I was accompanied by my three hosts for a short tour of the building and all three were happy and compassionate in their engagement with the residents we passed in the corridor or met in their rooms. Equally the residents I spoke with told me they liked living at 60 West and appeared to have a good sense of wellbeing. There appeared to be strong evidence of person-centred care with staff ensuring the residents feel that they are in their ‘home’ by ‘managing their milieu’. I also spoke to nursing staff who reported they love their job and obviously had a good working rapport with one another.

There is a large outdoor area where garden therapy is undertaken in raised garden beds for easy access. Residents are encouraged to garden and grow food to cook and eat. The garden area is also used for outdoor activities and parties and the week I visited a large life guard’s chair was sitting in pride of place, leftover from a recent beach party.

There is a therapy room used for specialist treatments such as occupational, speech and physical therapies. Life enrichment courses can be undertaken alongside substance abuse therapy provided by counsellors who come in for group therapy. Individual therapy is also available for those who require long term support.

There are two TV rooms, one with a couch for ‘lounging’ rather than the hard vinyl stiff back chairs you often see in similar nursing homes. One room also had an air hockey table, lowered, to make it accessible for play by residents in wheel chairs.

Pet therapy is provided by two cats that live in the home, and if the residents want, the cats are allowed to sleep on the residents’ beds.

Staff
60 West operates with 24 hour skilled nursing care and assistants for support with ADLs. It employs onsite physician services, secure dementia care, hospice and palliative care, mental health care, rehab services such as occupational and speech therapy, social work, pastoral care, dietary services and recreational therapies.

A chaplain has been employed from the outset. I was told that as chaplains often play an important role in prison, it was beneficial to ensure continuity for some residents to have access to a chaplain and particularly helpful to those transitioning from prison to a nursing home environment. The chaplain is there for the residents and the staff alike conducting services and also providing pastoral care.

15 Comment by host Bob Bourke
Management report that staff who work at the facility apply to work at 60 West because they want to work in this sort of environment. They know the type of residents they will be caring for when they apply and accordingly recruitment is easier because of that.

**Staff training and care**

My hosts reported that their biggest Investment is training. They have one full time nurse educator who does all training for staff, including the state requirement of 10 hours dementia training per year. Dementia training continues beyond the obligatory hours through day-to-day training as the need arises, especially training in ‘de-escalation’ and coping with behaviours.

Management believe training in behavioural programs is the best way to deal with the residents at 60 West. They claim to ‘treat them as people not as prisoners who deserve punishment’. They try not to label residents but treat each individually and according to their need.

If a resident is receiving palliative care their family is allowed to visit at any time just as they would in any nursing home environment. Once the dying process begins hospice care is brought in to accommodate the needs of the individual.

In discussion with my hosts I learnt that iCare management had already run facilities with behavioural programs for mental health patients and so had valuable experience to bring to this facility. They have a strong ethic of specialised, non-judgemental care and claimed: *we are health care professionals not correctional officers.*

**Stigma and risk**

Management personnel are well aware of the community backlash that occurred when the facility was first proposed and then opened, but they assert the facility’s residents are not fit and healthy, but frail aged, and very often immobile – a consideration that seems to be forgotten by many in the community.

Both Bourke and Landi claim stigma is one of the greatest causes of discontent in the community. However they claim it is 60 West staff who enable the reduction of stigma by educating their families and friends, who in turn, educate others. Landi and Bourke say they encourage people to come and see how the facility is run, especially those who fought against its location in their neighbourhood.

**The future**

In light of the ageing prison population, 60 West is aware that their success could result in similar facilities being established in other areas. In fact, ten other states have approached them for advice about starting a similar facility.

Staff from the Department of Mental Health and Addiction Services visited recently and were reported to be overwhelmed at the success of the facility. Furthermore Connecticut state representatives recently approached them about the possibility of employing former inmates who have nursing skills (such as the Gold Coat Program in California) or who have
certificates in nursing aid. Landi and Bourke report they would consider these workers as long as they did not have particular convictions such as elder abuse. Again there would be a stringent process of recruitment involved.

