Statement of Professor Henry Brodaty

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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 employed as a Professor at University of New South Wales. I have been in this role since 1990. I have over 30 years' experience as a psychogeriatrician and almost 50 years as a doctor. I have qualifications as a doctor (MB BS, U Syd, 1970), physician (Fellow of the Royal Australasian College of Physicians or FRACP, 1973), psychiatrist (Fellow of the Royal Australian and New Zealand College of Psychiatrists or FRANZCP, 1977) and academic (MD, UNSW 1985; DSc, UNSW 2006; Fellow of Australian Academy of Health and Medical Sciences or FAHMS, 2015).

4. Prior to working at UNSW I worked for South East Sydney Area Health Service at Prince of Wales and Prince Henry Hospitals as a psychiatrist, psychiatric superintendent, Aged Care Psychiatry Director and senior staff specialist.

5. In 1982, I became the Foundation President for the NSW Australia Alzheimer's Association until 1984 and again from 1988 to 1990. From 1988-1991 I was President of Alzheimer's Australia nationally. From 2002-2005, I was the Chairman of Alzheimer's Disease International and continue as one of its Honorary Vice-Presidents.

6. Among other awards, in 2013, I received a lifetime award from Alzheimer's Australia for a lifetime of leadership, clinical excellence and research dedicated to improving the quality of life and care of people living with dementia, and in 2016 I received the Ryman Prize, an annual award for the world's best discovery, advance or achievement that enhances quality of life for older people.

[Signature]  [Witness]
Quality of care

Person-centred care

7. Person-centred care (PCC) is based on the principles of Tom Kitwood which in essence state that the person's preferences and needs should have priority. In other words, person-centred care aims to provide care for the person not prioritise the task or the organisation.

8. The National Institute for Clinical Excellence in the UK summarised PCC as follows:

"The principles of person-centred care underpin good practice in dementia care, and they are reflected in the recommendations. These principles assert:

a. the human value of people living with dementia (regardless of age or cognitive impairment) and their families and carers
b. the individuality of people living with dementia, and how their personality and life experiences influence their response to dementia
c. the importance of the person's perspective
d. the importance of relationships and interactions with others to the person living with dementia, and their potential for promoting wellbeing.
e. Finally, the principles emphasise the importance of taking account of the needs of carers (whether they are family and friends or paid care-workers) and supporting and enhancing their input."


10. An organisational culture that specifies all residents should be showered before breakfast or that breakfast must be served between 7 and 8am is organisation-focused. A person-centred care (PCC) approach would aim to understand the resident's preferences – how often was bathing performed previously, what was the preferred time, and did resident prefer shower or bath? Similarly, allowing flexibility for breakfast e.g. tea/coffee and toast to be available between 6-10am and a hot breakfast available from 7-9am.

11. In our research studies, my colleague Professor Lynn Chenoweth has provided training in PCC over one to three days to interested nurses who have returned to their employing RACFs as 'Nurse Champions', whose role has been to train other nurses. We have found that the nurse champions providing education as mini-tutorials at hand-overs between shifts based on actual resident care has been effective.

12. An example follows. A male resident is repeatedly aggressive when staff try to change him for bedtime. At handover, the Nurse Champion suggests asking his family for advice. When the nurse tells his wife about the aggression at her next visit, his wife explains that he used to be a delivery milkman whose routine was to bathe and change

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into a tracksuit before bedtime so as to be dressed and ready for his 4am start. The nurses follow this routine and the behaviour ceases.

13. There is accumulating evidence that PCC interventions can reduce agitation and the need for psychotropics. Below are references to our own work. An independent review by Gillian Livingston and colleagues published in the Lancet 2017 provides a summary.

14. Despite the above, a UK expert on PCC stated that ‘the term person-centred care has become all-pervasive on the UK dementia care scene. It has been suggested that it has become synonymous with good quality care. It seems that any new approach in dementia care has to claim to be pc (person-centred) in order to be P.C. (politically correct). The term is used frequently in the aims and objectives for dementia care services and provision in the UK and the US, although what lies behind the rhetoric in terms of practice may be questionable’.

