Statement of Glenn Eric Rees

Name: Glenn Eric Rees
Date of birth: [REDACTED]
Address: Known to the Royal Commission
Date: 26th April 2019

1. This statement made by me accurately sets out the evidence that I am prepared to give to the Royal Commission into Aged Care Quality and Safety. This statement is true and correct to the best of my knowledge and belief.

2. The views I express in this statement are my own based on my education, training and experience. They are not intended to represent any views of my employer or any specific organisation.

Professional background

3. I am currently Chair of Alzheimer’s Disease International. I have been in this role since 2015.

4. I studied economics at Leeds University in the United Kingdom and worked at senior levels in the British and Australian Public Services. In the UK, I worked as Private Secretary to senior Ministers and in the Cabinet Office and in Economic Departments. In Australia since 1976, I have worked in program and policy areas including Prime Minister and Cabinet, Employment and Training, Aged Care, Disabilities, Housing and the Aboriginal and Torres Strait Islander Commission. I was Chair of the Nursing Homes and Hostels Review in 1986 and was involved in implementing the first wave of aged care reforms to 1993. I was CEO of Alzheimer’s Australia from 2000 to 2015. During this time, the Dementia Initiative: Making Dementia a National Health Priority was implemented in 2004. Important commitments were made to tackle dementia in the 2012 Aged Care reforms and in 2014 to dementia research with $200 million over five years. I am an independent Board Member of Parkinson’s Australia and a member of the National Health and Medical Research Councils Consumer Advisory Committee.

Background

5. Australia can be proud of taking a leadership role internationally in implementing the Dementia Initiative with additional funding of $330 million over 5 years in 2004 and sustaining a bipartisan commitment to that policy. This has been built on subsequently in Living Longer Living Better in 2012 and additional funding for dementia research of $200 million in 2014. The approach to advocacy on dementia by Alzheimer’s Australia (and
now Dementia Australia) has been followed by many countries. Australia has played a leading role in Alzheimer's Disease International, including in the Asia Pacific region.

6. In May 2017 the members of the World Health Organisation, including Australia, unanimously adopted the Global Dementia Action Plan 2017-2025 which identifies seven priority areas for action and with specific targets to be achieved. To date there are some 30 countries with plans, and many are in the course of development.

7. There are two aspects of Australia's approach which need to be addressed.

8. First, it has been difficult over a long period to get interaction between the aged care and the health parts of the Department of Health. This is critical because good dementia care depends not just on aged care services but primary care, acute care, mental health services and the NDIS (for younger people with dementia). For several years, a Ministerial Dementia Advisory Committee involving the Minister, people with dementia, carers, researchers and Alzheimer's Australia played this role by meeting with all parts of the Commonwealth Department from time to time. It discussed the range of issues on dementia, conducted expert meetings (e.g. on primary care and dementia) and resulted in several important initiatives including work by the Australian Commission on Safety and Quality in Health Care on the quality of dementia care within the hospital system. Unfortunately, the Ministerial Dementia Advisory Committee was disbanded in 2014 and as a result, progress in relation to dementia and health policy has lost its focus.

9. Second, while Australia has made dementia a national health priority and increased funding for dementia programs and research, it has done so without planning and measurement of outcomes. The National Framework for Action on Dementia 2015-19 addresses the key priority areas but has no stated outcomes beyond general statements in respect for example of diagnosis, access to special dementia care or specialist dementia respite services. This framework also lacks specific funding to achieve outcomes. As a result, outcomes against this framework are difficult to measure. If we are to achieve the changes required, this Framework must be outcomes focused and include an evaluation framework.

10. The third Dementia Plan of Korea for example contains an evaluation of the previous plan, has four clear objectives, actions, a budget and KPIs.

11. Aged care policy has been dominated by residential care and its funding, yet quality and safety issues endure. Despite what has been argued by the industry (perhaps rightly) to be an excess of regulation, it may have succeeded only in weeding out the worst residential care providers and little more. It has done little to drive or reward the quality care that older Australians deserve. Much depends on the Aged Care Quality and Safety Commission (ACQSC).

12. The good providers have got on with the job of embracing person-centred care, listening and responding to the needs of residents and their families, providing high-quality and meaningful training opportunities for staff and addressing the causes of behavioural and psychological symptoms rather than relying on medical and physical restraint. Others
have done the bare minimum and attracted criticism. It has been left by the industry to
the media to throw a national spotlight on quality issues in residential care.

13. The focus on residential care has arguably been to the detriment of other issues
important to people with dementia. There are many, but I would prioritise two.