This small scale setting with an emphasis on person-centred care seems to be ideal for placement of former prisoners. Each individual’s needs are met no matter what challenges are involved. As reported to me: they are not difficult to care for they are difficult to place.

Overall 60 West was a very impressive establishment and there was obvious pride in the staff who worked there, not just to have proven the Rocky Hill community wrong about the dangers they would bring to the neighbourhood but about the benefits they have been able to provide, in a calm person-centred way to the residents who live there.

The non-judgmental approach to all residents is an integral part of 60 West’s success and its essence is encapsulated in Bob Bourke’s question:

Is their history significant to the care they are entitled to be given?

Key Learnings and Conclusions

- State and privately run organisations can work together effectively to meet the needs of the state’s prison system
- A reputable residential care provider can have the necessary expertise to accommodate former prisoners with dementia
- Well trained, cooperative staff are essential for quality residential care
- A calm environment and person-centred care can reduce behaviours of dementia
- A non-judgemental approach is integral to the care of frail older people who are ‘difficult to place’
- Facilities such as 60 West will begin to reduce the stigma associated with the transfer of frail aged prisoners into the community.
INTERVIEWS

In this section I outline interviews conducted with individuals from different areas of expertise in the prison sector.

Dr Linda Redford, University of Kansas Medical Center, Kansas, USA

Dr Linda Redford has developed and implemented training programs for staff at a number of prisons, to enable them to meet the needs of ageing prisoners, including those with cognitive impairment and dementia.

Redford acknowledges the increased number of ageing prisoners brings similar health concerns to the mainstream ageing community but treating them appropriately within a prison environment can be difficult and costly.

Often ageing prisoners are left in the general prison population with correctional officers who, untrained in dementia awareness and dementia care, punish prisoners for inappropriate actions. The training programs Dr Redford delivers to prisons have assisted staff to become more aware of the symptoms of dementia and to understand the behaviours of someone in cognitive decline. Redford explained:

*The officers need to be able to recognize the difference between someone who is acting out and someone suffering from dementia.*

Redford also spoke of the value of enabling interaction between health and correctional staff:

*By encouraging a dialogue between prison health staff and the correctional officers, information regarding a specific inmate’s behaviour and their health condition can be used to determine appropriate care and discipline.*

**Education and training**

Redford also educates inmates in some prisons in palliative and hospice care which enables them to become ‘daily living attendants’ to people with dementia and geriatric health conditions. These inmates, who must meet very strict criteria, often live in close proximity to the ageing or dying patient, support them in their ADLs, their recreational activities and transport them around the prison.

Redford claims educating staff as well as the inmates enhances the culture of the prison and provides a common ground of understanding between the two cohorts. Correctional staff are more empathic and accepting of behaviours and the inmates have ownership of something worthwhile.

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Dr Brent Gibson, Vice President Operations, National Commission for Correctional Health Care, Chicago, USA

The National Commission on Correctional Health Care (NCCHC) is a not-for-profit organisation established in 1975 under the American Medical Association to evaluate health care in correctional facilities in the U.S. and to develop policy and programs to set standards for care. It employs both core staff and many subcontractors to assist with peer review and education.

I met with Chief Health Officer Dr. Brent Gibson to discuss the current work of NCCHC and healthcare standards for those with cognitive impairment and dementia in prison. Gibson explained that while their work does not have a direct focus on geriatrics it does include the ageing population in the various programs and studies it undertakes.

In 2014, NCCHC updated their widely recognised Standards for Health Services. Using the Standards as a basis, NCCHC offers accreditation to correctional facilities who volunteer to have their delivery of health care assessed for compliance with the Standards. These Standards present recommendations for those being accredited to meet professional, legal, and ethical requirements.

The Standards provide a framework for correctional facilities to produce the best outcomes for inmates and staff. Compliance with these nationally recognized standards provides facilities with a guide for acceptable care for inmates and direction for ongoing improvement. By adhering to these Standards facilities can reduce the risk of inadequate care and safety procedures as well as the risk of financial or legal penalties for non-compliance with universal care standards.

