What is Capacity Australia?
Capacity Australia (capacityaustralia.org.au) is a not-for-profit, medico-legal organisation with charity DGR status, led by senior legal, medical/psychiatric and allied health academics, clinicians and practitioners. We are committed to supporting the rights of people with decision-making disability.

How do we do this?
One of the ways we do this is by providing education regarding capacity (decision making ability) across medical, allied health, legal, financial and community sectors across Australia and internationally.¹ A major element of our mission is to ensure that people with decision making disability can make the decisions that they are capable of making, while preventing abuse. We note that these dual, sometimes competing priorities are asserted in Articles 12 and 16 of the United Nations Convention of the UN Rights of Persons with Disabilities

(CRPD)\(^2\) relating to the rights of older people under United Nations human rights conventions to which Australia is a party. Another equally important priority is to ensure that when decisions are made, people with disability are afforded access to the highest attainable standard of health without discrimination on the basis of disability, as asserted in Article 25 of CRPD. These issues are extremely relevant to the question of aged care quality and safety.

Capacity Australia has had extensive experience in providing submissions of this kind, having been invited to provide verbal and written evidence to:-

- NSW Legislative Council General Purpose Standing Committee No. 2: Inquiry into Elder Abuse, \(^3\)
- the ALRC enquiry into elder abuse; \(^4\)
- the Review of the Australian Banking Association Code;
- Submission to NSW Law Reform Commission re review of Guardianship Act 1987;
- ASIC (Australian Securities and Investment Commission) to consult on the issue of reverse mortgages, capacity and abuse.

Furthermore, as active clinicians working with people living with dementia in nursing homes, in their homes and in the hospital, as well being experts in Guardianship, human rights, capacity and decision-making, Capacity Australia has been entrusted by the Dementia and Aged Care Services Fund with a large grant ($942,260.00) that specifically focuses on quality care and rights in aged care:


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\(^3\) Elder abuse in New South Wales / General Purpose Standing Committee No. 2 [Sydney, N.S.W.]: the Committee, 2016. [xx, 186] p.; 30 cm. (Report no. 44 / General Purpose Standing Committee No. 2);  

Notably, and in line with the objectives of the Commission, the Empowered project is a consumer choice-driven project.

We note that the Royal Commission has already acknowledged some of our previous work with the former Alzheimer’s Australia (now Dementia Australia), (see Royal Commission transcript interview with Maree McCabe, 19th February 2019).

The submission
We understand that the Commission is required and authorised to inquire into the following matters:

a. the quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response;

b. how best to deliver aged care services to:
   i. people with disabilities residing in aged care facilities, including younger people; and
   ii. the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services;

c. the future challenges and opportunities for delivering accessible, affordable and high quality aged care services in Australia, including:
   i. in the context of changing demographics and preferences, in particular people’s desire to remain living at home as they age; and
   ii. in remote, rural and regional Australia;

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d. what the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe;

e. how to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters;

f. how best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure;

g. any matter reasonably incidental to a matter referred to in paragraphs (a) to (f) or that [the Commissioners] believe is reasonably relevant to the inquiry.

In this submission Capacity Australia wishes to address the questions posed by the Commission in which we have particular expertise and which speak to the human rights principles outlined above, and our mission. We note and will address the questions posed by the Commission:

1. **What is the quality** of the aged care services delivered by the provider to you or someone you know? Do you consider the care services provided were substandard? If so, why? Please provide as much detail as you can about any specific incidents or events which occurred.

2. **What are the challenges and how can the provider, or Australia generally, better deliver aged care services to people with disabilities and/or persons living with dementia and what are your primary concerns?**

3. **What are the challenges and how can the provider, or Australia generally, better deliver aged care services to those who wish to remain living at home and/or living in remote, rural and regional Australia and what are your primary concerns?**
4. What are the challenges and how can the provider, or Australia generally, better ensure aged care services are person-centred and what are your primary concerns?
5. What are the challenges and how can the provider, or Australia generally, improve the quality and safety of end of life care and what are your primary concerns?
6. What are the challenges and how can the provider, or Australia generally, provide high quality, safe and affordable aged care services and what are your primary concerns?
7. What do you think are examples of good practice and innovative models in delivering aged care services and why do you think these practices or models have been effective?
8. What changes would you like the Royal Commission to recommend?

Question 1 What is the quality of the aged care services delivered by the provider to you or someone you know? Do you consider the care services provided were substandard? If so, why? Please provide as much detail as you can about any specific incidents or events which occurred.