14. First, the need for a timely diagnosis and post diagnostic support. This means
strengthening primary care, making better use of nurses in diagnostic assessment, and
making more effective use of specialists. It also must include supporting families to
understand the needs of people with dementia, including planning and documenting
peoples wishes, how to adapt physical and social environments for people with
dementia, and the role of unmet needs in some of the symptoms and behaviours
experienced by the person with dementia. It the journey with dementia does not start
well, and the person with dementia and family members are not armed with good
information, it is unlikely to end well. I suggest the adoption of a one-year post diagnosis
guarantee of support for the individual with dementia and their informal care partner to
receive information on dementia, information on things they can do to manage living with
dementia (i.e. exercise, memory aids, strategies to maintain domestic and leisure
activities), plan their care and finances and access support and care if needed.

15. Second, a higher priority needs to be given to reform of care at home and of respite
care. About 70 per cent of people with dementia live in the community and may do so for
many years. The current wait-times for home care packages are unreasonable and lead
to people not being able to access the care they need. This creates extreme stress for
family members and may lead to placement in residential aged care earlier than planned
or needed.

16. The issue is bigger than integrating the CHSP and Home Care Packages. The question
to be asked is why we do not consider having a single disability scheme which provides
support to people with disabilities regardless of age as a long-term objective even if the
budget and administrative implications are great? If we are to achieve a truly equitable
system which supports the human rights of people with disabilities regardless of age a
single system would be the goal. (see paragraphs 44-48).

17. In respect of quality dementia care, services of primary importance are a better
understanding of dementia, commitment to person centred care and relational care,
strong leadership and management, a positive emotional environment, a dementia-
friendly physical environment, commitment to competency-based training, a commitment
to specialist dementia units or services for those with complex issues and lastly outcome
based indicators of quality of care and life. These issues have been advocated by
Dementia Australia for most of this century.\textsuperscript{iv,v}\textsuperscript{vi}

18. An interesting study has categorised residential service providers in to organisational
(those focussing on the basics of clinical care and safety), consumer directed (those
who focus on marketability e.g. good design, activities) and relationship centred quality.
\textsuperscript{vi} The distinction between person centred care and relational care is subtle but important
in the stress on engagement and communication which is central to social support and
reducing the social isolation experienced by people with dementia. At end stage
dementia care for example reminiscence, verbal communication strategies, and non-verbal communication strategies will be important. viii

19. Mandated minimum levels of training of the workforce is required, but to be effective needs strong industry leadership from the top. The culture of a care facility is as important as the training that the staff receive. A more flexible and values-based aged care system may help responsiveness to the needs of special groups, but it will not be enough – for example, there is a need to consider the role of Aboriginal controlled health services or ethnic services, strategies to address the special needs of LGBTI and the needs of those in rural areas.

Delivery of aged care

Key care needs of people living with dementia

20. The word care needs to be understood as embracing the social, physical and cognitive demands of the support and care needs of a person with dementia. Dementia, like any form of disability, is both a social and medical issue. Those diagnosed may be at an early stage of dementia and for people in this situation they may have many years of life in the community.

21. Although life will never be the same, people living with dementia have the same need for “purpose in life” as we all do. For those diagnosed later in the progression of dementia, there may be a need for more immediate access to services. The needs of the individual will vary greatly by their age, by the cause of their dementia and the extent to which their care is complicated by BPSD (see paragraph 52-56).

22. Alzheimer’s disease is the prototypical dementia, so people with less common forms of dementia and less typical symptoms are not as well understood/cared for. People with Frontal Temporal Dementia (FTD) and Lewy Body might need different types of support. For instance, someone with FTD might have communication difficulties but their cognition may not be as affected. But without staff that have the skills and time to understand them, they are increasingly isolated and frustrated.

23. So, flexibility of response is the key throughout the journey with dementia, starting with post-diagnostic support which is variable and too often non-existent. People with dementia are all too often de-valued post diagnosis by lack of support, rehabilitation and assistance of a kind available to those with other chronic conditions such as heart disease and cancer. This adds to the stigma already present in our society and can also affect the capacity to maximise levels of physical and cognitive functioning.

24. If the journey with dementia starts out badly, it is all too likely to finish badly. A guarantee of post-diagnostic support would help the person with dementia and the informal carer to:
   a. Get information about dementia and adjust to their diagnosis.
   b. Plan support, care, interests and relationships and finances drawing on family and local groups and services.
c. Access services, particularly if diagnosed late.

d. Identify ways in which the person can develop strategies to manage the symptoms of dementia whether this is helping with disabilities, behaviour and mood, or their changed relationships with others.

e. Provide support on how to adapt physical and social environments to support ways in which the person with dementia can continue to have a quality of life in terms of their interests and relationships.

f. Have a continuing point of contact.

25. Such an approach, which has been adopted in Scotland, would respond to the human rights of a person with dementia and their informal carer to support and empower the person with dementia. Currently in Scotland about 46 per cent of those diagnosed with dementia are offered post diagnostic support through Alzheimer’s Scotland and other agencies. It might be of especial assistance to a person with dementia who has no informal carer. In the Netherlands and UK there are approaches to assisting the individual adjust to dementia. Good post diagnostic care may help contribute to reducing the fear of a diagnosis because there would be the assurance of support post diagnosis and an opportunity to develop a reablement approach to dementia support. Discussion of services might encourage carers to access support and reduce carer “guilt”. The staffing, location and funding of a guarantee can be based on existing experience in Australia and overseas. This would give the aged care system the human face which My Aged Care lacks and place an emphasis on a recovery type of approach.

