

# Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

Submission to the Queensland Health, Communities, Disability Services and Domestic and Family Violence Prevention Parliamentary Committee

April 2019

# Introduction

The position of Public Advocate is established under the *Guardianship and Administration Act 2000* (Qld). The primary role of the Public Advocate is to promote and protect the rights, autonomy and participation of Queensland adults with impaired decision-making capacity in all aspects of community life.

More specifically, the Public Advocate has the following functions:

- promoting and protecting the rights of adults with impaired capacity (the adults) for a matter;
- promoting the protection of the adults from neglect, exploitation or abuse;
- encouraging the development of programs to help the adults reach the greatest practicable degree of autonomy;
- promoting the provision of services and facilities for the adults; and
- monitoring and reviewing the delivery of services and facilities to the adults.<sup>1</sup>

Many users of aged care, end-of-life and palliative care services have, or will potentially develop, impaired decision-making capacity (permanently or intermittently) as a result of a range of circumstances and conditions, including, but not limited to:

- conditions from birth (e.g. intellectual disability);
- acquired brain injury from illness or trauma (e.g. stroke or motor vehicle accident);
- age related conditions (e.g. dementia or Alzheimer's disease); and
- mental health issues (e.g. a psychotic illness).

The Public Advocate welcomes the opportunity to make a submission to the Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying. The issues this Inquiry is investigating will eventually, and for some of us sooner rather than later, be very relevant to our own lives. Ultimately, it is in all of our interests that these sensitive issues are explored with compassion and respect, to ensure that Queensland delivers the best possible health and quality-of-care outcomes, and protects the rights and interests of some of the most vulnerable people in our community.

This office is in the process of preparing a submission to the Royal Commission into Aged Care Quality and Safety, which raised a number of issues pertinent to this Inquiry including; the use of restrictive practices in residential aged care facilities; effective complaint mechanisms; the aged care workforce; end-of-life and palliative care for people with dementia; younger people with disability residing in aged care facilities; and substitute decision-making in the aged care sector. The near-final submission is attached for the Committee's review and reference.

As this Inquiry has a focus on many issues similar to those included in the terms of reference for the Royal Commission, this submission will concentrate on the State based environment and context associated with aged care, end-of-life, palliative care and voluntary assisted dying. It will refer the Committee to the attached submission to the Royal Commission for more detailed information where necessary.

## Voluntary assisted dying

The debate surrounding voluntary assisted dying is complex, involving significant moral, ethical, medical and values based considerations. Essentially, and at its purest level, the debate is about choice and control being extended to people who wish, on the basis of a life-limiting condition, to voluntarily end their life.

Legislation providing for choice and control to voluntarily make a decision of this nature inherently assumes that a person making this decision is doing so of their own free will and having the legal capacity to make that decision.

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<sup>1</sup> *Guardianship and Administration Act 2000* (Qld) s 209.



Taking these matters into account, people in the cohort whose rights and interests I represent, namely, adults with impaired decision-making capacity, should be specifically excluded from accessing voluntary assisted dying, under any future legislation that is enacted.

While I support the concept of advance care planning for people to express their wishes in relation to their care following a loss of capacity, it should not extend to voluntary assisted dying.

Further, any future voluntary assisted dying legislation should not permit people to consent to, or actively seek, voluntary assisted dying in any advanced care planning documents, such as Enduring Powers of Attorney or Advance Health Directives, or in any other health planning documents (such as Statement of Choices, Advance Health Directive for Mental Health etc.). There should be no possibility that a person can make a decision to voluntarily end their life after losing legal capacity. The power to make such a decision should never be able to be conferred on a substitute decision-maker such as an enduring attorney, guardian or statutory health attorney.

Existing guardianship and power of attorney legislation does not allow for particular decisions to be made by substitute decision-makers, including, for example, consent to marriage, the making or revoking of a will, voting, the termination of a pregnancy, sterilisation or organ donation.<sup>2</sup>

Most international laws, and the voluntary assisted dying legislation recently passed in Victoria, require that a person must have capacity to request to die voluntarily. In Victoria, two separate tests of capacity are required to be conducted by two different health professionals, prior to any request being considered.<sup>3</sup> However, it is noted that two countries in Europe (the Netherlands and Belgium) are now beginning to grant access to voluntary assisted dying for people suffering from dementia or psychiatric illnesses.<sup>4</sup>

I recognise the many submissions to the Inquiry that recounted people's experiences and distress about a family member or friend who lost decision-making capacity (from dementia or Alzheimer's or another progressive aged-related illness) before death, that appear to be advocating for voluntary assisted dying to be able to be accessed by people who have lost capacity. While acknowledging the extreme distress that the deterioration in a loved one's capacity can cause, I cannot support any laws that would permit a person to access voluntary assisted dying after losing decision-making capacity.

I request that the Inquiry make the following recommendation:

#### **Recommendation 1**

Any future voluntary assisted dying legislation must include the necessary safeguards to ensure that only people with decision-making capacity can access voluntary assisted dying and that there should be no opportunity for voluntary assisted dying to be provided for in Queensland advance care planning documents.

## Aged care

### The unlawful use of restrictive practices

The use of restrictive practices to manage the challenging behaviours of people in the aged and disability sectors has become a key human rights issue in Australia.<sup>5</sup> Detention, seclusion, restricted access to objects, physical, chemical and mechanical restraint (as well as electronic forms of

<sup>2</sup> *The Guardian and Administration Act 2000 (Qld)*

<sup>3</sup> *Voluntary Assisted Dying Act 2017 (Vic)*

<sup>4</sup> Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, Cohen J. Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada and Europe. *JAMA*. 2016; 316(1):79-90.

<sup>5</sup> Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Report No 124 (2014) 243.



restraint such as tracking bracelets, camera surveillance, or restrictions on media devices)<sup>6</sup> are all types of restrictive practice currently employed across the aged care sector. Restrictive practices are used in these settings despite studies indicating that their use may result in negative physical and psychological effects on the person being restrained<sup>7</sup> and may also constitute a breach of law and human rights.<sup>8</sup>

While some jurisdictions in Australia regulate the use of restrictive practices in the disability and/or mental health sectors,<sup>9</sup> the law governing these practices in residential aged care is unclear and, for the most part, non-existent.<sup>10</sup> The *Aged Care Act 1997* (Cth) does not formally regulate the use of restrictive practices in residential aged care facilities.

My views on the use of unregulated restrictive practices in residential aged care is addressed extensively in the attached submission to the Royal Commission into Aged Care Quality and Safety (see pp 4 to 16).

Following some particularly disturbing media reports about the misuse of restrictive practices in residential aged care facilities, the Minister for Indigenous Health, Minister for Senior Australians and Aged Care, The Honourable Ken Wyatt AM, MP, announced that he would act to regulate the use of restrictive practices. This has culminated in the release, on 30 March 2019, of an amendment to the *Quality of Care Principles 2014*, making specific provision for the use of physical and chemical restraint in residential aged care.<sup>11</sup>

While any tightening of the standards of care around the use of physical and chemical restraint are supported, the proposed amendment does not adopt many of the fundamental features of an accountable and transparent restrictive practices regulatory framework as recommended by the Australian Law Reform Commission in its report, *Elder Abuse — A National Legal Response*.<sup>12</sup>

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<sup>6</sup> Alistair R. Niemeijer et al, 'Ethical and practical concerns of surveillance technologies in residential care for people with dementia or intellectual disabilities: An overview of the literature' (2010) 22(7) *International Psychogeriatrics* 1129, 1136.

<sup>7</sup> Sarah Mott, Julia Poole and Marita Kenrick, 'Physical and chemical restraints in acute care: Their potential impact on the rehabilitation of older people' (2005) 11 *International Journal of Nursing Practice* 95, 96; Jenny Gowan and Louis Roller, 'Chemical restraint or pharmacological treatment for abnormal behaviours' (2012) 93 *The Australian Journal of Pharmacy* 58, 60; Jeffrey Chan, Janice LeBel and Lynne Webber, 'The dollars and sense of restraints and seclusion' (2012) 20(1) *Journal of Law and Medicine* 73, 74.

<sup>8</sup> Donal Griffith, 'Substituted decision making: Part 1 When are restraints off the rails?' (2014) 17(2) *Retirement & Estate Planning Bulletin* 1, 1; *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3rd sess, 183rd mtg, UN Doc A/810 (10 December 1948); Juan E. Mendez, 'Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment' (A/HRC/22/53, 1 February 2013); The potential for human rights breaches in relation to the use of restrictive practices has been reinforced by the United Nations Committee on the Rights of Persons with Disabilities, which expressed concerns about the use of unregulated restrictive practices in its concluding observations on Australia's initial report under the *Convention on the Rights of Persons With Disabilities*. See Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Australia* (adopted by the Committee at its tenth session 2-13 September 2013) 5.

<sup>9</sup> See, for example, *Disability Services Act 2006* (Qld) pt 6; *Mental Health Act 2016* (Qld) ch 8.

<sup>10</sup> Michael Williams, John Chesterman and Richard Laufer, 'Consent versus scrutiny: Restricting liberties in post-Bournewood Victoria' (2014) 21(3) *Journal of Law and Medicine* 641, 644; Judy Allen and Tamara Tulich, 'I want to go home now': Restraint decisions for dementia patients in Western Australia' (2015) 33(2) *Law in Context* 1, 4.

<sup>11</sup> The Honourable Ken Wyatt AM MP (Minister for Indigenous Health, Senior Australians and Aged Care), *Stronger Restraint Regulations to Protect Senior Australians*, Parliament House, Canberra, 30 March 2019.

<sup>12</sup> Australian Law Reform Commission, *Elder Abuse-A National Legal Response*, Report No 131 (2017) 11; Carnell, Kate AO and Paterson, Ron ONZM, *Review of National Aged Care Quality Regulatory Processes*, October 2017; Standing Committee on Health, *Aged Care and Sport, Report on the Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia* (October 2018), Canberra Australia.



Some of the key features absent from the Australian Government's proposed new scheme include:

- the proposed scheme does not provide for the appointment of a formal independent decision-maker who is at arms-length from the provision of care to the person subject to the restrictive practice;
- there is no requirement for an appeal process;
- there is no requirement for regular reviews of the use of restrictive practices;
- there is no requirement that providers develop a behaviour support plan for the person which would guide the care provided to the person and decision-making and ensure the focus is on reducing and eliminating the use of restrictive practices;
- there is no requirement that the restrictive practices be applied for the least time necessary;
- there is no requirement that the restrictive practices used be proportionate to the risk of harm; and
- the proposed regime only requires that the consumer pose 'a risk of harm' which is a much lower threshold than the ALRC's recommendation that restrictive practices only be used to 'prevent serious physical harm'.

The approach that the Australian Government has taken to the issue of regulation of restrictive practices in residential aged care demonstrates a complete lack of knowledge and understanding of three key issues:

- the previous reviews and recommendations about restrictive practices in aged care that have been undertaken;<sup>13</sup>
- the law that applies to the use of restrictive practices and of basic legal and human rights; and
- the principles of positive behaviour support which should underpin any approach to restrictive practices, and yet, is not mentioned in the *Aged Care Act 1997*, the Principles or Standards or any of the supporting resource material provided by government.

Ultimately, the new measures announced by Minister Wyatt do not establish the legal framework required to lawfully permit and regulate the use of restrictive practise in residential aged care facilities.

I request that the Inquiry make the following recommendation:

**Recommendation 2** The Queensland Government advocate for the Australian Government to immediately implement a comprehensive residential aged care restrictive practices regulatory framework with all of the characteristics and protections recommended by the Australian Law Reform Commission in its report *Elder Abuse – A National Legal Response* in Recommendations 4-10 and 4-11.

### State considerations - Human Rights Act 2019

The *Human Rights Act 2019 (Qld)*, which comes into effect from January 2020, specifically includes, a protection from torture and cruel, inhuman or degrading treatment under Division 2 – Civil and Political Rights (17);

- 17 Protection from torture and cruel, inhuman or degrading treatment  
A person must not be –
- a. subjected to torture; or
  - b. treated or punished in a cruel, inhuman or degrading way; or
  - c. subjected to medical or scientific experimentation or treatment without the person's full, free and informed consent.

<sup>13</sup> Australian Law Reform Commission, *Elder Abuse-A National Legal Response*, Report No 131 (2017) 11; Carnell, Kate AO and Paterson, Ron ONZM, *Review of National Aged Care Quality Regulatory Processes*, October 2017; Standing Committee on Health, *Aged Care and Sport, Report on the Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia* (October 2018), Canberra.



Further, under Division 4 – Obligations on public entities:

- 58 Conduct of public entities
1. it is unlawful for a public entity
    - a. to act or make a decision in a way that is not compatible with human rights; or
    - b. in making a decision, to fail to give proper consideration to a human right relevant to the decision

While it is questionable whether the Act will apply to residential aged care facilities, it will definitely apply to residential aged care facilities operating in Queensland under the auspices of Queensland Health. Consequently, the use of restrictive practices in these facilities without informed consent may be in breach of the *Human Rights Act 2019*.

With this in mind, the Inquiry should consider recommending that, failing the Australian Government acting to properly regulate restrictive practices in residential aged care, the Queensland Government adopt a restrictive practice regime similar to that under the *Disability Services Act 2006* for State-operated aged care facilities.

The regulatory framework for the use of restrictive practices included in the *Disability Services Act* contains appropriate safeguards and oversight mechanisms, and has resulted in greater transparency around the use of restrictive practices in Queensland's disability sector and increased consistency, professionalism and oversight of these practices.

More specifically, the regulatory process for the use of restrictive practices in Queensland includes:

- Assessment by one or more qualified professionals.
- The development of a behaviour support plan, which must be reflective of the principles of the *Disability Services Act 2006* (Qld) in relation to restrictive practices. This requires that it be informed by a best practice evidence base, producing behavioural change focused on skills development and environmental design, recognises that restrictive practices should only be used when necessary to prevent harm and that their use is the least restrictive way of ensuring the safety of adults and others.
- The plan must aim, overall, to reduce the intensity, frequency and duration of the adult's behaviour and reduce or eliminate the need to use restrictive practices.
- Approval for the use of restrictive practices must be obtained from the Queensland Civil and Administrative Tribunal (QCAT).
- Approval for the use of certain restrictive practices is valid for a period of up to 12 months, after which time the approval is reviewed and reconfirmed or revoked.
- The Public Guardian can also give short-term approval for restrictive practices when there is an immediate and serious risk.<sup>14</sup>

I request the Inquiry make the following recommendation:

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<sup>14</sup> *Disability Services Act 2006* (Qld) pt 6 – provisions relating to positive behaviour support and restrictive practices; *Guardianship and Administration Act 2000* (Qld) ch 5B – provisions relating to restrictive practices.



### Recommendation 3

In the event the Australian Government fails to properly regulate restrictive practices in residential aged care, the Queensland Government implement the restrictive practices regulatory framework under the *Disability Services Act 2006* in all Queensland Government operated residential aged care facilities.

## Effective complaints mechanisms

Effective complaints mechanisms are integral to a comprehensive system of rights and safeguards for older people receiving aged care services. While such mechanisms and their supporting frameworks are primarily an Australian Government responsibility, there is a vital role for the Queensland Government to play in advocating for better oversight and transparency to protect the rights and interests of Queensland aged care residents.

A project undertaken by this office about complaints management systems for adults with impaired decision-making capacity identified a range of barriers that prevent many people with decision-making impairments from seeking to have their complaints or concerns resolved through formal complaints mechanisms.<sup>15</sup> In addition to the usual reasons for not making formal complaints,<sup>16</sup> people with impaired decision-making capacity (including older people with dementia and other similar conditions) may experience greater barriers to making complaints for a range of reasons including:

- not understanding their rights;
- the process or the entry points for making complaints are less accessible;
- not being believed or taken seriously when they do make a complaint;
- not being able to manage and present evidence to support their complaint;<sup>17</sup> and
- people who rely on others for services and care are often reluctant to make complaints for fear of reprisals or withdrawal of services.<sup>18</sup>

The project also identified that complaints systems were not always sufficiently responsive to people with impaired decision-making capacity who may be unable to take the action necessary to initiate and progress a complaint through to resolution.<sup>19</sup>

In this environment, there is a strong need for the Australian Government framework for complaints in the aged care sector to be complemented by advocacy and community visitor programs.

### Advocacy and community visitor programs

The Australian Government funds the National Aged Care Advocacy Program (NACAP) which provides free, independent and confidential advocacy support and information to older people receiving, or seeking to receive, Australian Government funded aged care services. It is critical that the NACAP is adequately funded to meet current and future demand for aged care advocacy services. Insufficient funding of advocacy services could become a significant barrier to aged care residents being able to seek redress for mistreatment and abuse and to access consumer protection mechanisms.

<sup>15</sup> Office of the Public Advocate, *Strengthening Voice: A Scoping Paper About Complaints Management Systems for Adults with Impaired Capacity* (February 2015) 8-15.

<[http://www.justice.qld.gov.au/\\_data/assets/pdf\\_file/0020/362342/strengthening-voice-scoping.PDF](http://www.justice.qld.gov.au/_data/assets/pdf_file/0020/362342/strengthening-voice-scoping.PDF)>.

<sup>16</sup> Sarah Cook, *Complaint Management Excellence: Creating Customer Loyalty Through Service Recovery* (electronic version, Kogan Page, 2012); Clay M Voorhees, Michael K Brady and David M Horowitz, 'A Voice from the Silent Masses: An Exploratory and Comparative Analysis of Noncomplainers' (2006) 34(4) *Journal of the Academy of Marketing Science* 514-527.

<sup>17</sup> Office of the Public Advocate, above n 15, 8-10.

<sup>18</sup> See, for example, Alisoun Milne, 'Commentary on Protecting My Mother' (2011) 13(1) *The Journal of Adult Protection* 53-56; Queensland Parents for People with a Disability (QPPD), *Papering Over the Cracks: The Veneer of Prevention* (2005) 39 <[http://www.qppd.org/images/docs/ci\\_report\\_2005.pdf](http://www.qppd.org/images/docs/ci_report_2005.pdf)>.

<sup>19</sup> Office of the Public Advocate, above n 15.



The issue of adequate resourcing of advocacy is particularly relevant to this inquiry given that data provided by the NACAP agencies indicate that elder abuse and the mistreatment of older people is an increasing concern among advocacy services across Australia.<sup>20</sup> Accordingly, there is a need to revisit the Productivity Commission's 2011 report<sup>21</sup> and the Department of Social Services' 2015 report<sup>22</sup> recommendations to expand the NACAP to meet anticipated demand:

The predicted increase in the proportion, and absolute numbers, of people aged over 65 years of age is likely to drive higher demand for advocacy services. At a minimum, funding could increase in line with these projections and inflation to maintain current service levels.<sup>23</sup>

The Commonwealth-funded aged care community visitor scheme also has potential to reduce the incidence of elder abuse in aged care. At present, the Commonwealth scheme links volunteer community members with aged care residents for the purpose of companionship and friendship.<sup>24</sup> These individuals may or may not have the skills or inclination to identify and address the mistreatment of residents appropriately and effectively.

In contrast, the Queensland community visitor program for adults with impaired decision-making capacity employs community visitors to undertake regular announced and unannounced visits to specified accommodation sites for the purpose of monitoring service delivery<sup>25</sup>. Queensland community visitors have legislative authority to undertake functions such as lodging and resolving complaints on behalf of residents with impaired decision-making capacity, talking with staff and residents to clarify issues and concerns, and reviewing documentation and programs relating to their support and care<sup>26</sup>. Community visitors can lodge reports with the Office of the Public Guardian<sup>27</sup> that provides the report to the service provider for follow-up action<sup>28</sup>.

