SUBMISSION TO THE ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY

by Ted O'Brien MP
on behalf of the electorate of Fairfax
7 March 2019

SUBMISSION TO AGED CARE ROYAL COMMISSION OF FAIRFAX ELECTORATE

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CHAPTER I EXECUTIVE SUMMARY

Australia has every right to be proud of its aged care sector.

However, there is much room for improvement and the calling of a Royal Commission by the Commonwealth Government is welcomed.

This submission draws on input from hundreds of residents, together with organisations, across the Sunshine Coast, in particular, from the Federal Electorate of Fairfax.

Based on the views of those people who participated in this process, there are four key areas that the Royal Commission may wish to consider:

1. Availability of Service Packages - People with little or no support in the community may take a passive approach to seeking assistance until forced by circumstance into a residential care facility;
2. Communications - The MyAgedCare process is too complex and difficult to access for people without computer skills and advanced knowledge;
3. Models of Care and Sustainability - Models of care should reflect the needs of senior Australians, should be developed through careful planning, should be scalable and responsive to changes in patient needs, and should be able to be maintained at a specific level for as long as is required;
4. Staffing - Staffing of organisations is the most critical issue and has been raised by people at every level, from residents to service providers. How staff perform their duties reflects not only the culture of the organisations, but the value that the community at large places upon senior Australians.

Over and above the issues relating to the Terms of Reference of the Royal Commission, the Federal Member for Fairfax, Ted O'Brien has also made a personal contribution at the end of this submission relating to the importance of culture and leadership in addressing the broader issue of an ageing Australia.

CHAPTER II CONTEXT

The electorate of Fairfax is within Queensland's Sunshine Coast Region. Fairfax stretches from Mountain Creek, Mons and Flaxton in the South to Peregian Springs and Eumundi in the North and to Kenilworth in the West. It occupies an area of 1,004 square kilometres and is both a rural and regional area, with major industries being tourism, health care and construction and longstanding strength in food and agriculture. The Sunshine Coast is well-recognised not only as a tourist destination, but is also recognised by Australians for its lifestyle, education and retirement benefits.

Data derived from the last Census taken by the Australian Bureau of Statistics in 2016 indicated that the total population of the Electorate of Fairfax at the point of the Census was 153,463, of which 28,351 (19%) were people 65 years of age or older. There are 123 retirement villages in the Sunshine Coast, of which 30 (approximately 25%) are located in the electorate of Fairfax.

The electorate of Fairfax had a total of 1,880 operational aged care places as at 30 June 2018 comprising:

- 1,768 Residential aged care places
- 44 Short Term Restorative Care places
- 68 Transition care places

Ted O'Brien has been the Federal Member for Fairfax since the 2016 Federal Election. As the Federal Member, he has been particularly cognisant of issues raised by the seniors' community, and is supported by a Seniors' Advisory Committee that assists him in addressing these issues.

Upon the Terms of Reference for the Royal Commission into Aged Care's being announced on 9 October 2018, Ted O'Brian publicly committed to formulating this submission to the Inquiry, on behalf of the Fairfax electorate.

This Submission draws on information from several sources:

1. Annual Seniors' Forums hosted by Ted O'Brien:

a) 2016 - Seniors' Issues Forum

b) 2017 – Aged Care and Health Forum

c) 2018 - Cost of Living Forum

* *2019 – Personal Safety and Technology Forum, scheduled for 7 March 2019 .*

2. Royal Commission Forums hosted by Ted O'Brien

Three forums were held in October 2018 that sought feedback on the terms of reference of the Royal Commission, with each forum consisting of representatives from different stakeholder groups:

a) Families of those receiving aged care services;

b) Workers in service provider companies and institutions;

c) Service providers with management level representation.

3. Constituent engagements at Ted O'Brien's Electorate Office, and at his mobile offices around the electorate

CHAPTER III A POSITIVE FOUNDATION

While the Royal Commission is to inquire into the quality of aged care in Australia and how it can be improved, it is worth recognising that Australia's track record in the areas of aged care and treatment of senior Australians is worthy of praise.

Beyond Aged Care—which is the primary area of focus for the Royal Commission—a broader set of measures and support facilities exist for senior Australians.

Age Pension

In 2016, the Melbourne Mercer Global Pension Index (MMGPI) compared the retirement income systems of 27 countries and gave each of them a grade and index score. In that Index, Australia rated 3rd, after Denmark and the Netherlands.