26. The rights of people with Dementia are protected by the UN Convention on the Rights of Persons with a Disability. Often the adjustments which may be made for a person with a disability are not always considered for a person with dementia. It is essential that people with dementia have a strong voice in the design of dementia services, supports and policy.

Challenges in the delivery of care services for people living with dementia

27. The challenges are great in the community and in residential care. People in the community have a need to get on with their lives and need help from their families, the community and governments whether national, state or local. Services need to be flexible and respond to the individual needs of the person with dementia and their informal carers. The coordination of those services is often very difficult for the individual and their informal carer.

28. There are multiple strategies to improve co-ordination. Assessment services could take on a stronger role, as could memory clinics where they exist. Case managers may be necessary to achieve collaboration in more complex cases. In less complex cases, an identified support worker post-diagnosis, or at other times, may assist in access to services or providing information on services.

29. Placement in residential care is an acknowledgement that for whatever reason life in the community is no longer possible, so the challenge is both to provide the care and other
support necessary to give meaning to life through social interaction, meaningful engagement and decision making over the daily activities of life. Access to allied health services is a critical part of meeting those challenges if reablement approaches to maintain, restore or improve function are to become a reality.

30. There also need to be innovative approaches to improving the experience of ‘institutionalisation’. Some facilities have cottage style set-ups with almost a small-group home approach. This allows a more ‘normal’ home like environment and routine with residents being involved in cooking, enjoying activities like gardening. It also promotes a more relationship-focused style of care and support from staff.

31. The biggest challenge for those delivering services whether social or care for the individual with dementia is respect, acknowledgement of their uniqueness as a person and building on their cognitive capacities to the extent possible.

32. The general view is that the majority of people with dementia who require residential care should be cared for in mainstream facilities assuming appropriate dementia training of staff and an appropriate environment rather than specialist units. (see paragraphs 52-57)

Substandard and/or differing levels of care

33. A key question for the policy maker is why some residential care providers provide good care and so many do not with much the same resources? Why do some have a well thought out strategy for reducing the use of medical and physical restraints to a minimum and others use restraints as a first resort when that is contrary to best practice prescribing guidelines? The characteristics of the good provider include strong leadership, a positive organisational culture of respect and commitment to person-centred/relationship-based care, and a good understanding of dementia care informed by a real empathy for the person living with dementia. They will also have a commitment to not only minimum standards of training, but appropriate ongoing training of staff and support of staff through coaching and mentoring which ensures the application of the learnings. Having dementia practice leaders can also be key to ensuring the effective ongoing application of good dementia practice.

34. So, from a policy perspective the priority is to maximise the use of existing resources as exemplified by those providers identified as providing a high quality of care. The second is to look at the adequacy of funding to ensure that, based upon the assessed needs of residents, there are staff with the necessary mix of knowledge and skills. There is a risk in allowing for-profit providers to determine an appropriate level of staffing to be able to provide quality care, as they have an incentive to reduce costs. At the same time, mandating staffing ratios reduces the ability for organisations to develop flexible, innovative models of care. The approach should be one of transparency. People with dementia and their informal carers should have easy access to information about staffing and skills mix at aged care facilities. The third to determine where incentives are needed in respect of dementia care.

35. A strategy for reform needs to embrace issues such as:
a. understanding about dementia by staff, and in the broader community
b. staffing levels and skill mix
c. staff training
d. the effectiveness of the current quality and safety regime
e. funding
f. interfaces between the aged care and health systems

36. The interfaces between aged care and health systems (primary, acute, mental) are problematic in three ways. First, within the Department of Health dementia is regarded as the responsibility of the aged care division. It is a positive that there is one place in a complex department that stakeholders can go to and which over a long period has been “dementia friendly”. But there needs to be a commitment from the top of the department to co-ordinating action on dementia across health systems. In the past, a Ministerial Dementia Advisory Committee has played this role effectively and should again be put in place.

37. Second, in the community the problems which residential care providers and their residents have in respect of access to doctors and mental health support are of long-standing concern. This has the consequence of often inappropriate admissions to hospitals which can have adverse outcomes for people with dementia.

38. Third, for the consumer in transiting between different services (e.g. residential and hospital care) and co-ordination of service delivery in more complex cases.

Differences and similarities of key systemic contributors to substandard care in residential aged care settings and in-home care settings

39. There are three related common factors. First, lack of respect for the person with dementia, their choices and ability to express these and willingness to partner with the informal carer. Second, lack of commitment to person centred care and relational care. Third, lack of sound leadership which promotes the above not just with the person living with dementia but with staff as well. Within this context training can fail to be introduced and applied in a regular, consistent way.

