

Submission to the Australian Government, Department of Health and Aged Care: New Aged Care Act – Exposure Draft consultation submission

NB: Should you wish to publish this submission, please remove any personal identifying information by using either a pseudonym or abbreviation.

[REDACTED]

8 March 2024 (Extension granted – COB, 12 March 2024)

I welcome the opportunity to provide a submission to the New Aged Care Act, Exposure Draft. This submission will explain why I believe that Australia should support the new draft but equally, why some aspects of the draft could be better defined and improved. I also support extending the timeline for review and amendment of this draft Act to incorporate further recommendations from the *Royal Commission into Aged Care*, ensuring the best possible outcome for our most vulnerable in the community.

1. I am writing this submission to represent my recently passed [REDACTED], and the many residents in aged care facilities who are not receiving safe and high-quality care, accommodation, and services promised in the *Aged Care Charter* and the *Aged Care Act, 1997 (Cth)*.

2. This also resonates Article 12 of the *International Covenant on Economic, Social and Cultural Rights (ICESCR)*, where ‘1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health’, of which Australia is a signatory, (ratified in 1975).

3. Section 37 of the *Human Rights Act (QLD) 2019*, states that ‘(1) Every person has the right to access health services without discrimination’. This right to health services is only protected in QLD and is not in any other human rights legislation in Australia. This right under s 37, is also significantly narrower in scope than it is in Article 12 of the ICESCR and must be remedied to secure the nation’s rights to health services, particularly in the aged care sector.

4. As the right to health services is only protected in QLD, it suggests that the rights of all Australians, specifically vulnerable Australians in aged care facilities or home packages, must be properly protected under federal legislation to ensure that they too have the right to high-quality care, accommodation and services clearly legislated, mandated and enacted.

5. Clear guidelines and pathways for complaints must be accessible to all. To be handled effectively and efficiently for residents, carers, their family, friends, and supporters. It must be legislated to allow for the right to seek judicial review eg via mediation, a court, or tribunal, if unsatisfied with the internal complaint system of the

provider or the Commissioner, as opposed to s 21(3) of the current draft. Without the means to enforce these rights, how are those in the aged care system expected to protect themselves, contrary to section 20 of the draft, without judicial scrutiny? Section 21(2) under 'The Effect of Statement of Rights' means nothing without adequate judicial enforcement.

6. Further recommendations of the *Royal Commission into Aged Care* must be considered. Australia should actively help develop and become a signatory to the UN International Covenant for the Rights of the Older Person based on the current *Principles (United Nations Principles for Older Persons (UN General Assembly Resolution 46/91, 1991))*. As the numbers of older people in Australia increase, they are more susceptible to poverty, elder abuse, homelessness, crime and other specific human rights abuses. Without acting upon this as a matter of urgency, further human rights abuses and denial of rights will continue.

My background and connection to the Aged Care system:

I taught secondary school for 17 years and I am currently studying my final year of a LLB at The University of Adelaide. My Dad recently passed away last August after suffering from complications related to advanced Parkinson's and Alzheimer's diseases in an aged care facility in SA.

When my Dad was forced into care, I was entering my own personal battle with a Stage 3 Breast Cancer diagnosis. Subsequently, I endured two mastectomies – one with a lymph node axial clearance, 6 months of aggressive chemotherapy and 2 months of radiotherapy, as well as hormone adjunct therapy. I was forced to stop working as a full-time secondary teacher, and eventually made the decision during COVID to try to reinvent myself and study Law.

My Mum, [REDACTED], had been coping at home trying to support and care for my Dad alone, but as an older person with her own ailments and frailty, she could no longer safely provide for Dad's care at home. I was physically unable at this time to support my parents either, and there was no one else we could turn to for Dad's care. Dad was admitted to the RAH following a sudden increase in his dementia symptoms and inability to walk after falling sick with Influenza and was not allowed to return home. Subsequently, he entered the aged care system prior to the COVID 19 outbreak, and so did we.

1. Case Study - How this has affected my family:

Prior to Dad's diagnosis, my parents had a very comfortable existence and enjoyed the many luxuries of life, including a comfortable home and garden, access to excellent

food and private medical care, travel, and enjoying going out to restaurants, visiting friends and many other luxuries that we often take for granted. This ceased when my Dad became so unwell, that he had to enter aged care and I was diagnosed with Breast Cancer. It is here that our lives changed dramatically.