Superannuation

Australia has an enviable compulsory superannuation system, which was put into place to address the demographic shift which would, in part arise from the ageing of the "Baby Boomers", and which would challenge the sustainability of the Age Pension regime into the future. The superannuation system, carried forward as a bipartisan solution, was a "three pillars" approach to retirement income:

a) compulsory employer contributions to superannuation funds;
b) further contributions to superannuation funds and other investments; and
c) if insufficient, a safety net consisting of a means-tested government-funded age pension.

The compulsory employer contributions were branded "Superannuation Guarantee" contributions. The Superannuation Guarantee rate has been 9.5% of employee earnings since 1 July 2014, and after 30 June 2021 this rate is set to increase by 0.5% each year until it reaches 12% by 2025.

These contributions are invested during the working life of the investors, under strict rules, and are paid to the investor at retirement, or at other restricted trigger events, which may include medical hardship.

Development of Retirement Villages

Australia has developed a system of retirement villages which, in 2017, were home to approximately 5% of Australia's population aged over 65 years.

Aged and Community Services Australia in its December 2017 report, defined a retirement village broadly as "a complex containing residential dwellings that are predominantly or exclusively occupied by residents who are aged over 55 years, or who have retired from full-time employment. While this has been a common entry specification, recent surveys have found that the average age of entry is 75 years and the average age of residents is 80 years. The average length of stay of residents is seven years".

The 2015 Productivity Commission Report found the popularity of retirement villages is increasing faster than any other age-specific housing option in the country.

Health Care

Australia has an excellent health care system, comprising universal health care (public) and private providers (insurance). Every citizen and permanent resident of Australia has the right to Medicare, which provides access to primary health care (general practitioners) and hospital care in public hospitals. In addition to Medicare, there is a separate Pharmaceutical Benefits Scheme funded by the Commonwealth government which provides considerable subsidises for a range of prescription medications.

Private health insurers fund ancillary services such as surgery through private hospitals, and services such as physiotherapy and dental. In addition, a number of other schemes cover specific circumstances involving defence veterans, indigenous Australians, and those injured in workplace accidents and motor vehicle accidents.

MyAgedCare

MyAgedCare is a gateway, which can be accessed either by the internet or by phone. Through this gateway, senior Australians are able to source information about services available to them, arrange for assessment to determine level of support required, and be referred to service providers to access the service required by their assessed level. This gateway was developed as a result of the 2011 Productivity Commission report "Caring for Older Australians" and is continually being modified and aligned with the needs of senior Australians.

With respect to Aged Care themes, and notwithstanding clear evidence in the public domain for considerable improvement, the majority of experiences by residents and their families are overwhelmingly positive, and the caregivers in these facilities tend to the residents in a caring and empathetic manner. It is also noteworthy that Australian care institutions are generally well-regarded in other countries. For example, China made its first ever commitment on aged care services in the Free Trade Agreement it negotiated with Australia, allowing Australian medical service suppliers to establish wholly Australian-owned profit-making aged care institutions in China with no geographical restrictions.

Good News Stories

Though there are some difficult and disturbing stories arising out of many aged care facilities in Australia, there are also countless stories about facilities doing a wonderful job in making the last years of life for its residents as comfortable and happy as possible, for example:

Mavis's daughter says:

"My mother and our family are fortunate. Once the decision was made by Mum, at the age of 94, to move from independent living to aged care support, we found ourselves knee deep in navigating the online and local office assistance in finding the right kind of accommodation. Mum has no diminished mental capacity; she is a warm and interactive conversationalist and prides herself on being in control of her circumstance. She is only too aware of how her physical self is failing her.

She resides at Boyanda (Blue Care) Aged Care in Bli Bli. Their care and consideration for her wellbeing, daily needs and medical support is hugely appreciated by Mum and her family. Those who work at Boyanda are kind and professional in the execution of their duties. "

Doug's wife says:

"My husband has been a resident in Opal Nambour Nursing home for about 18 months now. He is a resident in the home because he has been a wheelchair-bound paraplegic since the age of eight and I am no longer able to lift him or care for him properly. The nursing home is old but clean and homely with plenty of optional activities, good care and excellent meals. Visitors are encouraged and visitors and relatives are welcomed to join residents for a meal.

During my husband's time in the nursing home I have visited almost daily and have not seen any ill-treatment of patients, verbal or physical. On the other hand, I have seen abuse from some of the residents towards staff in the form of offensive language and punching. This abuse has generally been handled with patience and residents are treated with respect."

CHAPTER IV THE CASE FOR IMPROVEMENT

Whilst the Government can be proud of its legacy in supporting senior Australians, it also acknowledges, by virtue of this Royal Commission, that there is considerable room for improvement.