Professor Peisah, in her role as an aged care psychiatrist of over 28 years experience and former Clinical Director Specialist Mental Health Services for Older People (SMHSOP) Northern Sydney Local Health District 2012-2017, has had direct experience working with a range of aged care services, both of a high and low standard. Additionally, she has provided direct consultation as an in-house psychiatrist to several nursing homes chosen specifically for their provision of good care. Importantly, at the other extreme, in 2018 she was engaged as Consultant to the Riviera Health for their Nursing Home Closure and Resident Assessment & Transfer Project, precipitated by a nursing home’s failure to meet most of the accreditation standards. In her experience, there is often little difference between nursing homes that pass accreditation and those such as this, that don’t. Often, the only difference is the skill in meeting accreditation (see below for solutions).

In previous submissions (e.g. to ALRC6) Capacity Australia has equated the provision of substandard aged care with elder abuse. Probably more than 80% of residents in Australian...

Government-subsidised aged care facilities have dementia. Separately, approximately 25% of older people in residential care have depression. The presence of dementia increases the vulnerability of residents, and makes them even more susceptible to inadequate health care. Many of these people are unable to communicate their needs (e.g. pain, loneliness, hunger, intimacy) due to expressive (speaking) or receptive (understanding) language disturbance, hopelessness or apathy. As a result, these needs are not met. This is neglect. Moreover, while depression screening is mandated in residential care, poor scores are not followed up. This is neglect.

Behavioural and psychological symptoms of dementia (BPSD) are symptoms of disturbed perception, thinking, mood and behaviour occurring in people with dementia, often an expression of these unmet needs or some kind of distress. BPSD include agitation, aggression, calling out/screaming, disinhibition (sexual), wandering, night time disturbance, shadowing, swearing, depression, anxiety, apathy, delusions, hallucinations, irritability and elation/euphoria. They occur so commonly as to be virtually ubiquitous in dementia, with up to 97% of people experiencing BPSD of variable severity during the course of their illness (Brodaty et al, 2001). BPSD can be disruptive in the care home environment, cause distress to other residents and time-poor staff and very often, rather than meeting the underlying needs, people are restrained chemically or physically. Both types of restraints cause harm. This is abuse both by lack of action and neglect, as well as direct harm.

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Reliance on chemical restraint to “manage” BPSD occurs commonly and is increasing in Australia. Antipsychotics and other psychotropics are often used off-label to manage behaviours and these medications have a range of serious side effects and are associated with increased mortality for people with dementia, while the evidence supporting their efficacy is modest at best. Additionally, there is evidence that consent is often not obtained for the use of these medications by either the person or their authorised substitute decision-maker. To treat without consent is battery.

The persistent over-use of these medications continues despite a growing body of evidence for non-drug interventions and deprescribing studies demonstrating successful and sustainable withdrawal of antipsychotics in 80% of residents without an increase in BPSD.

Consequently, international consensus guidelines recommend the use of multidisciplinary, individualised (person-centred) psychological and social interventions as a first line approach to behavioural symptoms of dementia. Such person-centred care relies on comprehensive knowledge of the resident and assessment involving observation, measurement and monitoring of BPSD to assess the antecedents, triggers and consequences of behaviours – often a communication of unmet needs or a response to too much or not enough stimulation in the environment. Thought, time and expertise needs to be given to working out why the behaviour is occurring, not a phone call to the GP for a prescription of sedation.

One of the most common unmet needs in dementia is pain, the detection of which can be problematic in people who have language deficits, rendering many people with dementia in nursing homes “silent and suffering”\(^\text{19}\) (see below). To ignore and neglect pain is elder abuse.

Another unmet need is mobility. Mobility is an important quality of life indicator which contributes to independence.\(^\text{20}\) Access to specialised occupational therapy and physiotherapists to promote mobility and the best use of mobility aids is a right owed to all in residential care. At minimum, we know that training staff in ‘mobility care’ can reduce physical deconditioning, pressure injuries and, most importantly, falls in nursing home residents.\(^\text{21}\) Even at the end of life guided assistance to routinely mobilise can satisfy a person’s desire to move and should be encouraged.\(^\text{22}\) Meaningful and creative mobility opportunities, no matter how small, can promote wellbeing even in people living with advanced dementia.

Another manifestation of inadequate care provision is abandonment and eviction. Recently, nursing homes seemed to have put the meeting of needs and care provision of patients in the “too hard” basket by using a policy of exclusion of residents with challenging behaviours (Professor Peisah encountered such a refusal in response to a request for admission of one of her patients on the 8\(^{th}\) March 2019). If nursing homes can’t provide care for the medical disorders besetting 85% of their eligible residents, well then who can?

Residents who have been accepted often subsequently develop challenging behaviours. When the “going gets tough” residents are evicted, often via hospital. Such evictions,

Despite security of tenure, guaranteed by the Aged Care Act Division 2, User Rights Principles 2014 (s 96-1 Aged Care Act 1997), is another manifestation of substandard care and abuse. Nursing home residents who are transferred, dumped, or evicted from long-term care facilities are victims of nursing home abuse. A similar but related example encountered by Professor Peisah on the 29th March 2019, was the discharge of a patient from a nursing home three days after transfer from hospital where they had been held awaiting a guardianship hearing for 5 months. The Guardianship application was made due to the person’s lack of capacity to decide on accommodation and a “need” for guardianship because of the serious risks associated with being discharged home.