15. Sixteen years later, this still accords with my experience that while many residential aged care facilities (RACFs) claim to provide PCC, their actions do not always match the rhetoric. Task-orientated rather than person-orientated approaches continue to prevail.

16. Change to a more PCC approach requires leadership and willingness to embrace change in practice and attitudes. These barriers, plus concerns about financial implications, need to be dispelled by evidence that adopting a PCC approach is cost-efficient, by demands from the public and consumers, and by adoption and evaluation of standards that accord with PCC.

17. My recommendation is that PCC should become business as usual. For this to occur there needs to be bottom up (re: training, culture, attitudes) and top down (leadership, manager led) change as well as incorporation into standards expected of RACFs and evaluation by assessors by continuing to talk to residents, families and staff. More research to provide evidence of practical and financial feasibility would help drive these changes.

Medical reviews and multidisciplinary approach

18. As the average age of residents in RACFs rises, now estimated to be 85 years, the complexity and severity of complex physical comorbidities are also increasing. Many residents require frequent reviews by a general medical practitioner, specialist geriatricians and/or specialist psychogeriatricians. By and large, medical care is reactive rather than proactive. Assertive follow-up by a geriatrician and clinical nurse consultant of patients discharged to nursing home from geriatric wards can halve representations to Emergency Departments and readmissions and prove cost effective (Cordato N et al, 2018).

19. Polypharmacy (five or more medications) and hyperpolypharmacy (ten or more) are common. Medications are often not reviewed or if reviewed remain unchanged despite Residential Medication Management Reviews (RMMR).

20. There is an overuse of medication, especially psychotropic drugs (those that affect the mind), and a reluctance to question medications of patients discharged from hospital.

21. Oral health declines in the aged in general, people with dementia, and those in RACFs in particular. Poor oral health can lead to infections, risk of aspiration pneumonia, poor nutrition and depression. Yet oral health is easily neglected; few nursing homes have systems in place to ensure regular oral health reviews or to institute practices that can improve oral health. We found that training nurses in oral health techniques was acceptable and well performed.

**Safety**

*Psychotropic medications*

22. Safety is an issue in RACFs in many ways. There are safety issues in the use of medications and a failure to realise the many side effects that can ensue from their use, especially from psychotropics.

23. Even though psychotropic medications require informed consent from the resident or, if the person lacks capacity, from a proxy, documented informed consent is usually absent. In our survey, we found that only one in thirteen residents receiving psychotropics who lacked capacity to give informed consent had documented written proxy consent and another one in thirteen had documented oral consent. This may be a failure of the facility, the prescribing doctor or the family to realise that this is their responsibility. In my view the family have a responsibility to check on medications and ask questions and mostly they do neither. I think families of older people just as parents of sick children should be involved in their loved ones' care.

24. Another aspect of safety is the tension between safety and autonomy and freedom. RACFs are keen to protect their residents from any harm and given a choice between increased risk (eg of a fall) and increased freedom (eg of ability to walk) may see their duty of care as to lean to restriction even if families clearly state that their preference is to take the risk. This is a hard decision for facilities who want to protect their residents and their reputation.

25. A patient of mine has severe Parkinson's disease and dementia. His love was to walk and he would go on the street and walk around the neighbourhood and return. Unfortunately, his Parkinson's meant he sometimes 'froze'. His wife was willing to take the risk to ensure his quality of life; the facility was fearful that he might freeze in the

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middle of the road and be run-over; the management of the home refused. Ultimately, he was moved to a locked section of the facility where he eventually settled. A year later his Parkinson’s and dementia are both worse and he no longer has the desire to walk.

26. My recommendation is that guidance from regulatory authorities that a reasonable level of informed risk should be allowed would provide a safety net for facilities and reassurance that would help enhance quality of life.

27. Another issue of concern for me is the involuntary detention of residents in nursing homes. I can recall several patients whom I have been asked to assess for depression or agitation. Their main complaint is that they do not want to be in the nursing home. They say they feel trapped or imprisoned. Sometimes they are in a locked section of the nursing home and physically cannot “escape”. Others simply do not have the means or ability to leave the home. Unfortunately, there is no realistic alternative. Family are unable or unwilling to care for them and they are unable to care for themselves. Very seldom has there been a legal framework such as a Guardianship Tribunal which has approved their admission over the person’s objections to keep the person in the facility.