Because the Australian population is rapidly ageing, it is vital to the well-being and dignity of senior Australians that these issues, and others, are addressed in the most expeditious way. The report "Older Australia at a glance", published in September 2018 by the Australian Institute of Health and Welfare, indicated that in 2017, there were 3.8 million Australians aged 65 and over (comprising 15% of the total population) —increasing from 319,000 (5%) in 1927 and 1.3 million (9%) in 1977.

The number and proportion of older Australians is expected to continue to grow. By 2057, it is projected there will be 8.8 million older people in Australia (22% of the population); by 2097, 12.8 million people (25%) will be aged 65 and over. There, simply, is no time to lose.

The matrix below consolidates issues raised most frequently in the forums and discussions that have informed this submission. These issues fall under four broad themes:

1. Availability of Service Packages
2. Communications
3. Models of Care and Sustainability
4. Staffing

(Note that reference to "TOR NO." in the matrix below denotes the relevant Term of Reference from the Inquiry which is attached as an appendix to this submission)..

NO.	THEME	ISSUE
1.	**Availability of Service Packages**	***People with little or no support in the community may take a passive approach to seeking assistance until forced by circumstance into a residential care facility.***
		SUMMARY OF ISSUES RAISED: *(a) There are those who are proudly independent, yet afraid to be seen as not coping, and do not want to lose their independence, so they carry on the illusion of coping, until they can no longer maintain that illusion. This, coupled with the long waiting lists for higher level home care packages, may mean that they are not gently transitioned from home care to residential care, from level to level, and no longer have any choices but residential care, and have to accept a facility which is available, rather than chosen;* *(b) Many senior Australians are afraid that they are going to be pushed into a care facility without their consent, and as a result they hide their issues, similarly to those in (a);* *(c) There are those who live independently until a catastrophic event, such as a fall, causes them to be hospitalised in a primary care facility, which won't discharge them unless to a "safer facility";* *(d) Hospitals are not set up nor staffed for the level of personal care that elderly patients require, and the patient may find that they are ignored or even disrespected when they are in a primary care facility, before being placed in a residential facility.* *(e) Many express a fear that going into a residential facility means the end of life as they know it. They fear the isolation, the lack of contact with the outside world, and the lack of day-to-day conversation. This is compounded when "able-minded" persons*

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are mixed in a facility with those suffering from dementia, and where residents are exposed to behaviour and language which makes them feel less safe.
(f) There are those who, having accepted their frailties, have reached out for assistance through MyAgedCare, been assessed as having Level 3 and 4 needs, then find themselves in a holding pattern from 1-2 years, where they cannot obtain the assistance they need . These people are at risk of having a catastrophic event, such as described in 1(c).
(g) Further, there are people who would like to compare facilities, to be able to make a choice as to the facility in which they would like to reside when they are ready. Currently, there is no easy way to do this, especially for those who are not computer literate and able to spend the time researching each facility.
(h) Some primary care facilities have placed the efficiency and/or profitability of the organisation ahead of the well-being of the patient – for example moving a dying man from a single room into a dark corner of a four-bed room so that his room could be cleaned, thereby precipitating his death.
<table>
<tr><th>SELECTED QUOTES FROM CONSTITUENTS</th><th>TOR NO.</th></tr>
<tr><td>“People living in aged care facilities are often alone with no network of support. They just stay at home and eventually end up in a hospital and are directed by the hospital to a residential aged care facility.”</td><td>5</td></tr>
<tr><td>“People are scared that they are going to be pushed into a nursing home without their consent, so are quiet about their issues.”</td><td>5</td></tr>
<tr><td>People want to be seen as coping and are often too proud or too frightened to admit that they are not coping.</td><td>5</td></tr>
<tr><td>“More availability of services are required for older persons in their own homes – often they are placed on a lengthy wait list for services at Levels 3 and 4”</td><td>3a</td></tr>
<tr><td>“Home Care Package system – there are a lack of places, long wait times, insufficient funding. What happens to those who are on the wait list for extended periods?”</td><td>3</td></tr>
<tr><td>“When people are assessed as qualifying for a package, they are put on a waiting list for far too long – 12, 14, 15 months even when they are assessed as needing the higher package now – this may mean that they are pushed into residential care too early”</td><td>3</td></tr>
<tr><td>In relation to care within a hospital, not an aged care facility: “In short, without family consultation nor doctor consultation, my 83 year old father was forcibly moved from a single room to a dark corner in a 4 person room. He was in palliative care and familiar surroundings are key for comfort and stability at this stage, as stated by his Doctor that morning. The move caused such mental and physical distress for my father, that rather than coming home Monday, he” [passed away and never came home].</td><td>5</td></tr>
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NO.	THEME	ISSUE	
		"The consultant Physician who has worked very hard to prepare my father to come home, has agreed: • That the move to the high density room, away from my father's familiar room, was to suit the nurses, not the patient • That the doctor's efforts were undermined by the nurses. It took us escalating the matter to the Director of Clinical Services, on Saturday evening, to get my father back to familiar surroundings, but the damage was done. His medical regression [was] so significant that he [never came] home again. By the way, all the Director keeps saying is "all I can do is apologise". There is no ownership of the underlying issues, and an intent to improve. My thoughts are: • What is the accountability framework for the hospital? • Who is accountable and how will this be addressed? Clearly it is a regular process that nurses do, not a one-off random event? It seems that some processes have altered already today (Sunday). • Clearly the protocols were not followed on Saturday. • What can the Health Dept do to ensure quality care in private institutions?. The treatment of my father, as a very sick and elderly man, was disrespectful. The hospital waited until visitors had left to make the move on a defenceless and dying man. It was only that a family member returned that the matter was discovered."	
		"Service provider staff have to manage patients who are on Level 1 time/funding when, in fact, they are assessed as Level 4. They have to deal with that situation as best they can." This comment from a constituent flows directly from the delays in awarding packages. Service providers often have funding for Level 1 or 2 packages but they are trying to manage a patient with higher needs who are on a waiting list. Providers are often trying to stretch Levels 1 and 2 funding to give greater assistance to those with higher needs.	5
2.	**Communications**	***The MyAgedCare process is too complex and difficult to access for people without computer skills and advanced knowledge***	
		SUMMARY OF ISSUES RAISED : *(a) People cannot get information easily from MyAgedCare if they are not computer literate. They wait for long times on the phone, and are confused by the digital menu on the telephone site and have difficulty understanding their choices. These are people*	