These problems are amplified amongst several groups of older Australians who are particularly vulnerable to inadequate care provision, abuse and neglect by virtue of what we call the “triple jeopardy” of disadvantage, namely being aged, with dementia and an additional vulnerability. A significant example of people with an additional vulnerability are those from Culturally and Linguistically Diverse backgrounds. They are particularly vulnerable to both abuse and needs neglect, by virtue of the combined effects of communication difficulties compounding any such communication difficulties in dementia, as well as inadequate advocacy. Also, people ageing with intellectual disabilities are a socially vulnerable group by virtue of their complex support needs. They are known to be underserved in healthcare, experience substantial health inequalities and higher rates of premature death compared with the general population. Thirdly, the invisibility of our

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23 Peisah C., Jessop T., Brodaty H. Nursing homes “no-returns” policy, when residents are discharged to the Emergency Department at 4am: what does the law say Medical Journal Australia 2018; 209 (7): 7. doi:10.5694/mja17.01196; see also https://www.americannursetoday.com/dumped-nursing-homes-abandon-patients-hospital/


LGTBI elders means that their needs are often neglected. Finally, “mentalism” (stigmatisation of, and discrimination against those with mental illness akin to ageism) means that older people with severe mental illness are perhaps the most neglected of all residents, due lack of specialised expertise and inadequately resourced facilities.

While the current standards include Standard 7 (Human resources) and Standard 8 (Organisational governance), our experience is that there are significant deficits in these areas that impact on care. As requested by the Commission, Appendix 1, highlights a specific example of the interaction between substandard care and inadequate organisational governance and human resource management and support. This example also highlights the vulnerability of residents with dementia.

**Question 2** What are the challenges and how can the provider, or Australia generally, better deliver aged care services to people with disabilities and/or persons living with dementia and what are your primary concerns?

Accreditation has failed in making a difference to the provision of quality aged care services. In April 2018, Professor Peisah was contacted by the Australian Aged Care Quality Agency, to give guidance on the development of the Draft Aged Care Quality Standards. Professor Peisah sent a raft of resources/publications, but any further offer of assistance was then declined due to the need to finalise the Draft. This was a missed opportunity to have useful input and interaction between clinicians working in the field (who can offer more than librarian assistance) and regulators. Her opinion then, and still is, that we have an aged care industry geared to using a tick box approach to the standards. In this way, there is a lack of transparency regarding the real issues, obfuscation and passing the buck with regard to responsibility. Despite the advent of random audits which do help, this system still supports a loophole structure that encourages expedient, money-saving approaches such as bringing

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28 In reply: Peisah C., Jessop T., Brodaty H. Nursing homes “no-returns” policy, when residents are discharged to the Emergency Department at 4am: what does the law say to Medical Journal Australia (in Press).
in an educator or an accreditation expert for the two weeks prior to accreditation. Her major recommendation is for a shift from an accreditation system that reviews policies, procedures and/or protocols and cross-sectional ratings (the Document and Forget approach) to one that is linked to concrete, genuine and meaningful outcomes. For example, in our review of pain management for people with dementia,\(^\text{30}\) we found that pain assessment and management was regulation-driven, in response to pending accreditation, assessment mandated by funding instruments or routine, or three monthly, or even worse twelve monthly review, rather than patient need-driven.

Capacity Australia recommends the use of a publicly available and transparent, outcome-driven, consumer choice-driven review system akin to the “5-Star Rating system”\(^\text{31}\) used in the US. Alternatively, an Incident Monitoring System similar to that used in public hospitals may also generate data. This would lend itself to reporting of meaningful and real data including rates of psychotropic medication use (including type, dose and indication) and the obtaining of consent, adverse events such as falls and pressure injuries and hospital transfer. In the US, the (CMS.GOV) Centers for Medicare and Medicaid Services (CMS.GOV) has partnered with federal and state agencies, nursing homes, other providers, advocacy groups, and caregivers to improve comprehensive dementia care to monitor and reduce antipsychotic use and enhance the use of non-pharmacological approaches and person-centred dementia care practices.\(^\text{32}\) Public reporting is intrinsically part of this programme, but in addition, this US programme pursues national goals such as a 15% reduction in medication use, an approach from which we can learn in Australia. Another example is evidenced in a study of pressure injuries in 60 facilities in the ACT and NSW. This study showed considerable variation among facilities in pressure injury incidence and demonstrated the potential of routinely-collected care management data to monitor

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\(^{31}\) https://www.medicare.gov/NursingHomeCompare/About/nhcinformation.html

pressure injury incidence and to identify facilities that may benefit from targeted intervention.33

Obligations to report such data regularly is important to prevent the cross-sectional meaningless review. Importantly, the Commission needs to be aware that collection of both quality use of medication data and consent-related data will in fact be feasible with the pending finalisation of the WebsterCare e-medication initiative.34

At the same time, this needs to be measured and reasonable. We can’t have laborious data collection detracting from time and resources spent providing actual clinical care, a phenomenon which happens too often in our hospital systems. Nevertheless, minimal data sets are needed for informed consumer choice, which tends to be more informed for restaurants than it is for residential care. Consumers, in their choice of facility, are often hoodwinked by the chandeliers and champagne at lunch, not real care indicators.

