ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY

RESIDENTIAL DEMENTIA CARE

SUBMISSION OF THE AUSTRALIAN NURSING AND MIDWIFERY FEDERATION

INTRODUCTION

1. This submission concerns the safety and quality of dementia care delivered to people with dementia in residential aged care facilities (RACFs).

2. This submission is provided in response to the matters the Royal Commission will inquire into at the public hearings to be held in Sydney between Monday 6 May 2019 and Friday 17 May 2019. It addresses:
   - The perspective and experience of people in residential aged care and people living with dementia, and their family and care workers
   - Quality and safety in residential aged care, particularly for people living with dementia
   - The use of restrictive practices in residential aged care
   - The extent to which the current aged care system meets the needs of people in residential aged care
   - Good practice care for people living with dementia, particularly in the context of residential aged care.

3. This submission focuses on these issues from the perspective of Australian Nursing and Midwifery Federation (ANMF) members delivering aged care and in particular dementia care in RACF's.

4. The ANMF conducted a national survey from 26 March 2019 to 12 April 2019 of members working in aged care. The full results of this survey which received over 3000 responses are still being analysed at the time of preparing this submission. Preliminary results and member responses with respect to dementia care have been referred to in this submission, however, a full survey report will be provided to the Royal Commission at a later date. The survey is further to the survey conducted in 2016 referred to in Ms Butler's evidence to the Royal Commission in Adelaide Hearing 1.

5. This submission identifies the problems that are experienced in the provision of dementia care and then puts forward elements of what constitutes good practice in dementia care.

The AUSTRALIAN NURSING AND MIDWIFERY FEDERATION

6. The Australian Nursing and Midwifery Federation (ANMF) is Australia's largest national union and professional nursing and midwifery organisation. In collaboration with the ANMF's eight state and territory branches, we represent the

professional, industrial and political interests of more than 275,000 nurses, midwives and care workers across the country.

7. Our members work in the public and private health, aged care and disability sectors across a wide variety of urban, rural and remote locations. We work with them to improve their ability to deliver safe and best practice care in each and every one of these settings, fulfil their professional goals and achieve a healthy work/life balance.

8. Our strong and growing membership and integrated role as both a trade union and professional organisation provide us with a complete understanding of all aspects of the nursing and midwifery professions and see us uniquely placed to defend and advance our professions.

9. Through our work with members we aim to strengthen the contribution of nursing and midwifery to improving Australia's health and aged care systems, and the health of our national and global communities.

10. The ANMF represents almost 40,000 nurses and care-workers working in the aged care sector, across both residential and home and community care settings. (Care workers can be referred to by a variety of titles, which vary, for example from assistant in nursing to personal care worker or assistant. For the purposes of this submission, workers providing assistance in nursing care will be referred to as care workers.

BACKGROUND

11. The ANMF considers all people who are residents of aged care facilities should have access to and experience safe, best practice care regardless of their location, health conditions or personal circumstances and background.

12. Nurses and care workers are central to the provision of care encompassing all aspects of health care- including promotion of health, prevention of illness, care of the ill, disabled and dying. Care is holistic in addressing physical, mental, social and emotional wellbeing.

13. People with dementia are a significant cohort of people in residential care, however, all people in residential care must be treated equally and with dignity regardless of their respective health conditions.

14. Dementia is a broad term used to describe a progressive decline in a person's mental functioning characterised by behavioural changes, memory loss, impaired intellect and rationality, reduced executive skills, difficulty navigating social skills,

heightened emotional responses, rapid changes in mood, personality changes, and a higher than average risk of apathy and depression.

15. Dementia may be as a result of a range of different possible diseases, such as Alzheimer's disease, vascular dementia, frontotemporal dementia, Lewy Body Disease, Huntington's Disease, Parkinson's Disease or drug and alcohol abuse. The varied nature and progression of dementia as a disease requires sophisticated knowledge in the provision of care.

16. In 2016 it was estimated that over 400,000 persons with dementia were living in Australia. The prevalence of dementia is projected to increase by 90% over the next 20 years from 2017 to 760,672 people and by 2.75 fold to 1,100, 890 by 2056.[1]

17. In 2016 approximately 95,000 people with dementia lived in cared accommodation- 94% in residential aged care facilities.[2]

18. People with dementia represent just over half of all residents in RACF's and they tend to have much higher care needs than residents who do not have dementia.[3]

19. People with dementia have complex care needs as a result of having a degenerative disease that affects cognitive, emotional and physical function.