The Standards are highly recognized as authoritative and address nine key areas of health care:

- health care services and support
- patient care and treatment
- special needs and services
- governance and administration
- personnel and training
- safety
- health records
- health promotion
- medical-legal issues

The Standards also provide indicators to define quality outcomes and aid in self-assessment, guidelines for facilities of various sizes and best practice recommendations.
The NCCHC is also recognised for its standards and accreditation for opioid treatment programs and is the only body to focus on corrective facilities that has the backing of the Substance Abuse and Mental Health Services Administration. Facilities providing care for those living with the effects of substance abuse and mental health conditions would be treating many inmates with cognitive impairment and dementia, so the work of this authority goes some way in addressing their needs and ensuring they are met.

The organisation also publishes a series of Position Statements emanating from work they have done in specific fields. These are used as guidelines for special needs groups such as those affected by drug and alcohol abuse, HIV AIDS and women’s health issues, all of which could include those who are cognitively impaired.

Gibson told me that currently a very significant concern is the escalating mental health crisis in the U.S. With inadequate numbers of dedicated mental health treatment facilities nationwide, sheriffs in particular have to deal with offenders in county jails where there is often inadequate experience or training in mental health care.

Education programs are also provided by NCCHC during their highly regarded conferences. The Certified Correctional Health Professional program recognises individuals who have demonstrated expertise in leadership and the delivery of good health services within correctional facilities.

**Key Learnings and Conclusions**

- The NCCHC is a prominent national not-for-profit organization working to ensure rigor and quality care amongst U.S. correctional facilities alongside continuous reflective learning and improvement
- Recognition of the need for extra mental health training and support for county sheriffs who have responsibility for providing services to the U.S. jail population, including a substantial segment with mental health concerns
- Given the growing ageing prison population, geriatrics and care for age-related disorders like dementia is an important area for providers and administrators alike to develop and maintain competency
- There are clear benefits for institutions to comply with NCCHC Standards and then seek accreditation which validates this compliance.
Prof Tina Maschi, Fordham University Graduate School of Social Service, New York, USA

The influential and informative work of Prof Tina Maschi \textsuperscript{xviii, xix} underpins the type of quality care work being carried out across the U.S. in the programs described in this project. I was fortunate to meet with Maschi in her home town of New Brunswick, NJ.

Maschi has long been an advocate for the vulnerable and disadvantaged. She advocates for prisoner rights and in recent times has pushed for change regarding the care of prisoners with dementia and the need to use a human rights approach in their care and accommodation.

While important developments have taken place regarding the diagnosis and treatment of dementia Maschi claims ‘the same initiatives have not always been extended to the large and growing cohort of adults with dementia in prison’. \textsuperscript{xx}

Maschi was one of the first to advocate for reform, due to the vulnerability of prisoners with a diagnosis of dementia. She reasons it’s not surprising that the risks for dementia in prison are high due to the harsh prison environment. A setting that historically was primarily for punishment where small overcrowded cells and cruel and violent treatment at the hands of other inmates can be the norm. Furthermore she believes the mental health of prisoners has not always been a priority, especially for those whose mental health deteriorated after incarceration.

In the work Maschi has undertaken she highlights the denial of basic human rights of dignity and respect and the right to adequate health care within prisons until very recent times. While she acknowledges the good work being undertaken in a number of prisons across the U.S. she would like to see a national strategy developed across the country with practice, policy and research responding to what she calls the ‘growing crisis among ageing prisoners in the U.S. prison system’ \textsuperscript{xii}.

Maschi stresses an appropriate response must have a multi-layered approach due to the complex nature of dementia in the prison setting. Her best practice recommendations\textsuperscript{xxii} include:

- a continuum of care, due to the fatal and progressing nature of dementia - from screening to palliative care
- early detection and disclosure of diagnosis
- person-centred care and treatment
- quality education for staff and other inmates.

Importantly Maschi believes that prisoners should be educated about their rights early in their prison career, especially their right to make their own health care decisions, make advance care directives and participate in their advance care planning. If staff know how to
test for an individual’s cognitive capacity to make decisions patients can still participate in planning their own life course if they have the capacity to do so.