**Question 3** What are the challenges and how can the provider, or Australia generally, better deliver aged care services to those who wish to remain living at home and/or living in remote, rural and regional Australia and what are your primary concerns?

About 50% - said to be increasing – of people with dementia prefer to live at home, 35 a choice which is associated, at least in the phase of mild dementia, with higher social connectedness and quality of life and less distress than living in residential care.36 However, remaining at home is contingent upon the provision of adequate and appropriate support, responsive to the individualised and changing needs of the person, and equally important, to the needs of the person who shares their daily life, their carer. As stated below, such needs become increasingly complex as the person progresses towards the end

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of life, and while dying at home is most people’s preference, it is not always possible. Placement is often seen as a “failure” – and sometimes it is a failure of professional support system - placement can never be seen as a failure of the caregiver. For many, placement is the appropriate and individualised solution for both the person and carer.

Having said this, it is the provision of social support to the carer that can make the difference between staying at home and moving to residential care. Jorgensen et al (2018) found that greater volume of home care services was associated with significantly delayed entry into permanent residential care.

**Question 4** What are the challenges and how can the provider, or Australia generally, better ensure aged care services are person-centred and what are your primary concerns?

See Answer to Question 1. Many Aged Care Services seem to be either unaware of the efficacy, or fearful of the cost – benefits of person-centred care. The evidence for the benefits of PCC for people with dementia, particularly those with BPSD has been building however there is a significant problem with knowledge translation in this area. Many aged care providers disregard PCC approaches on the basis of being too resource-intensive, including time to train staff, purchase of equipment/facilities (e.g. sensory rooms, etc) and the requirement for staff time to be dedicated to individual residents’ needs which is in conflict with the current task-driven culture within the sector. Anecdotal feedback from nurse participants in the Halting Antipsychotic use in Long Term care project (HALT) indicated that while putting PCC strategies in place for residents with BPSD required time investment initially, identifying successful approaches to preventing or minimising subsequent episodes of disruptive behaviours such as aggression, agitation or calling out, actually made their job easier and freed up time that would otherwise have been spent

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trying to deal with repetitive episodes of the same behaviour. An economic analysis looking at the cost of PCC vs usual care for residents with agitation stated that the whole intervention cost $2,250 per facility (far more economical than dementia care mapping at over $10,000) and a cost of $6·23–9·79 for every Cohen Mansfield Agitation Inventory point averted for PCC compared with usual care immediately after the intervention. This was further reduced to $5·00–7·86 at follow-up indicating a sustainable effect of the intervention. 29 In other words, the excuse that providing person-centred care is not affordable, is not defendable.

To influence change in policy around PCC in nursing homes, a larger economic analysis needs to be undertaken taking into account potential cost savings related to reductions in psychotropic medication use, decreased hospitalisations and reablement/preservation of function in residents, to offset the modest cost of implementing and mandating PCC widely.

An important, but oft-unrecognised key to providing PCC in complex care environments is support for the staff providing such care. As highlighted in Appendix 1, providers need to be more cognisant of supporting their staff, beyond providing education on basic care issues such as incontinence. Our older people living in facilities are more frail than ever and have some of the most complex care needs amongst all patients – with multiple medical and psychological co-morbidities, often compounded by the existential despair associated with living in residential care and a constellation of family support situations, some positive and some conflictual. Staff are often from overseas, with minimal training in these complex medical and psychological/mental health conditions, and often with minimal inter-collegial support. Furthermore, our own university and TAFE nursing/aged care curricula do not provide sufficient education in dementia and dementia care. We need to do better to acknowledge this career path, often considered the most lowly, yet at the same time often driven by altruism and love for the elderly,41 and often not rewarded. Professor Peisah has direct experience of good practice, having been involved in providing both staff education and staff support sessions in several nursing homes that recognised this. On a similar note, there is no routine support for General Practitioners (GPs) in providing healthcare for the

sickest and frailest members of the community. There has been a dumbing down of nursing home medicine that needs to be addressed, this fact often lost in the politically correct stance that holds contempt for “the medical model.” Quality care in residential care requires access to state of the art nursing, allied health AND medical care.