20. Care needs for people with dementia increase in complexity as normal aging advances and with the addition of other health conditions/co-morbidities. Compared with people of the same age, PWD over 65 are more likely to have concomitant health conditions[4] - Over 90% of PWD have at least one concomitant health care conditions,[5] on average, people with dementia have two to eight other concurrent health care conditions.[6]

21. While the incidence increases with age, as many as 10% of all people with dementia have onset before the age of 65;[7] most people diagnosed with younger-onset dementia are in their fifties or forties.[8]

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[1] The Economic Cost of Dementia 2016-2056 p viii-ix

[2] ibid

[3] ibid

[4] Poblador-Plou, B., Calderón-Larrañaga, A., Marta-Moreno, J., Hancco-Saavedra, J., Sicras-Mainar, A., Soljak, M. and Prados-Torres, A. (2014) Comorbidity of dementia: a cross-sectional study of primary care older patients *BioMed Central Psychiatry* 14(1):84-92 ttps://doi.org/10.1186/1471-244X-14-84

[5] Browne, J., Edwards, D.A., Rhodes, K.M., Brimicombe, D.J., and Payne, R.A. (2017) Association of comorbidity and health service usage among patients with dementia in the UK; a population-based study *BMJ Open* 7(3):1-8 doi:10.1136/bmjopen-2016-012546

[6] Wilkinson, E. (2013) Providing quality dementia care *Nursing and Residential Care* 14(2):93-5 https://doi-org.ez.library.latrobe.edu.au/10.12968/nrec.2012.14.2.93

[7] Professor Dennis Velakoulis (consultant neuropsychiatrist and director of the Neuropsychiatry Unit at the Royal Melbourne Hospital), "Young Onset Dementia – a shared journey into the unknown" public lecture, October 24 2018

[8] Rossor, M.N., Fox, N.C., Mummery, C.J., Schott, J.M., Warren, J.D. The diagnosis of young-onset dementia *Lancet Neurol.* 2010 Aug; 9(8): 793–806 doi: 10.1016/S1474-4422(10)70159-9

22. In some instances dementia may be as a result of a reversible disease. The knowledge and skill to differentiate the disease is important.

THE PROBLEMS

Lack of mandated minimum staffing levels and skills mix

23. Despite the high proportion of people with dementia living in residential care there are no mandated minimum staffing levels, skills mix or models for aged care to ensure elderly people receive the care they need.

24. The ANMF refers to the witness statement of Ms Annie Butler dated 1 February 2019 at paragraphs 14-32. The evidence provided in Ms Butler's statement of 1 February 2019, the annexures and the evidence given by Ms Butler to the Royal Commission on 13 February 2019 with respect to the need for and benefits of mandated minimum staffing levels and skills mix is equally pertinent to the provision of care to people with dementia.

25. The 2019 ANMF survey included these comments from members of the impact of high workload and lack of adequate staffing levels:

-I often think I wish I could split myself into 2 or 3, the workload is so high. I work PM shifts. It is 15 minutes into my shift, and Mr N has fallen again. He was on the floor even before his chair alarm mat had gone off. He has hit his head and has 4 large skin tears on his arm. He is distressed. His wife has dementia (they share a room together) and she is worried and upset.

Mr N needs his wounds dressed and he and his wife need reassurance and compassion. He requires neurological observations (half hourly head injury observations for 4 hours and then 4 times a day for 3 further days) only a trained nurse can do this. I am lucky to have an EEN working. But she is a valuable asset to manage the drug round. Mr N has a progressively deteriorating condition, and he has short term memory loss, and no insight into his falls risk.

And so we manage it the best we can humanly do. But he keeps on falling. And we have to keep on trying to manage. And the government think this is normal aging?

-When the dementia resident is in distress/verbally or physical agitate/aggressive, we need extra staff to do 1:1 work, to make sure co-workers and co-residents are safe.

Lack of dementia care training

26. There is a lack of specialist trained nurses and care workers providing dementia care. For example, Ms Marie McCabe of Dementia Australia provided evidence to the Royal Commission that a Certificate III in Aged care does not provide any education around dementia, neither mandatory or as optional training[9].

27. The lack of training in dementia care has an impact on the quality of care[10] - meaning opportunity for the best outcome is sometimes lost and sub-optimal care is provided in some instances.

28. In the 2019 ANMF survey one member response highlighted the link between training and quality of care:

    When dementia care is improved care standards also increase. Better training in dementia care is needed.