While speaking with Maschi she pushed the notion that transitioning older prisoners out of the system must be a paramount consideration when planning strategies to deal with their future health care and wellbeing. In a comprehensive analysis undertaken by Maschi and others xxiii regarding the compassionate and geriatric release laws that exist in 47 states Maschi recognises the existence of the legislation as hope for frail ageing prisoners but claims their application and implementation is inconsistent across the U.S. If there is evidence that prisoners with dementia can be better cared for outside prison rather than inside Maschi believes there should be a pitch to government by authorities in the geriatric space for compassionate release alongside the consequent benefits of reducing costs and responsibility to the state.

In general, the work that Maschi xxxiv and others have undertaken highlights the urgent need to address the future care for ageing prisoners including replication of release programs established around the world where prisons work with community and families to care for dying and elderly prisoners.

**Key Learnings and Conclusions**

- The human rights entitlements of people living with dementia in prison need to be addressed and acted upon
- Screening and assessment needs to take place as early as possible to ensure the inmate still has the capacity to make decisions about their future care
- The harsh prison environment can increase the risk of dementia and mental health conditions amongst inmates
- A national strategy for the care of people with dementia in prison should be set up across the U.S. and in other countries where practice, policy and research encompasses the good work being done to respond to the lack of initiative in other locations
- The geriatric interdisciplinary professionals are in a position to influence policy
- Early release for dying and elderly prisoners into community or family care would relieve the human, social and economic costs of caring for older prisoners in prison
DISCUSSION

Evidence collected for this project suggests that while mandatory and longer sentencing continue; numbers of older first offenders increase; and the absence of alternative accommodation for prisoners with mental health conditions is prolonged, the instigation of good dementia care is essential for the individual, the staff who work with them and the people they live with.

My visit to Rimutaka prison in New Zealand provided the opportunity to engage with an Australian neighbour and observe programs in place to assist and support people with cognitive impairment and dementia living in prison. The HDU at Rimutaka is leading the way in New Zealand and offers an opportunity for Australian prison authorities, as geographical neighbours, to work in collaboration to develop optimum care outcomes, as both country’s’ ageing prison population increase.

At Rimutaka Prison however the sense of overcrowding and urgency to meet the needs of people living with dementia in prison was not as evident as it was in the U.S.

The prisons I visited in the U.S., and the nursing home for ‘difficult to place’ residents, provide evidence for the need to address an urgent and growing concern about the numbers of people living with cognitive impairment and dementia in prison. The innovative and caring programs being implemented in the U.S. can also guide Australia in the way we approach the care of our ageing inmates.

All prisons I visited and the people I interviewed indicated a person-centred approach is imperative for the inmate-patient due to the diverse range of causes of cognitive impairment and dementia, alongside the diverse ways in which each cause can play out. Individual care plans are created for patients in all the units I visited and regular reviews are undertaken. However there is a striking need to screen for dementia as early as possible to ensure a timely care plan is implemented.

My investigation found that many people with dementia living in prison go unnoticed for lengthy periods of time, often enduring confusion, memory loss and cognitive decline alone without appropriate treatment and support. Regularly it’s not until a person’s changed behaviour causes concern for themselves, correctional staff and other inmates that their symptoms are identified.

Educating correctional staff and mainstream inmates in all prisons about the symptoms of dementia and cognitive decline is a vital step toward improving the health, safety and risk management of inmates. Early identification of cognitive decline means early diagnosis and early intervention and treatment. Furthermore in some prisons patients were not formally diagnosed with an illness that causes dementia, such as Alzheimer’s disease, but were simply assessed on their functional capacity. This means that many patients are missing out on appropriate medical treatment and the opportunity to further reduce the behaviours of dementia that can be distressing to them and those around them.

Some of the prisons provide dementia-specific training on a regular basis but others did not. Knowing how to quell and cope with behaviours of dementia is an important tool but other aspects of dementia also need to be addressed such as:
how behaviours of dementia will change over time
how the environment can impact on the person’s state of mind
how the person’s physical wellbeing can be impacted by dementia, for example, by the increased propensity to fall and
the very specific nature of dying with dementia.

Dementia-specific training on site by trained educators increases cost effectiveness and ensures the capacity for expert knowledge is always at hand.