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who would prefer to have face-to-face contact with a person, rather than to deal with faceless persons. Further, these people have said that some phone operators have difficulty explaining the system to the caller.

(b) Further, even people who have both education and experience in business find that the language of the MyAgedCare website is directed toward those who have intrinsic understanding of the system, and not toward those who are first-time users of the system. They find the MyAgedCare system to be counterintuitive.
(c) Some assessors do not understand ageing issues when they are assessing the aged person. Further, the assessor may treat the assessment as perfunctory and not understand the feelings of the person being assessed, nor the potential outcome of the assessment on the independence of the person being assessed.

(d) There have been complaints that the complexity of the MyAgedCare system and the inability of staff to match the person with the “right place” is causing people to be placed in facilities which may not be a good match for them.
(e) Service providers often don’t understand the funding models, and cannot adequately explain the entitlement of the recipient of the services to the recipient. In addition, there is often a misunderstanding of future funding, or “what comes next”, causing worry that there will be no future provision of services.
(f) Residents within facilities are often treated without dignity. There have been reports that residents are berated unnecessarily, in front of other people, when they misunderstand routines, or when they intervene to help a fellow resident. There have been instances where residents have been allowed to soil themselves because their communications with staff have been ignored.

(g) There are issues with staff who have difficulty with the English language, or strong accents, where the outcome is that the resident does not understand the explanation or information provided by the staff member.
(h) A consistent remark has been made by many constituents, that they have not received satisfactory and intelligible answers from service providers and from MyAgedCare officers as to the amount of funding to which they are entitled, what they can use it for and how they can deal with changes to what they want. For example, several people with mobility issues have asked whether they can use their entitlement to have a lift put in their home so that they do not have to climb stairs.

<table>
<tr><th>SELECTED QUOTES FROM CONSTITUENTS</th><th>TOR NO.</th></tr>
<tr><td>“Better explanations of what clients’ expectations of what their entitlements are:
(a) Modifications
(b) Amount of funding
(c) Want vs Need”</td><td>3a, 5</td></tr>
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NO.	THEME	ISSUE	
		One of the comments made by educated constituents (having both tertiary education and extensive business backgrounds) is that "the language used in the MyAgedCare website is 'technical language', and that it is written for people who have an intrinsic understanding of the system, but not for those who do not. Therefore, working with the MyAgedCare website is counterintuitive."	
		"The MyAgedCare process is 'mind-boggling' in its complexity. Seniors often end up in the wrong place because the MyAgedCare staff are not properly trained to recognise the "right place" for people"	5
		"Simplify the admission process to aged care residences"	5
		"The digital menu on the MyAgedCare telephone site is often challenging for elderly people to navigate and to be able to understand their choices"	5
		"Due to a lack of computer and mobile phone literacy, there are many people who can best be managed face-to-face by agencies."	5
		"My concerns are: 1. Communication. The need for myself and [my sister] to discuss Dad and his recent history and needs with every shift as staff do not seem to know from one shift to the next what is happening and what his care needs are. 2. Communication. The fact that Cathy and I called several times over the weekend and were unable to contact anyone re Dad and discuss his condition and his care. 3. Communication. The fact that the attending GP is unable to be contacted. This must also be a constant source and frustration for staff trying to contact the Doctor for any client. 4. Pain relief. Prior to Dad's second hospital admission it seemed that the staff were trying to manage Dad's pain with a TDS order for Endone when this clearly was inadequate. Dad now has a fentanyl patch in situ that will last 1 week AND this will need to be reviewed and continued if necessary, or the dose be reduced over a period of time… 5. Mobility. The need to get Dad up and walking to avoid many preventable complications."	1
3.	**Models of Care and Sustainability**	***Models of care should reflect the needs of senior Australians, should be developed through careful planning, should be scalable and responsive to changes in patient needs, and should be able to be maintained at a specific level for as long as is required.***	
		SUMMARY OF ISSUES RAISED: *(a) Planning of models of care involve placing senior Australians into facilities appropriate for their needs. For example, it may be difficult to intermingle people with severe dementia with those who do not have dementia, and the intermingling may cause unintended consequences for those patients without dementia.*	