29. Training and ongoing professional development in the absence of adequate staffing levels is not effective on its own. There must be capacity to deliver best practice.

Lack of regulation for care workers.

30. Vulnerability of people with dementia exposes them to greater risk of harm from unscrupulous or unsuitable workers. While nurses are regulated and this provides a system that should ensure unsuitable nurses do not remain in aged care, care workers are not subject to a statutory scheme that ensures fitness and suitability for the role.

31. This issues of skills mix and appropriate level of training and regulation for members providing dementia care is highlighted in the following member comment from the 2019 ANMF survey:

    The excessive reliance of the aged care sector on unregulated workers goes against the research on appropriate skill mix levels. Aged care is a complex area requiring specialised skills in order to provide safe and appropriate care for residents. Staff need to have skills and knowledge of the common co-morbidities facing the elderly, in the management of dementia and other mental health and behavioural issues, in palliative and end of life care, pain management and wound care. Staff also need to be able to assess the condition of residents effectively to prevent deterioration and avoid illnesses and incidents with early intervention and appropriate clinical management. At present, there are too few registered and enrolled nurses - and Assistants in Nursing/Personal Care Attendants/Care Companions simply do not possess the level of skill required to ensure adequate and safe care delivery. It is

[9] Royal Commission 19.2.19R2 P-414

[10] Edberg, K-A., Bird M., Richards, D.A., Woods, R., Keeley, P., and Davis-Quarrell, V. (2008) Strain in nursing care of people with dementia: Nurses' experience in Australia, Sweden and United Kingdom *Aging and Mental* Health 12(2): 236-43 https://doi-org.ez.library.latrobe.edu.au/10.1080/13607860701616374

recognised that these unregulated staff do play a vital role in aged care, however, their increasing presence within the workforce means they are often required to undertake roles that are outside their scope of practice. This is particularly concerning due to the vulnerability of residents in aged care and the inherent potential for harm in the delivery of care.

32. The problem of inadequate numbers of trained staff is made in the member comment below, pointing out that in some instances non-direct staff are filling the role of direct care:

Cleaners being asked to "special" dementia patients due to insufficient trained staff.

Workforce challenges

33. There is an identified shortage in aged care workers. In 2017 there were an estimated 94,672 paid care workers looking after people with dementia in the residential aged care setting. It is projected that by 2036 173,225 care workers will be needed in the paid care accommodation sector[11].

34. To meet the needs of the growing population of people with dementia living in residential care the workforce needs to increase. There is a need to attract suitably qualified people to work in the area of dementia care.

35. In rural and remote areas of Australia, there are even greater challenges in providing suitably qualified staff to support the needs of people with dementia.

36. There are approximately 900 residential aged care providers and approximately 2,500 RACF's operating in Australia. There is no structured career pathway within aged care, meaning career recognition and development is ad hoc and dependent on the policy and operations of each provider.

Occupational violence and aggression

37. Experiencing violence and aggression from residents and their family members is disturbingly common for workers in aged care.

38. Research consistently demonstrates that both anticipated and actual behavioural and psychological symptoms of dementia (BPSD), including physical and verbal aggression, causes staff distress[12] and contributes to turnover, reducing continuing of care.

39. Member participants in the 2019 ANMF survey identified physical and emotional abuse as a problem and also the 'burn out' effect this has:

[11] The Economic Cost of Dementia 2016 -2056 p ix
[12] Ibid.

-Physical abuse from dementia patients against care workers also needs to be looked into. Staff ratios are required urgently in the industry.

-Despite the negative images which broadcast on media, I do get to know the people who are absolutely dedicated to deliver the best possible quality care to the elderly. But when we get misunderstood, we get abused too (and we are asked not to make a big fuss so we all tend to put up with it), sometimes by the families and sometimes the violence comes from residents themselves. These days, aged care facilities accept more residents with mental illnesses, ranged moderate to severe. Dementia is not an exemption. They can be quite full on, requires lot of 1:1 to de-escalate their behaviours. However, we never get enough support. The recommendations from the offsite mental health services never consider the levels of staffing and resources, most of the suggestions are general but unrealistic. Imagine if you under pressure of everything, over time, you will lose your compassion... till the day you can handle no more, then you will leave the industry.

Continuity of care

40. People with dementia need continuity of care to ensure the best outcomes.[13,14] RACFs need to be funded and managed to ensure rostering and shifts are organised in a way that provides continuity of staff so residents can feel assured of routine and familiarity.[15]

41. Culture has been identified as a key component of quality care for people with dementia. Establishing and maintaining a robust, consistent, person-centred culture is not possible in environments where staff turnover is brisk and/or there is heavy reliance on casual staff. RACF's that engage staff on a casual basis, rely heavily on agency staff or have poor staff retention may not be providing best practice in continuity of care.