The Public Advocate supports the establishment of an Australian Government-funded aged care community visitor scheme based on the community visitor program under the *Public Guardian Act 2014* (Qld). Such a program, along with an expanded NACAP, would form a significant part of a comprehensive government response to elder abuse in residential and community-based aged care services.

I request that the Inquiry make the following recommendation:

#### **Recommendation 4**

The Queensland Government advocate for the Australian Government to:

- adequately fund the National Aged Care Advocacy Program (NACAP) to ensure that older people receiving aged care services can access advocacy to assist them to make complaints and raise issues about their treatment and care; and
- establish a fully funded aged care community visitor scheme (with paid employees, not volunteers) based on the Queensland community visitor program under the *Public Guardian Act 2014* (Qld).

<sup>20</sup> Department of Social Services, *Review of Commonwealth Aged Care Advocacy Services: Final Report* (December 2015) 44 <<https://agedcare.health.gov.au/support-services/aged-care-advocacy/review-of-commonwealth-aged-care-advocacy-services-final-report>>.

<sup>21</sup> Australian Government Productivity Commission, *Caring for Older Australians* (Productivity Commission Inquiry Report No 53 Vol 1) (2011) lxix <<http://www.pc.gov.au/inquiries/completed/aged-care/report>>.

<sup>22</sup> Department of Social Services, *Review of Commonwealth Aged Care Advocacy Services: Final Report* (December 2015) 6-7 <<https://agedcare.health.gov.au/support-services/aged-care-advocacy/review-of-commonwealth-aged-care-advocacy-services-final-report>>.

<sup>23</sup> *Ibid.*

<sup>24</sup> Australian Government Department of Health, Ageing and Aged Care: *Review of the Commonwealth Aged Care Advocacy Services* (20 February 2016) <<https://agedcare.health.gov.au/support-services/national-aged-care-advocacy-framework-consultation>>; See also *Aged Care Act 1997* (Cth) ch 5 pt 5.6 div 82 s 82-1(1)(a)(b)(c).

<sup>25</sup> Office of the Public Guardian, *Community Visitors*, Office of the Public Guardian <[www.publicguardian.qld.gov.au/adult-guardian/adult-community-visitors](http://www.publicguardian.qld.gov.au/adult-guardian/adult-community-visitors)>.

<sup>26</sup> *Ibid.*

<sup>27</sup> *Public Guardian Act 2014* (Qld) s 47(1).

<sup>28</sup> *Ibid* s 47(3).





## The reporting of deaths in residential aged care

The final potential oversight mechanism available for the protection of consumers of aged care services, is the investigation of aged care deaths by the Coroner when the death may be related to the quality of care provided at a residential aged care facility.

Currently there is no system or framework in Australia for reviewing deaths in residential aged care facilities unless a number of circumstances (as described below) make the death reportable to the Coroner. As noted in an article in the *Journal of Law and Medicine* examining the Coroner's role in the prevention of elder abuse;<sup>29</sup> a residential aged care facility is currently:

... not a prescribed setting in any Australian coronial legislation. Consequently, a death in a residential aged care facility does not automatically trigger coronial investigations. A death in a residential aged care facility may trigger a report to the coroner if the death was violent, unnatural, suspicious, health-care related or where the death certificate was not issued.<sup>30</sup>

The article also highlighted age being used as a constraint to the reporting of deaths in care in many Australian jurisdictions, including NSW, where the age of 72 is used to limit deaths that are reportable to the coroner. The article went on to say, based on evidence from a variety of scholars, that under-reporting of deaths in residential aged care facilities to the coroner is prevalent, particularly in cases associated with advanced bed sores.

In recent years I have been invited by Coroners to make submissions in inquests into the deaths of people with complex health needs in disability and aged care. One particular case involved the death of a younger person with disability residing in an aged care facility who dies from choking on food. The Deputy State Coroner asked for submissions from the Public Advocate as a result of work undertaken by my predecessor for the report, *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland*, which identified a range of risks for people with dysphagia (difficulty swallowing) that contributed to their deaths.

The Deputy State Coroner in this case acknowledged choking to be a systemic issue in residential aged and disability care, and noted that strategies to monitor, review and report on this particular issue should be built into the National Disability Insurance Scheme (NDIS) quality assurance and reporting framework.

It is pleasing to note that the new Aged Care Standards now include specific reference to "managing the risks of choking" under *Standard 3 - Effective management of high-impact or high-prevalence risks associated with the care of each consumer*.

I also suggested the Coroner consider recommending the introduction of an Aged Care Death Review Process (or alternatively, an Elder Abuse Death Review process) on the basis of the following:

- The wide-ranging care and systemic issues that have been identified in this and other coronial matters that demonstrate the benefits of taking a broader systemic view in certain types of coronial investigations;
- The specialist knowledge and skills that can be developed from the adoption of specialist death review processes that could help to reduce unexpected and potentially avoidable deaths in the target population;
- The risk that without these specialist review processes, the limitations of the definitions in the *Coroners Act 2003* for reportable deaths or deaths warranting coronial investigations could result in missed opportunities to identify systemic issues in the residential aged care and disability care systems that are causing or contributing to potentially avoidable deaths.

It is important to note, in relation to the choking case above, that the Autopsy Report identified significant deterioration in the health of the deceased's lungs that evidenced serious ongoing difficulties with eating and swallowing. In the opinion of the forensic pathologist this deterioration

<sup>29</sup> Catherine Sharp, Jennifer Sarah Schulz Moore and Mary-Louise McLaws, The Coroner's Role in the Prevention of Elder Abuse: A study of Australian Coroner's Court Cases Involving Pressure Ulcers in Elders, *Journal of Law and Medicine*, Vol26, No2, p494, 28 October 2018, Lawbook Co. Australia

<sup>30</sup> Ibid p498.



was due to food aspiration, which causes severe necrotising pneumonia and over time can lead to death. Had the deceased not died from choking on food, an event which caused his death to be viewed as 'unnatural' and therefore reportable under the *Coroners Act 2003* (Qld), he may well have died from aspiration pneumonia. Had he died from aspiration pneumonia, the death would have been considered 'natural', because without an autopsy it would only be identified as death by pneumonia. As a consequence, there would have been no basis to investigate the death and improve the level of care provided to patients with these type of conditions, even though it would have been a preventable death resulting from lack of appropriate care and mealtime supervision.

While it is acknowledged that Australians entering residential aged care facilities or using services provided by the aged care sector in their homes are potentially suffering from conditions that are life-limiting, **not** actively reviewing deaths in aged care has the potential to allow poor practices and quality of care to go unchecked. Our ultimate objective (and indeed the objective reinforced in the revised Aged Care Quality Standards) should be to treat our aged (and most vulnerable) with dignity and respect, and this standard should apply to their deaths as well as their lives. If we continue to not report and review deaths in aged care facilities and conduct investigations only in very limited circumstances, those individual and systemic failures contributing to those deaths will remain unaddressed.

The epidemiological analysis of deaths in residential aged care by Professor Ibrahim et al<sup>31</sup>, found that a significant number of deaths in aged care are 'premature' and potentially 'preventable', challenging the misconception that all deaths of frail, older people living in residential aged care are natural. It also found that the incidence of these deaths of nursing home residents has increased over the past decade. The research noted that, although there are mechanisms to actively monitor residential aged care, there is no one organisation responsible for the reduction of harm by improving practice. In contrast, general health care has a leading national agency, the Australian Commission on Safety and Quality in Health Care which monitors and investigates preventable harm and provides resources, training, education and research to address problems and improve care.

The reporting of deaths people in aged care and investigation by the Coroner is the first step towards greater scrutiny of deaths in residential aged care to improve practices, so that the prevalence of external deaths, which are by definition, preventable, can be reduced in the future.

A key priority of this submission is therefore for the State Government to consider including deaths in residential aged care facilities across the State as reportable deaths in the *Coroners Act 2003*, similar to the reportable deaths of people with disability living in care and receiving certain classes of support under the National Disability Insurance Scheme (NDIS).

I request that the Inquiry make the following recommendations:

**Recommendation 5**

The Queensland Government amend the *Coroners Act 2003* to treat deaths in residential aged care facilities across Queensland as reportable deaths.

## Younger people with disability residing in aged care facilities

I have addressed the issue of younger people with disability residing in aged care facilities in my submission to the Royal Commission. However, I would respectfully suggest to the Committee that this issue also has significant implications for State government agencies and legislation.

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<sup>31</sup> Ibrahim, Joseph et al, Premature deaths of nursing home residents: an epidemiological analysis, *Medical Journal of Australia* 206 (10), 5 June 2017, Australia.



As at 30 June 2017, there were 1236 younger people (under 65 years of age) living in residential aged care facilities in Queensland – 111 of these people were under 50 years of age.

Various studies (including a Senate Committee Inquiry conducted in 2015<sup>32</sup>) have identified that residential aged care is an unacceptable environment for younger people with disability as it does not offer:

- independent living options;
- rehabilitation options to support transition to more independent living;
- age appropriate activities and friendships;
- options for supported accommodation;
- advocacy support for young people and their families; and
- a sense of community and economic involvement.

The Senate Committee, as well as most advocacy organisations working in this area, note that a residential aged care facility is simply not an acceptable living arrangement for a younger person with disability. It is instead the 'last resort' for people with particularly complex needs – the only facility that can provide the level of health and disability supports that they require, often on a 24/7 basis.

## Moving back into the community

The Public Advocate's submission to the Royal Commission reflects the urgent need for specialist accommodation to better address the needs of this group. While Supported Disability Accommodation (SDA) is available through National Disability Insurance Scheme (NDIS) funding, the number of NDIS participants with SDA in their plans (6,400)<sup>33</sup> and the rate of construction of this accommodation (996 places currently under construction), demonstrates there is a need for a review, and potentially the commencement of a new and/or fast-tracked construction program. If new approaches to the construction or acquisition of accommodation are not considered, the waiting times for SDA (if applicants are fortunate enough to be considered eligible for the funding) will be prohibitive, leaving younger people in unsuitable accommodation and the goals of the NDIS for this group, unfulfilled.

However, the problem of young people with disability living in aged care facilities is not merely about accommodation, there is also a need to address the necessary health care supports that are required by this cohort if they are to safely transition to community living. For many people with disability living in residential aged care, it is their complex health care needs that is the principal reason they are in these facilities.

At present, the NDIS does not fund the provision of what it considers to be mainstream health supports, which can include on-site care from registered nurses, monitoring and responding to seizures and other medical care such as respiratory checks for residents with respiratory and/or swallowing issues. Many young people with disability living long-term in health facilities and residential aged care require these types of care.

This can result in the situation where, when young people are moved from residential aged care facilities and into accommodation in the general community, there may be no specialised health supports in place. Living without these necessary health supports means that people with very complex conditions, including epilepsy, respiratory and circulatory system diseases, cerebral palsy and dysphagia, combined with intellectual and physical disabilities need to rely on mainstream health services (emergency, hospital, and doctors) to both monitor and manage their conditions, and respond in emergency situations.

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<sup>32</sup> The Senate (Cth) Community Affairs Reference Committee, *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*, Parliament House, Canberra (2015).

<sup>33</sup> *Ibid.*



While this may seem to be acceptable, the complex nature of the conditions with which this cohort of people with disability lives requires proactive and timely medical interventions using the services and skills of health professionals, as opposed to disability support workers.

These health challenges and risks were evidenced in the report prepared by my office (referred to earlier in this submission), *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland*, which investigated the circumstances and conditions surrounding the deaths of 73 Queenslanders living in supported accommodation between 2009 and 2014.

This review found that 53% of the deaths examined were potentially avoidable, highlighting a range of systemic issues that need to be addressed as a government priority. These included:

- The need to address risk factors and vulnerabilities for people with disability in care, including issues associated with respiratory diseases (mainly pneumonia and aspiration pneumonia), epilepsy, circulatory system diseases (including Ischaemic heart disease), choking/food asphyxia and the use of psychotropic medications to manage challenging behaviours
- The need to improve the quality of health care and disability supports, including improving primary care and intervention practices with regular general health and annual comprehensive health checks, identifying the signs of serious illness early, improving access to health care and support including medical specialists for complex conditions, enhancing the coordination of health care and disability services and end of life care and decision making.<sup>34</sup>

## The Action Plan recently released by the Commonwealth Government

On 25 March 2019, the Commonwealth Government released a Younger People in Residential Aged Care – Action Plan, as part of its commitment to minimising the need for younger people to live in residential aged care facilities.<sup>35</sup>

This plan outlines a series of actions to fast track younger people residing in (or at risk of entering) residential aged care that are eligible for funding under the National Disability Insurance Scheme (NDIS) towards appropriate accommodation and supports within the community. The action plan relies on the implementation of the NDIS complex support needs pathway and specialist disability accommodation (SDA) that can be provided as a component of NDIS plans, for which all residents of residential aged care facilities will now be eligible.

While the plan acknowledges that 'younger people with disability often have complex health needs and the difficulty in accessing appropriate health supports in other settings is one of the main reasons younger people go to live in aged care'<sup>36</sup>, the focus of the national plan is on appropriate accommodation and disability supports only, rather than health care needs.

This rate of avoidable deaths will potentially escalate if young people residing in residential aged care facilities are transitioned into accommodation within the general community without a commitment from either the Queensland or Australian Governments to also providing the necessary health supports to manage their various health conditions.

I request the Inquiry recommend:

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<sup>34</sup> The Queensland Government recently released a formal response to the *Upholding the Right to Life and Health* report, which can be accessed at: <https://www.justice.qld.gov.au/public-advocate/activities/current/deaths-of-people-with-disability-in-care>

<sup>35</sup> Australian Government, *Younger People in Residential Aged Care – Action Plan*, <<https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-younger-people-with-disability-in-residential-aged-care-initiative/younger-people-in-residential-aged-care-action-plan>> (2019)

<sup>36</sup> Op. cit. 2



### **Recommendation 6**

The Queensland Government, as a matter of urgency:

- ensure that individual health care plans are developed for Queenslanders with disability in care, especially those transitioning from residential aged care and Queensland Health facilities to community living arrangements;
- require that those plans are reviewed and updated annually;
- ensure that the person's health care needs, as identified in their plans, inform their disability service providers of the supports required to adequately meet their health care needs and inform their NDIS plans;
- seek to clarify and finally settle with the Australian Government the funding issues associated with the provision of necessary health supports for people with disability seeking to transition from residential aged care facilities (and other health and disability facilities,) so that they can live healthy lives in the community.

## Deaths of young people residing in aged care facilities

The deaths of young people with disability residing in residential aged care facilities can also potentially go unreported, as deaths in aged care are reported under a different, narrower regime than deaths of people with disability in care.

The *Coroners Act 2003* (Qld) currently requires a death to be reportable if it was a death in care. Under section 9 (1)(a), a person's death is a death in care if, when the person died, the person had a disability noted in the *Disability Services Act 2006*, section 11 and is living in certain types of accommodation (such as level 3 accredited residential services) or is living in accommodation funded by the department administering the *Disability Services Act*. This legislation is currently under review to respond to the changes to the disability service environment associated with the introduction of the NDIS. However, it is anticipated that a similar definition will continue to apply in the future, i.e. a death will be reportable if it is a death in care.

The arrangements for reporting and investigating deaths in aged care facilities are quite different from disability deaths. Residential aged care facilities are not prescribed places for reporting deaths in any Australian coronial legislation. Therefore, unless the death of a young person with disability residing in an aged care facility is considered to be 'unnatural', suspicious or health care related, it will not be reported to the coroner. Nor will it be reported by the NDIS Quality and Safeguards Commission, in the way any other death of a person receiving NDIS funded services would be.

When a young person with disability is accommodated in a residential aged care facility, that person is unable to access the oversight and other accountability mechanisms available under the NDIS. This further highlights the inappropriateness of residential aged care facilities as a home for younger persons with disability.

I request the Inquiry make the following recommendation:

### **Recommendation 7**

The Queensland Government amend the *Coroners Act 2003* to include deaths of NDIS eligible younger people living in residential aged care facilities across Queensland as reportable deaths.



# Substitute decision-making in the aged care sector

It is becoming common practice in the Australian community to move older people against their will from their homes and into residential aged care. These decisions are often made on behalf of the older person without giving serious consideration to the possibility of the person remaining in their own home with appropriate support and services, even when the older person has indicated that is their preference. While family members clearly have genuine concern for the health and safety of their aged relatives, these decisions can often be driven by a desire to do 'what's best' for their family member and to protect them from risk.

Often these decisions occur after an older person has experienced a significant health event and is admitted to hospital, and family members or hospital staff apply to the Queensland Civil and Administrative Tribunal for guardianship over the older person to make a decision about their accommodation and care needs. Alternatively, this process can also be facilitated by a person appointed under an enduring power of attorney made by the older person, if they can obtain a medical assessment that the older person has impaired capacity.

While enduring documents can protect older people who have lost decision-making capacity from being exploited and abused by others,<sup>37</sup> there is now a practice being employed by residential aged care facilities of requiring that a person has either a valid enduring power of attorney or a guardianship order before accepting the person into the facility. It seems aged care providers have adopted this practice to ensure that all people seeking placement in a facility have a mechanism in place for continuity of decision-making in the event the person ceases to have capacity sometime in the future.

Decisions about the living arrangements for older people that are made without taking the older persons' views and wishes into account and seeking to implement them, even when the person has been found to have impaired decision-making capacity, breach their human rights under the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD). The *Guardianship and Administration Act 2000* (Qld) contains numerous provisions supporting the rights of people with impaired capacity to make, and be supported to make, decisions. This includes their right to make decisions with which others may not agree (section 5(b)) and the General Principles that recognise the importance of empowering adults to exercise their basic human rights and make their own decisions (General Principles 2 (2) and 7(2)).

The Australian Law Reform Commission (ALRC) considers that appointing a representative decision maker should not be required as a condition of receipt of residential aged care<sup>38</sup> and recommended that aged care legislation should provide that agreements cannot require that the care recipient has appointed a decision-maker for lifestyle, personal or financial matters<sup>39</sup>

In the Report, *Equality, Capacity and Disability in Commonwealth Laws*,<sup>40</sup> the ALRC recommended a set of four decision-making principles and accompanying guidelines to guide the reform of Commonwealth laws and the review of State and Territory laws. These principles emphasise the autonomy and independence of people with disability who may require support in making decisions. The ALRC advocated that a person's will and preferences must drive decisions that they are supported in making, or that others may make on their behalf.

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<sup>37</sup> Australian Law Reform Commission, *Elder Abuse*, Discussion Paper 83, Australian Law Reform Commission, Sydney 2016.

<sup>38</sup> Australian Law Reform Commission, *Elder Abuse – A National Legal Response Final Report*, report No 131 (2017) 152.

<sup>39</sup> Australian Law Reform Commission, *Elder Abuse – A National Legal Response Final Report*, report No 131 (2017) 151.

<sup>40</sup> Report 124, (2014).



The ALRC's recommendations reflect increasing national and international recognition for people with impaired decision-making capacity to be treated equally under the law and exercise their right to make decisions for themselves. For the most part, this paradigm shift originates from the Convention on the Rights of Persons with Disabilities.<sup>41</sup>

I have been informed by advocacy agencies, and have observed cases myself, where applications have been made for guardianship of a patient who resisted efforts to move them into residential aged care, instead expressing a strong desire to return to their home. These people have expressed the view that they have felt that they have been 'abducted by the system' and experienced a distressing loss of control of their lives.