NO.	THEME	ISSUE	
		(b) The reality is that many placements occur where there is a vacancy, rather than where there is a suitable facility, or that placements occur because there is no availability of a higher level home care package for a person who wishes to remain at home. *(c) There is often inconsistency in the way that medical interventions are handled within the facility, often because of a lack of trained medical staff in the facility.* *(d) More reasonable amounts of money should be taken by the service providers for administration fees, and there is limited control to go over the amounts charged—with a wide divergence of fees levied by different organisations for the same services. Also, unallocated money from the packages does not seem to get returned to the government, nor is it able to be used for different purposes to assist the client.*	
		SELECTED QUOTES FROM CONSTITUENTS	***TOR NO.***
		"It is the opinion of many health care professionals, including me, that each person who enters residential care should have an Advanced Care Plan (ACP) developed as a consultative process involving the nurses, primary care physician, the resident (if cognitively capable) and the relatives. Such a Plan enhances the standard of care and can avoid unnecessary transfer to hospital. This is not the same as a Health Directive which is a legal document. Insisting that the ACP should be introduced on an 'opt out' basis which would be the ideal, would of course require assessment and involvement by the responsible primary care doctor."	5
		"It is up to the organisations servicing the aged care sector to teach and grow the culture in the organisation for the benefit of its residents"	6
		"Mixing patients with severe dementia with non-dementia patients is often problematic, because it reduces conversation and may lead to the unintended consequence of isolation of the people without dementia"	4
		"I have a friend who suffers from physically incapacitating Parkinson's disease. He has no cognitive impairment but requires care because his wife can no longer handle his physical needs. Currently he is housed in a secure dementia 'ward' which is quite depressing for him and the only respite he receives is when relatives or friends distract him or he is taken out in a wheelchair (for lunch for example). This example emphasises the need for adequate assessment and service categorisation but also stresses that the standard of care should not be driven by convenience and cost factors"	6
		"We are always behind in knowledge, pro-active solutions, etc. There are many models already working—A greater focus on innovative solutions is needed."	6
		"The loved ones show a lack of interest/involvement in the care of their elderly family member. Government should	4

NO.	THEME	ISSUE	
		help families look after their own." This was a direct quotation from a constituent, demonstrating a lack of understanding of the roles of governments in the lives of people.	
		"There should be more options and choices in models of care for those who don't need to go into residential care though they find that planning and cooking are too much for them – this is a significant gap in the system"	6
		"Nutrition and appropriate food selections are vital to prolonging good health. It is worrying that providers will often cut back on basic food items as part of cost-cutting strategies and with little or no consideration to the medical consequences. The flow on effect impacts situations like recovery from ulcers due to lessened vitamin intake. Also, the preparation of food can be, in many cases, pre-packaged or cooked offsite. Although expedient for the provider, this translates to poor quality and sometimes inedible meals for residents." "Consideration is often not given to the fragility of dental capacity or managing meals on the plate. Frustration can lead to disgruntlement and lower food intake engendering negative nutritional outcomes."	3
		"The money spent in home care packages contains waste – what happens to the unallocated funds?"	6
		"People who do have funds which are sitting in their account with a service provider unused—all that money just sits there untouched and is not available for any other purpose."	6
		"As I understand it, a bond required for Aged Care entry is considered an 'asset' of the resident yet they do not reap any financial benefit after the money is paid to the provider. These bonds can vary from $250k to $1m+. Variations on monthly fees are still payable for basic care if bonds are not paid in full and any medications required are paid separately as an on top charge. Many senior Australians in need of live-in aged care are precluded from entering a facility, as amassing such an exorbitant amount can be ruinous for themselves and their families. In most cases, a property will need to be sold and additional funds sought to meet entry requirements. Exit fees are also high with little justification. Why was Aged Care legislation developed to clearly financially benefit the provider and place the recipient at a disadvantage?"	3
4.	**Staffing**	***Staffing of organisations is the most critical issue and has been raised by people at every level, from residents to service providers. How staff perform their duties reflects not only the culture of the organisations, but the value that the community at large places upon senior Australians.***	
		SUMMARY OF ISSUES RAISED Some of the major comments have been: *(a) Staff need to be better qualified to provide high standard*	