42. Some 80% of hospital admissions of people with dementia are for preventable conditions (e.g. urinary tract or chest infections, falls, and hip fractures).[16] Continuity

[13] Kitwood, T. and Bredin K. Towards a Theory of Dementia Care: Personhood and Well-being *Ageing and Society* 1992;12: 269-287

[14] Nazzarko, L. Providing high quality dementia care in nursing homes *Nursing and Residential Care* Vol. 11, No. 6 pp. 296-300

[15] Edgar, C.P. (2016) Knowing the resident *The management of chronic wounds and pain in older people who have dementia and are living in nursing homes: a grounded theory study* Doctoral thesis, La Trobe University pp. 79-83

[16] Scrutton, J. and Brancati, C.U. (2016) *Dementia and comorbidities: ensuring parity of care* The International Longevity Centre

of care reduces hospital presentations and associated disruption to people with dementia.[17,18]

Healthcare and wellbeing challenges

43. The 2019 ANMF survey asked members to identify from a list of options which standards of care most concerned them in relation to aged care. Participants were able to select more than one standard of care. Of the 2,767 participants who responded to this question, 62.5% selected dementia management as the standard of care that concerned them most. The chart below shows the response to this question in graph form:

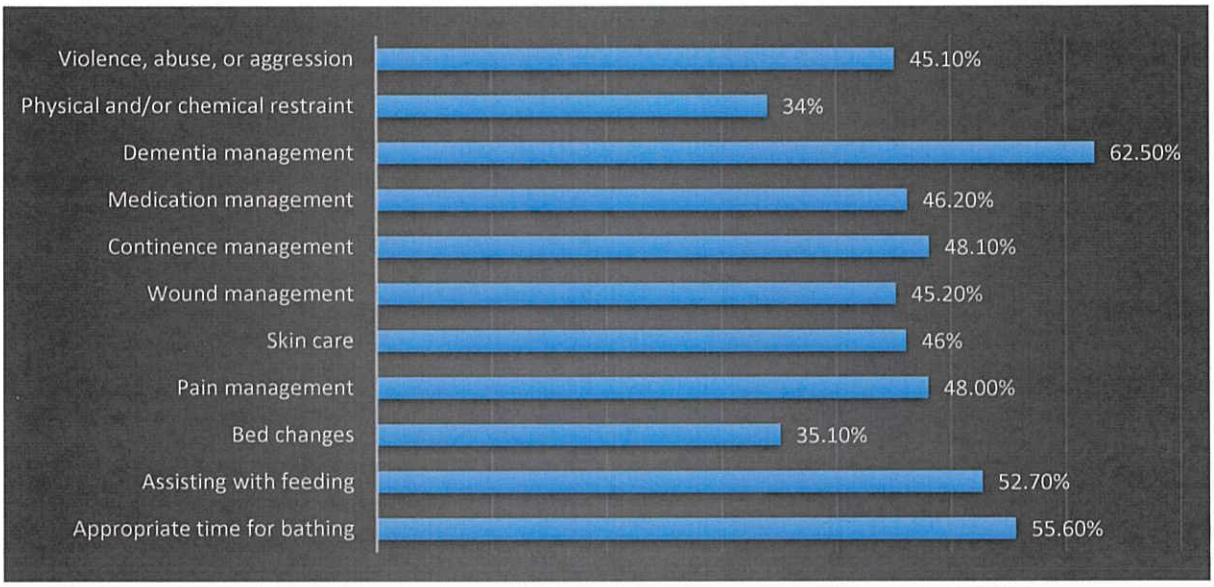

Figure 1: What standards of care are you most concerned about? (Staff: 2019)

44. All aspects of aged care including nutrition, hydration, oral care, hygiene, wound care and health care in general can be and often are more complex to manage for people with dementia.

    a. Nutrition: weight loss is an indicator, as well as a complication, of Alzheimer's and some other dementias.[19] It is a significant and complex problem for people

[17] Amjad, H., Carmichael, D., Austin, A.M., Chang, C-H., and Bynum, J.P.W. (2016) Continuity of Care and Healthcare Utilization in Older Adults with Dementia in Fee-for-Service Medicare *JAMA Internal Medicine* 176(9): 1371-8 doi: 10.1001/jamainternmed.2016.3553

[18] Van Walraven, C., Oake, N., Jennings, A. and Forster, A.J. (2010) The association between continuity of care and outcomes: a systematic and critical review *Journal Of Evaluation In Clinical Practice* 16(5):947-56. doi: 10.1111/j.1365-2753.2009.01235.x.