The Commonwealth Government's aged care reforms are designed to encourage people to remain in their own homes, and such an approach has great potential to reduce costs to the community. However, many of the guardianship applications made in these circumstances appear to disregard any accommodation and support options other than placement in a residential aged care facility.

I have personally observed a case where a clearly competent, elderly man, who was in hospital as a result of a fall in his home, was assessed by doctors as 'lacking insight' because he wanted to return to his home with support and did not want to discuss moving to an aged care facility. This lack of insight was interpreted by the doctors as an early sign of dementia and indicative of a loss of capacity and formed the basis of the guardianship application.

In that case, neither the hospital social workers nor the man's family were prepared to explore how he might be able to live in his home with support, even though this was the outcome he clearly wanted. This approach to the 'care' of older people, is often driven by what is considered convenient for family and health services and involves the least risk for the older person. It fails to recognise the rights of older people to make decisions with which others may not agree (*Guardianship and Administration Act* s 5(b)) and the rights of all people, especially older people, to the dignity of risk and self-determination.

The problem for the older person in these circumstances is that they often do not have access to an advocate who can meaningfully support the person to put their views before the tribunal and to explore alternative options to residential aged care. Often the person may be unwell rather than lacking decision-making capacity. Further, they are unlikely to have experience of legal processes and may feel embarrassed and overwhelmed by being the subject of legal proceedings. All of these things will affect the ability of the person to advocate for themselves and put a coherent alternative to residential aged care forward, but do not necessarily point to a loss of decision-making capacity.

Taking all of this into account, I respectfully suggest to the Committee that it consider recommending the funding and provision of advocacy services to older people who are the subject of guardianship applications for the purpose of making decisions to move them to residential aged care. I recognise that there will be many cases where accommodation in residential aged care may be the only realistic option for the older person. However, these decisions need to be worked through with people in a respectful way while considering all other practical alternatives. There will also be cases where the older person does not want advocacy support, which they are entitled to refuse. However, for those who want to exercise the capacity and actively participate in the proceedings, advocacy services should be available and accessible.

Further, for the tribunal hospital hearings to operate effectively and in a way that is supportive of the rights of the person the subject of the proceedings, the tribunal needs to ensure that any hearings conducted for the purposes of considering a person's capacity, occur at a time when the person's health conditions are no longer acute, i.e. the condition has been treated and stabilised, and the person is not experiencing significant pain or symptoms (e.g. urinary tract infection

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<sup>41</sup> United Nations, *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007 [2008] ATS 12 (entered into force 3 May 2008), art 12.



symptoms) that may impact the person's ability to engage with the proceedings or exercise their capacity.

I request the Inquiry make the following recommendation:

### **Recommendation 8**

The Queensland Government:

- Ensure all relevant State laws comply with the four decision-making principles recommended by the Australian Law Reform Commission in its report, *Equality, Capacity and Disability in Commonwealth Laws*;
- Fund appropriate and accessible advocacy services for older people the subject of guardianship applications to ensure they can meaningfully participate in tribunal proceedings and express their views and wishes and put alternative accommodation and care options to residential aged care before the tribunal; and
- Require that tribunal proceedings dealing guardianship applications for older people who are in hospital do not proceed until the person's condition has been treated and stabilised and the person is not experiencing significant pain or symptoms that may impact the person's ability to engage with the proceedings or exercise their capacity.

## End-of-life care for people with impaired capacity

The issues of end-of-life care and decision-making for people with disability were addressed in a chapter of the Public Advocate's 2016 report, *Upholding the right to life and health: a review of the deaths in care of people with disability in Queensland*.<sup>42</sup>

The report, which investigated the deaths of 73 people with disability residing in residential care facilities during the period from 2009 to 2014, found that decisions were routinely being made by medical professionals with substitute decision makers (usually next of kin who would be the person's statutory health attorney) about the withdrawal and withholding of treatment, including life sustaining treatment for people with intellectual disability.

The report recommended that end-of-life care for people with disability must take into account the same medical and ethical issues that would apply for people without disability who were in the same circumstances. People with disability are entitled to be accorded the same dignity and respect at the end of their lives as other members of the community. The question should always be asked 'but for' this person's disability, would treatment be provided.

In terms of end-of-life and palliative care for people with disability, the report recommended:

- A decision to withhold or withdraw treatment for people with disability should only be made by the relevant decision maker after referral to a palliative care team or senior specialist who can provide professional advice.
- The diagnosis of a long-term, chronic or terminal condition should prompt appropriate discussions and decisions around treatment and care at the end-of-life that involve the person with disability, their family, supporters and carers and health professionals involved in their treatment and care
- End-of-life care and advance care planning activities should be empowering of people with disability and ensure that decision-making processes are robust and accountable at all times
- Health professionals should receive further education and training (both in medical school and as per of continuing education) about the law that applies to end-of-life decision-making,

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<sup>42</sup> Public Advocate, Queensland, February 2016, pp 67-73.





within the wider context of medical ethics, including the ethical issues concerning making decisions about life sustaining treatment and quality of life for people with disability.<sup>43</sup>

The findings of a 2017 study of knowledge of end-of-life law in the provision of health care<sup>44</sup> supported these recommendations. It identified major gaps in the knowledge of end-of-life law among those medical specialists most often involved in end-of-life decision-making in Queensland, New South Wales and Victoria. The study also raised concerns about compliance with the law and the impact that legal considerations have on medical decision-making.

Overall, the research demonstrated that the current level of knowledge of medical specialists working in the end-of-life area, as well as the complexity of the law and practitioners' attitudes to it, puts medical practitioners and patients at risk.

To address this risk, the research recommended that three things must occur; law reform, improved training and resources; and a shift in the level of importance that medical practitioners place on knowing the law.

In relation to law reform, the report recommended that work be undertaken to harmonise end-of-life laws nationally (at present different laws are applicable in different states) and to simplify the law, particularly in relation to Advance Directives for health.

Recommendations for training and resources suggested changes across the three main stages of education:

- Undergraduate training in basic ethical principles and the law at the end-of-life, within a wider framework of dedicated coursework in ethics, law and professional practice (universities and medical schools, Australian Medical Council);
- Continuing training for interns and junior doctors in the hospital setting, in relevant rotations, and as components of educational packages under accreditation requirements; and
- Specialist college-sponsored non-elective, systematised continued professional development training programs in all specialities concerned with end-of-life decision-making.

I request the Inquiry recommend the following:

#### **Recommendation 9**

The Queensland Government support and actively encourage appropriate medical professional training in end of life law (including a focus on people with disability and complex health needs) at an undergraduate, junior doctor and specialist college levels.

## Advance care planning

Enduring documents associated with advance care planning arrangements in Queensland are numerous and potentially confusing for people who want to plan for their end-of-life health care and decision-making.

At present, there are two legally binding advance care planning documents available under the *Power of Attorneys Act 1998*:

- Advance Health Directive – this form (currently under review by the Department of Justice and Attorney General) is a legally binding document that states a person's instructions for health

<sup>43</sup> *Ibid* at p 73.

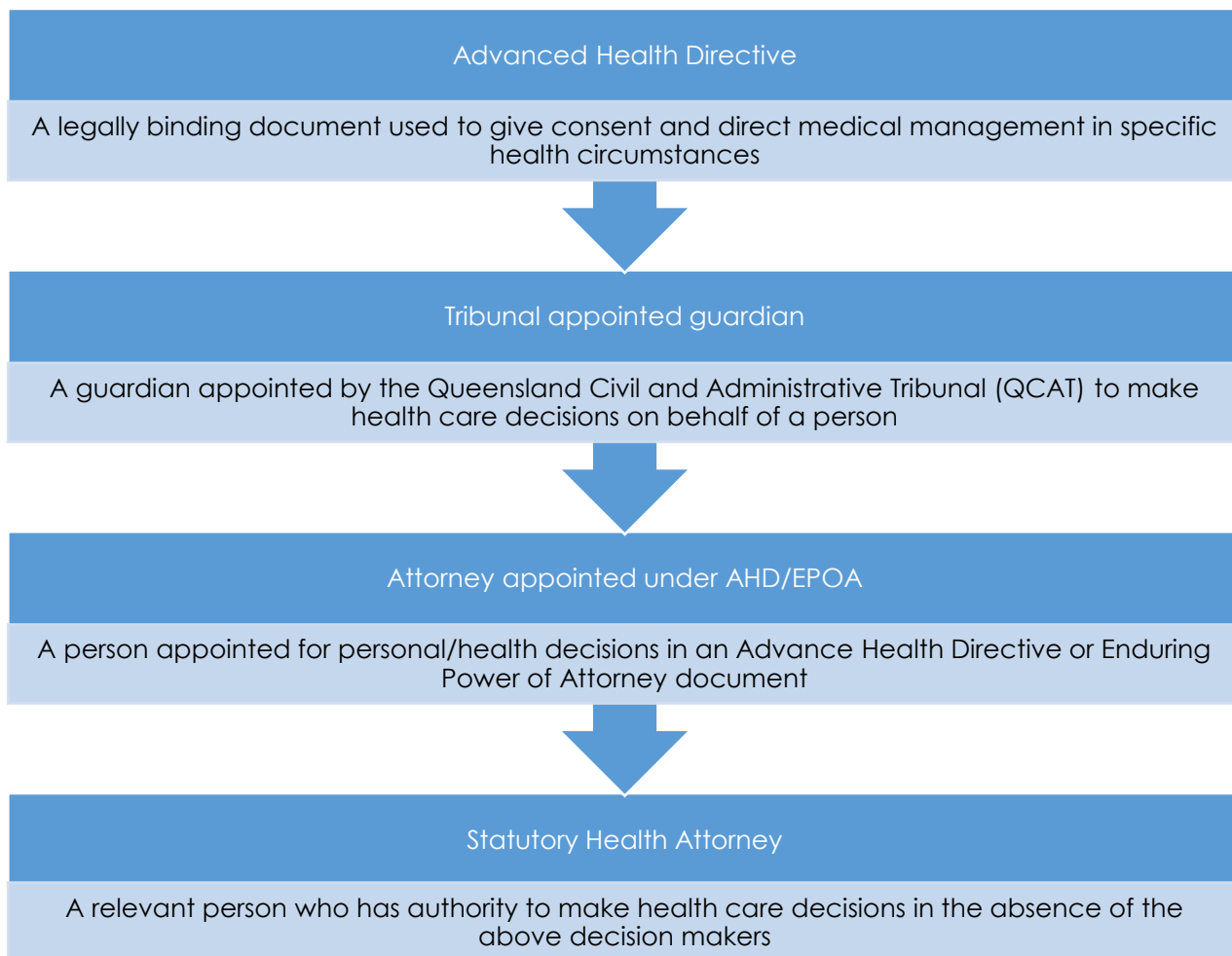
<sup>44</sup> B.White, L.Willmott, C.Cartwright, M.Parker, G.Williams, *Withholding and withdrawing life-sustaining medical treatment from adults who lack capacity: the role of law in medical practice Final Report*, Queensland University of Technology <https://eprints.qut.edu.au/118303/> >, 2017.



care in specific circumstances. It must be completed with a doctor and signed in front of a qualified witness.

- Enduring Power of Attorney – this form is also a legally binding document that can appoint one or more people to make personal, health and/or financial decisions on another's behalf. It must also be signed in front of a qualified witness

When a person is unable to make or communicate their own health care decisions, Queensland legislation establishes a statutory hierarchy of substitute decision-makers as follows:



There are also two additional documents that do not have formal legal status:

- Statement of Choices – this document has a focus on the wishes, values and beliefs of the person. It is a form used in some Queensland hospitals, residential aged care facilities and GP clinics to support advance care planning discussions, as a guide for decision-making about the person's health when the person is no longer able to make or communicate their decisions.
- Acute Resuscitation Plan (ARP) – this was implemented in Queensland Health facilities in 2009 as a state-wide form to replace Not for Resuscitation Orders. The ARP is a medical order signed by the most senior doctor available and is designed to provide clinical direction in the event of acute deterioration in the patient's condition. The ARP records resuscitation planning outcomes, following discussions with the patient or their substitute decision maker (if the person lacks capacity), and other members of the multidisciplinary team.

The Statement of Choices form and the Acute Resuscitation Plan complicate the advance care planning process, particularly as they do not have formal legal status. Further complicating (and concerning) aspects of these documents is that they can be completed by a third party on behalf of the person about whom the health decisions are being made and they do not require formal witnessing by a qualified witness.



This plethora of advance planning documents can lead to situations where people, in the later stages of life:

- Have multiple advance care planning documents which potentially conflict with each other, which may result in their wishes not being taken into account, or being applied differently from what was intended when they originally prepared the documents.
- Complete a Statement of Choices form under the misapprehension that it will override or revoke an earlier Enduring Power of Attorney, when it does not.
- Complete a Statement of Choices form with a representative of a Health and Hospital Service that is recorded on the Queensland Health electronic filing system, while having a valid Enduring Power of Attorney document, and the hospitals and medical practitioners acting on the Statement of Choices document rather than consulting the person's Attorney.

While it is clear that the development of these advance care planning documents was intended to assist people to have their views and wishes about their end-of-life care recorded and acted upon, they have also had the effect of creating some confusion and uncertainty about what documents take priority and how they can be identified and recorded in appropriate systems for access when necessary.

In the circumstances, I respectfully suggest to the Committee that the appropriateness, legality and relative risks of these various documents should be reviewed, with a goal to simplifying the range of advance care planning documents that members of the public have to consider before making a decision.

Such a review should address the following issues:

- Establish a consistent State-wide approach to advance care planning and enduring documents;
- Clarify the goals of advance care planning for the community, e.g. to ensure people can record their end-of-life views and wishes in relation to their health care and treatment; establish a system for registering these documents so they can be accessed when necessary and in an emergency; and/or to reduce futile care and unnecessary costs to the health system etc.;
- Provide community education to ensure that people understand what the documents are for and how to effectively use them and ensure their wishes are acted upon;
- Establish a system for registering advance care documents to ensure they can be accessed when necessary, and in an emergency, to guide decisions about the person's health care at end-of-life.

I request the Inquiry make the following recommendations:



### Recommendation 10

The Queensland Government undertake a review of advance care planning and the current suite of legally binding and non-legally binding documents that addresses the following:

- Establishes a consistent State-wide approach to advance care planning and enduring documents;
- Clarifies the goals of advance care planning for the community, e.g. to ensure people can record their end of life views and wishes in relation to their health care and treatment; establish a system for registering these documents so they can be accessed when necessary and in an emergency; and/or to reduce futile care and unnecessary costs to the health system etc;
- Provides community education to ensure that people understand what the documents are for and how to effectively use them and ensure their wishes are acted upon;
- Establishes a simple and accessible system for registering advance care documents to ensure they can be accessed when necessary, especially in an emergency, to guide decisions about the person's health care at end of life.

### Recommendation 11

The Queensland Government continue to work with other States and Territories to harmonise end of life/advance care planning documentation and laws nationally.

## Concluding comments

Many thanks to the Committee for undertaking this ambitious but important piece of work. It is hoped that the findings and recommendations from this Parliamentary Inquiry will complement those of the Royal Commission into Aged Care Quality and Safety, and will provide a valuable State-based perspective and response to the many and complex issues associated with providing aged care, end-of-life and palliative care and voluntary assisted dying.

My submission has drawn to the attention of the Inquiry issues relating to:

- the unlawful use of restrictive practices in residential aged care facilities;
- effective complaint mechanisms, including advocacy, community visitor programs and the reporting of deaths in care;
- younger people with disability residing in aged care facilities;
- substitute decision-making in the aged care sector;
- end-of-life care for people with impaired capacity; and
- advance care planning.

I have suggested a series of recommendations for the Inquiry to consider, which are summarised below.

## Summary of recommendations

<i>Issue</i>	<i>Recommendations</i>
<i>Voluntary Assisted Dying</i>	<b>Recommendation 1</b> Any future voluntary assisted dying legislation must include the necessary safeguards to ensure that only people with decision-making capacity can access voluntary assisted dying and that there should be no opportunity for voluntary assisted dying to be provided for in Queensland advance care planning documents.



Restrictive practices

### **Recommendation 2**

The Queensland Government advocate for the Australian Government to immediately implement a comprehensive residential aged care restrictive practices regulatory framework with all of the characteristics and protections recommended by the Australian Law Reform Commission in its report *Elder Abuse – A National Legal Response* in Recommendations 4-10 and 4-11.

### **Recommendation 3**

In the event the Australian Government fails to properly regulate restrictive practices in residential aged care, the Queensland Government implement the restrictive practices regulatory framework under the *Disability Services Act 2006* in all Queensland Government operated residential aged care facilities.

Effective complaint mechanisms

### **Recommendation 4**

The Queensland Government advocate for the Australian Government to:

- adequately fund the National Aged Care Advocacy Program (NACAP) to ensure that older people receiving aged care services can access advocacy to assist them to make complaints and raise issues about their treatment and care; and
- establish a fully funded aged care community visitor scheme (with paid employees, not volunteers) based on the Queensland community visitor program under the *Public Guardian Act 2014* (Qld).

### **Recommendation 5**

The Queensland Government amend the *Coroners Act 2003* to treat deaths in residential aged care facilities across Queensland as reportable deaths.

Younger people with disability residing in aged care facilities

### **Recommendation 6**

The Queensland Government, as a matter of urgency:

- ensure that individual health care plans are developed for Queenslanders with disability in care, especially those transitioning from residential aged care and Queensland Health facilities to community living arrangements;
- require that those plans are reviewed and updated annually;
- ensure that the person's health care needs, as identified in their plans, inform their disability service providers of the supports required to adequately meet their health care needs and inform their NDIS plans;
- seek to clarify and finally settle with the Australian Government the funding issues associated with the provision of necessary health supports for people with disability seeking to transition from residential aged care facilities (and other health and disability facilities,) so that they can live healthy lives in the community.

### **Recommendation 7**

The Queensland Government amend the *Coroners Act 2003* to include deaths of NDIS eligible younger people living in residential aged care facilities across Queensland as reportable deaths.

Substitute decision-making in aged care

### **Recommendation 8**

The Queensland Government:

- Ensure all relevant State laws comply with the four decision-making principles recommended by the Australian Law Reform



End-of-life care for people with impaired capacity

Commission in its report, *Equality, Capacity and Disability in Commonwealth Laws*;

- Fund appropriate and accessible advocacy services for older people the subject of guardianship applications to ensure they can meaningfully participate in tribunal proceedings and express their views and wishes and put alternative accommodation and care options to residential aged care before the tribunal; and
- Require that tribunal proceedings dealing guardianship applications for older people who are in hospital do not proceed until the person's condition has been treated and stabilised and the person is not experiencing significant pain or symptoms that may impact the person's ability to engage with the proceedings or exercise their capacity.

#### **Recommendation 9**

The Queensland Government support and actively encourage appropriate medical professional training in end of life law (including a focus on people with disability and complex health needs) at an undergraduate, junior doctor and specialist college levels.

