

A Shocking Tale of Neglect

It's not easy growing old. We avoid thinking and talking about it. As we age, we progressively shift our focus from work to the other things that give us purpose and joy: our children and grandchildren, our friends, our holidays, our homes and gardens, our local communities, our efforts as volunteers, our passions and hobbies. The Australian community generally accepts that older people have earned the chance to enjoy their later years, after many decades of contribution and hard work. Yet the language of public discourse is not respectful towards older people. Rather, it is about burden, encumbrance, obligation and whether taxpayers can afford to pay for the dependence of older people.

As a nation, Australia has drifted into an ageist mindset that undervalues older people and limits their possibilities. Sadly, this failure to properly value and engage with older people as equal partners in our future has extended to our apparent indifference towards aged care services. Left out of sight and out of mind, these important services are floundering. They are fragmented, unsupported and underfunded. With some admirable exceptions, they are poorly managed. All too often, they are unsafe and seemingly uncaring. This must change.

Australia prides itself on being a clever, innovative and caring country. Why, then, has the Royal Commission found these qualities so signally lacking in our aged care system? We have uncovered an aged care system that is characterised by an absence of innovation and by rigid conformity. The system lacks transparency in communication, reporting and accountability. It is not built around the people it is supposed to help and support, but around funding mechanisms, processes and procedures. This, too, must change.

Our public hearings, roundtable discussions with experts, and community forums have revealed behaviour by aged care service providers that, when brought to public attention, has attracted criticism and, in some cases, condemnation. Many of the cases of deficiencies or outright failings in aged care were known to both the providers concerned and the regulators before coming to public attention. Why has so little been done to address these deficiencies? We are left to conclude that a sector-wide focus on the need to increase funding, a culture of apathy about care essentials, and a lack of curiosity about the potential of aged care to provide restorative and loving care—all of which is underpinned by an ageist mindset—has enabled the aged care system to hide from the spotlight. This must also change.

Left isolated and powerless in this hidden-from-view system are older people and their families. 'This is not a life.' 'This is not my home.' 'Don't let this happen to anyone else.' 'Left in her own faeces, and still no one came.' 'Mum doesn't feel safe.'

This cruel and harmful system must be changed. We owe it to our parents, our grandparents, our partners, our friends. We owe it to strangers. We owe it to future generations. Older people deserve so much more.

We have found that the aged care system fails to meet the needs of our older, often very vulnerable, citizens. It does not deliver uniformly safe and quality care for older people. It is unkind and uncaring towards them. In too many instances, it simply neglects them.

Confronting the system

Understandably, it is relatively common for older people to avoid thinking about their long-term care needs or to plan for their future because this might signal their decline and eventual death. Most people remain confident that they will be looked after when the time comes.

It is therefore a difficult choice when things begin to go wrong about whether to access aged care or whether to struggle along independently. Very often, older people avoid accepting care for as long as possible. Many families help their loved ones to live independently by providing ongoing support, doing their shopping, driving them to appointments, mowing the lawn, fixing the things that go wrong around the house, supporting them financially, and generally tending to their needs. Other people can buy the support they need.

Nevertheless, there comes a time when some older people are confronted with their declining capability, poor health, failing cognitive function or a crisis involving hospitalisation. A number of people will seek out aged care services either independently or at the urging of family, friends, doctors and hospitals. Unfortunately, it is at this point, when the aged care system should be welcoming and easy to navigate, that the first problems emerge.

People are met with a telephone and internet-based national aged care entry system called My Aged Care that many people in their eighties and nineties find frightening, confronting and confusing. They are then referred for a face-to-face discussion to assess how much care they can receive and whether that will be in their own home or a residential care provider. This is the first of many assessments. Too often they must tell their story over and over again.

Left to fend for themselves at this point, they have to navigate their own way into the system. Older people and their families often find that their choices are limited by a combination of inflexible system design, lack of services near where they live, and cost. In these difficult circumstances, people have a right to expect that they will be given useful information in a helpful way. Unfortunately, useful information is the exception, not the rule.