Despite my parents owning their own lovely home in a nice area, and having no other debts, they could not afford to buy into an expensive or what could be considered as a 'first-class' facility without selling the family home, which would leave my Mum homeless. Therefore, Dad entered an aged care facility that was government subsidised, and Mum had to pay a monthly fee on top of this, which incorporated his full pension, plus money Mum had to pay to top up his care. This impacted our life significantly financially, let alone emotionally, and we constantly travelled between our individual homes and our medical appointments and my hospital visits for chemo and radiotherapy.

Finding an appropriate aged care facility that was at a standard we could bear to see Dad enter was emotionally difficult, frustrating, and deflating. It opened our eyes to the very poor standards many older people endure if they have no one to help them, advocate for them, or lack the extra funds to choose an alternative. Fortunately, we found a relatively acceptable residence close to our family home with a vacancy, so that the ability to maintain my Dad's standard of living and care was not overly onerous in relation to our travel. Many facilities we visited were run-down, crowded, dirty, and understaffed, whereas the nicer ones, didn't have vacancies or were too expensive.

After having then to invest in an 'aged-care broker' to help us navigate the incredibly complex system of Aged Care and Centrelink, we expected that the *Aged Care Charter* given to us stating that Dad was entitled to 'high quality care and services' was a given. We did not realise this was essentially a worthless piece of paper and we had no recourse to ensure his rights were upheld, either internally or through the courts. Nonetheless, we visited him almost daily, bringing nice home-cooked food or treats that he was accustomed to and ensuring he was clean, toileted appropriately and well dressed, which he liked, and was as comfortable in his surrounds as possible.

Initially, Dad's facility seemed to be generally clean, roomy and provided some privacy for him and us to maintain an adequate level of care, but nothing like he was accustomed to at home - this was **not** home. Mum and I entered a great cavern of sadness, guilt and frustration settling in to the fact that Dad could never come home again, along with the torture of Dad pleading to go home until eventually his disease obliterated that memory. The only thing that Mum and I could cling to was that Dad was 'safe' in this aged care facility, receiving what we were told would be 'high quality care and services' promised in the *Charter* given to us.

However, what was promised in the *Aged Care Charter* and what was provided did not stack up, nor help us very much when we needed to address issues as they arose. We knew of no system of complaint to remedy these issues that were effective. I tried sending written complaints to the office but did not receive any response or see any changes. I talked to the staff, nurses, carers and office staff about issues, but nothing was resolved. In fact, when COVID 19 struck, and we began our lockdowns, the standard of care plummeted dramatically and never recovered. I had just undergone my second mastectomy and had to recuperate at Mum's. All the while, we could not check on Dad physically and had to trust that he was being taken care of at the expected 'high' standard. We knew this was not happening and could do nothing. At this stage of his disease, it became more difficult and disturbing for Dad to use a phone, as he could no longer manage talking freely and found the phone confusing at times. We felt we had left him adrift on a boat - we were powerless and could not help him.

COVID brought the aged care industry almost to its knees and highlighted to everyone how vulnerable, poorly funded, and understaffed this sector of society had become. Worst of all, we saw how unaccountable these services were to maintain and resolve issues even after COVID. We saw horrific numbers of older people succumb to COVID and loved ones were denied their right to be close to their dying family member and say their goodbyes. It was a cruel turn of events on families around the country, that also affected us deeply over several lockdowns and denied us precious time with Dad whose memory and cognition was quickly diminishing. His body was betraying him, and he was becoming more and more unresponsive, surrendering to Parkinson's and Alzheimer's.

We must be ready for the next pandemic or emergency to ensure these tragic situations never occur again.

2. The rights of older people in aged care:

Following the horrible COVID lockdowns, it became immediately obvious that the economic impact on Dad's facility was significant, and the decline in standards of care was due to fewer employees, including doctors, nurses and carers on site. There were several factors which impacted care, such as COVID infections of staff, residents and available staffing replacements. The nature of care was also reduced due to third party goods and service providers such as laundry and food services being impacted. At what point, however, should these services continue to negatively impact the expected level of care provided to residents, as the effects of COVID start to recede? It also begs the question – is funding sufficiently high enough to provide a 'high' standard of care? Or is it being mismanaged or squandered? Are providers seeking profit over quality of service?

These questions need to be answered and considered further when drafting the new Act.