Advance care planning

#### **Recommendation 10**

The Queensland Government undertake a review of advance care planning and the current suite of legally binding and non-legally binding documents that addresses the following:

- Establishes a consistent State-wide approach to advance care planning and enduring documents;
- Clarifies the goals of advance care planning for the community, e.g. to ensure people can record their end of life views and wishes in relation to their health care and treatment; establish a system for registering these documents so they can be accessed when necessary and in an emergency; and/or to reduce futile care and unnecessary costs to the health system etc;
- Provides community education to ensure that people understand what the documents are for and how to effectively use them and ensure their wishes are acted upon;
- Establishes a simple and accessible system for registering advance care documents to ensure they can be accessed when necessary, especially in an emergency, to guide decisions about the person's health care at end of life.

#### **Recommendation 11**

The Queensland Government continue to work with other States and Territories to harmonise end of life/advance care planning documentation and laws nationally.

Thank you for the opportunity to provide this submission to the Inquiry. Should the opportunity arise, I would be pleased to be part of further discussions in relation to these matters or any other issues raised in my submission.

Yours sincerely



Mary Burgess  
Public Advocate (Queensland)



**DRAFT**

# Aged Care Quality and Safety in Australia

Submission to the Royal Commission on Aged Care  
Quality and Safety

April 2019

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# Introduction

The position of Public Advocate is established under the *Guardianship and Administration Act 2000* (Qld). The primary role of the Public Advocate is to promote and protect the rights, autonomy and participation of Queensland adults with impaired decision-making capacity in all aspects of community life.

More specifically, the Public Advocate has the following functions:

- promoting and protecting the rights of adults with impaired capacity (the adults) for a matter;
- promoting the protection of the adults from neglect, exploitation or abuse;
- encouraging the development of programs to help the adults reach the greatest practicable degree of autonomy;
- promoting the provision of services and facilities for the adults; and
- monitoring and reviewing the delivery of services and facilities to the adults.<sup>1</sup>

Many users of aged care services have, or will develop, impaired decision-making capacity as a result of a range of circumstances and conditions, not the least of which is dementia. It is estimated that in 2018, there were 436,366 Australians living with dementia. Without new medical discoveries and interventions, this number is expected to increase to 589,807 in 2028 and almost 1.1 million by 2058.<sup>2</sup>

In 2015, more than half of people who permanently resided in residential aged care had a diagnosis of dementia.<sup>3</sup> This proportion is expected to increase over time as the number of people living with dementia increases as a proportion of the population.<sup>4</sup> In light of this, it is likely that a significant proportion of aged care recipients will have or will experience impaired decision-making capacity at some point during their engagement with the residential aged care system.

The Public Advocate welcomes the opportunity to make this submission to the Royal Commission into the Aged Care Quality and Safety in Australia.

Old age is the future for all of us, and the likelihood of living with impaired decision-making capacity as we enter old age is increasing. We therefore need to remind ourselves that the issues this Royal Commission is investigating about the quality of care being provided in residential aged care facilities, will eventually, and for some of us sooner rather than later, be very relevant in our own lives. Ultimately, it is in the interests of all Australians that we explore the issues of quality and safety in aged care with compassion and respect, so that we have the best chance of developing responses that deliver the best health and quality of care outcomes, while protecting the rights and interests of some of the most vulnerable people in our community.

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<sup>1</sup> *Guardianship and Administration Act 2000* (Qld) s 209.

<sup>2</sup> Dementia Australia, *Dementia Prevalence Data 2018-2058*, cited in *Dementia Australia, Key Facts and Statistics* (November 2018), Dementia Australia <https://www.dementia.org.au/statistics>.

<sup>3</sup> Australian Institute of Health and Welfare, *Australia's Health 2016*, Commonwealth Government, 109 <<https://www.aihw.gov.au/getmedia/9844cefb-7745-4dd8-9ee2-f4d1c3d6a727/19787-AH16.pdf.aspx?inline=true>>.

<sup>4</sup> *Ibid* 108.



# The use of restrictive practices in residential aged care facilities

It is noted that the Royal Commission has received evidence about the use of restrictive practices in residential aged care facilities from a number of perspectives. Evidence to date has focussed primarily on the experience of aged care residents who have been subjected to restraint or other restrictive practices (particularly chemical restraint in the form of anti-psychotic medications used as a form of sedative to manage the behaviours of unsettled residents) and the consequent impacts it has had on those residents and their families and supporters.

The Commission has heard evidence from:

- Medical professionals including Associate Professor Strivens, a geriatrician and President of the Australia and New Zealand Society for Geriatric Medicine, and Dr Bartone, the President of the Australian Medical Association.
- Ms Glenys Beauchamp PSM, Secretary of the Commonwealth Department of Health.
- Ms Maree McCabe, the CEO of Dementia Australia, a peak advocacy body for people living with dementia, their families and carers.
- Mr Mersiades, the CEO of Catholic Health Australia and Mr Rooney, the CEO of Leading Age Services Australia.

While the evidence of these witnesses has explored issues related to policy and practice for restraint use in residential aged care facilities, the Commission has not, to date, heard any evidence addressing the law relating to the use of restrictive practices and the various legal and human rights issues associated with their use.

The use of restrictive practices to manage the challenging behaviours of people in the aged and disability sectors has become a key human rights issue in Australia.<sup>5</sup> Detention, seclusion, restricted access to objects, physical, chemical and mechanical restraint (as well as electronic forms of restraint such as tracking bracelets, camera surveillance, or restrictions on media devices)<sup>6</sup> are all types of restrictive practice currently employed across the aged care sector.

Restrictive practices are used in these settings despite studies indicating that their use may result in negative physical and psychological effects on the person being restrained<sup>7</sup> and may also constitute a breach of law and human rights.<sup>8</sup>

While some jurisdictions in Australia regulate the use of restrictive practices in the disability and/or mental health sectors,<sup>9</sup> the law governing these practices in residential aged care is unclear and,

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<sup>5</sup> Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Report No 124 (2014) 243.

<sup>6</sup> Alistair R. Niemeijer et al, 'Ethical and practical concerns of surveillance technologies in residential care for people with dementia or intellectual disabilities: An overview of the literature' (2010) 22(7) *International Psychogeriatrics* 1129, 1136.

<sup>7</sup> Sarah Mott, Julia Poole and Marita Kenrick, 'Physical and chemical restraints in acute care: Their potential impact on the rehabilitation of older people' (2005) 11 *International Journal of Nursing Practice* 95, 96; Jenny Gowan and Louis Roller, 'Chemical restraint or pharmacological treatment for abnormal behaviours' (2012) 93 *The Australian Journal of Pharmacy* 58, 60; Jeffrey Chan, Janice LeBel and Lynne Webber, 'The dollars and sense of restraints and seclusion' (2012) 20(1) *Journal of Law and Medicine* 73, 74.

<sup>8</sup> Donal Griffith, 'Substituted decision making: Part 1 When are restraints off the rails?' (2014) 17(2) *Retirement & Estate Planning Bulletin* 1, 1; *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3rd sess, 183rd mtg, UN Doc A/810 (10 December 1948); Juan E. Mendez, 'Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment' (A/HRC/22/53, 1 February 2013); The potential for human rights breaches in relation to the use of restrictive practices has been reinforced by the United Nations Committee on the Rights of Persons with Disabilities, which expressed concerns about the use of unregulated restrictive practices in its concluding observations on Australia's initial report under the *Convention on the Rights of Persons With Disabilities*. See Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Australia* (adopted by the Committee at its tenth session 2-13 September 2013) 5.

<sup>9</sup> See, for example, *Disability Services Act 2006* (Qld) pt 6; *Mental Health Act 2016* (Qld) ch 8.



for the most part, non-existent.<sup>10</sup> At present, the *Aged Care Act 1997* (Cth) does not formally regulate the use of restrictive practices in residential aged care facilities.

This is concerning for a number of reasons. As noted, the number of people living with dementia is expected to increase substantially, and many people with dementia will eventually experience the behavioural and psychological symptoms (such as challenging behaviours) associated with dementia. There is a growing body of research indicating that dementia-related behaviours are often being managed by unregulated restrictive practices,<sup>11</sup> and that restrictive interventions are in widespread use in both formal and informal aged care settings.<sup>12</sup>

Evidence also suggests that some residential aged care staff do not have the knowledge and/or skills to manage behaviours appropriately,<sup>13</sup> and that the wellbeing of the person being restrained may be negatively affected as a result.<sup>14</sup> It is concerning that the inappropriate use of restraints in aged care facilities in Australia has been a factor in the deaths of some people upon whom the restraints were used.<sup>15</sup>

A study led by Professor Joseph Ibrahim from Monash University in Victoria in 2015 investigated the nature and extent of physical restraint deaths reported to coroners in Australia over a 13 year period (2000-2013)<sup>16</sup>. The study found that five deaths due to physical restraint were recorded in this period, with neck compression and entrapment being the mechanism of harm in all cases, resulting in asphyxia and mechanical asphyxia.

Further research undertaken by Professor Ibrahim and others in 2017 involved the conduct of epidemiological analysis of premature deaths of nursing home residents.<sup>17</sup> This study examined the causes of death among residents of accredited Australian nursing homes, whose deaths were reported to coroners between 1 July 2000 and 30 June 2013, and determined to have resulted from external causes. This study found that the incidence of premature and potentially preventable deaths of nursing home residents has increased over the past decade, particularly in relation to deaths associated with falls and choking. Over the 13 year period, there were 2679 deaths associated with resident falls and a further 261 caused by choking. Given that there is a direct correlation between the inappropriate use of psychotropic drugs (as a form of chemical restraint) and fall risks<sup>18</sup> the increase in fall incidence leading to premature deaths in nursing homes over the last decade may be related.

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<sup>10</sup> Michael Williams, John Chesterman and Richard Laufer, 'Consent versus scrutiny: Restricting liberties in post-Bournewood Victoria' (2014) 21(3) *Journal of Law and Medicine* 641, 644; Judy Allen and Tamara Tulich, 'I want to go home now': Restraint decisions for dementia patients in Western Australia' (2015) 33(2) *Law in Context* 1, 4.

<sup>11</sup> Sally Borbasi et al, 'A Nurse Practitioner Model of Service Delivery in Caring for People with Dementia' (2010) 36(1-2) *Contemporary Nurse: A Journal for the Australian Nursing Profession* (Supplementary Advances in Contemporary Nursing: Workforce and Workplaces) 49-60; Tanya Davison et al, 'Non-Pharmacological Approaches to Managing Challenging Behaviours Associated with Dementia in Aged Care' (2010) 32(5) *InPsych*.

<sup>12</sup> See, for example, Janet Timmins, 'Compliance with best practice: implementing the best available evidence in the use of physical restraint in residential aged care' (2008) 6(3) *International Journal of Evidence-Based Healthcare* 345, 345; Cath Roper, Bernadette McSherry and Lisa Brophy, 'Defining seclusion and restraint: Legal and policy definitions versus consumer and carer perspectives' (2015) 23(2) *Journal of Law and Medicine* 297, 298; Sarah N. Hilmer and Danijela Gnjidic, 'Rethinking psychotropics in nursing homes' (2013) 198(2) *Medical Journal of Australia* 77, 77; Office of the Public Advocate (SA), 'Annual Report 2012-2013' (2013) 46; Mary Courtney et al, 'Benchmarking clinical indicators of quality for Australian residential aged care facilities' (2010) 34(1) *Australian Health Review* 93, 98. Additionally, in a study of family carers of people with dementia, the use of psychotropic medications was the second most commonly used strategy for managing behavioural and psychological symptoms of dementia. See Kirsten Moore et al 'How do Family Carers Respond to Behavioural and Psychological Symptoms of Dementia?' (2013) 25(5) *International Psychogeriatrics* 743-753.

<sup>13</sup> See Sally Borbasi et al, above n 12.

<sup>14</sup> Nicholas G Castle, 'Mental Health Outcomes and Physical Restraint Use in Nursing Homes {Private}' (2006) 33(6) *Administration and Policy in Mental Health and Mental Health Services Research* 696-704; K Cubit et al, 'Behaviours of Concern in Dementia: A Survey of the Frequency and Impact of Behaviours of Concern in Dementia on Residential Aged Care Staff' (2007) 26(2) *Australasian Journal on Ageing* 64-70.

<sup>15</sup> See, for example, *Plover v McIndoe* (2000) 2 VR 385; Sarah Farnsworth, *Woman dies of heart attack while strapped to toilet* (17 August 2011) ABC News <<http://www.abc.net.au/news/2011-08-17/seymour-health/2843252>>.

<sup>16</sup> Ibrahim et al (2017), *Physical Restraint deaths in a 13-year national cohort of nursing home residents*, *Age and Ageing* 2017; 46:688-693 <[www.https://doi.org/10.1093/ageing/afw246](https://doi.org/10.1093/ageing/afw246)>.

<sup>17</sup> Ibrahim, Joseph et al, *Premature deaths of nursing home residents: an epidemiological analysis*, *Medical Journal of Australia* 206 (10), 5 June 2017, Australia.

<sup>18</sup> Westbury et al, *RedUse: reducing antipsychotic and benzodiazepine prescribing in residential aged care facilities*, *Medical Journal of Australia* 208 (9), 21 May 2018, 398.



A series of Australian newspaper articles<sup>19</sup> over the last 2 years also highlight individual stories and reports regarding the use of psychotropic medications as a form of chemical restraint in aged care facilities. Research by Dementia Australia<sup>20</sup> indicates that around half of all people living in residential aged care facilities and up to 80 per cent of those with dementia are receiving psychotropic medications as a first response to managing behaviour. A study conducted by the University of Tasmania<sup>21</sup> has reinforced these statistics, finding that nearly two in three aged care residents are given psychiatric medication every day, mostly inappropriately prescribed, which can lead to death or falls and seizures. The Royal Australian College of GPs president was quoted in an article that appeared in *The Australian* stating that; '*medical sedation is a foul compromise for inadequate nursing care. People think they're in a safe place in residential care and everything (will) be fine, but the reality is what's being reflected in the research*'.

The increasing number of people with dementia and the potential harm (or worse) that may occur as a result of ad hoc or poorly applied restrictive practices<sup>22</sup> suggest an urgent need to clarify the legality of restrictive practices in the Australian aged care system. Further, restrictive practices should be regulated to achieve a more consistent, evidence- and rights-based approach to responding to dementia-related behaviours.

## The legislative framework

As noted, while some jurisdictions in Australia regulate the use of restrictive practices in the disability and/or mental health sectors,<sup>23</sup> the law governing these practices in residential aged care is unclear and, for the most part, non-existent.<sup>24</sup>

At present, the *Aged Care Act 1997* (Cth) does not formally regulate the use of restrictive practices such as chemical, physical and mechanical restraint in residential aged care.

Under section 96-1 the Minister for Health can create user rights, principles and standards which are reflected in the *Quality of Care Principles 2014* (Cth). These principles outline standards that may be used to protect residents who are vulnerable to restrictive practices, for example, the requirements to manage challenging behaviours effectively;<sup>25</sup> provide a safe living environment;<sup>26</sup> or to respect residents' independence,<sup>27</sup> dignity,<sup>28</sup> choice, and decision-making.<sup>29</sup>

Section 65-1 of the Act further states that if an aged care provider breaches any of its responsibilities under the Act (including its responsibility to act consistently with the care principles)<sup>30</sup>, the Secretary of the Department of Health may impose sanctions that include the

<sup>19</sup> Magarey, Joel, *Aged care homes' drug use slammed as 'elder abuse'*, *The Australian*, August 14, 2018 <<https://www.theaustralian.com.au/national-affairs/health/agedcare-homes-drug-use-slammed-as-elder-abuse/news-story/8101e54e5dc89a8bfcdecf5663be727a>>. Dowling, Jason, *'My Dad was given drugs 'like potato chips': how the elderly are being restrained*, *The Age* 18 February 2016 <<https://www.theage.com.au/national/victoria/my-dad-was-given-drugs-like-potato-chips-how-the-elderly-are-being-restrained-20160218-gmxc3o.html>>.

<<https://www.theguardian.com/society/2018/apr/21/dementia-patients-dehumanised-hospital-restraint-techniques>>.

<sup>20</sup> Dementia Australia, *Dementia Key Facts and Statistics*, viewed on website 10 April 2019

<<https://www.dementia.org.au/files/documents/2019-Dementia-Key-facts-stats.pdf>>.

<sup>21</sup> Westbury et al, 'RedUSE: reducing antipsychotic and benzodiazepine prescribing in residential aged care facilities', *Medical Journal of Australia* (MJA) 208 (9), 21 May 2018, p.398-403

<sup>22</sup> For example, behaviour driven by undiagnosed pain may be misinterpreted as a behavioural or psychological symptom of dementia and subsequently 'treated' with inappropriate administration of psychotropic drugs which can lead to complications such as falls, fractures, impaired cognition, and increased risk of death. See Edwin Tan et al, 'Analgesic Use, Pain and Daytime Sedation in People With and Without Dementia in Aged Care Facilities: A Cross-Sectional, Multisite, Epidemiological Study Protocol' (2014) 4(6) *BMJ Open*.

<sup>23</sup> See, for example, *Disability Services Act 2006* (Qld) pt 6; *Mental Health Act 2016* (Qld) ch 8.

<sup>24</sup> Michael Williams, John Chesterman and Richard Laufer, 'Consent versus scrutiny: Restricting liberties in post-Bournemouth Victoria' (2014) 21(3) *Journal of Law and Medicine* 641, 644; Judy Allen and Tamara Tulich, 'I want to go home now': Restraint decisions for dementia patients in Western Australia' (2015) 33(2) *Law in Context* 1, 4.

<sup>25</sup> *Quality of Care Principles 2014* (Cth), sch 2 pt 2 item 2.13.

<sup>26</sup> *Ibid* sch 2 pt 2 item 4.4.

<sup>27</sup> *Ibid* sch 2 pt 2 item 3.5.

<sup>28</sup> *Ibid* sch 2 pt 2 item 3.6.

<sup>29</sup> *Ibid* sch 2 pt 2 item 3.9.

<sup>30</sup> *Aged Care Act 1997* (Cth) s 56-1(m).



removal of funding or license to operate. In the case *Saitta Pty Ltd v Secretary, Department of Health and Ageing*<sup>31</sup> the use of restrictive practices were found to be a breach of the care principles.

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***Saitta Pty Ltd v Secretary, Department of Health and Ageing.*** *The Administrative Appeals Tribunal upheld the Department of Health and Ageing's imposition of severe sanctions that led to the closure of the Belvedere Park Nursing Home in Melbourne, following an assessment that residents' safety was at severe and immediate risk. The tribunal described an incident where an unattended resident had been restrained to a chair with a lap-belt an hour after it should have been removed. This was considered a breach of the principle for the right to dignity, for residents to be assisted to achieve maximum independence, and for management to actively work in providing a safe and comfortable environment consistent with the residents' needs. However, there was no further discussion of restrictive practices as the matter focussed on many other serious incidents that led to the finding of severe immediate risk, including poor infection control; poor sanitation; inadequate incontinence management etc.*

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While these provisions are available, the need for court cases to establish breaches and define what is included in the care principles still means that the legislation is not sufficiently clear in relation to restrictive practices, which needs to be remedied.

## Reports and Reviews

Aged care inquiries and reviews that have addressed the issue of restrictive practice use in aged care facilities are numerous, with three reports released in the last three years alone that make recommendations for legislative change in this area.