28. A patient had strokes resulting in dense hemiplegia (paralysed down one side) and decline in executive abilities such as planning and having insight. He owned a house and wanted to return. However he needed 24/7 care, often requiring two persons to assist say with showering. He was unable to afford this privately. His family did not have the means or capacity to care for him. He was angry, cursing everyone and swearing vilely. I sympathised with him but was powerless to assist.

Dementia

29. Dementia is defined as decline in cognition in one or more domains associated with functional decline.

30. There are over 100 causes. The main types (defined by the cause) are:
   a. Alzheimer’s disease (AD)
   b. Vascular dementia (VaD) — several subtypes
   c. Mixed AD & VaD
   d. Lewy body dementia
   e. Fronto-temporal dementia (several subtypes; used to be called Pick’s disease)
   f. Alcohol
   g. Head Injury
   h. Some reversible causes (rare)

31. The first three account for over 80% of dementias; the first five for over 90%.
The Brodaty Triangle

32. We conceptualised a seven-tiered model as a framework to organise services for behavioural and psychological symptoms of dementia (BPSD). See figure below. The seven tiers represented different levels of severity, with corresponding prevalence and management strategies at system level: 1) no dementia; 2) dementia no BPSD – 40%, prevention; 3) mild BPSD 30%, education, working with families and aged care staff; 4) moderate BPSD 20%; 5) moderate – severe BPSD 10%; 6) Severe BPSD – ≤1%; 7) Extreme BPSD – rare.

33. Management at Tier 2 is prevention by education of families and professional carers; e.g., in communication skills, techniques to engage people with dementia, understanding the drivers of BPSD. Tier 3 can be managed by families, aged care staff and primary care. Tier 4 may require specialist consultation; e.g. with a psychogeriatrician, psychologist or specialist nurse or (since we published this, with the Dementia Behaviour Management Advisory Service or DBMAS). Tier 5 may require admission to a Dementia Special Care Unit (now about to be established by Commonwealth from July 2019 or (since we published this paper) referral to Severe Behaviour Response Team or SBR). Tier 6 may require admission to hospital. The very rare severely aggressive and unresponsive person with dementia may need to go an intensive care unit. We estimated that there may be only one such unit needed for each of the larger states; (NSW Health is considering establishing such a unit).

34. People can move up and down the pyramid. For example, a person who develops a urinary tract infection can become agitated and aggressive moving from Tier 3 to 5; when they are treated for the UTI, they move back to Tier 3.
35. The typical Behavioural and Psychological Symptoms of Dementia (BPSD) that arise in the context of residential aged care are:
   a. Agitation
   b. Aggression
   c. Anxiety
   d. Apathy
   e. Appetite/eating disorders
   f. Delusions
   g. Depression
   h. Disinhibition (can be sexual)
   i. Euphoria
   j. Hallucinations
   k. Inappropriate vocalisations (calling out, screaming)
   l. Intrusive behaviour
   m. Irritability/ Lability
   n. Motor behaviour (repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly)
   o. Night-time behaviours
   p. Resistance to care
   q. Wandering/ roaming

36. The consequences of BPSD be for a person living with dementia can include distress to the person, including anxiety, panic, confusion and fear, distress to families and to others in his/her environment, isolation, and increased risk of medications, falls and mortality (mortality independent of medication effects).

37. Risks to aged care workers and carers when BPSD are not managed and the needs of a person with dementia go unmet include staff stress and physical assault. Risks to other residents include stress, irritability and physical assault. For family carers, risks include stress, depression and lack of sleep.

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Managing BPSD in a residential aged care context

38. In order to manage BPSD in the context of residential aged care, I propose the following steps:
   a. Understanding meaning or source of behaviour through discussion with the person and separately with the family;
   b. Understand behaviours as means of communication;
   c. Rule out a physical cause such as a urinary tract infection, pain;
   d. Chart frequency and severity before intervening;
   e. Try psychological, social and environmental strategies first;
   f. Almost never use medications as first line interventions;
   g. If medications are to be started, obtain consent from the person affected if that person is competent or from the proxy as determined by the local jurisdiction, review frequently and consider tapering off as soon as the behaviour settles.