Accessing home care

It is particularly challenging when an older person is deemed eligible for a Home Care Package, because they must first wait in the national prioritisation queue before a package of services is 'assigned', and then they must find a service provider to deliver their care. That can all take a very long time, especially for those who have higher care and support needs. Once someone is assessed as needing the highest level of care, a Level 4 Home Care Package, they can wait for a year and often longer for the Package to become a reality. Such waiting times would be unacceptable in any other system, but are common in home care today.

The Australian Department of Health, which oversees this system, has no mechanism to follow up with people who are on waiting lists to give them updates, including about whether they have progressed up the waiting list or how long it will be before a Package is available. In the interim, there is a clear and present danger of declining function, inappropriate hospitalisation, carer burnout and premature institutionalisation because necessary services are not provided. We have been alarmed to find that many people die while waiting for a Home Care Package. Others prematurely move into residential care.

By any measure, this is a cruel and discriminatory system, which places great strain on older Australians and their relatives. It is unfair. Older people should receive the home care services they need to live safely at home. Funding should be forthcoming from the Australian Government to ensure the timely delivery of these services. It is shocking that the express wishes of older people to remain in their own homes for as long as possible, with the supports they need, is downplayed with an expectation that they will manage. It is unsafe practice. It is neglect.

The path to residential care

Older Australians' transition from their homes into residential aged care can be very challenging for them and their loved ones. The decision to enter residential care often follows a traumatic event, such as a fall or a sudden decline in health. People feel under pressure to find suitable accommodation for themselves or someone they care for.

We have heard many accounts of older people and their loved ones having to contact service after service to find out if there is a suitable place available. My Aged Care often does not provide helpful information about local services. Perhaps even more worryingly, there is no easily accessible public information about the quality of services or reliable information about whether the services deliver on their advertised promises. Older people and their loved ones do not know what to look for when choosing a home. Choices about where to go are invariably rushed and made on the run, determined by whether or not a bed is available or if a service is close to family or run by a provider thought to be compatible with the older person's wishes or cultural or religious affiliations.

People do not usually enter residential aged care willingly. They often do so with great trepidation. They fear loss of autonomy, of individuality, of control over their own lives. They fear ceasing to be a person with distinct needs and preferences, with an emotional and intellectual life and freedom to do what they want, when they want to do it.

We have heard countless stories about how much people grieve for all they have lost when they arrive in residential care. They become 'just a resident', just another body to be washed, fed and mobilised, their value defined by the amount of funding they bring with them. They become infantilised, lose autonomy, and are prevented from making decisions or doing physical things that were routine when they lived at home, on the grounds that they 'could hurt themselves'. They lose their basic rights to take risks, to choose what to do in their day, to live a life as close as possible to their previous home and community. There is no joy in this.

Their families and friends often feel intense guilt, loss and fear: guilt at not being able to guarantee care at home any longer; loss of the person who, even if living from dementia or otherwise cognitively impaired, is still a unique personality; and fear of how this loved older person or young person living with disability will be treated when there is no one there to look out for them.

For older people who are alone before entering residential aged care, these feelings are magnified by the knowledge that no one will visit them. They are completely reliant on the kindness of strangers. For younger people with disability, their friends stop dropping by and rarely visit over time. It is an isolating and daunting experience. It is not a life.

Given that there is so much evidence about these feelings of loss and abandonment experienced in the aged care system, we are dismayed at the apparent lack of acknowledgement and understanding by those who manage and control the aged care system. As a nation, as a community, we must find a way to ease these transitions and ensure that residential care services are made much more attractive and enjoyable for those in care. This will necessarily require a clear focus on meeting the needs of the people in care, respecting their rights, and building good relationships with them. It will involve finding a way to bring the outside world into residential care homes, or taking those in care out. We will delve deeply into these matters in our Final Report. In the meantime, we encourage the Australian community and the aged care sector to work with people in care to harness their ideas and to develop solutions on the ground.

What happens in care

We have heard substantial direct evidence about what can happen to older people once they move into residential care. The case studies have given us invaluable insights into the vulnerability and isolation of older people in care.

Older people and family members have shown great generosity and courage in recounting painful events that have shocked and dismayed all who have heard about them. We have been told about people who have walked into an aged care residence, frail but in relatively good spirits and mentally alert, only to die a few months later after suffering from falls,

serious pressure injuries and significant pain and distress. We have seen images of people with maggots feeding in open sores and we have seen video and photographic evidence of outright abuse.