In its June 2016 *Elder Abuse Issues Paper*, the Australian Law Reform Commission (ALRC) recognised that some restrictive practices can constitute elder abuse, deprive people of their basic legal and human rights and be classified as assault, false imprisonment and/or other civil or criminal acts.<sup>32</sup>

In May 2017, the ALRC published the final report for the Elder Abuse Inquiry – *Elder Abuse: A National Legal Response*. In that report, the Commission recommended that aged care legislation should regulate the use of restrictive practices in residential aged care:

Recommendation 4–10 Aged care legislation should regulate the use of restrictive practices in residential aged care. Any restrictive practice should be the least restrictive and used only:

- (a) as a last resort, after alternative strategies have been considered, to prevent serious physical harm;
- (b) to the extent necessary and proportionate to the risk of harm;
- (c) with the approval of a person authorised by statute to make this decision;
- (d) as prescribed by a person's behaviour support plan; and
- (e) when subject to regular review.

Recommendation 4–11 The Commonwealth Government should consider further safeguards in relation to the use of restrictive practices in residential aged care, including:

- (a) establishing an independent Senior Practitioner for aged care, to provide expert leadership on and oversight of the use of restrictive practices;

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<sup>31</sup> *Saitta Pty Ltd v Secretary, Department of Health and Ageing* (2008) 105 ALD 55.

<sup>32</sup> Australian Law Reform Commission, *Elder Abuse Issues Paper* (IP 47) (June 2016) 238.



- (b) requiring aged care providers to record and report the use of restrictive practices in residential aged care; and
- (c) consistently regulating the use of restrictive practices in aged care and the National Disability Insurance Scheme.<sup>33</sup>

The 2017 independent review of the Commonwealth's aged care quality regulatory processes, conducted by Ms Kate Carnell and Professor Ron Paterson<sup>34</sup> also recognised this gap in the legislation, making a recommendation (7, p.xii) to government to legislate to regulate the use of restrictive practices as follows;

7. Aged care standards will limit the use of restrictive practices in residential aged care
  - i. Any restrictive practice should be the least restrictive and used only:
    - a. as a last resort, after alternative strategies have been considered, to prevent serious physical harm;
    - b. to the extent necessary and proportionate to the risk of harm;
    - c. with the approval of a person authorised by statute to make this decision;
    - d. as prescribed by a person's behaviour support plan; and
    - e. when subject to regular review.
  - ii. Approved providers must record and report the use of restrictive practices in residential aged care to the Aged Care Commission
  - iii. Accreditation reviews will review the use of psychotropic agents
  - iv. Chief Clinical Advisor must approve the use of antipsychotic medications for aged care residents

More recently (October 2018), the Standing Committee on Health, Aged Care and Sport released its *Report on the inquiry into the Quality of Care in Residential Aged Care Facilities in Australia*<sup>35</sup>. That report also recommended the Commonwealth Government amend the *Aged Care Act 1997* to legislate for the use of restrictive practices in residential aged care facilities.

## International Comparisons

On 15 June 2017, World Elder Abuse Awareness Day, my office released the paper *Legal frameworks for the use of restrictive practices in residential aged care: An analysis of Australian and international jurisdictions*.<sup>36</sup> The paper explored the existing laws, policies and practices in Australia and other international jurisdictions.

The paper found that, unlike Australia, New Zealand, the United Kingdom, Scotland, the United States of America and most provinces of Canada have formal legal frameworks regulating the use of restrictive practices in residential aged care facilities.

The key features of these systems include:

- the implementation of legislation, standards, regulations and/or safeguards that outline best-practice, evidence-based requirements regarding the use of restrictive practices;
- establishing principles that underpin the framework – for example, that restrictive practices may only be used in instances where a person is at risk and when all other less restrictive measures have been attempted;
- prohibiting the use of medication as a form of chemical restraint;
- a rigorous system of auditing for restrictive practices;
- substantial penalties for non-compliance with aged care services and restrictive practice standards;
- ensuring that state and national restrictive practice frameworks are congruent; and

<sup>33</sup> Australian Law Reform Commission, *Elder Abuse-A National Legal Response*, Report No 131 (2017) 11.

<sup>34</sup> Carnell, Kate AO and Paterson, Ron ONZM, *Review of National Aged Care Quality Regulatory Processes*, October 2017.

<sup>35</sup> Standing Committee on Health, Aged Care and Sport, *Report on the Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia* (October 2018), Canberra Australia

<sup>36</sup> Office of the Public Advocate, *Legal frameworks for the use of restrictive practices in residential aged care: An analysis of Australian and international jurisdictions* (June 2017).

<[http://www.justice.qld.gov.au/\\_data/assets/pdf\\_file/0005/524426/restrictive-practices-in-aged-care-final.pdf](http://www.justice.qld.gov.au/_data/assets/pdf_file/0005/524426/restrictive-practices-in-aged-care-final.pdf)>.



- encouraging the judiciary to promote the freedoms and independence of older people.

## The Government's response

Following some particularly disturbing media reports about the misuse of restrictive practices in residential aged care facilities, the Commonwealth Minister for Indigenous Health, Minister for Senior Australians and Aged Care, The Honourable Ken Wyatt AM, MP, in a 17 January 2019 media statement<sup>37</sup>, committed to better regulation of chemical and physical restraint in aged care facilities. In that media statement the Minister outlined the Government's response to the issue as follows:

- The new Aged Care Quality Standards that come into force on 1 July 2019 'stipulate best-practice clinical care to minimise the use of chemical and physical restraint';
- The Department of Health has provided all aged care homes with the *Guiding principles for medication management in residential aged care facilities* to assist managers and staff to practice quality use and safe management of medicines;
- The Department of Health has also provided the *Decision-Making Tool Kit – Supporting a restraint free environment in Residential Aged Care* to residential aged care homes
- The Government has invested \$4.1M in two separate research projects – the RedUSE Project and the HALT Project – to reduce the use of sedative and antipsychotic medications in residential aged care (see further comment about these projects below).

In a further media release dated 30 March 2019<sup>38</sup>, the Minister foreshadowed further 'regulatory changes', setting out specific provider responsibilities in relation to the use of physical and chemical restraint in aged care facilities to apply from 1 July 2019.

These proposed actions by the government and their likely legal and practical impacts will be considered in turn.

### The Aged Care Quality Standards

The new Aged Care Quality Standards are contained in the *Quality of Care Amendment (Single Quality Framework) Principles 2018*. The relevant part of the Aged Care Quality Standards is Standard 8 — Organisational Governance which provides:

#### *Consumer outcome*

- (1) I am confident the organisation is well run. I can partner in improving the delivery of care and services

#### *Organisation statement*

- (2) The organisation's governing body is accountable for the delivery of safe and quality care and services

#### *Requirements*

- (3) The organisation demonstrates the following:
  - (a) consumers are engaged in the development, delivery and evaluation of care and services are supported in that engagement;
  - (b) the organisation's governing body promotes a culture of safe, inclusive and quality care and services and is accountable for their delivery;
  - (c) effective organisation wide governance systems relating to the following:
    - (i) information management;
    - (ii) continuous improvement;
    - (iii) financial governance;
    - (iv) workforce governance, including the assignment of clear responsibilities and accountabilities;

<sup>37</sup> Ken Wyatt AM MP (Minister for Indigenous Health, Senior Australians and Aged Care), *Aged Care Restraint Regulations to Protect Senior Australians*, Parliament House, Canberra, 17 January 2019.

<sup>38</sup> Ken Wyatt AM MP (Minister for Indigenous Health, Senior Australians and Aged Care), *Stronger Restraint Regulations to Protect Senior Australians*, Parliament House, Canberra, 30 March 2019.



- (v) regulatory compliance;
- (vi) feedback and complaints;
- (d) effective risk management systems and practise, including but not limited to the following:
  - (i) managing high impact or high prevalence risks associated with the care of consumers;
  - (ii) identifying and responding to abuse and neglect of consumers;
  - (iii) supporting consumers to live the best life they can;
- (e) where clinical care is provided – a clinical governance framework, including but not limited to the following:
  - (i) antimicrobial stewardship;
  - (ii) **minimising the use of restraint;** [emphasis added]
  - (iii) open disclosure.

It is reasonable to observe that Quality Standard 8 provides the absolute minimum reference possible to the use of physical or chemical restraint. Merely stating that there should be a 'clinical governance framework ... minimising the use of restraint'. In terms of setting standards and an appropriate and accountable regulatory framework for the use of physical or chemical restraint, it must be said that Standard 8 is wholly inadequate.

Residential aged care facility providers will be required to report under this standard, in accordance with the reporting requirements specified in the National Aged Care Quality Indicator Program, which will be a mandatory reporting program from 1 July 2019 (the program was previously voluntary).

## Aged Care Regulations

Following his statement on 30 March 2019, on 3 April 2019, the Minister released the amendment to the *Quality of Care Principles 2014*, making specific provision for the use of physical and chemical restraint.

While any tightening of the standards of care around the use of physical and chemical restraint are supported, this amendment does not adopt many of the fundamental features of an accountable and transparent restrictive practices regulatory framework as recommended by the ALRC. Some of the key features missing from the Commonwealth Government's proposed new scheme include:

- the proposed scheme does not provide for the appointment of a formal independent decision-maker who is at arms-length from the provision of care to the person subject to the restrictive practice;
- there is no appeal process;
- there is no requirement that there should be regular reviews of the use of restrictive practices;
- there is no requirement that providers develop a behaviour support plan for the person which would guide the care provided to the person and decision-making and ensure the focus is on reducing and eliminating the use of restrictive practices;
- there is no requirement that the restrictive practices be applied for the least time necessary;
- there is no requirement that the restrictive practices used be proportionate to the risk of harm; and
- the proposed regime only requires that the consumer pose 'a risk of harm' which is a much lower threshold than the ALRC's recommendation that restrictive practices only be used to 'prevent serious physical harm'.

It is also a matter of extreme concern that the proposed regime provides for a doctor (most often a general practitioner), nurse practitioner or registered nurse to make decisions in relation to the use of restrictive practices, when most of these health practitioners will not have any formal training or recognised specialty in relation to the provision of aged care services or positive behaviour management.

This concern is further compounded by the fact that the health practitioners making the decisions have an interest in the outcome of the decision in terms of the management of the resident, the staff and the facility, because they also work there or are paid by the service provider. Decisions to





'manage' residents who are displaying challenging behaviours will necessarily be influenced by other considerations including management views, staff numbers and skills, and convenience.

Another key legal issue that arises from the proposed new Quality of Care Principles is that they make provision for the provider to obtain 'the informed consent of the consumer or the consumer's representative' to the use of restraint. It should be noted that this consent is not required by the Principles in relation to the use of chemical restraint, apparently because it is a 'clinical' decision (more about this later).

Across the country, the law is unclear about whether a person's guardian or formal decision-maker can actually consent to the use of restrictive practices on a person for whom they are appointed to make decisions.

... absent specific legislative authorisation either through restrictive practices or coercive powers provisions in the legislation, questions remain about authorising restrictive practices through the guardianship system. This is despite the apparent widespread reliance on it, including with some apparent endorsement of this position by guardianship bodies.<sup>39</sup>

It is particularly concerning that the Australian Government is proposing an approach to using restrictive practices that relies on the consent of guardians and other substitute decision makers when the legality of this approach is uncertain. Instead, it only raises further legal questions and leaves residents and staff in a legal limbo. It is wholly inappropriate for such an obviously inadequate response to be proposed when the focus of the Royal Commission is to address issues around the treatment and quality of care of people in residential aged care facilities.

The problems associated with representatives' consent to the use of restrictive practices is compounded by the very informal 'representation' arrangements that are provided for under the *Aged Care Act 1997*. Under section 5 of the *Quality of Care Principles 2014*, other than under an enduring power of attorney or guardianship appointment, the following representative arrangements can be made:

- the consumer can nominate 'a person to be told about matters affecting the consumer';
- a person can nominate themselves to be 'a person to be told about matters affecting a consumer' and the approved provider 'is satisfied the person has a connection with the consumer' and is concerned for that person's safety, health and well-being;
- the person can be 'a partner, close relation or other relative of the consumer'; or
- it can be as relaxed as 'the person represents the consumer in dealings with the approved provider.

It is unclear who can make the determination that the person can be regarded as the consumers' representative. However, again it seems wholly inappropriate that a person accepted as a 'representative' in most of the circumstances outlined under section 5 of the Principles should also be the authority for providers to physically restrain a person in aged care or be the person notified about the use of chemical restraint. It is difficult to envisage how most ordinary people trying to fulfil such a role could provide 'informed consent' to the use of restraint on the aged care consumer they are supporting.

The 'use of chemical restraint' provisions under the Principles also raises significant concerns. This term is not one in general medical use, is not evidence-based and is poorly understood. Its meaning is not clear. It is particularly concerning to see the term enshrined in a legislative instrument, particularly, as it appears to amount to an acknowledgement and endorsement of a particular intervention, namely the use of medication as a chemical restraint to control behaviour, which is not generally considered to be good medical practice within the medical profession. It is concerning that a government policy document should be apparently dictating medical practice in aged care facilities in this way, when there is no clear endorsement of the approach by the medical profession or the relevant specialist college. This approach could create difficulties for professional and disciplinary bodies when seeking to discipline a doctor for poor prescribing and

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<sup>39</sup> Kim Chandler, Ben White and Lindy Willmott, 'What role for adult guardianship in authorising restrictive practices?', (2017), *Monash University Law Review*, (Vol 43, No 2) p 496.



medical practice where they have inappropriately prescribed antipsychotic medication to purportedly control a person's behaviour without a formal medical diagnosis. The government standards appear to be actively promoting medical practice that should be discouraged.

The fundamental issue associated with the Commonwealth Government's approach to chemical restraint in the new regulations is that it appears confused. The drafting suggests that decisions about chemically based restrictive practices are clinical ones, but uses legislative instruments to dictate the clinical approach.

In my opinion, the approach that the Commonwealth Government has taken to the issue of regulation of restrictive practices in residential aged care demonstrates a complete lack of knowledge and understanding of three key issues:

- the previous reviews and recommendations about restrictive practices in aged care, such as the ALRC Elder Abuse Report and the Carnell-Patterson review;
- the law that applies to the use of restrictive practices and of basic legal and human rights; and
- the principles of positive behaviour support which should underpin any approach to restrictive practices, and yet, does not rate a mention in the *Aged Care Act 1997*, the Principles or Standards, or any of the supporting resource material provided by government.

### National Aged Care Quality Indicator Program - Resources

The resource manual<sup>40</sup> accompanying the National Aged Care Quality Indicator Program is extensive. However, it has not been updated to reflect the recent amendment to the Quality of Care Principles dealing with chemical restraint. Accordingly, the resource manual provides no guidance on this issue. However, it provides a great deal of detail in relation to the use of physical restraint, what constitutes physical restraint and how to count instances of it.

The resource manual notes that there are a number of adverse clinical events associated with physical restraint, including death, mental health decline, depression, social isolation, development of pressure injuries, falls, confusion, aggression and pain.

The manual also provides additional key facts and other useful, but confusing information for aged care staff looking for guidance about how to make a decision about using physical restraint. Those key facts include the following statements:

- Physical restraint is an infringement of the individual's right to freedom, dignity and autonomy.
- A family member and legal representatives do not have the legal right to request that a resident be restrained.
- There are many reasons why physical restraint is used but there is no evidence that demonstrates any benefit of its use to aged care residents.
- The evidence indicates that restraint does not prevent falls or fall-related injuries and is likely to exacerbate behaviours.
- A restraint free environment is the recommended standard of care.

A particularly concerning aspect of the Quality Indicator Program Resource Manual regarding its handling of the use of physical restraint is that it requires providers to assess **every** resident for physical restraint. Accordingly, instead of restraint being the exception and the last resort in managing the challenging behaviours of residents, it is assumed that all residents may be subject to this treatment at some point in time. Such an approach is inconsistent with a least restrictive approach to the care of residents. Again, it is difficult to understand why the manual would formally require that every resident be assessed for physical restraint while acknowledging that it is an infringement of their right to freedom, dignity and autonomy, that the evidence indicates it does not prevent falls or fall-related injuries and is likely to exacerbate behaviours.

An equally concerning aspect of the relevant chapter of the resources manual dealing with the use of physical restraint is that it contains no guidance for aged care staff or clinicians about the relevant considerations when making a decision about the use of physical restraint. This is a significant and dangerous oversight. It is unacceptable that a resource manual that is held out as a

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<sup>40</sup> MyAgedCare (Cth), *National Aged Care Quality Indicator Program – Resource Manual for residential aged care facilities*, September 2016 edition, viewed on myagedcare website 10 April 2019 <myagedcare.gov.au>



'Handbook for residential aged care facilities' providing them with 'a set of meaningful and measureable QIs [quality indicators] to assist in monitoring and improving important aspects related to quality of care' should provide no specific guidance and no quality indicators relating to the decision-making of care providers who use physical restraint on their residents. The relevant chapter of the resource manual makes no mention of the *Decision-making tool: supporting a restraint free environment in residential aged care* referred to by the Minister in his media release of 17 January 2019.

The resource manual contains an 'Appendix 5 – Quality Indicator 2: Use of physical restraint' which contains additional material about the use of restraint.

The manual informs the reader that 'the reasons for the decision to restrain and the process by which the decision was reached should be documented, as those making the decision are legally accountable for the decisions and their consequences'. This effectively amounts to an admission that the use of restraint is not lawful (without proper informed consent) and will potentially expose staff at residential aged care facilities to legal risks.

Overall, the new provisions announced by the Commonwealth Government in recent months do little to improve or create an appropriate legislative or operational framework for the use of restrictive practices in residential aged care facilities.

The new measures do not establish the legal framework required to lawfully permit and regulate the use of restrictive practice in residential aged care facilities.

Simply put, the Commonwealth Aged Care Minister's proposed response is wholly inadequate to address this key issue in residential aged care provision and operations. It completely fails to recognise the legal implications of these actions by aged care providers and their staff and attempts to characterise the use of restrictive practices as a clinical decision. It is unlawful to actively limit a person's movement or to administer stupefying substances to them outside of a proper legal framework that permits such actions within prescribed limits.

## Best Practice – Legislation and Operations

### Legislation

As noted above, the legislation intended to govern the use of restrictive practices in residential aged care facilities is flawed, meaning that there remains a lack of a strong, enforceable legal framework for using practices in aged care settings across Australia.

Some jurisdictions in Australia currently regulate the use of restrictive practices in the disability and/or mental health sectors and, as such, could be considered as potential models for the regulation of restrictive practices in residential aged care.

Queensland has a comprehensive regulatory framework for the use of restrictive practices by state government-funded disability service providers, under the *Disability Services Act 2006* (Qld). The model is considered best practice, providing that restrictive practices can only be used within a framework of positive behaviour support. A positive behaviour support process requires multi-disciplinary assessments of the person who would be subject to the restrictive practices and their care and support needs, along with the development of a positive behaviour support plan that identifies the person's challenging behaviours and contains strategies for responding positively to those behaviours. The object of the process is that the use of a restrictive practice is to be the least restrictive option and applied for the shortest period necessary, with a view to reducing the use of restrictive practices over time. Ultimately, the restrictive practice must be formally approved before it can be used.<sup>41</sup>

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<sup>41</sup> *Disability Services Act 2006* (Qld) pt 6 – provisions relating to positive behaviour support and restrictive practices; *Guardianship and Administration Act 2000* (Qld) ch 5B – provisions relating to restrictive practices.



This model is one that could be adapted for Australia's aged care sector. The adoption of a properly regulated regime has resulted in greater transparency around the use of restrictive practices in Queensland's disability sector and increased consistency, professionalism and oversight of these practices.