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clinical care and there need to be more medically trained staff to understand and manage the complexities of diseases which accompany the “normal” progression of ageing.

(b) Staff need to be skilled and educated, well-paid and want to be in that job, and the staff-to-patient ratio in nursing homes needs to be higher. Because of the attitudes of some staff, many elderly residents are afraid that they are a nuisance to the staff, and are afraid to ask for assistance when they need it.

(c) More facilities and specially-trained staff are required for dementia patients. Non-dementia patients may be accosted by patients with dementia who wander at night, and are disturbed by patients with dementia who shout out.

(d) It is critical that the right people are trained to be staff in aged care facilities. The fact that there is a skill shortage in the aged care sector does not mean that just anyone can work in it.

(e) Weekends are often not adequately covered by staff at residential facilities, though the need is still there. This has been expressed to be because the wages are higher on the weekends.

(f) Staff performance needs to be adequately monitored, education of staff should be continuous and routines should be developed by the organisation, which place the needs of the patient ahead of the efficiency of the facility.
<table>
<tr><th>SELECTED QUOTES FROM CONSTITUENTS</th><th>TOR NO.</th></tr>
<tr><td>“Unemployed people are pushed towards the aged care sector because it is such a big industry with such big needs regardless of their individual suitability to work in this sector. The fact that a person is unemployed does not necessarily mean that they are the right person for the job.”</td><td>6</td></tr>
<tr><td>“We need better funding for more qualified staff to provide high standard clinical care which will then improve older people’s quality of life”</td><td>1</td></tr>
<tr><td>“There is no accountability on where or how funds are spent or what metric indicates required staffing.” (This was a direct quotation from a constituent, reflecting that staffing levels appear to be too low to warrant the administration fee charged).</td><td>6</td></tr>
<tr><td>“There is a lack of awareness of ageing issues in many who are assessing the aged care requirements of the elderly”</td><td>4</td></tr>
<tr><td>“The staff to patient ratio is too low”</td><td>6</td></tr>
<tr><td>“We need skilled staff who are well-paid, educated and motivated to be a meaningful carer in this sector.”</td><td>6</td></tr>
<tr><td>“The level of staffing is insufficient to manage the complexities of diseases and education of the carers in the requirements of each person in care. As a group, these</td><td>5</td></tr>
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NO.	THEME	ISSUE	
		mostly elderly patients are medically complex with a number of co-morbidities."	
		"Staff training is important, but also staff should be evaluated as to suitability for work with the elderly"	6
		"Governments both State and Federal need to be aware of the needs of ageing patients in nursing homes as everyone is different. Not everyone can afford a private nursing home. The most basic need even for public nursing homes is for dedicated, well-trained and well-paid staff—and adequate staff for the numbers of residents in each nursing home. A continuation of familiar faces among staff for nursing home residents is essential as many do not have family to visit them. Reliable volunteers, pleasant surrounds, colourful garden beds and trees are also needed". "Staff that are too busy to look after patients are no use to anyone".	6
		"More facilities and appropriately trained staff are required to ensure that patients with dementia are cared for in a safe, dignified manner that does not negatively impact upon other residents."	3b, 4
		"Re the lack of activity officers in the dementia unit: When dad first entered care an activity officer was allocated to the dementia unit for specific shifts. This provided some form of stimulation and diversion and Dad participated and enjoyed the activities. In 2018 these officers were no longer allocated to the unit and we were advised that it would be on a needs basis and that the carers would do activities. There are 2 carers allocated to the unit and at times only one when the other staff member is on break. It is unrealistic to believe that they would be able to fulfil this role. The result of this is little or no activity for the residents. When visiting Dad, I saw a program on the wall called the Rainbow Calendar [showing regular activities]. At no time when visiting did I ever see any evidence that this calendar was being followed."	2b
		"The work force supplying services to the aged often have difficulty explaining future funding to their clients, leading to uncertainty for older Australians." This comment reflects the inconsistency of training of service providers, indicating that the staff who are often the first points of contact to the client often do not completely understand the system, and, therefore, provide inadequate information to the clients.	3
		"Weekend penalty rates will often see less staff on duty over two days each week. The needs of residents do not change on Saturday and Sunday. This time each week can be detrimental to residents as waiting periods are longer, sometimes significantly longer, for assistance, etc. Greater capital outlay needs to be part of viable business practices that offer sustained and consistent care to residents."	3
		"Ongoing education and professional development of aged care workers"	6, 5