**Question 5. What are the challenges and how can the provider, or Australia generally, improve the quality and safety of end of life care and what are your primary concerns?**

The end of life is the most vulnerable period for people with dementia and the most likely time to be deprived of quality care. If ever there was a time to ensure needs are met, it is at the end of life (empoweredproject.org.au). By this stage, communication is impaired and deciphering needs is particularly difficult, and impossible with inadequate nursing ratios and inadequate specialised nursing and palliative care input. There is variable availability and quality of palliative care in residential care facilities, with some facilities having access to local public palliative care services, others offering an in-house palliative care nurse for the whole facility, and others still having no access to any palliative care input at all.

Pain is just one of the many and often unmet needs at the end of life, which include fear, hunger and at other times anorexia, adequate temperature control, loneliness and need for intimacy. Important causes of distress at this stage include pressure injuries and neglect of oral care and the usual palliative approaches must be assiduously adhered to. We know that the total symptom burden in end-stage dementia is similar to that in terminal cancer. 42 People with advanced dementia are usually bed-bound and at risk of pressure sores and contractures, variably interested in food yet at risk of aspiration and infections. 43

Guidelines for provision of palliative care in residential care abound. 44 Such guidelines do not ensure the provision of quality care at the end of life. We need, as with general

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42 Livingston et al Lancet Dementia Guidelines
Accreditation Standards, concrete evidence of the use of these with meaningful outcome measures., for example the number of deaths in the last month, existence of and adherence to advance care directives (written by GPs or expert nurse practitioners, not by administrative assistants upon entry to the facility), time of commencement of palliation, doses and agents, family satisfaction with dying (using valid measures).

**Question 6.** What are the challenges and how can the provider, or Australia generally, provide high quality, safe and affordable aged care services and what are your primary concerns?

Overseas, quality aged care monitoring initiatives are FUNDED collaborative and expert driven on a national level, supported by regulatory agencies. Such initiatives include the aforementioned CMS.GOV initiative in the US, plus also the ALCOVE initiative from Europe. In 2017, Capacity Australia proposed the development of the Asia Pacific Alliance for Better Prescribing and Care in Dementia (APAC) as a collaborative effort across the Asia Pacific rim to improve knowledge and promote the exchange of information regarding quality prescribing for and better care of people living with dementia. Modelled on the ALCOVE (Alzheimer Cooperative Valuation in Europe) the Alliance aimed to provide a forum for the exchange of experiences and knowledge and to signpost the implementation of good practice with regard to psychotropic use including deprescribing, and person-centred care.

In addition to a national expert-driven collaborative approach to promoting better care that is separate from but works with regulatory agencies, nursing home health needs a total boost in Australia. Equitable access to both primary care, medical specialist and allied health support on par to that offered to Australians living at home is owed to all older Australians living in residential care. In Australia access to specialist services across medicine, psychiatry, and allied health is patchy and dependent on the Local Health District resources or specific partnerships developed between facilities and individual practitioners. Overseas, nursing home medicine is a specialty. Nursing homes are attached to Universities and have in-house geriatricians or psychiatrists. In Australia, it is likely that when you walk into a residential facility, you lose access to your Parkinson’s disease specialist, the pain clinic and

often, palliative care services. Mandated registered nurse ratios at all times, but supplemented at the end of life, are essential to this, the absence of such are a breach of the human right both to the equitable access to health, and the Declaration of Montreal (Declaration that Access to Pain Management is a Fundamental Human Right). A concrete example of the consequences of inadequate staffing for access to quality care and pain relief is evidenced by our research into pain management. We reported that facilities who lacked registered nurses with S8 (Schedule 8 Drugs of addiction including morphine-like drugs integral to the relief of pain and distress in dementia per se, plus at the end of life) administering rights were unable to give their patients analgesia at those times (e.g. usually at night). To deprive a person of relief of distress or pain in order to cost-save with staffing ratios is elder abuse.

**Question 7.** What do you think are examples of good practice and innovative models in delivering aged care services and why do you think these practices or models have been effective?

See above regarding CNS.GOV and ALCOVE.

Additionally, Capacity Australia wishes to inform the Commission that the Commonwealth has divested a large sum of money through the DACS grant into the Empowered Project. We are very proud of the achievements we have made with regard to informing and educating the community.

**Question 8** What changes would you like the Royal Commission to recommend?

Capacity Australia makes the following recommendations to the Royal Commission:

1. Overhaul of current regulations and reporting on the use of psychotropic medications in RACFs. Harsh penalties in line with the legislation (e.g. NSW Guardianship Act 1987 Division 2 Section 35, for carrying out treatment on a patient without consent) for prescribers and providers that are not adhering to

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46 Huesbo BS et al., Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial *BMJ* 2011;343:d4065
best practices, including first-line use of person-centred care and consent, need to be promoted and implemented. Previous work by Professor Peisah and Dr Jessop demonstrate the indifference shown by prescribers for the law and the rights of patients and substitute decision makers around consent for prescribing psychotropics, with consent rates in these studies of 6.5% and 16% respectively. The way psychotropic prescribing is reported also needs updating so that at any time a report can be generated for a nursing home that captures rates of psychotropic medication use (including type, dose and indication) whether consent was obtained, adverse events such as falls and pressure injuries and hospital transfer. This data should be regularly provided, and readily available to policy-makers, industry and consumers (see recommendation 2).