The perception in the community is that many businesses of goods and services continue to use COVID as an excuse to keep raising their prices, including major banks, airlines, supermarkets, petrol, utilities, etc. Whereas in aged care, the biggest concern was and still is a lack of properly trained staff who are appreciated and paid appropriately to do the hard work they must do when looking after our most vulnerable. This staffing inadequacy was reflected in the quality of my Dad's care, and the other residents' care. Without ongoing accredited training these standards cannot be reached. This requires greater funding and commitment to a mandated training program by all providers and regulated by legislation and supervision by an independent body.

We had to witness the decline in the quality and quantity of food provided, the little extras like afternoon tea disappeared, the numbers of carers and nursing staff to patient ratio declined to dangerous levels. Permanent staff disappeared, and contract or agency staff with little to no experience or training replaced them. The turnover of staff was incredible, and very confusing for us, but especially the residents, particularly those with dementia, as their families relied on effective communication. This turnover created a level of anxiety and frustration for many of the residents, including Dad, as well as us.

How could we trust that he was being properly cared for when we couldn't be there? We would witness several patients trying to get out of the facility by banging the entrance doors relentlessly with their walkers, and emotional responses such as anger, yelling, showing aggressive behaviour and frustration were common. Obviously, this could be connected to their dementia, but I have never seen my Dad with such anger and anxiety that caused him to physically lash out. This staffing issue created a horrible mental health environment that I believe exacerbated the residents' dementia and placed the staff under considerable pressure where they were not able to provide a basic standard of care. How can the new draft reassure friends and family of those in care that they will receive the legislated standard of care, particularly when they cannot be there? I believe this is where an independent statutory body can provide some level of peace of mind if properly funded and staffed. I cannot see this currently in the draft legislation.

My Mum and I had to take on much of the care for my Dad that should have been provided by the service provider and staff. Even basics such as towels, pillows, sheets and face washers could not be found at times, and we had to bring our own. Yet, despite the huge pressures placed on staff due to reduced numbers, higher expectations by the provider and reduced funding, they were always compassionate and did their best with what little they had to do their job.

This decline in the standard of care continued past the time of using COVID as an excuse. During Dad's tenure at the home, he had accumulated over 50 falls! Of course, this can be attributed to Parkinson's, but how well supervised and attended was he when Mum and I weren't there? This is a reasonable question to ask. Dad was not getting his rights met, and without us, his standard of care had become appallingly limited. We witnessed many residents left alone for hours without water or being changed for soiled 'pull-ups' and clothes. This is unacceptable, but worse, we felt utterly helpless to get any action or change, despite constantly seeking change from the provider. We knew of no other complaint system other than to write personally to the CEO. These most vulnerable people in care cannot write to the CEO. How are they to be realistically protected?

I understand that the facility was subject to higher costs to provide care post COVID, but they are being subsidised by government funding and other family members are paying fees to ensure their loved ones are properly taken care of. Yet, I observed care that was inadequate, food that was inedible and little to no activities provided other than a large TV. These examples and observations represent a fundamental abuse of the residents' basic rights to safe, high level health care, services and accommodation, contrary to the *Aged Care Charter*. Equally, this also undermines Article 12 of the ICESCR where 'everyone [has the right] to the enjoyment of the highest attainable standard of physical and mental health', of which Australia is a signatory.

According to the Exposure Draft under S 21(3) there are also no rights or duties that are enforceable by proceedings in a court or tribunal. Like Dad's rights, the *Aged Care Charter*, or even the proposed statutory rights in this draft, are pointless and powerless words on a page, which effectively cannot protect his rights or anyone else's when it comes down to it. It offered no recourse for a cause of action by family, friends or a representative to seek a formal resolution or remedy. There must be a legal pathway for those who have had their rights removed, ignored, silenced, or violated, to ensure they have the means to stand up and have their voice heard in mediation, a tribunal or court, where the benefit would be widespread and restore dignity, at the very least, to those who were once voiceless and invisible.

Many residents do not have the benefit of family or friends to help or support them and must survive on what is given, or not given to them, by the provider. The biggest concern for us was the radical decline in the quality and quantity of food provided, which personally, I would not feed to a dog. I took several photos of grey, overcooked, tasteless looking food, that some residents also refused to eat. Their complaints and ours fell on deaf ears. I tried to give suggestions of using programs to help improve the quality and variety of food for the residents, but this was ignored. Some staff mentioned the issue was a limited budget, and several 'chefs' came and went. The most upsetting experience was one of my Dad's final meals. It was completely inappropriate and

inedible – a grisly, small lamb chop, grey mushy tinned beans and pasta in white sauce, smothered with gravy to hide its shame served as his dinner. Despite food being Dad's final pleasure in life, other than our visits, he spat out this meal and went without. I know that this was also a similar result regularly felt by many other residents who were not listened to either. How will this new Aged Care Act ensure that providers do not make excuses about their budget and properly provide residents with variety and nutritious meals, drinks, and snacks that are tasty and enjoyable?