These accounts of unkindness and neglect have been difficult to tell and difficult to hear.

Just as striking is the love, dedication and determination of people who are, or have been, a parent, relative, friend, carer or advocate. We have been left with a sense of great pride in the way most ordinary Australians care for their loved ones and overwhelmed by their devotion and commitment.

We have heard about spouses who visit their partners every day to tend to their care and to keep them company. They stop doing other things or give up or reduce their work to do so, and accept the financial and other costs that are imposed on them. Such is their devotion.

At a time in their lives when an older person and their family members and friends should be able to spend peaceful time together, we have heard how these relationships can become subsumed by the battle with staff and managers in aged care services to advocate for basic personal care. We now know these battles go on every day.

Sons and daughters, aghast at seeing the poor state of a parent, insist on calling an ambulance so that they can be admitted to hospital, suspecting or knowing that a fall or other injury has occurred, or that their relative's health is declining. They insist on talking directly to doctors, just as they insist on meeting with senior management at aged care facilities or corporate representatives of the provider, to get answers, explanations and treatment. They pay for extra services, such as physiotherapy. They bring in palliative care clinicians if their family member is nearing the end of their life. They bring in food and feed it to a relative who can no longer eat without help, for fear that not to do so will condemn them to malnutrition. They have even installed hidden cameras in a family member's room to ensure their safety, and been horrified to see occasions of rough treatment and even assault.

Some of these people have been prepared to bear witness to what they have seen, heard, said and done, determined to bring an end to such practices. Their insights are invaluable.

Substandard care

We are concerned that there are no measures available to quantify the extent of substandard aged care. However, the combined impact of the evidence, submissions and stories provided to the Royal Commission leads us to conclude that substandard care is much more widespread and more serious than we had anticipated. We consider substandard care to include care that does not meet the relevant quality standards or other legislative obligations, or which otherwise does not meet community expectations.¹

1 This is explained in more detail in the Introduction to Volume 2, and is consistent with the guidance provided by the Royal Commission for the November 2018 Service Provider Survey.

The often shocking evidence reveals too many unacceptable practices and an aged care sector that is too often failing to satisfy basic community expectations or legislated requirements.

The major quality and safety issues which have been brought to our attention during this Royal Commission are:

- inadequate prevention and management of wounds, sometimes leading to septicæmia and death
- poor continence management—many aged care residences don't encourage toilet use or strictly ration continence pads, often leaving distressed residents sitting or lying in urine or faeces
- dreadful food, nutrition and hydration, and insufficient attention to oral health, leading to widespread malnutrition, excruciating dental and other pain, and secondary conditions
- a high incidence of assaults by staff on residents and by residents on other residents and on staff
- common use of physical restraint on residents, not so much for their safety or wellbeing but to make them easier to manage
- widespread overprescribing, often without clear consent, of drugs which sedate residents, rendering them drowsy and unresponsive to visiting family and removing their ability to interact with people
- patchy and fragmented palliative care for residents who are dying, creating unnecessary distress for both the dying person and their family.

It is shameful that such a list can be produced in 21st century Australia. At the heart of these problems lies the fundamental fact that our aged care system essentially depersonalises older people. A routine thoughtless act—the cup of coffee placed too far from the hand of a person with limited movement so that they cannot drink it, the call buzzer from someone left unanswered, the meal left uneaten with no effort to help—when repeated day after day, becomes unkindness and often cruelty. This is how 'care' becomes 'neglect'.

More than half the online submissions to us raised issues about substandard care. Forty per cent raised concerns about neglect, 39% about dignity, 37% about personal care, 33% about clinical care, 33% about medication management, 25% about nutrition and malnourishment, 22% about emotional abuse, 16% about physical abuse or assault, 13% about discrimination and 13% about restrictive practices.²

² Based on issues selected from a list by the person making the submission through the online submission portal.

A little over 1000 providers responded to our Service Provider Survey. They self-reported 274,409 instances of substandard care over the five year period to June 2018, including almost 112,000 occasions of substandard clinical care and close to 69,000 occasions of substandard medication management. They also reported 79,062 complaints about substandard care. Of these complaints, 15,700 were about personal care, 8800 were about compromises to an older person's dignity, and 7500 were about a lack of choice and control for the people receiving aged care services.