2. Development of an outcome-driven, consumer choice-driven review and accreditation system that eliminates the policy and guideline-driven, tick-box approach to meeting care standards. This will incorporate outcome data related to the quality standards and prioritise palliative care, nutrition and restraint for residents with dementia. Similar concrete outcome data can also be mapped to meeting the needs of diverse ageing Australians. As well as being used for regulatory purposes, results of reporting will be made publicly available and transparent, a system akin to the “5-Star Rating system” used in the US. Capacity Australia recommends the development of an Australian “Trip Advisor-style” platform similar to the Nursing Home Compare site for nursing homes in the US. This would provide transparency and real indicators of quality for consumers to base their choices around, comparisons between nursing homes and updated regularly. Such a system could be built upon Capacity Australia’s APAC proposal.

Development of a new, rigorous outcome-driven accreditation and reporting system should not come at the expense of nurse time needed to carry out their...
vocational endeavours – caring for people. Human-beings with the desire and
calling to help others do not enter a nursing career to be paper shufflers. Nurses
and carers need to be available to do their job within a flexible, person-centred
system. Directors of nursing should be encouraged to get out of their offices and
retain their nursing skills and keep up to date with evidence-based practice and
research evenly spread with their administrative duties.

3. Pain identification and management in nursing home residents with dementia
should not, and in fact cannot due to the disease, be reactive, it should be
proactive. Undiagnosed and/or untreated pain are a major cause of changed
behaviour and distress in people with dementia. Regular screening for signs of
pain, particularly when a person appears agitated or distressed needs to be
incorporated into daily care of people with dementia and new technologies such
as PainChek (or similar) should be utilised across the board and regularly. To
ignore and neglect pain is elder abuse.

4. Consistent and regulated implementation of the plethora of Clinical Guidelines
for palliative care, that is tailored to the needs of people living and dying with
dementia is urgently needed. In addition, once established, training of nurses
and carers in implementing the guidelines needs investment and promotion
within the industry. This feeds into a broader need for improvement and
standards in the provision of quality care at the end of life. We need, as with
general Accreditation Standards, concrete evidence of the use of these with
meaningful outcome measures., for example the number of deaths in the last
month, development of and adherence to advance care directives (written by
GPs or expert nurse practitioners, not by administrative assistants upon entry to
the facility), time of commencement of palliation, doses and agents, family
meetings and family satisfaction with dying (using valid measures). Mandated RN
ratios so that administration of S8 medications is available at all times is essential
for quality comfort care at the end of life.
5. There must be investment into development of a nation-wide program for the implementation of Person Centred Care (PCC) as business as usual in residential care. The evidence for the benefits of PCC to improve care outcomes and in the prevention and minimisation of BPSD is growing. In Australia, we have world-leaders in this field and their expertise should be utilised to put the evidence into practice. This is another example of the tick-box approach of the current accreditation standards with no meaningful outcome data on whether and how well aged care facilities are implementing and delivering person centred care to their residents. A large, detailed economic evaluation needs to be undertaken to determine feasibility and funding for training of staff at all levels within aged care including GPs and specialists who should be “prescribing” PCC in many instances instead of harmful drugs for BPSD. Adequate staff: resident ratios are essential to this, not staff ratios that are industry-driven. It is time for a substantial investment in high-level practice change which also includes a significant altitudinal and culture shift within aged care (see recommendation 7).

6. Development of the nursing curriculum is needed across all levels and including aged care courses (university, TAFE and private RTO’s). Currently the knowledge of dementia care amongst aged care workers at all levels is unacceptable, especially taking into account the growing prevalence of dementia in residential aged care. Along with general education about dementia, education and training about BPSD and PCC should be focal points of this education. In addition, complementary courses for social workers, allied health, hospitality, administrative and maintenance staff members who work in the aged care sector, should be developed covering the basics of dementia, communication and person-centred approaches to care. Proper credentialing in these areas is essential before any staff member can walk into a facility and provide care to our most frail and vulnerable Australians.

7. Whether one or all of the above recommendations were to be taken up, none can be implemented successfully or reach full impact without culture change across the aged care sector. Other industries invest significant resources into
change management for trivialities such as changing office layouts or implementing a new technology. The rationale behind this is to engage the stakeholders (employees) and to build organisational capabilities and competencies. In the business of caring for our society’s elders, the frail and vulnerable, there should be no question to make this investment in the industry and the workforce behind it. It will take considerable resources and investment into the sector to change long entrenched attitudes and work practices in aged care, these changes being vital to improving the care of people living in aged care facilities and receiving care in the community. There needs to be appreciation and validation of the workforce, up-skilling and dementia education across the board to improve self-efficacy of care staff and empower them to be advocates for the people they care for.