40. Residential care is more problematic because the older person is likely to be resentful about being placed in care and risks becoming isolated and fearful and vulnerable to poor care.

The Australian aged care system

Australia's current policy approach to dementia care

41. The funding of dementia since the Dementia Initiative in 2004, Living Longer Living Better in 2012 and the additional funding for research in 2014 represent significant policy change, but there is no good evidence on what it has meant in terms of quality of care. The funding has attracted service providers and researchers to dementia. The
principle of incentives in-home care packages and residential care are important, and their adequacy should be reviewed. Important because we need reform of two kinds:

a. systemic reform which gives a reality to the claim that dementia is core health and aged care business

b. specialist programs (e.g. awareness, planned dementia respite, care for those with severe to extreme behaviours, education for informal carers on psycho-social approaches, dementia risk reduction, end of life care) that recognise that dementia care presents special issues and additional costs.

42. An important barrier to improving on what has been achieved is lack of planning and defined outcomes and evaluation. The National Framework says all the right things. But what commitment is there from government to achieving outcomes in respect of proposed actions? For example, does the government want to make sure that everyone with dementia gets diagnosed? What is the funding commitment to providing care in special units or access to special services for the 10 per cent those with the severe to extreme Behavioural Psychological Symptoms of Dementia in the Brodaty triangle? Progress against the framework is usually provided as a listing of current Federal and State dementia programs to support people living with dementia, but there is a lack of planning to drive real change.

43. Program structures and lack of flexibility are a barrier from the perspective of people with dementia, their informal carers and service providers. Two issues are of particular importance, if the objective of enabling people with dementia to stay at home longer is to be a reality are the integration of care at home and respite.

44. First, the integration of the Commonwealth Home Support Program (CHSP) and Home Care reports. The summary consultation report concludes there is agreement on broad objectives but differing views on many issues including how to tackle differing user charges policies, assessment processes and the need for block funding. What is surprising to the outside observer is the absence of references in the summary document of the consultations or submissions to the human rights of older people. How different the approach to integration might be if driven by disability advocates.

45. The key question for the policy maker is how can it be right to have a situation where the access to care and support for someone aged 64 years is different in principle, funding and flexibility in NDIS from that of someone aged 66 years in aged care? It seems that aged care continues to be driven by the consensus politics of the National Aged Care Alliance and administrative convenience rather than starting from a human rights approach. A sensible starting point is to contrast the assistance available to older people through NDIS and aged care as the Evaluation of NDIS has done and become more aware of the inequities that exist and the lessons learnt from NDIS.

46. The fundamental change of the NDIS is that it provides choice and control to the individual with a disability. After an initial eligibility assessment, it is about the person with a disability working with NDIS planners to identify their goals and reasonable support needs and then receiving a plan which identifies clear goals and provides the
appropriate level of funding for those goals. The person with a disability then can make choices about how they achieve those goals (including self-management) and can make choices (greater flexibility than aged care) about who provides services, where they receive them and when they get them. The focus on supporting people to engage with the community contrasts with the current situation in aged care. Let's assess what has been learnt from a consumer perspective from the NDIS that would help aged care services be more client driven and achieve the flexibility needed to respond to the needs of the individual.

47. The conclusion of the NDIS Evaluation on older people and disability is important:

"Overall, the systems which fund and provide supports to older people with disability are going through a period of change and uncertainty. While the NDIS is presenting modest improvements and some optimism, the big picture remains uncertain and precarious for some of the most vulnerable older Australians. Currently there is considerable variation in the funding and provision of supports to older people with disability across the different funding schemes. In order to address this inequity, a single funding scheme which provided funding and supports to all people with disability regardless of their age was recommended." xv

48. The time has passed for inflexible packages which were an administrative artifice to assist bureaucrats (it was my idea) move funds from an excess of hostel care places to community-based care in the late 1980s. Regardless of age, people with a disability (including dementia) deserve to receive the funding that they need for the support they require.

49. Second, the provision of respite is currently supported through a plurality of programs (residential care, home care packages and the Commonwealth Home Support Program). As a result, substantially different arrangements apply for respite services, including with regard to funding, eligibility and assessment arrangements and consumer contributions, depending under which program individuals are accessed, notwithstanding that similar policy objectives apply across all types of respite services.xvi

50. I have a concern that in the process of integration, respite will be lost sight of and continue to be acknowledged as a problem to be sorted out. The important commitment to strengthening respite in Living Longer Living Better should again be a priority. The greater problem I believe is for those with higher dementia care needs as reports suggest residential care providers find respite problematic in the level of subsidy available and the management demands it makes.