All the prisons I visited use their own staff as well as outside agencies when required and all work together to offer a wide range of services to inmate-patients. The use of integrated care to manage the complexities of people ageing in prison proves correctional systems are now acknowledging the means to quality care and safety outcomes. This was especially relevant in CMC and Fishkill prisons that are feeder prisons for inmates requiring extra care.

While the modus operandi of the stereotypical correctional officer prioritises safety and adherence to rules the staff working in the units I visited also prioritise compassion and care in their day-to-day work with patients. Staff I spoke with emphasised the need to be non-judgemental and to treat each patient equally and individually.

I found evidence of a human rights approach and acknowledgement of the inmates’ entitlement to have their care needs met, no matter their crime. There was significant evidence that collaborative, holistic and integrated care from assessment to death ensures the human rights of the inmate-patient are upheld.

Risk management is inherent in the care of someone with dementia especially in a prison setting and there was obvious evidence of this in all prisons. However there is also a need to take risks occasionally to allow for flexible and holistic care practices. 60 West nursing home, of course, is a case in point. Equally the use of inmates as care assistants at CMC and JCCC and the risk to allow patients and Gold Coats to have their own cell key at CMC is evidence of successful risk taking.

The success of inmate-peer assistance such as the Gold Coat Program at CMC highlighted how quality and cost effective care can be provided with benefits to all stakeholders. It was good to learn similar models are being rolled out across the U.S. including the suggestion to use trained inmates once they are released in care facilities such as 60 West.

Physical and social stimulation is important to everyone’s health and research xxv tells us physical and social stimulation is particularly beneficial to the wellbeing of people with dementia. The opportunities for social interaction and exercise varied across the sites that I visited. While CMC’s vast open area was not aesthetically pleasing with its drought ridden fields it provided a wonderful opportunity for inmates to walk, exercise and socialise. Rimutaka’s HDU and others encouraged socialisation but opportunities for physical exercise were not always available in all sites.

The ageing prison population around the world means correctional systems are facing the high cost of providing special physical accommodations, support for inmates who need assistance with ADLs, aged care and hospice care, all within a high security setting. It was therefore surprising to learn from 60 West personnel and my interview with Maschi that so many states in the U.S. have legislation for compassionate and geriatric release, but are not
utilizing them to relieve overcrowding and the high cost of aged and dementia care in prisons.

The New Zealand and U.S. personnel I interviewed emphasised the need to investigate alternative accommodation for frail aged inmates including the option of safe compassionate release into community care. It was suggested that a smooth transition from prison to community occurs when good working relationships between correctional authorities and community agents exists. Specifically, 60 West personnel reported the challenges they faced with stigma and neighbourhood concerns but, with backing from the state government who could see cost efficiencies, accessibility to information about the facility in the neighbourhood, and iCare’s good reputation they are quietly providing quality nursing home care to ‘difficult to place’ residents.
CONCLUSION

Good dementia care in a high-security environment is challenging however some prisons in the United States and New Zealand have faced these challenges head on and implemented creative and caring interventions to meet the needs of prisoners with dementia and cognitive impairment. But for many, the task is overwhelming.

Victims’ rights of course must be acknowledged and safety for the prisoner and others is integral to success. However as dementia is a progressive degenerative condition that in most cases renders a person incapable of re-offending alternative and suitable care facilities need to be considered and created either within the prison walls or in specific community sites. This could alleviate current overcrowding in Australian and overseas facilities, provide cost effective specific care in central locations and appease the rights of victims.

While Australia’s ageing prison population is increasing at a rapid rate the numbers are still relatively small compared to other countries, especially the U.S. However it is important for Australia to plan for the future care of this vulnerable cohort now. Australian correctional and health care authorities should use this time, while numbers are still manageable, to collect data and establish the actual number of people with dementia in the Australian prison system and work toward policy and practice that can relieve the human, economic and social costs of caring for these people as they age.
RECOMMENDATIONS

In light of the key learnings from this investigation my recommendations for the Australian correctional healthcare system are that:

- An evaluation be undertaken to determine the number of prisoners living with, or the onset of, dementia in the Australian prison system