Sundowning

39. Sundowning is increasing confusion and agitation from late afternoon towards evening. Some people with dementia exhibit this diurnal variation more markedly than others. Exposure to light therapy has not been successful. Strategies that are often successful are:
   a. Sleep rhythm management – nap after lunch; with an enjoyable activity in the late afternoon/distraction;
   b. Ask families to time visits at these times;
   c. Ensure resident spends at least 20 mins in sunshine each day;

Drug treatments are not successful but if person is on a psychotroic, time the administration to occur 30-60 minutes before the expected period of agitation. Disruption of sleep architecture is common in dementia so that sleep becomes fragmented, reverse day-night sleep can occur (especially if there is a superimposed delirium) and the quality of sleep deteriorates leading to more confusion and more disturbed behaviours. Residents being up during the night, often with agitation, can be very disruptive for other residents and staff. Management is difficult. Strategies such attempting to reduce day-time naps and to structure activities and exercise during the day are difficult to institute. Medications such as hypnotics can assist with sleep but can increase the risk of confusion and falls.
Person-centred care and dementia

40. There are tools to measure PCC practices such as the Person-Centred Environment and Care Assessment Tool (PCECAT) and The Person-centred Care Assessment Tool (P-CAT) developed at LaTrobe University.

Chemical restraints in aged care

41. Chemical restraints include antipsychotics, benzodiazepines, antiepileptics, antihistamines, and opiates.

42. These medications are generally not used to treat a physical condition. The exceptions are anti-epileptics for epilepsy, antihistamines for allergies and opiates for pain.

43. Risks associated with the use of these medications include falls, fractures, and increased confusion.

44. Extra-pyramidal side effects (Parkinson-like) include a slow shuffling gait, slowing of movements and increased muscle rigidity.

45. Anticholinergic effects include constipation, difficulty with urination, dry mouth, and poor oral health. Many medications have anticholinergic side effects especially antipsychotics and many antidepressants, and so do other drugs such as antihistamines and drugs for urinary bladder instability and even digoxin and frusemide. The anticholinergic burden from different drugs is additive. Paradoxically, some residents are simultaneously prescribed cholinesterase inhibitors which increase cholinergic action and drugs with anticholinergic effects which counter the possible benefits of the cholinesterase inhibitors. Some antipsychotics increase risk of high sugar, high cholesterol and weight gain. Antipsychotics in people with dementia have been linked to increased risk of stroke and death.

Current practices regarding chemical restraint in residential aged care

Westbury et al (2018) reported from a cross-sectional, retrospective cohort study of residents from 150 residential aged care facilities distributed nationally during April 2014–October 2015 antipsychotic, anxiolytic/hypnotic, antidepressant, anticonvulsant and anti-dementia drug use. Full psychotropic prescribing data was available from 11,368 residents. Nearly two-thirds (61%) were taking psychotropic agents regularly, with over 41% prescribed antidepressants, 22% antipsychotics and 22% of residents taking benzodiazepines. Over 30% and 11% were charted for ‘pm’ (as required) benzodiazepines and antipsychotics, respectively. More than 15% of the residents were taking sedating antidepressants, predominantly mirtazapine. Antidepressants, as were

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residents from outer regional residential aged care facilities. Antipsychotic use was not associated with State, rurality or residential aged care facility size. They concluded that regular antipsychotic use appears to have decreased in residential aged care facilities but benzodiazepine prevalence is higher, particularly in South Australian residential aged care facilities. Sedating antidepressant and ‘prn’ prevalence is higher, particularly in South Australian residential aged care facilities. Effective interventions to reduce the continued reliance on psychotropic management, in conjunction with active promotion of non-pharmacological strategies, are urgently required.

46. Chemical restraints are more commonly used of people living with forms of dementia which feature more BPSD such as Fronto-temporal dementia (behavioural variant). Those with Lewy body dementia (which is part of the spectrum of Parkinsonian syndromes and commonly features visual hallucinations and delusions) are more sensitive to antipsychotics, as such residents are more prone to develop parkinsonian symptoms such as slowing of movement, rigidity and tremor.