51. Resolving this issue for people with dementia and their informal carers is critical – it is the service informal carers of people with dementia give high priority.xvii The starting point is to recognise two different but related objectives in residential respite that may require different funding. First, planned respite in regular blocks designed to give the carer a break and the person with dementia an interest and social interaction. Second, respite as a transition to residential care. Residential care providers seem to manage the second as it plays to their long-term care focus and fills vacant beds. Providers may struggle with the first with current funding as it creates greater demands in responding to...
the needs of different individuals for time limited periods. Individuals accessing planned respite care would be required to opt out of their individualised package for the time they are in planned respite care.

Dementia care as “core business” and incentivisation of good practice dementia care

52. The vast majority of individuals with dementia who are entering residential aged care (over 90%) receive mainstream aged care services and they make up the majority of total aged care residents (63%).

53. For the majority of residents with dementia, there is no need to separate them from individuals who do not have cognitive impairment in dementia specific care. The elements of good care include:
   a. Accurate and detailed ongoing assessment for development of tailored care plan
   b. Staff selection, initial induction of staff and ongoing training and education
   c. Individualised, flexible care
   d. Access to timely specialised services (i.e. continence, dental, speech, occupational therapists, and psychogeriatric services)
   e. Appropriate and engaging activities
   f. Physical environments that are based on dementia friendly environment principles

54. The care of individuals with dementia is often complicated by the Behavioural and Psychological Symptoms of Dementia (BPSD). These symptoms can include agitation, depression, psychosis, lack of inhibition and aggression. Individuals with dementia will have different levels of BPSD at different points in the disease, with some people progressing from no BPSD to severe BPSD in later stages of disease. In many cases BPSD is a sign of unmet physical, social or environmental needs. Often these symptoms can be reduced or eliminated once the unmet needs are identified and addressed. For example, this includes addressing pain that a person might be experiencing, loneliness, boredom, or other similar needs.

55. According to the Brodaty triangle, 40% of individuals with dementia in the community may have no BPSD, 30% are estimated to have mild BPSD and 20% moderate BPSD. Individuals with mild to moderate BPSD can usually be cared for in the community or in main stream residential care facilities. Psychosocial interventions may be used to minimise the frequency and severity of BPSD in these individuals.

56. The remaining 10% of individuals with dementia have severe to extreme BPSD. This group is likely to require more specialised, intensive care and may benefit from a specialist multidisciplinary team, or care in a psychogeriatric unit. These individuals,
often younger may have difficulty getting placed in mainstream services due to their high care needs and concerns about the disruption of other residents.

57. The quality and number of special places and whether, and if so how, they differ from mainstream is uncertain. The three-tiered approach to strengthening dementia care reported in Background Paper 1 of the Commission includes strengthening mainstream residential providers through DBMAS, Severe Behaviour Response Teams and Specialist Dementia Care program. I am not able to judge whether the first two of these initiatives have resulted in a strengthening of the residential aged care sector and there is no sense of urgency. There seems to be continuing dispute over the need for units as opposed to access to specialist services. This suggests that the priority to providing access to residential care for this high-needs group is to identify current providers who provide such care and to pay an additional payment to expand their service. The need for such a payment was recognised in Living Longer Living Better.

58. In community-based programs there is an incentive in home care packages to cover the higher costs of dementia care, another priority recognised in Living Longer Living Better. But there is a gap in respite care for those with higher care needs. (see paragraphs 49-51).

59. The objective of making dementia core business in the health and aged care system is supported, but only if it is accepted that mainstream services are made "dementia friendly" and that specialist services will be needed in primary health care, hospitals and mental health as well as aged care.

60. Hospitals too are a problematic area. Nearly half of those with dementia in NSW hospitals did not have their dementia recorded as a diagnosis, stayed longer in hospitals on average and were more likely to be discharged to residential care. There are strategies in Australia and internationally that can improve outcomes and reduce costs. The commitment of the Australian Health and Safety Commission to integrating cognitive impairment within the National Health Safety and Quality Health Standards, monitoring those standards and providing guidance on action to take to clinicians, health service managers and consumers on care of people with cognitive impairment holds some hope of progress system wide in hospitals.

The role of the market in driving improvement for safe, quality dementia care, and limitations of this

61. I have been a strong advocate of consumer-directed care (CDC) since 2000 and I am broadly happy with policy developments. I have seen CDC as a means of achieving a more equal relationship between the person with dementia and their informal provider and care providers in accessing information and fully understanding their care options than a belief in an aged care market.

62. Competition has in my view only a small part to play in respect of aged care services where many are disadvantaged, may have cognitive problems and information is inadequate. For the market to have a larger role, there is a critical need for better access to information for consumers. At the moment choice of residential aged care facility is
often down to location, or availability rather than an understanding of the difference in the quality of services available at different facilities. Providing information to consumers also serves another important role, it provides an opportunity to highlight good practice, and also to shine the light on facilities that are meeting the minimum criteria to stay open but are not providing high quality care.