[19] Kurrle, S., Hogarth, R., and Brodaty, H. (2017) Physical Comorbidities Associated with Late-Life Dementia in *Mental Health and Illness in the Elderly* (Chiu, H. and Shulman, K. eds) Springer Publishing

living with dementia,[20] and malnutrition (both in terms of total calories and balanced intake) is common in this population.[21] This in turn leads to frailty, reduced mobility, increased falls and fracture risk, deconditioning, skin fragility, the exacerbation and development of concomitant conditions, and higher mortality.[22,23]

Among many other contributing factors, people with dementia may:

- have loss of appetite, not recognise hunger, or forget to eat[24]
- lose the capacity to recognise or use cutlery[25]
- have an altered sense of smell and taste[26, 27]
- need prompting to open their mouths as food approaches[28]
- forget how to or have difficulty chewing and/or swallowing[29]
- not notice or be unable to recognise food[30, 31]
- be fearful or avoidant of food, requiring patient and skilled care to ensure adequate nutritional intake[32]
- take longer to assist with meals than people without dementia (40 minutes to an hour per meal) [33, 34]

These issues are exacerbated when alcohol consumption meets baseline energy needs[35] (thus meeting few nutritional requirements). In addition, many

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[20] Barrie, M. (2016) Dealing with patients with concurrent dementia and urinary incontinence *Journal of Community Nursing* 30(3):37-46

[21] Kaiser, M.J., Bauer, J.M., Rämsch, C., Uter, W., Cederholm, T., Thomas, D.R., Anthony, P.S., Charlton, K.E., Maggio, M., Tsai, A.C, Vellas, B., and Sieber, C.S. (2010) Frequency of Malnutrition in Older Adults: A Multinational Perspective Using the Mini Nutritional Assessment *Journal of the American Geriatrics Society* 58(9): 1734-8. doi:10.1111/j.1532-5415.2010.03016.x

[22] Kurrle et al. op. cit.

[23] Prince, M., Albanese, E., Guerchet, M., and Prina, M. (2014) Nutrition and dementia: A review of available research https://www.alz.co.uk/sites/default/files/pdfs/nutrition-and-dementia.pdf

[24] Jansen, S., Bal, L., Desbrow, B., Morgan, K., Moyle, W. and Hughes, R. (2014) Nutrition and dementia care: Informing dietetic practice *Nutrition and Dietetics* https://doi.org/10.1111/1747-0080.12144

[25] Rullier, L., Lagarde, A., Bouisson, J., Bergua, V., and Barberger-Gateau, P. (2013) Nutritional status of community-dwelling older people with dementia: associations with individual and family caregivers' characteristics *International Journal of Geriatric Psychiatry* 28(6): 580–8 https://doi.org/10.1002/gps.3862

[26] Yong-ming, Z., Lu, D., Liu, H., Zhang, H., and Zhou, Y. (2016) Olfactory dysfunction in Alzheimer's disease *Neuropsychiatric Disease and Treatment* 12: 869-75 doi: 10.2147/NDT.S104886

[27] Kurrle et al. op. cit.

[28] Kai, K., Hashimoto, M., Amano, K., Tanaka, H., Fukuhara, R., and Ikeda, M. (2015) Relationship between Eating Disturbance and Dementia Severity in Patients with Alzheimer's Disease *PLoS One* 10(8) doi: 10.1371/journal.pone.013366610.1371/journal.pone.0133666

[29] Ibid.

[30] Alzheimer's Society UK *Eating and Drinking fact sheet* (N.D.) https://www.alzheimers.org.uk/sites/default/files/pdf/factsheet_eating_and_drinking.pdf

[31] Ibid.

[32] Prince et al. op. cit.

[33] Ibid.