NO.	THEME	ISSUE	
		"Dad died on Christmas morning after succumbing to influenza. We can accept that these infections happen and are hard to confine. On the 24th December I requested that Dad be seen by a doctor either his GP or the palliative care doctor. [The doctor] attended at 12:30 and determined that dad was at a terminal stage of his life and a palliative pathway was commenced. He ordered a PRN dose of morphine and midazolam for his comfort…the first dose was administered at approx.. 1315. My sister and I stayed with Dad for a period after this. We did verbalise our concern that based on past history experience information is not handed over and medication is not administered, despite being ordered…We made it very clear to the staff that we wanted Dad to be kept comfortable. We returned at approx. 1830 and the staff were administering a second dose of medication. We stayed with him for a few hours. We again stressed our concern regarding a past history of information not being communicated to the next shift of staff. We were reassured it would be. At 5:18 and 5:19 the following morning my sister…attempted to ring the facility FOUR TIMES for an update, again her calls went unanswered. Eventually she spoke to the male RN who advised he had no knowledge that Dad was on a palliative care pathway or that he had been seen by the palliative care doctor even though handover was less than 12 hours after [the doctor] had visited. He denied seeing a medication chart with the drugs ordered on it, then advised that the medications were yet to be delivered to the facility. This again BEGS the question of what sort of handover do the staff perform and how effective is the consolidated electronic clinic record system that [the facility] wrote to us about on July 7th when addressing our last complaint re communication. The RN's defence was that Dad was not in pain. He did accept that Dad was probably suffering and it did appear that he was terminal. There was obviously a complete lack of understanding of palliative care procedures and [I suggested to the CEO that he should] refer to the World Health Organisations definition of it and train the staff SO AS TO HELP REDUCE SUFFERING…"	1
		"I am now living alone in a retirement village, as my wife died several years ago. I have had to spend some time in respite care following surgery on three occasions and found on those occasions that my dignity and the dignity of my fellow residents was not upheld: (a) I spent a month in an aged care hospital in Maroochydore where I noticed that there were a number of patients with dementia, and they were	6

NO.	THEME	ISSUE	
		not given knives at meals and had to put butter and jam on their toast with their fingers. I also noted at meal time that one male resident with a four-wheeled walker was desperately in need of escort to the toilet. He tried to get the attention of a nurse, and I tried to assist him, but no one would come. I then tried to assist him by getting him to sit on his walker and I wheeled him to the toilet. At that point, I was berated by a member of the staff saying I was not to touch any resident because of the insurance liability. I felt quite badly at the circumstance, because I felt that no one would choose to soil himself and to allow him to do so was not to allow him his dignity. (b) I spent 13 days at a nursing home at Twin Waters, shortly after it opened. During that time, whilst I was somewhat mobile, I required a stool in the shower. The first day I found that there was no soap or shower gel in the shower and I did not have anything with which to clean myself. The only thing there was some hand sanitiser on the wash basin but to get it was difficult as I had to get up and walk with difficulty from the shower. I asked every day that I was there for some shower gel or soap and never did get it. (c) The third occasion I spent several weeks at another nursing home in early 2018. Whilst this was not in Fairfax electorate, I was treated with little dignity on two occasions. The first was when my physiotherapist assigned under DVA showed me how to use the exercise bicycle in the gym, so that I could continue my exercise program whilst there. When I went back to the exercise bicycle the next day, I was admonished by a staff member for using it as I was advised that the machines were for the use of the retirement village only. The second occasion was on my day of discharge. I had laundry which had not been returned to me. I didn't know how to get it back, and I did not want to leave it there. I looked for the manager, and discovered that the manager was on leave. I then talked with the assistant manager, who went with me to the laundry to try to identify my laundry. Whilst I was with the assistant manager, I was chastised by a staff member for not filling out a form for the return of my laundry—a process with which I had no familiarity. On each of those three occasions, I felt diminished and treated as less of a person than I felt I should."	
		This following is not a direct quote, but a reflection that staff are often constrained by confidentiality agreements, and	6

NO.	THEME	ISSUE	
		cannot raise issues of neglect with their employers. "The girlfriend of a Fairfax constituent rang her boyfriend in tears after arriving at work to find one of her charges (an elderly man) with blood on his pillowcase. He had a dressing on his head which, according to the chart, had been logged as changed, but quite obviously had not. When the girlfriend checked it, she found an infestation of maggots in the man's wound. She was distraught, as she was quite fond of the old man, and after she had changed the dressing, she went to the management office to complain about his treatment. She threatened to make an outside complaint, and was told that as she had signed a confidentiality agreement when accepting the position, she would be dismissed if she spoke of anything outside the office walls."	