63. The US system of providing extensive public information on 16 different quality indicators, as well as star ratings on staffing, health inspections and quality provide a greater opportunity for consumers to utilise good information in their decisions. Importantly, it also provides an opportunity to drive improvement, as providers will want to achieve higher ratings to attract consumers.

64. Similarly, in the UK each facility is rating against five criteria: is it safe, is it effective, is it responsive, it is caring and is it well led, as well as an overall rating for the facility. Ratings against these criteria have been found to be highly correlated with measurement of resident’s quality of life.

65. Ratings should be part of the mix in Australia as they may help contribute to a better understanding of what quality care looks like, may change the behaviour of providers and assist consumers make choices. An important consideration is whether the disclosure provisions in the Aged Care Act 1997 have the balance right between protecting providers reputations and providing important information in a timely way to consumers about poor care.


Barriers dementia-centred advocacy groups face in representing and providing services to people living with dementia

66. The advances in making dementia a health priority suggests successive governments have been responsive this century. But funding for advocacy is difficult to access – governments do not want criticism and donors like to see services or buildings. At the same time, Government depends on advocacy organisations to provide expert advice, submissions and information on Government policy development. In my day as CEO of Alzheimer’s Australia our work would not have been possible without support from the community grants for administration and advocacy available to peak bodies from the Commonwealth Government.

67. The National Dementia Support Program administered by Dementia Australia has played an important part in promoting awareness of dementia, training and innovation. It enabled the organisation to develop the first dementia training competencies in Australia, deliver memory loss programs and dementia friendly projects on a national and consistent basis.

68. The lack of transparency in funding is a problem. Post the Living Longer Living Better aged care reforms and the change of Government, it was near to impossible to know what commitment was being made to implementation of the dementia element of the reforms. Some of the key priorities in respect of monitoring the quality of care are only now on the point of delivery.
69. Advocacy groups themselves have a responsibility to be inclusive of people with dementia and their informal carers and to promote self-advocacy as Dementia Australia has sought to do over many years. A welcome development is the establishment of Dementia Alliance International which has strong roots in Australia and has a membership only of people with dementia. The need for this Royal Commission suggests the Minister and Department need to do more to support grass roots feedback on the quality of care and life of older Australians from advocacy organisations, human rights organisations and community visitors that supplements advice from the peak organisations and National Aged Care Alliance.

**Improving the quality and safety of aged care services**

*Recommendations for improving the quality and safety of the care provided to people living with dementia in residential aged care*

70. The problem starts with government. There have only been two ministers for aged care in Cabinet since 1985 which says something about political priorities and in both cases major reform resulted. Dementia after centuries of neglect requires sustained and strong political leadership to get on the health and aged map. This has been well demonstrated by countries overseas and in Australia by the aged care reforms of the then Minister for Community Services Don Grimes in 1986, by the Dementia Initiative introduced in 2004 by John Howard's Government, by Living Longer Living Better by Mark Butler as Minister for Mental Health and Ageing and by the $200 million committed for dementia research by Tony Abbott when Opposition Leader.

71. The implementation of the recommendations made by the Review of Home and Hostel Review which I Chaired in 1985 in respect of multi-disciplinary aged care assessment teams, care standards, complaints mechanisms, innovative funding pool for dementia care and a new residential aged care funding mechanism and adoption of an aged care places funding ratio would not have been possible but for a government commitment to an eight year plan for implementation and a Department of Health which had policy competence.

72. The political power of the residential care sector has been significant. It has been the ABC over the years that has thrown the spotlight on the shameful quality of care of some residential care providers. Alzheimer's Australia documented in a consultation process 2011 the poor quality of dementia care, which contributed in part to the focus on dementia in the Living Longer Living Better Aged care reforms. In 2013 and 2014 Alzheimer's Australia released publications raising concerns about the quality of residential care and in particular the use of physical and medical restraints and suggested partnership with key industry bodies to work together. The industry response at various times was defensive - a few bad apples and the fault of doctors overprescribing. There were discussions with the Department and the Minister and experts, but nothing resulted.

73. Ministers and public servants need to hear the voice directly of people with dementia and carers and dementia experts. The Ministerial Dementia Advisory Committee proved an effective way of service providers, clinicians, service providers and Alzheimer's
Australia coming together with the Minister to share problems and solutions in respect of dementia care and in bringing the health and aged care parts of the Health and Ageing Department together.

74. It is progress that the new Aged Care Quality and Safety Commission is in place and new care standards adopted. But the warning signs are that it has taken over 10 years and three reports to get some progress. It may be hard to shake that mentality of 'if I do x actions, then I will pass accreditation' rather than 'if I achieve these outcomes, or am working towards these outcomes, then I will pass accreditation'.