Training and education

- Custodial staff and mainstream prisoners be educated to identify people with dementia and cognitive impairment as early as possible
- All custodial and health care staff are given dementia-specific training about the care of people with dementia from diagnosis to palliative care
- All custodial and health care staff are trained to manage the inherent risks associated with people who have dementia but also to allow risks to be taken in the name of good care practice

Screening and health checks

- Cognitive assessments are carried out by health professionals on a regular basis alongside other regular health checks for prisoners over 50 years
- Cognitive assessments are mandatory on entry to prison for prisoners over 50 years
- Custodial and health care staff work together and with other agents to obtain quality care outcomes

Healthy lifestyles for all prisoners

- All prisoners are required to undertake physical, social and intellectual stimulation on a regular basis according to their physical and intellectual capacity
- All state governments in Australia seek to reduce the risk of dementia in prison by educating all prisoners and staff through programs such as Alzheimer’s Australia’s Healthy Brain Ageing or the Is It Dementia? Toolkit

Alternative accommodation

- All state governments to investigate the possibility of moving prisoners in middle and end stage dementia, to alternative accommodation within the prison or the community

National Standards

- The Australian and state governments adopt a national approach of care for prisoners with dementia and develop Standards of care to be implemented across all Australian prisons.
ATTACHMENTS:

ATTACHMENT 1 - RIMUTAKA HIGH DEPENCY UNIT

Treatment Plan Template – End of Life HS 3.11.1
(This is a base template and should be adapted according to clinical requirements)

Prisoner name: XXXXX
Date Treatment Plan started:22/10/15
Review date: 21/4/16

**Key Staff Involved**
Prison Health Services Staff, Custody Staff and Community Probation Staff
Name _______ Designation / Role RN
Name _______ Designation / Role RN
Name _______ Designation / Role HCM
Name _______ Designation / Role RN TL
Name _______ Designation / Role MO

**External Providers** (if required)
District Health Board: Hutt Valley DHB
PHO __________________________
Doctor / Consultant ______________
Nurse __________________________

**Whanau / Family** (if required)
Name : Contact
Name: J  Contact EPOA as per patient.

<table>
<thead>
<tr>
<th>Date</th>
<th>Clinical problems and / or goals</th>
<th>Clinical interventions</th>
<th>Person(s) to action</th>
<th>Date resolved</th>
</tr>
</thead>
<tbody>
<tr>
<td>21/4/16</td>
<td><strong>Physical</strong></td>
<td>To stay in HDU observe changes in Physical needs.</td>
<td>RN/HCA</td>
<td>Ongoing</td>
</tr>
<tr>
<td></td>
<td>Safe environment while in Prison to meet current level of function.</td>
<td>Observe for behaviour changes or reports of pain.</td>
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<td></td>
<td>To be comfortable and free of Pain.</td>
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<td></td>
<td>Equipment required</td>
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<tr>
<td>21/4/16</td>
<td><strong>Emergency Plan</strong></td>
<td>In the event of emergency, Custody can contact Unit Nurse from (0800 hrs -1700hrs) Extn 84129</td>
<td>RN/Custody/ HCA</td>
<td>Ongoing</td>
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<tr>
<td></td>
<td>(e.g. haemorrhage, respiratory distress, how to access external services urgently)</td>
<td>Main Health Centre (0600hrs-2130hrs) Extn 74905 By Radio, HARRO- Nurses channel from (0600hrs-2130hrs) On call nurse thru Site Supervision from (2130hrs-0600 hrs) Not for CPR order currently in place.</td>
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<tr>
<td>21/4/16</td>
<td><strong>Medication</strong></td>
<td>Currently on regular medications to manage High blood pressure.</td>
<td>RN</td>
<td>Ongoing</td>
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<td></td>
<td>Anticipatory prescribing</td>
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<td></td>
<td>Pain Management</td>
<td></td>
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<tr>
<td>21/4/16</td>
<td><strong>Psychological</strong></td>
<td>Not to be transferred to another prison.</td>
<td>RN</td>
<td>Ongoing</td>
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<tr>
<td></td>
<td>To reside in HDU prison While incarcerated.</td>
<td>Does not want any family member to be involved or to be informed in the event he is dying.</td>
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<td></td>
<td>To respect wish in family Involvement when dying.</td>
<td>If still in prison he would like to die here in Rimutaka prison.</td>
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<tr>
<td></td>
<td>To respect Prisoner’s preferred end-stage location</td>
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<tr>
<td>Date</td>
<td>Category</td>
<td>Description</td>
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<tr>
<td>21/4/16</td>
<td>Compassionate release</td>
<td>Advise sent to custody to recommend application for compassionate grounds</td>
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<tr>
<td></td>
<td>Prisoner’s understanding of illness and outcome</td>
<td>Good understanding of current illness.</td>
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<tr>
<td>21/4/16</td>
<td>Social</td>
<td>Patient does not contact any family member or wished to hear from a family member when dying.</td>
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<td></td>
<td>Ability to communicate</td>
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<td></td>
<td>Communication plan with whanau / family</td>
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<td>21/4/16</td>
<td>Wairua/spiritual/religious</td>
<td>Does not practise any religion</td>
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<td></td>
<td>Prisoner’s wishes and access</td>
<td></td>
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<tr>
<td>21/4/16</td>
<td>Cultural Needs</td>
<td>Patient likes to be buried rather than cremated.</td>
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<td></td>
<td>Needs presently</td>
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<td></td>
<td>Needs post death</td>
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<tr>
<td>21/4/16</td>
<td>Clinical / General Support</td>
<td>Health advice to be sent to Custody as needed. Unit Nurse is based in the unit and meets with all custodial staff on a daily basis.</td>
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<td></td>
<td>Communication Plan developed for custody</td>
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<td></td>
<td>Prisoner placed on High Risk Register</td>
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<td>Key external agencies identified and included in planning</td>
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<td></td>
<td>Compansonate Release details</td>
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<td></td>
<td>CPS notified</td>
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<td>21/4/16</td>
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</table>