CHAPTER V A PERSONAL CONTRIBUTION

This is a personal contribution from the Federal Member for Fairfax, Ted O'Brien MP

"Last year, my wife Sophia and I stood over our newly born baby boy - Henry – in the hospital as we waiting excitedly for his older sister – Alexandra – to arrive and meet her little brother.

There we stood, mesmerised; marvelling at the miracle of life and how fortunate we were to have this beautiful little child as part of our family.

One of the magnificent midwives who witnessed our unashamed gush of parental pride walked towards us with a knowing smile on her face. She was lovely, as midwives always seem to be. And amidst our small talk, she made some flippant remarks that I've since reflected on deeply while consulting with people about the issues raised in this submission.

While I forget her precise words, she remarked along the lines that "when you're at the other end of life, you're just as vulnerable as you are as a baby - you're all gummy, you can't control your bowels and it's really hard to communicate what you want – but the problem when you're on your way out is that you don't have everyone doting over you like you do on your way in."

She was right! You could argue that her comments were a generalisation or that the same point could be made in more politically correct ways, but I found her remarks profound nevertheless.

I have facilitated public and private discussions on the terms of reference of the Royal Commission and I pass on the key takeaways from those discussions by way of this submission. Given the independent nature of the Royal Commission, it would be inappropriate for me, as a Federal Member of Parliament, to comment directly on the matters being inquired into.

I do, however, wish to make some broad comments that build on the insightful remarks of that lovely midwife with whom my wife and I spoke.

There's no doubt that the world is changing and at a rapid pace. One of those changes is the ageing of the population. This is a global phenomenon and is not limited to Australia. Meanwhile, we're also witnessing a gradual erosion of civil society. The rise of the individual and the welfare state has seen a commensurate weakening of community institutions that have previously filled the void where government or the marketplace have been unable to assist people at times of need.

There is no turning back the clock. However, I believe we have to recognise that responsibility to address the challenges of an ageing population does not lie with one person or one group alone: neither government nor private enterprise have a monopoly on this issue. It's up to every sector of society – government, business and civil society – to find new solutions. Indeed, it is incumbent upon us as a society of fortunate individuals to recognise our duty of care towards our older generations.

The pre-requisite for this is, more than anything, a cultural shift. As the midwife in my earlier anecdote intimated, there is no rational explanation for why we might treat our elderly citizens with less reverence, care and attention than we bestow on helpless newborns. While I don't believe that Australians are inherently disrespectful or negligent towards our senior citizens, there is a great deal more we can expect from ourselves and each other.

Cultural change, however, requires more than government policy or legislative change. It can't be bought with money nor demanded by authority. Rather, there's only one thing that is capable of changing culture: leadership. We need leaders to stand up – not just political and business leaders but also civil leaders. We need school principals, church pastors, sporting club presidents and chairs of local community organisations to see it as their responsibility to change mindsets and behaviours in this regard.

Advocating for cultural change is not a conventional recommendation from a Royal Commission, but I believe it's the single most important determinant of our success as a nation to jointly conquer the challenges of an ageing population.

Beyond this personal reflection, my hope is that the issues raised in this submission, on behalf of the people of Fairfax, are informative to the Royal Commission and helpful to its Inquiry."

APPENDIX – ROYAL COMMISSION TERMS OF REFERENCE

Royal Commission into Aged Care Quality and Safety

Terms of Reference

The Commissioners, Honourable Justice Joseph McGrath and Ms Lynelle Briggs AO, were appointed to be a Commission of inquiry, and required and authorised to inquire into the following matters:

1. the quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response;
2. how best to deliver aged care services to:
    a. people with disabilities residing in aged care facilities, including younger people; and
    b. the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services;
3. the future challenges and opportunities for delivering accessible, affordable and high quality aged care services in Australia, including:
    a. in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and
    b. in remote, rural and regional Australia;
4. what the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe;
5. how to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters;
6. how best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure;
7. any matter reasonably incidental to a matter referred to in paragraphs (a) to (f) or that [the Commissioners] believe is reasonably relevant to the inquiry.

This submission was tabled by
Ted O'Brien MP
on behalf of the electorate of Fairfax

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