75. The quality indicators under consideration are three clinical indicators - pressure injuries, use of physical restraint and unplanned weight loss. These are important, but a commitment to quality of life and social issues is necessary too - e.g. rates of antipsychotic prescriptions, changes in symptoms of depression/anxiety after entering care facility, staff turn-over and satisfaction, changes in behavioural symptoms of dementia, rates of involvement in meaningful social activities, consumer experience surveys.

76. The Government's most recent response to the antipsychotic issue is to issue guidelines which seem to fall far short of the recommendations made by the Australian Commission on Safety and Quality in Health Care (ACSQHC). The ACSQHC reports that around 1 in 5 people in residential care are receiving at least one antipsychotic medication and that only 1 in 5 receiving them benefit. There is a need for something to shake up the core of the system. The canary in the cage in the context of dementia is the excessive use of anti-psychotics, the variation in usage between residential facilities and the failure to get the consent of the consumer. So, an outcome indicator of say more than 15 per cent of residents using these medications would be a start in focussing the attention of ACSQHC on facilities that could improve their care.

77. There are of course issues around facilities that have a different resident profile and not wanting to create disincentives for facilities to take on residents who may have high behavioural and psychological symptoms of dementia and pre-existing prescriptions of antipsychotics. An alternative approach could be to look at the care being received by residents who have antipsychotics prescribed. (e.g. how often is the higher use of these prescriptions reviewed, what % are having reduction in antipsychotic prescription over time, have the appropriate consents been obtained).

Redesigning the current system to incentivise quality and safe care for people living with dementia in residential aged care

78. It seems that those providers committed to a good quality of care based on person-centred and relational care will do it anyway. It is important to have a system that is trusted by consumers, government and providers and reflects costs. Cultural change which seems to be the source of many of the problems in aged care may be best driven by respecting the rights of older people and enabling them to take decisions to the maximum extent possible, by strengthening grass roots advocacy and by more active use of community visitor schemes. The strategies include:
a. A new funding model: some of the features of the proposal now the subject of consultation based on the Resource Utilisation and Classification Study may cause it to have a better fate than its predecessors over the last thirty years. These features include independent assessment for funding, case-mix based on identified cost drivers and an explicit incentive for high quality services to focus on restorative care and re-ablement. The initial entry payment proposed would assist people with dementia who will find their new surroundings especially confusing. A case mix classification which recognises the costs of those people with dementia who are physically strong and mobile would be another positive. The trigger for re-assessment should include dementia.

b. Incentive payment: to providers targeted as able to care for those with severe to extreme dementia.

c. The introduction of ratings and indicators: to provide an incentive to providers to gain an edge on competitors and enable consumers to make choices.

d. Regulation through ACQSC: to achieve improvement in the basic level of care through approval processes, prompt action on poor care and access to resources and education.

e. Consumer experience surveys: to determine the extent to which residential care services are delivering fulfilled and meaningful lives for the residents.

f. Practical assistance: compulsory design audits and drawing on the extensive body of knowledge on good design for dementia in Australia.

g. Practical interventions: funded by government to handle difficult situations e.g. DBMAS

Integrating international best practice into the Australian aged care sector

The Organisation Economic Cooperation and Development (OECD) report 'Care Needed: Improving the lives of people with dementia' provides a comprehensive source of information on dementia care in high income countries while acknowledging that the evidence base for policy is sadly lacking. Given the differences in culture, funding mechanisms and health and care systems it would be preferable in my view to focus on the priorities and strategies being adopted across high income countries. My interpretation of the report is that Australia should prioritise:

a. Achieving higher rates of diagnosis and implementing systemic post diagnostic care.

b. Continue a priority for an expansion of community-based care – Australia has after Belgium the highest rates of institutionalised care among countries in the OECD (at about double the average rate) after over 30 years of a bipartisan policy based on the objective of enabling people in their homes longer.
c. Carer programs that adequately focus on the needs of those caring for people with dementia and tailoring respite care to the needs of those with moderate to high dementia care needs.

d. Access to dementia friendly small-scale homes for people with dementia care—we have the experts and know what to do in Australia. And recognise the needs of those with special needs in special units or access to special services.

e. Prioritise training and pay and conditions in a workforce strategy that has substance.

80. On quality, the OECD report concludes that “New data collected for this report confirm that the quality of care for people with advanced dementia remains in many cases poor. Despite widespread clinical agreement that antipsychotic medications should not be used to manage most difficult behaviour in dementia, rates of antipsychotic prescribing vary by a factor of more than two across the OECD.”

The Context

Stigma and promoting a better understanding of dementia, its symptoms and how to care for people living with dementia in Australia

81. The evidence in respect of stigma in Australia and world-wide is overwhelming xxxi xxxvii xxxix Those diagnosed will frequently say that the first consequence was loss of friends and family and self-respect. There are key strategies to overcome stigma:

a. Continuing support for the public provision of information through the My Aged care site and by Dementia Australia and Carers Australia.

b. The inclusion of dementia in education for health professionals.

c. Increased funding for dementia friendly initiatives

d. Recognition of the Human Rights of people with dementia through the Convention on the Rights of People with disabilities

e. Evidenced policy based on the means of reducing dementia. x1

82. Dementia friendly projects have the power to change the way dementia is thought about. It represents a shift in thinking from a focus on meeting the physical and health needs of the person with dementia to a holistic approach supporting the person to achieve the best quality of life reasonably possible. There are two objectives.

i. To reduce stigma by greater awareness of dementia

ii. To be inclusive of people with dementia by recognising their rights and capabilities so that they feel respected.