47. Ultimately, the treating GP prescribes the psychotropics, often in response to requests from staff, families or other residents’ families. Doctors may be called to prescribe medication to handle agitation or aggression. GPs have limited time and are inadequately compensated for attending patients in RACFs. A comprehensive review of reasons for the behaviour (see above) may be outside the expertise of the GP or staff. In our HALT study of deprescribing antipsychotics in nursing home, we were able to deprescribe antipsychotics successfully for 85% of residents and 75% of residents remained off antipsychotics for 12 months without emergence of behaviours or use of regular substitute medication. However, we were unable to deprescribe or to prevent represcribing for about 25% of residents. We interviewed staff about the reasons for represcribing and found that represcribing was most commonly initiated by the nurses and secondly, by the families of residents.

Quality and safety issues associated with chemical restraints

48. There should be clear instructions on how often medication is administered, with a maximum dose per 24 hours. There needs to be review at least monthly on use of PRN medication. If medication is being regularly used, e.g. daily, then it is no longer PRN and therefore should be charted as regular.

49. There are cost implications for residents if a pharmacy supplies a bottle of say 30 pills for prn use and the resident is only given less than a few tablets over 12 months by which time their use by date may have expired.

Consent and safeguards with chemical restraint

50. In our study, less than one in 13 residents had written consent for newly started psychotropic medications. One in 13 had verbal consent documented. 11

51. There are circumstances where the use of chemical restraints may be appropriate in residential aged care, but terminology is important here. If patient is prescribed antipsychotic for delusions or hallucinations, the medications are being used to treat a symptom and not as a restraint. This is similarly the case for depression or mood stabilisation. The boundary becomes blurred with, say, agitation or aggression.

52. There are times when no precipitant can be found, where the behaviour is distressing the patient and everyone else, and where a small dose of antipsychotic can work wonders. The usual caveats apply about informed consent, warnings about possible adverse effects, careful monitoring, and regular reviews and trial of tapering medication after a few weeks if behaviour has settled.

53. The current arrangements for monitoring the use of chemical restraints in residential aged care appear haphazard. While PBS rules allow a maximum of 12 weeks, this is not always observed. A Minister’s Advisory Committee has made recommendations which may be helpful.

Other quality and safety issues in the context of care for people living with dementia

Oral hygiene

54. Oral hygiene is important but neglected issue. I know of only two RACFs, the Montefiore Home in Randwick and Hammond at Hammonville, which have a dental chair. Montefiore also has regular weekly visits from two dentists and an in-house oral hygienist. There used to be a mobile dental clinic in NSW but I have not heard about this for some time.

55. Poor oral health leads to poor physical outcomes, including increased risk of aspiration pneumonia, cardiovascular disease, stroke poor nutrition and compromised quality of life. 12 Xerostoma or dry mouth which can interfere with eating and increase the risk of dental caries, is treatable. 13

56. We performed a small study to show oral health could be easily improved with brief training of nurses. 14


13 Siegel E et al. Interventions To Improve The Oral Health Of People With Dementia Or Cognitive Impairment: A Review Of The Literature J Nutr Health Aging Volume 21, Number 8, 2017:874-886


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57. My view is that annual or better semi-annual oral health assessments should be mandatory. Specialist dental opinion should be sought on the practicality of instituting such a policy.

58. One other issue is loss of dentures, which is not uncommon. This is demoralising for residents and affects their nutrition and ability to socialise.

Medication management

59. Medication management is improving with Webster packs, and electronic monitoring. However, there are still continuing medication errors like missed medication, wrong the medication, or too many medication distributed.

Design features for people living with dementia

60. There is a large literature on this. I refer you to Professor Richard Fleming from University of Wollongong.

61. Essentially, this involves a home-like (non-institutional) environment, outdoor spaces, personalised spaces (photos, mementos, favourite bedspread/pictures), use of colour, soft lighting, plants, soft non-absorbent flooring (for falls), small units (say 8 persons with own lounge), single bedrooms with en suites, and more.