More specifically, the regulatory process for the use of restrictive practices in Queensland includes:

- Assessment by one or more qualified professionals.
- The development of a behaviour support plan, which must be reflective of the principles of the *Disability Services Act 2006* (Qld) in relation to restrictive practices. This requires that it be informed by a best practice evidence base, producing behavioural change focused on skills development and environmental design, recognises that restrictive practices should only be used when necessary to prevent harm and that their use is the least restrictive way of ensuring the safety of adults and others.
- The plan must aim, overall, to reduce the intensity, frequency and duration of the adult's behaviour and reduce or eliminate the need to use restrictive practices.
- Approval for the use of restrictive practices must be obtained from the Queensland Civil and Administrative Tribunal (QCAT).
- Approval for the use of certain restrictive practices is valid for a period of up to 12 months, after which time the approval is reviewed and reconfirmed or revoked.
- The Public Guardian can also give short-term approval for restrictive practices when there is an immediate and serious risk.<sup>42</sup>

The paper released by my office referred to previously, *Legal frameworks for the use of restrictive practices in residential aged care: An analysis of Australian and international jurisdictions*<sup>43</sup>, provides a summary of the other restrictive practice regimes in Australia and some overseas jurisdictions.

## Operations

While the development and implementation of a legislative framework for the use of restrictive practices is essential, the implementation of longer term strategies to address challenging behaviours in these settings without having to resort to the use of restrictive practices should be the overall strategic goal.

Numerous aged care facilities in Australia and internationally are now creating specific environments for people with dementia, incorporating design features, programs and activities to improve quality of life and staff satisfaction levels.

IRT, a national community owned provider of aged care facilities and services in NSW, ACT and Qld, have recently commenced a 'Journey of Care' project, which incorporates the environmental re-design of its aged care facilities for people with dementia. This program assists with resident way-finding, minimises confusion, and increases independence for residents as well as improving the work environment for staff. Using environmental design expert Professor Richard Fleming and the resources of Dementia Training Australia, the renovated facilities include:

- Installation of life-like garden murals to hide walls, fences and secure doors.
- Renovations to improve resident and staff sightlines between rooms and the garden.
- Introduction of natural light.
- Colour coding of walls and skirting boards to minimise falls.
- The use of intuitive visual cues to identify corridors and the dining area.
- Personalised door decals on resident bedrooms that replicate the appearance of the front doors at former family homes so residents know which room is theirs.

As a result of the modifications, IRT's Flametree Lodge (one of the Group's specific facilities for people with dementia) has reported decreased agitation and frustration among residents and a

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<sup>42</sup> Ibid.

<sup>43</sup> Office of the Public Advocate, *Legal frameworks for the use of restrictive practices in residential aged care: An analysis of Australian and international jurisdictions* (June 2017).  
<[http://www.justice.qld.gov.au/\\_\\_data/assets/pdf\\_file/0005/524426/restrictive-practices-in-aged-care-final.pdf](http://www.justice.qld.gov.au/__data/assets/pdf_file/0005/524426/restrictive-practices-in-aged-care-final.pdf)>.



reduction in the use of anti-depressant medication. Staff morale has also been boosted, along with an increase in the number of compliments from residents' family members visiting the facility.<sup>44</sup>

The Whiddon Aged Care Group, based in Grafton in NSW has introduced various programs and activities for residents with cognitive impairment. The *Chat, Stories and Tea group* is designed for people with memory challenges, dementia or short term memory loss, based on Cognitive Simulation Therapy, which was developed in the United Kingdom by Professor Marin Orrell and Dr Aimee Spector. The groups have been proven to improve cognitive function and mood, and increase self-confidence and self-esteem around communication and social interaction. As a therapy, the groups are considered to be as effective as dementia medication at delaying or stabilising cognitive decline.

*HenPower* is another initiative of the Group, which is a program based around creative activities, arts, socialisation and "keeping chooks". While now undergoing a formal evaluation, the program has achieved some early positive results, particularly for residents showing early signs of dementia. The program was first developed by a British organisation, Equal Arts, and has been successfully running in the United Kingdom for a number of years, displaying significant health and wellbeing benefits, including a reduction in depression, loneliness and the empowerment of older people to build positive relationships.

The Whiddon Group examples above are a component of the organisation's commitment to a model of care known as 'Mylife', which was developed, trialled and evaluated using evidence based methods. The model is relationship based, placing a very strong level of importance on strong relationships between residents, clients and the employees who care for them. Staff are encouraged to get to know and understand residents and clients on a much deeper level – who they are, what they love, what makes them smile, what their life experiences are and the things about which they are passionate. Staff are trained through a specific program which equips them with the skills, techniques and approaches to deliver relationship based care.

When evaluated by the University of Sydney, the program was found, over a 12 month period, to significantly improve resident moods, physical function and social engagement and participation. It was also found to improve job satisfaction for staff as they were working in a stronger team environment.<sup>45</sup>

In addition, a series of academic studies have also found that environmental design and a reduction in the use of drugs like antipsychotics in residential aged care facilities have achieved positive results.

A Flinders University study<sup>46</sup> released in 2018 found that aged care residents living in small home-like clusters rather than standard types of aged care facilities have a better quality of life and experience fewer hospital admissions. The criteria for clustered home-like facilities included; having an independent accessible outdoor area, allocation of care staff to specific living units, meals cooked within units, self-service of meals by residents and resident participation in meal preparation.

In addition to resident benefits associated with the home care like model of operation (68% lower rate of being admitted to hospital and 73% lower chance of admission to the emergency department), the researchers estimate that the model can save governments approximately \$14,000 per resident per year in health and residential care costs.

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<sup>44</sup> IRT, Environmental Design in Dementia Care (8 November 2018), The Good Life e-newsletter, <<http://www.irt.org.au/the-good-life/environmental-design-in-dementia-care/>>.

<sup>45</sup> Whiddon Aged Care Group, material sourced from website <<https://www.whiddon.com.au>>, April 2019.

<sup>46</sup> Dyer et al, Clustered domestic residential aged care in Australia: fewer hospitalisations and better quality of life, *The Medical Journal of Australia* 2018; 208 (10): 433-438. | | doi: 10.5694/mja17.00861, published online 4 June 2018, <<https://www.mja.com.au/journal/2018/208/10/clustered-domestic-residential-aged-care-australia-fewer-hospitalisations-and>>



In relation to the use of chemical restraint, a new multi-disciplinary intervention program has recently been trialled (Australian New Zealand Clinical Trial ACTRN12617001257358)<sup>47</sup> in 150 residential aged care facilities across Australia. This program, called the Reducing Use of Sedatives (RedUSE) intervention, was designed to promote the appropriate use of antipsychotics and benzodiazepines in residential aged care facilities. It incorporated a psychotropic medication audit and feedback, staff education and interdisciplinary case review at base and three months, with a final audit following six months of operation.

Overall, during the six month intervention, the proportion of residents prescribed antipsychotics declined by 13% and that of residents regularly prescribed benzodiazepines by 21%. Both results were achieved without any increase in the prescription of other psychotropic drugs. The findings were also based on the total resident aged care facility population, as opposed to just residents with dementia.

The implications of this research are that targeted interventions can reduce over-reliance on psychotropic medication for managing mental and psychological symptoms of residential aged care facility residents.

The examples above are provided for illustrative purposes; I am sure there are many more meritorious program and design initiatives being used in aged care facilities to create environments where any type of resident restraint is the option of last resort.

Dementia Training Australia ([www.dementiatrainingaustralia.com.au](http://www.dementiatrainingaustralia.com.au)) provide a wealth of resources in the areas of environmental design, programs and activities, and general day to day planning for aged care facilities who have residents diagnosed with dementia. Most of these resources are available free of charge online, along with various training courses in key areas, addressing issues like; the use of antipsychotic medication in people with dementia, caring for people with dementia at night, and caring for lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI+) residents with dementia.

I suggest that additional, proactive measures also be considered in the recommendations of the Commission, potentially including the development of additional accreditation standards associated with; the design of care facilities, specific programs and the development, implementation and review of positive behaviour support plans for residents with dementia. This could be supported by the establishment of a funding program to initiate and trial best practice and innovative projects in this area.

I request that the Royal Commission make the following recommendations:

- That the Commonwealth Government:
  - Immediately implement a comprehensive residential aged care restrictive practices regulatory framework with all of the characteristics and protections recommended by the Australian Law Reform Commission in its report *Elder Abuse – A National Legal Response*<sup>1</sup> in Recommendations 4-10 and 4-11.
  - Introduce additional accreditation standards relating to: the design of aged care facilities; the development or adoption of specific programs to support residents with dementia; and the development and implementation of positive behaviour support processes.
  - Establish a funding program to support the initiation and trial of best practice and innovative projects in these areas.

<sup>47</sup> Westbury et al, RedUSE: reducing antipsychotic and benzodiazepine prescribing in residential aged care facilities, *Medical Journal of Australia* 2018 (9), 21 May 2018, 398.



# Effective complaints mechanisms

Effective complaints mechanisms are integral to a comprehensive system of rights and safeguards for older people.

A project undertaken by this office about complaints management systems for adults with impaired decision-making capacity identified a range of barriers that prevent many of these people from having their issues resolved through formal complaints mechanisms.<sup>48</sup> In addition to the usual reasons for not making formal complaints,<sup>49</sup> people with impaired decision-making capacity (including older people with dementia) may experience greater barriers to making complaints for a range of reasons including:

- they do not understand their rights;
- the process or the entry points for making complaints are less accessible;
- not being believed or taken seriously when they do make a complaint;
- not being able to manage and present evidence to support their complaint;<sup>50</sup> and
- those individuals who receive services from others are often reluctant to make complaints for fear of reprisals or withdrawal of services.<sup>51</sup>

The project also identified that complaints systems were not always sufficiently responsive to individuals with impaired decision-making capacity who may be unable to take the action necessary to initiate and progress a complaint through to resolution.<sup>52</sup> These adults frequently require additional support to use complaints systems effectively.<sup>53</sup> The type of support that people may require varies, from assistance to identify the need to make a complaint to assisting people with most or all aspects of the complaint-making process, including progressing the complaint to an external complaints agency. This support is not always offered through organisational complaints management systems. This was also observed to be the case for some organisations whose role it was to provide specialist supports to this group.

These and other issues are likely to significantly reduce the effectiveness of complaints systems for older people who are diagnosed with dementia or other capacity-affecting conditions. Complaints schemes for this group should therefore incorporate mechanisms that maximise accessibility and support to actively engage in the complaint-making process.

Many older people may require additional support to use complaints systems effectively, particularly those who do not have family, friends or other people available to provide them with support. The type of required support will vary from person to person. It may involve identifying the need to make a complaint, articulating and lodging the complaint or assisting people with most or all aspects of the complaint-making process, including progressing the complaint through complaints and review processes.

The *Convention on the Rights of Persons with Disabilities* places responsibility on Australia to take appropriate measures to ensure the accessibility of services and systems to all people (including

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<sup>48</sup> Office of the Public Advocate, *Strengthening Voice: A Scoping Paper About Complaints Management Systems for Adults with Impaired Capacity* (February 2015) 8-15

<[http://www.justice.qld.gov.au/\\_data/assets/pdf\\_file/0020/362342/strengthening-voice-scoping.PDF](http://www.justice.qld.gov.au/_data/assets/pdf_file/0020/362342/strengthening-voice-scoping.PDF)>.

<sup>49</sup> Sarah Cook, *Complaint Management Excellence: Creating Customer Loyalty Through Service Recovery* (electronic version, Kogan Page, 2012); Clay M Voorhees, Michael K Brady and David M Horowitz, 'A Voice from the Silent Masses: An Exploratory and Comparative Analysis of Noncomplainers' (2006) 34(4) *Journal of the Academy of Marketing Science* 514-527.

<sup>50</sup> Office of the Public Advocate, above n 36, 8-10.

<sup>51</sup> See, for example, Alisoun Milne, 'Commentary on Protecting My Mother' (2011) 13(1) *The Journal of Adult Protection* 53-56; Queensland Parents for People with a Disability (QPPD), *Papering Over the Cracks: The Veneer of Prevention* (2005) 39 <[http://www.qppd.org/images/docs/ci\\_report\\_2005.pdf](http://www.qppd.org/images/docs/ci_report_2005.pdf)>.

<sup>52</sup> Office of the Public Advocate, above n 36.

<sup>53</sup> Office of the Public Advocate, above n 36, 28; International sources also identify the importance of support during complaint making, see Healthwatch England, 'Suffering in Silence: Listening to Consumer Experiences of the Health and Social Care Complaints System' (A Healthwatch England Report, October 2014) <[http://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/complaints-summary\\_0.pdf](http://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/complaints-summary_0.pdf)>.



those with aged-related impairments) and provide appropriate assistance and support.<sup>54</sup> Further, the Convention proclaims that States must ensure that people receive the support that they need to exercise their legal capacity and make decisions for themselves.<sup>55</sup> This should include assisting people to enforce their rights as consumers and to exercise choice to change service providers when they are dissatisfied with their care and treatment. Accordingly, all complaints and consumer protection mechanisms in the aged care sector must uphold the principles of the Convention and, to the greatest extent possible, support people to exercise their autonomy and legal capacity.

Based on work undertaken by the SA Ombudsman<sup>56</sup>, which draws on the Australian and New Zealand Standard Guidelines for complaint management (AS/NZS 10002:2014), the essential components of an effective complaints management system include:

1. Commitment – developing a culture that welcomes complaints
2. Facilitation – making it easy for people to make complaints
3. Resourcing – appropriate training, empowerment and resourced staff to manage complaints
4. Learning – analysing complaints and their outcomes to improve systems and processes
5. Guidance – developing policies and procedures to assist staff in the management of complaints.

The Australian aged care system, until very recently, employed a referral based framework to register and manage aged care complaints, consisting of the Aged Care Complaints Commissioner, responsible for the initial receipt and resolution of complaints, supported by referral mechanisms to a range of external agencies, including; the Department of Health, the Aged Care Quality Agency, state and territory governments, Public Health Units, the police, coroners, the Australian Health Practitioner Regulation Agency and health care complaints bodies.

In 2017-18, the Aged Care Complaints Commissioner received 5779 complaints, an increase of 23 percent in comparison with 2016-17 and 47 percent more than it received in 2015-16. The vast majority of these complaints (75%) related to residential aged care and a significant proportion (1073 cases) were referred to the Aged Care Quality Agency, an increase of more than 100 percent in comparison with 2016-17.

The most common issues raised in complaints about residential aged care related to medication administration and management (706), personal and oral hygiene (473) and personnel numbers/ratios (452).

This broad level of categorising and reporting of complaints does not enable the public, or agencies such as the Public Advocate, to determine whether there are any, or many, complaints about specific issues such as the use or misuse of restrictive practices or other conduct that would amount to elder abuse in residential aged care facilities. It should also provide information about whether complaints are being substantiated, and whether they are increasing. Considering the vulnerability of many aged care residents and consumers, it is important that any complaints body is required to provide public information in greater detail about the type and nature of complaints received and the outcomes of those complaints.

Publishing more detailed information about complaints will facilitate greater system transparency and accountability. The community is entitled to this information. Most importantly, older Australians and their family members are entitled to know more about complaints that are made in relation to elder abuse in residential aged care settings and, more particularly, in the facilities that they are considering for their accommodation and care.

In January of 2019, the Aged Care Quality and Safety Commission replaced the Australian Aged Care Quality Agency and the Aged Care Complaints Commissioner, combining the functions of both into one independent agency, aimed at strengthening the focus on consumers, streamlining regulation, supporting improved engagement with consumers and providers and promoting

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<sup>54</sup> *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007 [2008] ATS 12 (entered into force 3 May 2008) ('*Convention on the Rights of Persons with Disabilities*') art 9.

<sup>55</sup> *Ibid* art 12.

<sup>56</sup> SA Ombudsman, *Complaint Management Framework March 2016*, Crown Copyright NSW Ombudsman June 2015, SA Ombudsman's Office, Adelaide SA (2016)





transparency. The Commission will begin assessment and monitoring against the new Aged Care Quality Standards from 1 July 2019.

It is hoped the new Commission will adopt processes for complaints handling and reporting that address the framework and reporting issues noted above, particularly in relation to facilitation, which is a particular issue for older people with impaired capacity.

The guiding principles associated with the facilitation of complaints include<sup>57</sup>:

- Visibility and transparency: widely publicising information about how and where complaints may be made
- Accessibility: the implementation of a system to manage complaints that is easy to understand and accessible to people who may require assistance
- Supporting: supports and assists are provided to assist people who need help to make a complaint
- Flexible: flexibility in how complaints may be made and ensuring that making a complaint is always free from charge
- Acceptance: allowing anonymous complaints to be submitted where they raise significant issues and there is enough information to be able to look at the issues raised.

At this time, it is not clear that the Aged Care Quality and Safety Commission has any specific practices or procedures in place to facilitate complaints and support people receiving aged care supports to make complaints to the agency.

Other methods of facilitating access to a complaints system that can complement existing complaints mechanisms include the funding of advocacy and community visitor programs, which are discussed below.

## Advocacy and Community Visitor Programs

While formal complaints mechanisms are essential in any properly regulated aged care system, they are insufficient in themselves for protecting older people from abuse and exploitation, and must be complemented by additional safeguards. Two such additional safeguards are community visitor and advocacy programs.

Community visitor programs (similar to the community visitor program that operates under the *Public Guardian Act 2014 (Qld)*) monitor the treatment and services provided to vulnerable people living in defined accommodation. They provide an on-going presence of external visitors, with a complaints and advocacy function, who may assist with identifying and raising issues for people with vulnerabilities and capacity issues and progressing them to resolution. Independent advocates can perform similar functions, although engaging their services generally requires proactive effort that may be beyond the capabilities of some aged care residents.

Anecdotal information suggests that aged care advocacy is insufficiently resourced to meet the needs of a rapidly growing cohort of older Australians with impaired decision-making capacity.

The Commonwealth Government funds the National Aged Care Advocacy Program (NACAP) which provides free, independent and confidential advocacy support and information to older people receiving, or seeking to receive, Commonwealth Government funded aged care services. It is critical that the NACAP is adequately funded to meet current and future demand for aged care advocacy services. Insufficient funding of advocacy services could become a significant barrier to aged care residents being able to seek redress for mistreatment and abuse and to access consumer protection mechanisms.

The issue of adequate resourcing of advocacy is particularly relevant to this inquiry given that data provided by the NACAP agencies indicate that elder abuse and the mistreatment of older people

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<sup>57</sup> SA Ombudsman, *Complaint Management Framework March 2016*, Crown Copyright NSW Ombudsman June 2015, SA Ombudsman's Office, Adelaide SA (2016)



is an increasing concern among advocacy services across Australia.<sup>58</sup> Accordingly, there is a need to revisit the Productivity Commission's 2011 report<sup>59</sup> and the Department of Social Services' 2015 report<sup>60</sup> recommendations to expand the NACAP to meet anticipated demand:

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*The predicted increase in the proportion, and absolute numbers, of people aged over 65 years of age is likely to drive higher demand for advocacy services. At a minimum, funding could increase in line with these projections and inflation to maintain current service levels.<sup>61</sup>*

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The Commonwealth-funded aged care community visitor scheme also has potential to reduce the incidence of elder abuse in aged care. At present, the Commonwealth scheme links volunteer community members with aged care residents for the purpose of companionship and friendship.<sup>62</sup> These individuals may or may not have the skills or inclination to identify and address the mistreatment of residents appropriately and effectively.