**APPENDIX 1 TO Question 1**

*Nick O’Neill’s submission in relation to a residential Aged Care Facility (not to be named)*

Capacity Australia wishes to draw the attention of the Royal Commissioners to examples of abuse by mistreatment of certain elderly people with dementia in a Residential Aged Care Facility run in the Sydney suburb of Bexley. The mistreatment occurred, and then continued, because the systemic failures in facility’s managerial arrangements and ethos. The managerial arrangements and ethos were such that matters of concern in relation to the care and treatment of residents in the Facility were not brought to the attention of the managers of the Facility which, in turn, ensured that more senior managers were not advised of this abuse.

These matters came to the notice of Nick O’Neill when he was a Deputy Chairperson of the then Nursing and Midwifery Tribunal of New South Wales (the NMT) (now part of the Occupational Division of the New South Wales Civil and Administrative Tribunal). The NSW Health Care Complaints Commission (HCCC) brought a Complaint against a Registered Nurse, MR D, to the NMT. The matter was heard and determined by a panel of the NMT chaired by Mr O’Neill. The panel also comprised two registered nurses and a community
member. The evidence is summarised and the findings of the panel of the NMT are set out in *HCCC v Davis (No 1)* [2013] NSWNMT 17 and its order to cancel Mr Davis’s registration as a registered nurse and the NMT’s reasons for doing so are set out in *HCCC v Davis (No 2)* [2013] NSWNMT 25.

The case was about MR D’s conduct towards four elderly residents at the Facility who were particularly vulnerable because each one of them had dementia and they could not defend themselves against his actions.

Patient A was 66 years of age at the relevant time. That time was between 2010 and March 2011 during night shifts in the Dementia Unit. Patient A had alcohol related dementia, behaviour disorder, depression and an unsteady gait due to tardive dyskinesia among other problems. MR D admitted that on three or four separate occasions, he made Patient A beg on his hands and knees for a cigarette, saying “Can you beg for a cigarette?” Eyewitnesses satisfied the NMT that MR D required Patient A to sit on the floor and to kiss the floor when begging for cigarettes. MR D also admitted that he would laugh when witnessing Patient A beg for cigarettes. The NMT also found that MR D humiliated a man with significant cognitive deficits, albeit self-imposed, and did so for his own amusement and out of spite.

Patient B was a 99 year old woman who was in the end stages of dementia. She was immobile and dependent on staff for assistance with all her activities of daily living. The NMT was satisfied that between February 2009 and March 2011 during night shifts in the Dementia Unit at the Facility, MR D on several occasions, and for a period of between two and five minutes, placed his thumb inside the mouth of Patient B and would laugh when witnessing Patient B suck his thumb. He would continue to laugh even when told by other nursing staff to stop.

Patient C was an 82 year old man who suffered from dementia and non-insulin dependent diabetes. He too lived in the Dementia Unit at the Facility. The HCCC alleged that between December 2010 and January 2011 during a night shift, MR D on two separate occasions while Patient C was watching television in the lunchroom, put his hand down Patient C’s pants in the area of his genitals. MR D denied this. However the NMT believed the eyewitness’s evidence and was satisfied that what was alleged had been proved.
Patient D was an 84 year old man who had dementia and behavioural problems, including outbursts of aggressive behaviour, arising from his dementia. However he was immobile. He was a resident of the Dementia Unit at the Facility.

The HCCC alleged that, between 2010 and March 2011, and during a nursing shift, Mr D put his face near Patient D, called him “Daddy”, tried to kiss him on the forehead. MR D admitted this; but denied that he actually kissed Patient D or that Patient D pushed him away physically. MR D admitted that Patient D told him; “I’m not your Daddy” but denied that Patient D said to him; “I don’t like you” and that he, MR D, continued this behaviour.

However, one of the Assistants in Nursing (AIN) at the Facility gave both written and oral evidence to the NMT. In her written evidence, she stated that Patient D did not like MR D coming anywhere near him because MR D would call him “Daddy”, put his face close to Patient D’s face and try to kiss him. Patient D would say to MR D something like; “I’m not your Daddy” and push MR D away. The AIN also stated that Patient D would be fighting MR D to keep him away. Nevertheless, MR D would carry on touching Patient D by pulling his arm while she, the AIN, was trying to change Patient D’s clothes. The AIN stated that she would try to change Patient D by herself, but would often find that MR D had followed her into Patient D’s room and would try to help her change Patient D even though Patient D did not like MR D near him.