By this stage we were handfeeding Dad and taking on more and more of his personal care, as no staff seemed to be around to help or responded to the assistance bell. This was one of the most upsetting moments, watching my Dad slowly succumb to these cruel diseases, which were exacerbated by the fact that inadequate service and care was at an all-time high. Like other residents, Dad didn't even have adequate, fit for purpose equipment such as a 'princess chair' to help support his failing body find some level of comfort and security. All that could be found by staff was a broken and very old chair that clearly was not good enough. My Dad had to wait for another resident to pass away before accessing, on our insistence, a newer more suitable princess chair, which was at a basic level of providing comfort and support. I had to watch other residents who were also totally dependent on the carers, sit or lie in undersized and inappropriate chairs for hours without being moved, often sleeping in groups in the lounge when they should have been in their bed, but for a lack of carers to manage the numbers of residents at any given time. This is far from a high standard of care. It is very upsetting.

At night we were told by day carers that there was only one nurse and one carer to look after an entire house or wing of the facility. Sometimes the registered nurse had responsibility for more than one wing. Not only is this inadequate, it is also dangerous for the residents and the staff. My heart screamed for the other residents who had no one to help them and had to rely on staff who never seemed to appear. They were left in dirty 'pull-ups', dirty clothes and suffering from dehydration, perpetual boredom and loneliness. This situation was far from acceptable and was a clear failure for the promises made in the *Charter* given to us, and Article 12 to look after the health, both physical and mental, of our vulnerable in care. There must be a mandated staff to patient ratio that is legislated to stop this neglect and trauma on those with high needs, who are dependent and reliant on care.

Although I am specifically representing our experience in the aged care system, it would be morally reprehensible of me to not try to advocate for the many vulnerable people still in care at not only this facility, but also, facilities across my State and the rest of the country. Our society is judged by how we care for our most vulnerable, and we are failing them. I do not believe that the current draft will adequately protect the aged and vulnerable, particularly those who do not have anyone to represent them.

Recommendations:

1. We must ensure any further laws made to protect older and vulnerable people is at the highest level of care, service and accommodation, and not just *adequate*. I believe we treat our inmates in Prison better. The act of considering human rights is about putting people at the heart of government decision-making and recognising rights and responsibilities within our community. It is about acknowledging that everyone deserves to be treated with dignity, equality and respect. This must be enforced, legally protected and mandated.
2. This health service must be better regulated, more transparent and monitored. It must be regularly checked and inspected by the government who should assign compliance officers to physically, and without notice, visit and spot-check aged care and residential homes across the country.
3. Each provider should reveal their budget and administrative management system to ensure that funds are appropriately spent and not misappropriated to other projects or unnecessary expenditure. Aged Care should **not be a profit-making business** – it is an **essential health care service** that we will all need to utilise.
4. The system of aged care is overly complex for older people and their families to navigate at a time that is highly emotional and sensitive. Easier websites and face-to-face help for families must be improved and government funded. The last Morrison Coalition government decimated the public service numbers to the public's detriment, this is clearly evident in Centrelink across Australia. This must change.
5. More support staff at Centrelink or a specialised government agency should be provided to manage and help families navigate their loved one's care without cost. Not everyone can afford an 'aged care broker', nor should they need to when a better resourced government body is provided and funded by our taxes.
6. Better accredited, ongoing training must be provided to all who work within the industry to ensure that our older community is looked after with the respect, dignity and rights that the Act provides. Current practices are not good enough, and there are too many cracks and loopholes that allow providers to fail their delivery of rights and standards with seeming impunity.
7. A website should provide how the providers are meeting the requisite standards or not and should provide a rating system to enable older people to navigate the system and make informed decisions and choices. They should provide information about how they run their services, including menus with real photos, activities and other information about accommodation that realistically reveals their available care and staff to resident ratios, as well as medical staff and services available onsite.

8. There needs to be a mandated nutrition and cooking course for the aged and vulnerable for those who work in aged care and more money budgeted to ensure fresh, tasty food is available at quantities that reflect high level care. This should also be audited regularly and spot-checked. People in these facilities cannot go to the fridge or pantry when they are hungry or get their own drinks to satisfy their thirst. Many, like my Dad, can no longer lift a cup to their mouth and often sit for hours without a drink. These are fundamental rights of nutrition and health that we take for granted. No one should be starving or dying of thirst in care.