If condition deteriorates, patient can be referred for Hospice care as per MO referral.

Admission to Hospital as needed in the event of accidents (e.g. choking, fracture due to falls).
No current application for compassionate release.

### Identified Risks

<table>
<thead>
<tr>
<th>Date</th>
<th>Identified risks</th>
<th>Mitigation strategies</th>
<th>Person(s) to action</th>
<th>Date resolved</th>
</tr>
</thead>
<tbody>
<tr>
<td>21/4/16</td>
<td>Falls</td>
<td>Exercise plan for balance and strength lower extremities.</td>
<td>HCA/RN</td>
<td>Ongoing</td>
</tr>
<tr>
<td>21/4/16</td>
<td>Risk for CVA</td>
<td>Monthly BP</td>
<td>RN</td>
<td>Ongoing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BP as needed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Seen and discussed with prisoner on (date) __________________________

Signed: Prisoner ___________________________ Date __________

Signed: Prison Services Health Services Nurse _______________________

Date __________
ATTACHMENT 2: FISHKILL PRISON – RMU, UCI ADMISSION FORM

ADMISSION ALGORITHM TO
THE UNIT FOR THE COGNITIVELY IMPAIRED (UCI)

FHSD identifies potential special need

Facility completes all required pre-screening documents and submits to Fishkill UCI

Fishkill UCI Inter-disciplinary Care Plan Team reviews data and makes determination

Inappropriate for Unit

Appropriate for evaluation

Work-up per UCI/In-transit status:
* Medical evaluation
* Psychiatric evaluation
* Psychological evaluation
* Neurology evaluation & diagnostic testing

Cognitive Disorder confirmed, Appropriate for Unit

Inappropriate for Unit

Returned to Facility or Special unit

Appropriate for admission
ENDNOTES

i ABS 4517.0 - Prisoners in Australia 2015 Canberra ABS

http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4517.0~2015~Main%20Features~Prisoner%20characteristics,%20Australia~28


xvi Hodel B. and Sanchez, H (2013) The Special Needs Program for Inmate-Patients with Dementia (SNIP): a psychological program provided in the prison system. Originally published online at http://dem.sagepub.com/content/12/5/654