The AIN also stated that she would comment to other AINs and registered nurses about this, but nothing ever happened. In her oral evidence to the NMT, the AIN confirmed what she said in her statement. During her oral evidence she gave a sense of Patient D’s aggressive behaviour. She said that the immobile Patient D pushed MR D away and hit out at him most of the times MR D came in contact with him. She also said that MR D’s response to Patient D’s pushing him away and hitting and punching was to laugh. As to MR D’s tone when he called Patient D “Daddy”, the AIN rejected the suggestions that it was “playful” or “friendly” and described it as “teasing and provocative”.

What also became clear during the AIN’s oral evidence to the Tribunal was that MR D would call Patient D “Daddy” every time she, the AIN, would go with MR D to change him and that Patient D’s pushing of MR D was in reaction to what MR D was doing.

The NMT accepted the AIN’s evidence about MR D’s interactions with Patient D. It also noted that MR D admitted that his conduct towards Patient D showed that he enjoyed making fun out of vulnerable patients and that he had disregard for their dignity. He also admitted that he enjoyed the power imbalance between himself and the patients and that his conduct in relation to both Patient A and Patient D extended over months and in circumstances where others had indicated to him to stop that conduct.

In her oral evidence, this AIN also told the NMT that she sent the letter to the General Manager of the Facility, but did not receive a reply. She also said that she tried to raise the matter with the General Manager at a staff meeting just before Christmas 2010. She told the NMT that she did not write a confidential log because staff were encouraged not to do that but rather to go and speak to the manager. They were welcome to write about compliments but not to write about concerns.

When one of the other AINs was asked why she did not report the incidents in relation to Patient C to management when they occurred. She told the NMT that she did tell another particular AIN about it on her break. That AIN asked her if she had any pictures or other evidence. The AIN under questioning then said that the AIN she spoke to on her on her break had told her that she had seen this many times but that she couldn’t do anything. The AIN under questioning then said that the AIN she spoke to on her on her break had advised that: “if you love your job you just keep quiet and do your work and go home otherwise you will be in trouble”.

The AIN under questioning also stated in her evidence to the NMT, in relation to Patient A, that she did not say anything to MR D about his behaviour because she was frightened of him.
Given that the AIN’s felt either powerless to or fearful to report matters of concern the question arises how did these matters come to light?

On the night of 23-24 January 2011, another Registered Nurse was on duty on night shift responsible for three wards at the Facility. Three AINs were also on duty under her supervision. Early on the morning of the 24th Patient A walked into the nurses’ station of the Dementia Ward and began begging for a cigarette. The Registered Nurse told him not to beg, but Patient A told her that MR D; “makes me go down on my hands and knees and beg for a cigarette”. Two of the AIN’s on duty with the Registered Nurse confirmed to her that they had seen MR D do this.

That Registered Nurse made a “confidential log” reporting this matter. The General Manager at the Facility received that confidential log on 24 January 2011 and took action which resulted in an inquiry being undertaken by the Facility. The two AIN’s were interviewed as part of the investigation as was MR D. MR D was also interviewed by the police.

On 24 January 2011, as a result of reports of an incident involving MR D and a resident known as Patient A in these proceedings, MR D was suspended from his employment while first a police investigation and then an internal investigation conducted by the Facility took place. As a result of the investigations, MR D was summarily dismissed from his employment on 18 March 2011. However, in March 2011, MR D was employed as a Registered nurse in another Residential Aged Care Facility in regional New South Wales.

On 28 June 2011, a senior officer of the Facility organisation made a “notification” to the Australian Health Practitioner Regulation Agency (AHPRA) under the *Health Practitioner Regulation National Law (NSW)*. That notification was investigated by the HCCC.

As a result of that investigation, the HCC lodged a Complaint dated 30 April 2011 with the NMT. In that Complaint the HCCC alleged that MR D engaged in unsatisfactory professional conduct in relation to four residents at the Facility and furthermore that that activity was of such a serious nature that it amounted to professional misconduct.

In September 2013, the HCCC’s Complaint was heard by the NMT. It found MR D guilty of professional misconduct in relation to his behaviour towards all four residents of the Facility
and adjourned the matter for a further hearing on the question as to what protective orders the NMT should make in the light of the findings made by it in September 2013.

In December 2013, the NMT cancelled MR D’s registration as a registered nurse and ordered that at least four years’ elapse, from the date of the order, before MR D could apply to the now Civil and Administrative Tribunal of New South Wales (NCAT) to be registered as a nurse.

While it is accepted that that the manager at the Facility did intervene when he received the “confidential log” from the Registered Nurse who observed MR D’s conduct towards Patient A, it was clear to the members of the NMT who heard the matter that, the AIN’s concerns were ignored and that they were discouraged from reporting matters of concern. It was only the intervention of the Registered Nurse that the matters referred to above came to light, some considerable time after MR D commenced his professional misconduct.

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