83. The concept of ‘dementia friendly’ has taken off around the world xxx and has captured the imagination of communities, policy makers and researchers. It is a social movement rather than a program and has the potential to give practical expression to protecting the
rights of people with dementia and fostering their participation in the community. Dementia friendly projects can be given practical expression in many ways:

a. **Through social support**: for example, memory cafes where people with dementia meet often with family carers and the wider community; volunteer programs in community gardens; activity programs to enable the person to continue their interests.

b. **Greater public awareness**: this approach is exemplified by the dementia friends' programs in Japan (over a million dementia friends) and the United Kingdom which provide basic dementia awareness training in the community.

c. **Inclusive communities**: for example, setting up an alliance in the community involving local government, people with dementia and their families, health services with a view to identifying ways in which the community could be made more inclusive.

d. **Better quality health and dementia services**: increasing capacity of the workforce to be dementia friendly through training and identification of staff in health services such as hospitals as dementia friends.

e. **Improving the physical environment**: whether in private homes or residential facilities, public spaces or government buildings.

84. While the movement should be driven by people with dementia and the community, to be sustainable it needs government support to support dementia friends approaches and inclusive communities, primarily in the form of project officers.

85. Dementia is included within the Convention on the Rights of Persons with Disabilities and the rights of people with dementia should be part of the monitoring processes in Australia. As a first step advocacy organisations in Australia and self-advocates should be invited to take part in monitoring and to be a part of the annual Convention of State Parties.

86. We may not be able to cure dementia but we can help people getting it in the first place. Even a five or ten year delay would have a massive global impact. The Lancet report that came out last year suggested that at least a third of Alzheimer's disease related to factors that could be influenced. Action is needed to encourage individuals to reduce their risk and governments to include dementia alongside other chronic diseases such as heart, diabetes and obesity which share similar risk factors. This is the positive message that can reverse the fatalistic attitude to dementia over the centuries. It can be embraced in awareness as in Dementia Australia's Your Brain Matters program and which should be supported by government.

87. Funding for YBM ceased at the last change of government. Risk reduction programs are essential to delaying the onset of dementia. If we could delay the onset of dementia by five years millions of people would die from other causes and not develop dementia significantly reducing the cost to the economy. The evidence is compelling that the principles of a program such as Your Brain Matters could achieve this.
The role of education and dementia-specific mandatory training

88. There should be minimum standards of dementia education required of anyone working in residential and community aged care. The key elements of this training are covered in the current unit of competency CHCAGEOOS:
   a. An understanding of dementia and an empathy for the person living with dementia.
   b. Support for effective communication
   c. Achieving purposeful engagement
   d. Applying a problem-solving approach to behaviour

89. In addition to this there needs to be a clear focus on ensuring workers have the right values and attitudes to support good practice through initial recruitment. Access to ongoing training needs to support this foundational training so that other areas like palliative care and responding effectively to pain can also be addressed.

90. Having strong leadership which promotes a learning culture is key to supporting the application of this training. As part of this the training the ongoing support of practice leaders at the care level who can coach, and mentor staff will assist the effective translation of knowledge.

91. There are also registration considerations given that for the majority of the aged care workforce there are no registration requirements. This needs to be a key consideration together with the overall remuneration rates and conditions of employment given the responsibilities of the positions and concerns about safety.

92. For direct care staff in special units or response teams there will be additional requirements in respect of training and ongoing supervision and support which should build on the foundational level outlined above. Work on creating clear career pathways for people to become dementia specialists needs to be a key part of this approach with providers recognising their role in supporting such practice leadership. There are existing specialist dementia Certificate and Degree courses which could form part of this accredited pathway.

Signed: 

Date: 28th April 2019

Witness: 

Date: 25th April 2019

https://www.alz.co.uk/dementia-plans Plans of countries around the world are listed here
STATEMENT OF GLENN ERIC REES CONTINUED


http://theses.lse.ac.uk/3772/1/Trigg_improving-the-quality-of-residential.pdf section 3.1

Theresa A Allison, Rafael T Balbino, Kenneth E Covinsky, Caring community and relationship centred care on an end-stage dementia special care unit, Age and Ageing, afz030, https://doi.org/10.1093/ageing/afz030


Ibid


Ibid.


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https://www.researchgate.net/publication/327866642_Regulator_Quality_Ratings_and_Care_Home_Resident_Quality_of_Life