In contrast, the Queensland community visitor program for adults with impaired decision-making capacity employs community visitors to undertake regular announced and unannounced visits to specified accommodation sites for the purpose of monitoring service delivery.<sup>63</sup> Queensland community visitors have legislative authority to undertake functions such as lodging and resolving complaints on behalf of residents with impaired decision-making capacity, talking with staff and residents to clarify issues and concerns, and reviewing documentation and programs relating to their support and care.<sup>64</sup> Community visitors can lodge reports with the Office of the Public Guardian<sup>65</sup> that also provides the report to the service provider for their information and follow-up action.<sup>66</sup>

The Public Advocate supports the establishment of a government-funded aged care community visitor scheme based on the community visitor program model provided for under the *Public Guardian Act 2014* (Qld). Such a program, along with an expanded NACAP, would form a significant part of a comprehensive complaints and oversight framework to ensure quality and safety in residential and community-based aged care services.

## Reportable deaths in care

The final potential oversight mechanism available for the protection of consumers of aged care services is the investigation of aged care deaths by the Coroner when the death is related to the quality of care provided at a residential aged care facility.

Currently there is no system or framework in Australia for reviewing deaths in residential aged care facilities unless a number of circumstances (as described below) make the death reportable to the Coroner.

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<sup>58</sup> Department of Social Services, *Review of Commonwealth Aged Care Advocacy Services: Final Report* (December 2015) 44 <<https://agedcare.health.gov.au/support-services/aged-care-advocacy/review-of-commonwealth-aged-care-advocacy-services-final-report>>.

<sup>59</sup> Commonwealth Government Productivity Commission, *Caring for Older Australians* (Productivity Commission Inquiry Report No 53 Vol 1) (2011) lxix <<http://www.pc.gov.au/inquiries/completed/aged-care/report>>.

<sup>60</sup> Department of Social Services, *Review of Commonwealth Aged Care Advocacy Services: Final Report* (December 2015) 6-7 <<https://agedcare.health.gov.au/support-services/aged-care-advocacy/review-of-commonwealth-aged-care-advocacy-services-final-report>>.

<sup>61</sup> *Ibid.*

<sup>62</sup> Commonwealth Government Department of Health, Ageing and Aged Care: *Review of the Commonwealth Aged Care Advocacy Services* (20 February 2016) <<https://agedcare.health.gov.au/support-services/national-aged-care-advocacy-framework-consultation>>; See also *Aged Care Act 1997* (Cth) ch 5 pt 5.6 div 82 s 82-1(1)(a)(b)(c).

<sup>63</sup> Office of the Public Guardian, *Community Visitors*, Office of the Public Guardian <[www.publicguardian.qld.gov.au/adult-guardian/adult-community-visitors](http://www.publicguardian.qld.gov.au/adult-guardian/adult-community-visitors)>.

<sup>64</sup> *Ibid.*

<sup>65</sup> *Public Guardian Act 2014* (Qld) s 47(1).

<sup>66</sup> *Ibid* s 47(3).



As noted in an article in the *Journal of Law and Medicine* examining the Coroner's role in the prevention of elder abuse;<sup>67</sup> a residential aged care facility is currently:

... not a prescribed setting in any Australian coronial legislation. Consequently, a death in a residential aged care facility does not automatically trigger coronial investigations. A death in a residential aged care facility may trigger a report to the coroner if the death was violent, unnatural, suspicious, health-care related or where the death certificate was not issued (498).

The article also highlighted age being used to constrain the reporting of deaths in care in many Australian jurisdictions, including NSW, where the age of 72 is used to limit deaths that are reportable to the coroner. The article went on to say, based on evidence from a variety of scholars, that under-reporting of deaths in residential aged care facilities to the coroner is prevalent, particularly in cases associated with advanced bed sores.

In recent years I have been invited by the Deputy State Coroner to make submissions in inquests into the deaths of people with complex health needs in disability and aged care. One particular case involved the death of a younger person with disability residing in an aged care facility who died from choking on food. The Coroner asked for submissions from the Public Advocate as a result of work undertaken by my predecessor for the report, *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland*, which identified a range of risks for people with dysphagia (difficulty swallowing) that contributed to their deaths.

The Coroner in this case acknowledged choking to be a systemic issue in residential aged and disability care, and noted that strategies to monitor, review and report on this particular issue should be built into the National Disability Insurance Scheme (NDIS) quality assurance and reporting framework.

It is pleasing to note that the new Aged Care Standards now include specific reference to "managing the risks of choking" under *Standard 3 - Effective management of high-impact or high-prevalence risks associated with the care of each consumer*.

I also suggested the Coroner consider recommending the introduction of an Aged Care Death Review Process (or alternatively, an Elder Abuse Death Review process) on the basis of the following:

- The wide-ranging care and systemic issues that have been identified in this and other coronial matters that demonstrate the benefits of taking a broader systemic view in certain types of coronial investigations;
- The specialist knowledge and skills that can be developed from the adoption of specialist death review processes that could help to reduce unexpected and potentially avoidable deaths in the target population;
- The risk that without these specialist review processes, the limitations of the definitions in the *Coroners Act 2003 (Qld)* for reportable deaths or deaths warranting coronial investigations could result in missed opportunities to identify systemic issues in the residential aged care and disability care systems that are causing or contributing to potentially avoidable deaths.

It is important to note, in relation to the choking case above, that the Autopsy Report identified significant deterioration in the health of the deceased's lungs that evidenced serious ongoing difficulties with eating and swallowing. In the opinion of the forensic pathologist this deterioration was due to food aspiration, which causes severe necrotising pneumonia and over time can lead to death. Had the deceased not died from choking on food, an event which caused his death to be viewed as 'unnatural' and therefore reportable under the *Coroners Act 2003 (Qld)*, he may well have died from aspiration pneumonia. Had he died from aspiration pneumonia, the death would have been considered 'natural', because without an autopsy it would only be identified as death by pneumonia. As a consequence, there would have been no basis to investigate the death and

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<sup>67</sup> Catherine Sharp, Jennifer Sarah Schulz Moore and Mary-Louise McLaws, 'The Coroner's Role in the Prevention of Elder Abuse: A study of Australian Coroner's Court Cases Involving Pressure Ulcers in Elders', *Journal of Law and Medicine*, Vol26, No2, p494, 28 October 2018, Lawbook Co. Australia



improve the level of care provided to patients with these type of conditions, even though it would have been a preventable death resulting from lack of appropriate care and mealtime supervision.

While it is acknowledged that Australians entering residential aged care facilities or using services provided by the aged care sector in their homes are potentially suffering from conditions that are life-limiting, **not** actively reviewing deaths in aged care has the potential to allow poor practices and quality of care to go unchecked. Our ultimate objective (and indeed the objective reinforced in the revised Aged Care Quality Standards) should be to treat our aged (and most vulnerable) with dignity and respect, and this standard should apply to their deaths as well as their lives. If we continue to not report and review deaths in aged care facilities and conduct investigations only in very limited circumstances, those individual and systemic failures contributing to those deaths will remain unaddressed.

The epidemiological analysis of deaths in residential aged care by Professor Ibrahim et al<sup>68</sup>, found that a significant number of deaths in aged care are 'premature' and potentially 'preventable', challenging the misconception that all deaths of frail, older people living in residential aged care are natural. It also found that the incidence of these deaths of nursing home residents has increased over the past decade. The research noted that, although there are mechanisms to actively monitor residential aged care, there is no one organisation responsible for the reduction of harm by improving practice. In contrast, general health care has a leading national agency, the Australian Commission on Safety and Quality in Health Care which monitors and investigates preventable harm and provides resources, training, education and research to address problems and improve care.

The reporting of the deaths of people in aged care and investigation by the Coroner is the first step towards greater scrutiny of deaths in residential aged care to improve practices, so that the prevalence of external deaths, which are by definition, preventable, can be reduced in the future.

Further, the Aged Care Quality and Safety Commission should be given responsibility for reduction of harm in aged care by improving practice, similar to the role of the Australian Commission on Safety and Quality in Health Care. Part of that work should include more detailed categorizing and reporting of complaint types and trends. This will assist the community and other agencies to identify systemic issues and trends in complaints and quality of care in aged care service provision.

I request the Royal Commission make the following recommendations:

- That the Australian Government:
  - Introduce a national Deaths in Aged Care Review Process, where deaths in aged care are reported to and investigated by State and Territory Coroners.
  - Introduce a fully funded Community Visitor scheme (paid employees, not volunteers) as a key component supporting the complaints management framework applicable to aged care service providers.
  - Give the Aged Care Quality and Safety Commission responsibility for reduction of harm in aged care by improving practice, similar to the role of the Australian Commission on Safety and Quality in Health Care.
  - Require more detailed categorising and reporting by the Aged Care Quality and Safety Commission of complaint types and trends to assist in the identification of systemic issues and trends in complaints and quality of care issues in aged care service provision.

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<sup>68</sup> Ibrahim, Joseph et al, Premature deaths of nursing home residents: an epidemiological analysis, *Medical Journal of Australia* 206 (10), 5 June 2017, Australia.



# The aged care workforce

The number and mix of appropriate skills, qualifications and experience within the aged care workforce has a direct impact on each of the issues addressed in this submission.

Calls for the development and implementation of staffing ratios within aged care facilities, similar to those used in childcare facilities, are now being made by various peak bodies, including the Australian Nursing and Midwifery Federation (ANMF), the Australian Medical Association (AMA) as well as various politicians and advocates.

As the Commission would be aware, the House of Representatives Standing Committee on Health, Aged Care and Sport released an Advisory Report in December 2018 on the Aged Care Amendment (Staffing Ratio Disclosure) Bill 2018, recommending the passing of an amendment which will require the Department of Health to publish staffing ratio data for aged care facilities in a form that allows consumers to consider resident acuity levels when comparing facilities.

The Committee also reiterated recommendations made in its report on the Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia, including that the Commonwealth Government:

- legislate to ensure that residential aged care facilities provide for a minimum of one Registered Nurse to be on site at all times; and
- specifically monitor and report on the correlation between standards of care (including complaints and findings of elder abuse) and staffing mixes to guide further decisions in relation to staffing requirements.<sup>69</sup>

On 10 April 2019, the Senate Community Affairs References Committee released its Final report<sup>70</sup> into the effectiveness of the Aged Care Quality Assessment and accreditation framework. Among other matters, the Committee recommended:

... that the Aged Care Quality and Safety Commission work collaboratively with the Department of Health, the Australian Commission on Safety and Quality in Health Care and aged care stakeholders to develop benchmarks for staffing levels and skills mix, which includes the requirement to roster a Registered Nurse on duty at all times, to assist residential aged care providers in staff planning and aged care assessors in regulating safe and appropriate staffing. (Rec 8)

The debate surrounding the development and implementation of staffing ratios in aged care facilities does, initially, look like a simple one – if you want residents to receive a good standard of care you need to make sure that there are sufficient staff to provide that standard of care. The fewer staff you have, the lower the standard of care and vice versa.

However, if thought is given to staffing ratios in terms of resident outcomes, namely the quality of care they receive, the application of ratios may oversimplify the issues involved.

The Productivity Commission considered the issue of quality care in residential aged care facilities in its report *Caring for Older Australians* released in August 2011<sup>71</sup>. In this report, the Commission recognised that defining and measuring the quality of care and support in aged care facilities is not straightforward. The Commission did, however, identify some common themes associated with quality care including effectiveness, safety, efficiency and the experience of care consumers.

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<sup>69</sup> House of Representatives Standing Committee on Health, Aged Care and Sport, *Advisory Report on the Aged Care Amendment (Staffing Ratio Disclosure) Bill 2018*, December 2018, Canberra.

<sup>70</sup> The Senate Community Affairs References Committee, *Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised*, Final report, April 2019.

<sup>71</sup> Commonwealth Government Productivity Commission, *Caring for Older Australians Inquiry Report*, August 2011



The Commission concluded that an across-the-board simple staffing ratio is a *'relatively blunt instrument for ensuring quality care, particularly given that the care resident profile of every facility will be ever changing.'*<sup>72</sup>

Instead, the Commission suggested that there could be a more direct link between the funding provided for the complex health needs of aged care residents and how much care providers allocate to health care funding, including wages for nurses, over a period of time. They suggested that aged care providers should be required to make available information about the staff and skill mix for the profile of aged care residents, so that consumers could make more informed choices about what services best suit their needs.

This position has been echoed more recently by The Council on the Ageing (COTA). In its position paper released in late 2018 – *Keep fixing Australia's aged care system ... taking the next steps in tandem with the Royal Commission*<sup>73</sup>, COTA took the view that mandated staffing ratios are not necessarily 'the answer' to issues around quality of care in aged care facilities and that, on their own, will not reduce or resolve whatever quality or safety concerns or gaps a facility may have.

COTA, in calling for 'the right staffing levels and skill mixes' for particular facilities, supports a report commissioned by the Australian Nursing and Midwifery Federation prepared by Flinders University, which proposed a skill mix of 30% registered nurses, 20% enrolled nurses and 50% personal care workers in aged care facilities. This skill mix approach has, however, also been questioned.

An alternative approach may lie in the development of a staffing ratio or mix that is directly and legislatively related to the care levels provided at each aged care facility, based on the Aged Care Funding Instrument (ACFI). The instrument assesses each resident of an aged care facility, focusing on the main areas that discriminate core care needs. It then assesses core care needs as a basis for allocating funding. Given that the instrument provides for high, medium and low rating scores for each resident in three main areas (activities of daily living, behaviour, and complex health care) it may be possible to link staffing ratios to actual care requirements that are already documented in a cost and time effective way. Of course, as new residents enter the facility the assessment levels will change and staffing ratios will also need to be altered, however there are examples in other areas of health service provision (eg. operating theatres in hospitals) where rostering based on care needs is undertaken, providing evidence that such an approach to staffing may be effective.

A staffing ratio system of this nature would require further research and feasibility work, including the identification of the skill mix required for each level of care. However it would potentially provide an additional layer of protection for residents in that it is transparent and accountable to government (ie. directly linked to the funding instrument and funding model for aged care) and would be consistent across all aged care facilities. It could also be used to set the minimum standards that need to be met, thereby encouraging aged care facilities to adopt higher staffing ratios and skill mixes than the minimum as a point of differentiation.

I request the Royal Commission make the following recommendation:

- That the Commonwealth Government direct the Aged Care Quality and Safety Commission to undertake further research and feasibility work, to develop a staff ratio and skill/experience mix for residential aged care facilities based on the Aged Care Funding Instrument and the level of need of residents.

<sup>72</sup> Ibid. p.370

<sup>73</sup> COTA Australia, *Keep fixing Australia's aged care system, ... taking the next steps in tandem with the Royal Commission*, September 2018 <<https://www.cota.org.au/wp-content/uploads/2018/09/Policy-Paper-Five-Fixes-Aged-Care-September-2018-FINAL-SOFT-COPY.pdf>>



# End of life Planning and Care

## Palliative care for people with dementia

Palliative and end of life care has been the subject of numerous reports and inquiries over the last 15 years in Australia, including the Senate's Community Affairs Reference Committee's inquiry into *Palliative Care in Australia*<sup>74</sup> completed in 2012 and the Productivity Commission's Inquiry Report; *Introducing competition and informed user choice into human services: reforms to human services*<sup>75</sup>, which was completed in late 2017 and included a chapter on end of life care in Australia.

Both of these inquiries acknowledged that end of life and palliative care is the core business of residential aged care but that the quality of end of life care provided throughout Australian aged care facilities is variable at best.

The right to palliative care has been recognised by both the United Nations and The World Health Organisation (WHO)<sup>76</sup>. WHO has released a set of recommendations as a guide to the minimum standards expected by the international community that include:

- all countries adopting a national palliative care policy;
- ensuring the training and education of health professionals;
- raising public awareness of palliative care and its principles;
- ensuring the availability of morphine in all health care settings; and
- ensuring that minimum standards for pain relief and palliative care are progressively adopted at all levels of care.

The 2018-19 Commonwealth budget recognised the need for the provision of comprehensive palliative care in aged care and, as a component of its commitment to an increase in aged care funding of \$5 billion over 5 years, allocated \$32.8 million to facilitate the development and implementation of new models of palliative care in aged care facilities.<sup>77</sup>

While this budget allocation is a commendable initiative, the provision of palliative care in aged care facilities for residents with dementia does appear to be an ongoing issue. In a joint policy statement issued in May 2018, Palliative Care Australia and Dementia Australia highlighted that many aged care services are 'not equipped to address the unique palliative care needs of people living with dementia due to limited resources or appropriately trained staff'.<sup>78</sup>

This statement is supported by statistics from the Australian Institute of Health and Welfare about the characteristics of aged care residents requiring palliative care. The figures indicate that of the very small percentage of aged care residents who receive palliative care (1.9%), residents with a dementia diagnosis are under-represented (42.9% compared with 52.4% of the general residential aged care population)<sup>79</sup>.

Personal stories also illustrate the need. An article that appeared in the Ageing Agenda in early 2017<sup>80</sup> highlighted the issues faced by families and carers of people living with dementia who are

<sup>74</sup> The Senate Community Affairs Reference Committee, *Palliative Care in Australia*, Canberra (2012)

<sup>75</sup> Productivity Commission, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, Report No. 85, (2017) Canberra.

<sup>76</sup> Frank Brennan, MBBS, FRACP, FChPM, LLB, Palliative Care as an International Human Right, *Journal of Pain and System Management*, Vol 33, No 5, 5 May 2007, doi:10.1016/j.jpainsymman.2007.02.022.

<sup>77</sup> Department of Health (Cth), *Budget 2018-19 Better Quality of Care – comprehensive palliative care in aged care*, budget fact sheet – ageing and aged care, Parliament House, Canberra, 2018.

<sup>78</sup> Palliative Care Australia and Dementia Australia, *Policy Statement – Palliative Care and Dementia* <<https://www.palliativecare.org.au>>, originally published October 2013, updated May 2018.

<sup>79</sup> Australian Institute of Health and Welfare (Cth), *Palliative care services in Australia*, web report <<https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-in-residential-aged-care/characteristics-of-residential-aged-care-residents-receiving-palliative-care>>, 17 October 2018.

<sup>80</sup> Megan Stoyles, People living with dementia face a lack of support on end-of-life care, *Australian Ageing Agenda*, 1 March 2017, <<https://www.australianageingagenda.com.au/2017/03/01/people-living-with-dementia-face-a-lack-of-support-on-end-of-life-care>>.



often not made aware of palliative and end of life care services and supports. The article tells the story of Rosemary and her husband Don, who had become a resident of an aged care facility following a diagnosis of Lewy Body Dementia seven years previously. While recognising Don's condition is terminal, Rosemary said that palliative care for Don had never been raised, however it was offered immediately when her son was diagnosed with terminal cancer. In Rosemary's view 'people with dementia, let alone their families and carers, don't seem to be considered worthy of palliative care. And yet their need can be much more protracted than others with dying relatives or family'.

Given that dementia has now been identified as the second most common underlying cause of death in Australia and that almost a million Australians will be diagnosed with the disease by 2050, recognition of the condition as terminal is essential, along with the adoption of a standard and consistent approach to palliative care in residential aged care facilities.

A number of peak bodies nationwide, including Palliative Care Australia, Alzheimer's Australia, COTA Australia, Aged and Community Services Australia, Leading Age Services Australia, Catholic Health Australia and the Aged Care Guild have released *Principles for Palliative and End-of-Life Care in Residential Aged Care*<sup>81</sup>. The principles demonstrate a commitment to recognising the diverse needs of residential aged care consumers, families, carers, aged care staff and service providers in providing palliative and end-of-life care.