9. We must start providing high-level care, service and accommodation to all ages of those who are vulnerable and dependent on care. We should not assume that younger people are comfortable sharing the services of older people. Many younger people suffer from early onset dementia, stroke, and attributed brain injury that means they need high-level, dependent care. This shouldn't mean they are also denied their rights to be young, including their freedom to express their youth among people of a similar age group. It is time to ensure high level care at any age and the facility be age appropriate and fit for purpose.

10. We must ensure that bedding, chairs, tables, pillows, linen, specialist medical equipment such as 'princess chairs' and personal lifts, etc, are available for all who require them in care and are not broken, damaged or old.

In summary:

Australians want to help build a society based on a culture of respect for human rights across government, parliament, the courts and our communities. We need a framework that requires the Australian government to consider everyone's basic rights when it designs new laws, regulations or policies.

Australians also need accessible pathways to resolve any disputes about their rights and achieve effective remedies if their rights have been unjustifiably breached. We want dispute resolution and rights protection that is focused on delivering practical solutions, without involving people in expensive litigation. This current draft fails to deliver a clear pathway for older persons and their supporters/families to raise a complaint that is in a meaningful and legally enforceable way with access to formal modes of negotiation, dispute resolution, mediation and access to the court system through judicial review if necessary. The draft Act, eg Part 5, section 183, fails to deliver a clear pathway for meaningful legal action and must be amended. Until I started this submission, I didn't know about the *Aged Care Quality & Safety Commission (ACQSC)* - I wish I had when Dad was in care. This is another problem for people out there - they have no idea how to make a complaint or who to access. It is really difficult to navigate through the online system, especially if you do not have IT or internet skills or access, or

someone in the know. Without implementing ‘user-friendly’ support frameworks for people having to access the aged care system, the new Act fails them.

It’s time for the Australian Government to take the next step and fully implement the *Royal Commission into Aged Care* recommendations. A more comprehensive Aged Care Act will help prevent human rights abuses because it will place human rights at the heart of decision-making by requiring the government to consider human rights when drafting laws, developing policies, delivering services, and making decisions.

More time to consider this draft will give every Australian the chance to have their say about new laws and policies that impact their rights before they are implemented. Providing more consultation time will help further develop and implement this Act, ensuring people with on the ground knowledge, expertise and ideas that allow innovation to be consulted and involved in service design and delivery, providing solutions and safeguards to ensure everyone is treated with dignity, regardless of their situation in life. Importantly, a carefully curated Act will give people the power to act if their rights are violated and seek reparations or remedy for violations.

Finally, a definitive Aged Care Act will foster respect for human rights in Australia, so we can work toward a future where everyone, everywhere understands their rights, and the rights of others. A new Australian Aged Care Act should include the human rights Australia has already promised to uphold under international law, including civil, political, economic, social and cultural rights under the *International Covenant of Civil and Political Rights* and the *International Covenant on Economic, Social and Cultural Rights*, as well as the rights of children, the elderly, and people with disabilities. Special consideration should also be given to the rights of Aboriginal people in Australia who should be consulted in the development of all aspects of the Act.

We must do better. We must do more. By enshrining these rights in an Act that is accessible, understandable, enforceable, and meets high level health care services, standards, and accommodations for vulnerable and older people, we will have a stronger scaffold on which to build a more dignified future. We can then hold our heads higher as a responsible signatory to the ICESCR and ICCPR and honour the rights of the vulnerable and the older person.

Equally, we should not ignore other valuable international instruments, but instead incorporate and utilise aspects of the *United Nations Principles for Older Persons* (UN General Assembly Resolution 46/91, 1991) to enrich this legislation for our community. We must work through these principles towards developing a UN International Convention for the Rights of Older Persons and being a signatory to it in the future. This is also supported by the Law Council of Australia.

<https://lawcouncil.au/media/news/international-convention-on-the-rights-of-older-persons>

We must ensure that access to quality healthcare is a fundamental right for all Australians, which is protected under greater legislation that clarifies and broadens this right beyond section 37 of the *Human Rights Act* (QLD) 2019.

Thank you for taking the time to listen, consider, and read my submission.

Yours sincerely,

[Redacted signature]

[Redacted line]

[Redacted line]

[Redacted line]

[Redacted line]

[Redacted line]

[Redacted line]