Expert evidence on clinical and personal care has also contributed to our understanding of the extent of substandard care:

- the Dietitians Association of Australia use current research to estimate that 22–50% of people in residential aged care are malnourished³
- an analysis of Aged Care Funding Instrument data reveals much higher than expected rates of incontinence, 75–81% of residents, with the majority in the most dependent category⁴
- recent Australia research reveals that pressure injuries occur in a third of the most frail aged care residents at the end of their lives⁵
- research involving 150 residential aged care facilities⁶ found that 61% of residents were regularly taking psychotropic agents, with 41% prescribed antidepressants, 22% prescribed antipsychotics, and 22% prescribed benzodiazepines⁷
- an Australian Department of Health expert clinical advisory panel estimated that psychotropic medication is only clearly justified in about 10% of cases in which they are prescribed in residential aged care⁸
- there were 4013 notifications of alleged or suspected physical and/or sexual assaults in aged care in 2017–18.⁹

In the face of these horrifying reports and the shocking tale of neglect we have heard throughout this Royal Commission, we will continue to attempt to quantify the level of substandard care in our Final Report.

3 Exhibit 6-1, Darwin and Cairns Hearing, General Tender Bundle, tab 82, DAA.0001.0001.0079 at 0080-0082.

4 PD Hibbert *et al.* 'CareTrack Aged: *the appropriateness of care delivered to Australians living in residential aged care facilities: a study protocol*, *BMJ Open*, 2019, 4, online supplementary appendix 1. p 2. file:///C:/users/acrc.allipa/Work%20Folders/Downloads/bmjopen-2019-June-9-6--inline-supplementary-material-1.pdf, viewed 1 October 2019.

5 Exhibit 6-1, Darwin and Cairns Hearing, General Tender Bundle, tab 51, CSH.0001.0001.0032 at 0041.

6 Exhibit 3-61, Sydney Hearing, Statement of Dr Juanita Westbury, 29 April 2019, WIT.0117.0001.0001 at 0008 [15].

7 Exhibit 3-80, Sydney Hearing, Statement of Henry Brodaty, 16 May 2019, WIT.0116.0001.0001 at 0009 [45].

8 Transcript, Brendan Francis Murphy, Sydney Hearing, 14 May 2019 at T1646.3–30.

9 Exhibit 1-37, Adelaide Hearing 1, Department of Health 2017-18 Report on the Operation of the Aged Care Act 1997, RCD.9999.0011.0001 at 0097.

How does the aged care sector respond?

Not very well.

People living in residential care, or receiving care in their homes, have told us of their feelings of frustration, despair and hopelessness. Their complaints, which should be a window into care practices, often go unanswered. Many people have told us that the complaints system is hard to access, slow to act and often effectively unresponsive to the concerns of the complainant.

People become unwilling to complain for fear that care will become worse, as they or their family member will be labelled as 'difficult' by the provider. Several submissions have highlighted occasions where the treatment of the older person deteriorated after complaints from family members—with neglect transforming into the withholding of care. It is disturbing that the aged care sector is not sufficiently mature or professional to listen to feedback from those who use and observe its services at close hand, particularly when the regulatory system appears so distant and ineffectual.

Some providers of aged care have appeared before the Royal Commission to be defensive and occasionally belligerent in their ignorance of what is happening in the facilities for which they are responsible. On many occasions when case studies were presented in hearings, providers were reluctant to take responsibility for poor care on their watch. Some providers have shown an unwillingness to accept that they could have, and should have, done better. Others have, rightly, accepted this. Those providers who have demonstrated a commitment to building relationships with people receiving care and their families stood out in sharp relief.

The aged care system lacks fundamental transparency. Witnesses from the Australian Department of Health told us that there is very little information available to the public about the performance of service providers. The number of complaints against them are not published. The number of assaults in their services are not published. The number of staff they employ to provide care are not published. Participation by providers in the collection of a very limited set of performance indicators only became compulsory on 1 July 2019. The Department has said that it will publish differentiated performance ratings of residential aged care providers, but there is still no clarity on what this information will look like.