These principles need to be incorporated into the appropriate residential aged care standards, and assessed as a component of the accreditation process.

Additionally, research is currently being undertaken under the auspices of Hammond Aged Care to improve palliative care for people with advanced dementia living in residential care.<sup>82</sup> The aim of this research is to develop case conferencing resources to facilitate communication between aged care staff, health professionals (including GPs) and substitute decision makers (family and/or guardians) to discuss the current stage of the illness and agree on a management plan utilising evidence-based best practice. The impact of case conferencing and joint planning will also be evaluated from the perspective of the resident, family satisfaction with care staff attitudes and care delivery.

This project is funded by the Commonwealth Department of Health and Ageing and is being undertaken in collaboration with investigators from the University of Technology Sydney (UTS), University of Queensland (UQ), QUT, and the University of Notre Dame (UND) in Perth. Further information is available on the Hammond Aged Care website, (<https://www.hammond.com.au/research/dementia-and-aged-care-research>).

The research will complement work already completed in this area by Dementia Australia<sup>83</sup> and the results may be available for reference during the course of the Royal Commission.

## Substitute Decision Making in the Aged Care Sector – Enduring documents

Enduring documents (including powers of attorney and enduring guardianships) are tools allowing people to choose the person (or persons) who will make decisions on their behalf should they lose decision making capacity in the future. Having these alternative decision-making arrangements in place may also protect a person who has lost decision making capacity from being exploited and abused by others.<sup>84</sup>

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<sup>81</sup> Palliative Care Australia et al, *Principles for Palliative and End-of-Life Care in Residential Aged Care*, accessed online on 22/3/2019 < [https://palliativecare.org.au/wp-content/uploads/dlm\\_uploads/2017/05/PCA018\\_Guiding-Principles-for-PC-Aged-Care\\_W03-002.pdf](https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2017/05/PCA018_Guiding-Principles-for-PC-Aged-Care_W03-002.pdf)>.

<sup>82</sup> Hammond Care Australia, *Research on Dementia and Aged Care*, < <https://www.hammond.com.au/research/dementia-and-aged-care-research>>.

<sup>83</sup> Dementia Australia, *Library resources*, < <https://dementiaresources.org.au/>>.

<sup>84</sup> Australian Law Reform Commission, *Elder Abuse*, Discussion Paper 83, Australian Law Reform Commission, Sydney 2016.





It is becoming common practice in the Australian community to move older people against their will from their homes and into residential aged care. These decisions are often made on behalf of the older person without giving serious consideration to the possibility of the person remaining in their own home with appropriate support and services, even when the older person has indicated that is their preference. While family members may have genuine concern for the health and safety of their aged relatives, some of these decisions appear to be driven by a sense of wanting to do 'what's best' for their aged family member. Often family members or hospital staff apply to the Queensland Civil and Administrative Tribunal for a guardianship appointment to make decisions on behalf of the older person.

This process can be facilitated by enduring documents. While the execution of the documents may protect an older person who has lost decision making capacity from being exploited and abused by others,<sup>85</sup> there is now a practice being employed by residential aged care facilities of requiring that a person has either a valid enduring power of attorney or a guardianship order before accepting the person into the facility. It seems aged care providers have adopted this practice to ensure that all people seeking placement in a facility have a mechanism in place for continuity of decision-making in the event the person ceases to have capacity sometime in the future.

Decisions about the living arrangements for older people that are made without taking the older persons' views and wishes into account and seeking to implement them, even when the person has been found to have impaired decision making capacity, breach their human rights under the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD). The *Guardianship and Administration Act 2000* (Qld) contains numerous provisions supporting the rights of people with impaired capacity to make, and be supported to make, decisions. This includes their right to make decisions with which others may not agree (section 5(b)) and the General Principles that recognise the importance of empowering adults to exercise their basic human rights and make their own decisions (General Principles 2 (2) and 7(2)).

The Australian Law Reform Commission (ALRC) considers that appointing a representative decision maker should not be required as a condition of receipt of residential aged care<sup>86</sup> and recommended that aged care legislation should provide that agreements cannot require that the care recipient has appointed a decision-maker for lifestyle, personal or financial matters.<sup>87</sup>

In the Report, *Equality, Capacity and Disability in Commonwealth Laws*<sup>88</sup>, the ALRC recommended a set of four decision making principles and accompanying guidelines to guide the reform of Commonwealth laws and the review of State and Territory laws. These principles emphasise the autonomy and independence of people with disability who may require decision-making support in making decisions. The ALRC advocated that a person's will and preferences must drive decisions that they are supported in making, or that others may make on their behalf. The National Decision-Making Principles are consistent with the CRPD and provide the conceptual framework for a Commonwealth decision-making model that encourages supported decision making.<sup>89</sup>

The four principles are:

- Principle 1: The equal right to make decisions
  - All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
- Principle 2: Support
  - Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.
- Principle 3: Will, preferences and rights
  - The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.
- Principle 4: Safeguards

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<sup>85</sup> Op.cit

<sup>86</sup> Australian Law Reform Commission, *Elder Abuse – A National Legal Response Final Report*, report No 131 (2017) 152.

<sup>87</sup> Australian Law Reform Commission, *Elder Abuse – A National Legal Response Final Report*, report No 131 (2017) 151.

<sup>88</sup> Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, report No 124 (2014).

<sup>89</sup> Australian Law Reform Commission; *Equality, Capacity and Disability in Commonwealth Laws*, Report No 124 (2014) 64.



- Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

While there is yet to be an official Commonwealth Government policy and/or legislative response to the report, there is some reference to the principles of supported decision making in the new Aged Care Quality Standards, which come into effect on 1 July 2019. The standards, under 'Standard 1 – Consumer dignity and choice', require residential aged care facilities to ensure that:

- (c) each consumer is supported to exercise choice and independence, including to:
  - (i) make decisions about their own care and the way care and services are delivered; and
  - (ii) make decisions about when family, friends, carers or others should be involved in their care; and
  - (iii) communicate their decisions; and
  - (iv) make connections with others and maintain relationships of choice, including intimate relationships;
- (d) each consumer is supported to take risks to enable them to live the best life they can.

The standards are supplemented by the *Supported Decision Making Policy Development Guideline*<sup>90</sup> developed by the University of Sydney, which is accessible to residential aged care providers via the Commonwealth Department of Health.

The Aged Care Quality Standards need to be supported by the official adoption of the four decision making principles and accompanying guidelines recommended by the ALRC as well as legislation prohibiting a requirement for prospective residential aged care residents to have an enduring document or guardianship order in place to gain entry into a residential aged care facility.

I request the Royal Commission make the following recommendations:

- That the Commonwealth Government:
  - Incorporate the Principles for Palliative and End-of-life care in Residential Aged Care into appropriate aged care standards and that they be assessed as a component of the accreditation process;
  - Officially adopt the four decision making principles and accompanying guidelines recommended by the Australian Law Reform Commission in its report *Principles for Palliative and End-of-Life Care in Residential Aged Care*; and
  - Legislate to prevent residential aged care facilities requiring prospective residential aged care residents to have an enduring document or guardianship order in place to gain entry into a residential aged care facility.

<sup>90</sup> Sinclair, C., Field, S., & Blake, M, *Supported decision-making in aged care: A policy development guideline for aged care providers in Australia*. (2nd Edition) Sydney: Cognitive Decline Partnership Centre 2018.



# Younger people with disability residing in aged care facilities

According to the Summer Foundation (a non-profit advocacy group for young people living in care) there are currently more than 6200 younger people with a disability living in residential aged care facilities across Australia. Around 50 younger people with disability enter an aged care facility every week, 59% of whom are transitioning to aged care from a hospital setting.<sup>91</sup>

The 2014-15 Senate Committee *Review of the adequacy of residential care arrangements for younger people with disability*<sup>92</sup>, received a range of evidence from individuals, families, peak bodies, advocacy and charity groups and service providers about the inappropriateness of aged care accommodation for younger people.

The Committee found that there was a lack of:

- independent living options;
- rehabilitation options to facilitate a transition to more independent living;
- age appropriate activities and friendships;
- options for supported accommodation;
- advocacy support for young people and their families; and
- a sense of community and economic involvement.<sup>93</sup>

A Fact Sheet produced by Synapse (an organisation providing supports for people with acquired brain injury)<sup>94</sup> adds to these findings, noting that:

- 82% of younger people residing in aged care facilities rarely or never visit their friends;
- 13% never or hardly ever go outside;
- 56% don't have a say in when they go to bed
- 52% will not receive a visit from a friend this year
- 27% are parents of school aged children.

The Senate Committee, as well as most advocacy organisations in this area, note that a residential aged care facility is simply not an acceptable living arrangement for a younger person with disability. It is instead the 'last resort' for people with particularly complex needs – the only facility that can provide the level of health and disability supports that they require, often on a 24/7 basis.

The introduction of the National Disability Insurance Scheme (NDIS) has not resolved this issue. Instead, the most recent commentary<sup>95</sup> about the NDIS and its provision of accommodation, particularly accommodation suited to younger people currently residing in residential aged care facilities, indicates that:

- More than one in twenty young people in residential aged care facilities have been determined as ineligible for NDIS funding (118 of those assessed);
- When approved for NDIS funding, the median amount of annual plans for younger people in residential aged care is \$104,563. Of this total, \$77,539 is allocated to aged care costs, leaving only \$31,990 for disability related supports, including making plans for alternate accommodation and transition out of residential aged care facilities. While 996 Specialist Disability Accommodation (SDA) places are currently under construction in Australia, only 22 young people with disability in residential aged care currently have SDA included in their SDA plans;
- While the overall admission rate for younger people associated with the trial of the NDIS in three regions fell by 5% in the period between 2013 and 2017, in one region in particular (Barwon,

<sup>91</sup> Summer Foundation, *The Issue*, <<https://www.summerfoundation.org.au/about-us/the-issue/>>.

<sup>92</sup> The Senate (Cth) Community Affairs Reference Committee, *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*, Parliament House, Canberra (2015).

<sup>93</sup> The Senate (Cth) Community Affairs Reference Committee, *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*, Parliament House, Canberra (2015).

<sup>94</sup> Synapse, *Get the Facts – Young People in Nursing Homes- Fact Sheet*, <<https://synapse.org.au/information-services/young-people-in-nursing-homes.aspx>>.

<sup>95</sup> Summer Foundation, *NDIS report card June 2018*, <<https://www.summerfoundation.org.au/wp-content/uploads/2018/06/ndis-report-card-june-2018.pdf>>.



ACT) the admission rate actually increased by 37%, due to a lack of suitable accommodation being available for NDIS participants.

Data is not currently available on the number of young people who became NDIS participants while living in residential aged care and have since moved to another form of accommodation.

This evidence demonstrates the urgent need for specialised disability accommodation to be constructed to better address the needs of young people with disability who need high levels of care. While the SDA can provide for this type of accommodation in individual NDIS plans, the number of NDIS participants with SDA in their plans (6,400)<sup>96</sup> and the rate of construction (as outlined above – 996 places currently under construction) indicates there is a need for a review and potentially the commencement of a new and/or fast-tracked construction program. If new approaches to the construction or acquisition of accommodation are not considered, the waiting times associated with SDA (if applicants are fortunate enough to be considered eligible for the funding) will be prohibitive, leaving younger people continuing to reside in unsuitable aged care facilities and the goals of the NDIS for this group unfulfilled.

There are a number of best practice examples of accommodation provision for younger people with disability requiring high level supports (such as those in residential aged care facilities), including projects undertaken by YoungCare<sup>97</sup> and The Summer Foundation<sup>98</sup> across the country.

## The Commonwealth Government Action Plan

On 25 March 2019, the Commonwealth Government released a Younger People in Residential Aged Care – Action Plan, as part of its commitment to minimising the need for younger people to live in residential aged care facilities.<sup>99</sup>

This plan outlines a series of actions to fast track younger people residing in (or at risk of entering) residential aged care that are eligible for funding under the NDIS into appropriate accommodation and supports within the community.

However, the plan continues to rely on the implementation of the NDIS complex support needs pathway and SDA which, as noted above, are currently stretched beyond capacity. This means that waiting times will potentially stretch to years, which will increase the degree of social isolation and potential mental health conditions experienced by younger people with disability residing in residential aged care facilities.

The plan also does not address the underlying reason why younger people are currently residing in residential aged care facilities – due to the complex health supports they require which at present cannot be provided in a community setting.

While the plan acknowledges that ‘younger people with disability often have complex health needs and the difficulty in accessing appropriate health supports in other settings is one of the main reasons younger people go to live in aged care’<sup>100</sup>, the focus of the national plan is on appropriate accommodation and disability supports only, rather than health care needs.

At present, the NDIS does not support the provision of what it considers to be mainstream health supports to people with disability.

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<sup>96</sup> Ibid.

<sup>97</sup> Youngcare, *Youngcare's High Care Housing*, Youngcare website, accessed on 12/4/19 <<https://www.youngcare.com.au/what-we-do/housing/>>

<sup>98</sup> The Summer Foundation, *Housing Prototypes*, The Summer Foundation website, accessed on 12/4/19, <<https://www.summerfoundation.org.au/housing/housing-prototypes/>>.

<sup>99</sup> Commonwealth Government, *Younger People in Residential Aged Care – Action Plan*, <<https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-younger-people-with-disability-in-residential-aged-care-initiative/younger-people-in-residential-aged-care-action-plan>> (2019)

<sup>100</sup> Op. cit. 2



This creates a situation where, if people are moved from residential aged care facilities and into accommodation in the general community, that there are no specialised health supports in place.

Living without these necessary health supports means that people with very complex conditions, including epilepsy, respiratory and circulatory system diseases, cerebral palsy and dysphagia, combined with intellectual and physical disabilities need to rely on mainstream health services (General Practitioners (when they get to see them), emergency rooms and hospital admissions) to both monitor and manage their on-going health conditions and respond in emergencies. The complex health conditions with which many people with disability live require proactive and timely health care and medical interventions that can only be provided by health professionals and specialists, rather than disability support workers.

At present, mainstream state based health services and the NDIS have no key points of connection that provide for engagement and follow up to coordinate care and services. This situation is further exacerbated by on-going unresolved issues between mainstream health services and the National Disability Insurance Agency about funding for health services that are critical to the health and wellbeing of people with disability.

The very real consequences of this situation was evidenced in a report prepared by my office, *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland*, which investigated the circumstances surrounding the deaths of 73 Queenslanders living in supported accommodation between 2009 and 2014.

This review found that 53% of the deaths reviewed were potentially avoidable, highlighting a range of systemic issues that need to be addressed as a government priority.

These included:

- The need to address risk factors and vulnerabilities for people with disability in care, including issues associated with respiratory diseases (mainly pneumonia and aspiration pneumonia), epilepsy, circulatory system diseases (including Ischaemic heart disease), choking/food asphyxia and the use of psychotropic medications to manage challenging behaviours
- The need to improve the quality of health care and disability supports, including improving primary care and intervention practices with regular general health and annual comprehensive health checks, identifying the signs of serious illness early, improving access to health care and support including medical specialists for complex conditions, enhancing the coordination of health care and disability services and end of life care and decision making.

Recommendations from the review included the development of frameworks and clinical leadership for improved health care, best practice and performance expectations at a local, regional and state wide level.

The number of avoidable deaths will potentially escalate if young people residing in residential aged care facilities are transitioned into accommodation within the general community without the necessary health supports.

I therefore urge the Commission to recommend that the Commonwealth Government, as a matter of urgency, seek to clarify and finally settle the funding issues associated with the provision of necessary health supports for people with disability seeking to leave residential aged care facilities (and other health and disability facilities) to live healthy lives in the community.

## Deaths of young people residing in aged care facilities

Deaths of young people with disability residing in residential aged care facilities can also potentially go unreported, as deaths in aged care are reported under a different, narrower regime (previously explained).

For example, the *Coroners Act 2003* (Qld) currently defines a death to be reportable if it was a death in care. Under section 9(1)(a), a person's death is a death in care if, when the person died, the person had a disability noted in the *Disability Services Act 2006*, section 11 and is living in certain



types of residential services (like level 3 accredited residential services) or receiving services providing accommodation funded by the department administering the *Disability Services Act*. This legislation is currently under review to reflect the changes to the disability service environment associated with the introduction of the NDIS, however, it is anticipated that a similar definition will also apply in the future, i.e. a death is reportable if it is a death in care.

As noted above, if a younger person with disability resides in an aged care facility (as opposed to disability support accommodation provided under the NDIS scheme), the facility is not a prescribed setting under any Australian coronial legislation. Accordingly, unless the death of a young person residing in residential aged care is considered to be 'unnatural', suspicious or health care related, it will not be reported to the coroner. Nor will it be reported by the NDIS Quality and Safeguards Commission, in the way any other death of a person receiving NDIS funded services would be.

When a young person with disability is accommodated in a residential aged care facility, that person is unable to access the oversight and other accountability mechanisms available under the NDIS. This further highlights the inappropriateness of residential aged care facilities as a home for younger persons with disability.

I request the Royal Commission make the following recommendations:

- That the Commonwealth Government:
  - Act immediately to resolve the funding issues (State vs Commonwealth) associated with the provision of necessary health supports for people with disability seeking to transition from residential aged care (and other health) facilities and reside in the community.
  - Fast-track the construction of Supported Disability Accommodation for younger people residing in residential aged care facilities as a matter of urgency or consider alternative means to construct or acquire the housing, disability and health support needs required by younger people with disability and complex needs.
  - Require the deaths of young people residing in aged care facilities who would otherwise be eligible for the NDIS, but cannot access appropriate accommodation and health supports to be reported by the NDIS Quality and Safeguards Commission and be potentially reportable to the Coroners in States and Territories as a death in care



# Concluding comments

This Royal Commission of Inquiry into Aged Care Quality and Safety will be the catalyst for enduring and positive policy, legislative and practice change across Australia's aged care sector.

The Commission has been preceded by 30 government reports, parliamentary inquiries and consultancy projects related to aged-care systems in Australia in the past three and half years.<sup>101</sup>

Now is the time for the Commonwealth Government to respond to the significant challenges associated with the delivery of quality care in the aged care sector. The change required will need strong leadership that delivers: clear legislative and regulatory frameworks; prescriptive and enforceable standards that clearly articulate service level expectations; and adequate safeguards to ensure that older Australians receiving aged care services, many of whom are some of the most vulnerable members of our community, can continue to enjoy appropriate standards of living, quality care and the dignity that they deserve.

This submission has drawn to the attention of the Commission issues related to:

- the use of restrictive practices in residential aged care facilities;
- effective complaint management frameworks, including advocacy, community visitor programs and the reporting of deaths in care;
- the aged care workforce;
- end of life care and planning; and
- younger people with disability residing in aged care facilities.

I have proposed a series of recommendations for the Commission to consider, which are summarised below.

Finally, I thank the Royal Commissioners and the Commission staff for the work that they are doing and will continue to do to finalise this very important piece of work and I look forward to the Commission's reports and recommendations.

Thank you for the opportunity to provide this submission to the Commission regarding the quality and safety of care in Australian residential aged care facilities.

Yours sincerely



Mary Burgess  
Public Advocate (Queensland)

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<sup>101</sup> Rick Morton, 'All our tomorrows hinge on the outcome of aged-care inquiry', *The Australian*, 19 January 2019 <<http://online.isentialink.com/theaustralian.com.au/2019/01/18/326d2123-0738-461a-a677-38656a5c059a.html>>.