Interfaces and mental health

62. Each Local Health District (LHD) should have a plan on how to service RACFs. It is in Local Health Districts’ interests to reduce demand on hospital services. Ideally there should be a team approach with a clinical nurse consultant and access to geriatrician, psychogeriatrician, clinical psychologist, OT and SW – sometimes called a flying squad. A model where there was a review of residents with clinical issues once a month might prevent/ameliorate medical and psychiatric issues emerging/occurring. The squad could see two homes a day; over a four week period such a squad could handle 40 homes, analogous to monthly targeted ward rounds.

Improving dementia care

Approved providers of residential aged care services

63. Carrots (incentives) and sticks (regulations, inspections and higher standards) should be used in regard to approved providers. Incentives would be making their facility more attractive and competitive in the market place. A transparent, internet-accessible system of rating quality care would drive ‘customers’ to highly ranked facilities. We would need to ensure that improving the independence of residents is not penalised by RACFs who do not receive as much of a subsidy from government funding.

Government, including regulators of aged care services.

64. Government should make Person Centred Care business as usual. Regulators should ensure more consistency, inter-rater reliability checks i.e. ensuring

different raters produce the comparable assessments, and a greater focus on quality of care.

**Workforce skills, capability and training**

65. The specific skills required by people who care for people living with dementia can be divided into several categories:
   1) Personal qualities – empathy, kindness, willingness to engage with their patients/clients as people
   2) Dementia knowledge including about BPSD
   3) Communication skills (with persons with dementia and with families)
   4) Practical skills in daily care
   5) For RNs – knowledge about medications

66. In my view, current education is clearly not sufficient for staff caring for people living with dementia. Improvement can be by requiring basic qualifications depending on level of work and by on the job training. We found mini-tutorials that are case based at handovers work well and do not disrupt workflow. These could be led by a nurse champion who has had extra training. I would recommend that RACFs promote one or more of their staff to be Champions who would have extra training and have this educational role.

67. Changes should definitely be made to the curricula for doctors, nurses and personal carers to improve the care provided to people living with dementia in residential aged care. It’s often a competition for space in curricula.

68. The levels of specialist geriatric and psychogeriatric services are not adequate to meet the needs of people living with dementia in residential aged care services in most metropolitan areas. This is presumably also the case in most regional and almost all rural and remote areas.

69. In areas where specialist geriatric and psychogeriatric services see patients in RACS admissions to hospital have been reduced by 50% (eg A/Prof Peter Gonski, Sutherland Area, SouthCare).

70. A study in St George Area demonstrated that assertive follow-up by a geriatrician and clinical nurse consultant (CNC) of patients discharged to nursing homes from geriatric wards reduced ED presentations and admission over the next 12 months and was cost effective (reducing costs by 50% even after paying for extra visits. The geriatrician and CNC visited monthly together or individually over six months, reviewed medications, ensured advance care directives were in place and treated medical conditions in consultation with residents’ GPs.¹⁵

71. Barriers to delivering specialist geriatric and psychogeriatric services to people living with dementia in residential aged care.

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72. One barrier is workforce, as too few geriatricians and specialists are available.
73. There is a lack of private geriatricians and psychogeriatricians; those in public service have competing demands with most acute patients in hospital. There are also structural problems, as models of care need to be organised at Local Health District level. Many LHDs realise they cut pressure on beds by having Geriatric Flying Squads.
74. What level of service ought to constitute the minimum level of specialist geriatric and psychogeriatric care for individuals living with dementia in residential aged care?
75. The minimum level of specialist geriatric and psychogeriatric care for individuals living with dementia should be access to consultation by staff and by GPs. Often, this can be done by phone or electronically. There should also be outpatient appointments.
76. The benefits of specialist geriatric and psychogeriatric care for people living with dementia in residential aged care are:
   a. Better management of multiple comorbidity
   b. Prevention of hospital admission
   c. Coordinating case management
   d. Better liaison with hospital and other specialist services
   e. Prevention and management of complications such as pressure sores, gait disorders, falls
   f. Prevention and management of BPSD
   g. Ensuring Advance Care Directives are documented

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References