We have heard evidence which suggests that the regulatory regime that is intended to ensure safety and quality of services is unfit for purpose and does not adequately deter poor practices. Indeed, it often fails to detect them. When it does so, remedial action is frequently ineffective. The regulatory regime appears to do little to encourage better practice beyond a minimum standard. We were flabbergasted to hear that, until recently, it was routine practice for large sections of the reports of accreditation audits of services conducted by the Aged Care Quality and Safety Commission to be generated by computer assisted text. In other words, the same positive words prompted by computers were used over and over again. Computers cannot determine quality; only people can and should do that.

We have heard about an aged care workforce under pressure. Intense, task-driven regimes govern the lives of both those receiving care and those delivering it. While there are exceptions, most nurses, carer workers and allied health practitioners delivering care are doing their best in extremely trying circumstances where there are constraints on their time and on the resources available to them. This has been vividly described by the former and current aged care staff who have given evidence.

The aged care sector suffers from severe difficulties in recruiting and retaining staff. Workloads are heavy. Pay and conditions are poor, signalling that working in aged care is not a valued occupation. Innovation is stymied. Education and training are patchy and there is no defined career path for staff. Leadership is lacking. Major change is necessary to deliver the certainty and working environment that staff need to deliver great quality care.

We have also heard about how the aged care system has not kept up with changing needs and community expectations. The preference for care at home is increasing significantly. Consequently, the complexity of the care needs of people entering residential care is also increasing. The aged care system as a whole has struggled to adapt to these developments, as have specific providers. These changes require different care models, investment in new expertise, reconsideration of funding models and a stronger, closer interface with the acute health care sector.

It is time for a reality check. The aged care sector prides itself in being an 'industry' and it behaves like one. This masks the fact that 80% of its funding comes directly from Government coffers. Australian taxpayers have every right to expect that a sector so heavily funded by them should be open and fully accountable to the public and seen as a 'service' to them.

As a service, aged care is an integral part of our social support system and, as such, it must aim to be the best service that an inventive, clever and compassionate country can provide. It should be delivering aged care services of an exemplary standard, in ways that are responsive to older people's care needs and aimed at delivering the best possible quality of life to them in their later years.

The overall impression we are left with is of a system that is failing, but there are some positive stories emerging from our inquiries. Provider organisations and consumer representative groups have highlighted great quality care and caring environments. We have heard many examples of providers who deliver innovative and effective models of care. Crucially, we have heard about these positive examples not just from the providers themselves, but from the people they care for. There have also been many examples of individual staff members dedicating themselves to providing exemplary and compassionate care, despite the challenges of their working environment. All of these positive examples provide us with confidence that a better aged care system is possible.

However, it seems that these providers and staff are currently succeeding due to their own passion and dedication. The aged care system provides no incentive or encouragement for these achievements. In short, they are succeeding despite the aged care system in which they operate rather than because of it.

The structure of the current system has been framed around the idea of a 'market' for aged care services where older people are described as 'clients' or 'customers' who are able to choose between competitively marketed services. But many older people are not in a position to meaningfully negotiate prices, services or care standards with aged care providers. The notion that most care is 'consumer-directed' is just not true. Despite appearances, despite rhetoric, there is little choice with aged care. It is a myth that aged care is an effective consumer-driven market.

Since the Royal Commission began its work, there have been calls from several quarters for government funding to aged care to be significantly increased, without waiting for our Final Report and recommendations. These interventions are essentially variations on a theme which has haunted this area of government policy for far too long: short-term solutions which will at best temporarily stave off the worst problems and, at worst, produce another set of unintended outcomes requiring further inquiries and reviews and further injections of public funds without addressing the underlying causal factors. These limited interventions are not enough to deliver an aged care system that meets the needs of older people.

Nevertheless, there are some areas identified in this Interim Report where there is a need for urgent action. These are:

- to provide more Home Care Packages to reduce the waiting list for higher level care at home
- to respond to the significant over-reliance on chemical restraint in aged care, including through the seventh Community Pharmacy Agreement
- to stop the flow of younger people with disability going into aged care, and expediting the process of getting those younger people who are already in aged care out.

We see no reason to delay action in these areas.

It is clear that a fundamental overhaul of the design, objectives, regulation and funding of aged care in Australia is required. This will be the central purpose of our Final Report and it also informs our approach to this Interim Report.