[34] Dementia Australia – Eating https://www.dementia.org.au/information/about-you/i-am-a-carer-family-member-or-friend/personal-care/eating [accessed April 24, 2019]

[35] Ibid.

medications can negatively contribute to metabolic and functional barriers to optimal nutrition. [36, 37]

b. Hydration: Inadequate hydration contributes to the development or worsening of constipation, confusion, urinary tract infection, pressure sores, delayed wound healing, depression, anxiety, venous thrombosis, and renal impairment.[38,39,40] Dehydration is a significant contributor to adverse health outcomes, including mortality, particularly as climate change means longer periods of extreme hot weather conditions. In addition to the contribution of prescription antidiuretics, the complex network of regulators that monitor and compensate for dehydration can become less responsive and effective as we age.[41,42] People with dementia have at higher risk than other populations because they may:
   - restrict fluids for fear of incontinence[43]
   - not recognise thirst, or forget to drink[44, 45]
   - have difficulty recognising sources of fluids (both containers like glasses, and taps)[46, 47]
   - not be able to process multiple stage requirements[48] (e.g. experience thirst, get up, go to the kitchen, find a cup, go to the sink, turn on the tap, fill the glass, turn off the tap, drink)

   Residents of ACFs are ten times more likely than older people in the community to be admitted to acute care via ED for re-hydration;[49] while current, local figures are difficult to find, a US analysis of Medicare records found a

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[36] Aziz, N.A., van der Marck, M.A., Pijl, H., Olde Rikkert, M.G., Bloem, B.R., and Roos, R.A. (2008) Weight loss in neurodegenerative disorders *Journal of Neurology* 255(12):1872-80. doi: 10.1007/s00415-009-0062-8

[37] Kurrle et al. op. cit.

[38] Murray, S. (2017) Identifying and managing dehydration in care homes *Nursing and Residential Care* 19(4): 197-200 https://doi-org.ez.library.latrobe.edu.au/10.12968/nrec.2017.19.4.197

[39] Woodward, S. (2015) Addressing the dangers of dehydration *British Journal of Neuroscience* 11(3): 215 https://doi-org.ez.library.latrobe.edu.au/10.12968/bjnn.2015.11.5.215

[40] Bak, A., Wilson, J., Tsiami, A, and Loveday, H. (2018) Drinking vessel preferences in older nursing home residents: optimal design and potential for increasing fluid intake *British Journal of Nursing* 27(2):1298-1304 https://doi-org.ez.library.latrobe.edu.au/10.12968/bjon.2018.27.22.1298

[41] Ibid.

[42] Hooper, L. (2016) Why, Oh Why, Are So Many Older Adults Not Drinking Enough Fluid? *Journal of the Academy of Nutrition and Dietetics* 116(5), 774-8 http://dx.doi.org/10.1016/j.jand.2016.01.006

[43] Victorian Continence Resource Centre (N.D.) *Water for wellbeing: a resource kit to promote adequate fluid intake for the older person* https://continencevictoria.org.au/wp-content/uploads/2015/04/Water_for_wellbeing_FINAL.pdf

[44] Jansen, et al. op. cit.

[45] Alzheimer's Society op. cit.

[46] Manning, C.A. and Ducharme, J.K. (2010) Chapter 6 - Dementia Syndromes in the Older Adult in *Handbook of Assessment in Clinical Gerontology* Lichtenberg, P.A. (ed).

[47] Palmer, S. (2018) Combatting dehydration, one drop at a time *Nursing and Residential* Care 20(11):.575-navigating7

[48] Heacock, P.R., Beck, C.M., Souder, E. and Mercer, S. (1997) Assessing dressing ability in dementia: Behavioral assessment offers a practical approach that can reveal abilities and disabilities and provide direction for intervention *Geriatric Nursing* 18(3): 107-111

[49] Wolff, A., Stuckler, D., and McKee, M. (2015) Are patients admitted to hospitals from care homes dehydrated? A retrospective analysis of hypernatraemia and in-hospital mortality *Journal of the Royal Society of Medicine* 108(7):259–265. https://doi-org.ez.library.latrobe.edu.au/10.1177/0141076814566260

236.2/10,000 rate of dehydration as an admission diagnosis in older Medicare-eligible Americans.[50]

c. Oral care is too often seen as being of secondary importance to other components of hygiene, but poor oral care has significant effects of the health of older people in general, and people with dementia in particular.[51] Dehydration, malnutrition, and some medications increase the risks of oral complications.[52] Effects of sub-optimal oral hygiene (including developing and untreated decay, exposed nerve roots from gingivitis, ulceration, and denture pain caused by any of these) contribute to reduce oral intake,[53] creating a cycle that is difficult to disrupt. People with dementia are more likely than people without dementia to contract, be admitted to acute care, re-present within three months, and die of pneumonia;[54] one of the most common forms is aspiration pneumonia, the incidence of which may be reduced with increased attention to oral hygiene.[55]

d. Hygiene: recognising the need for assistance with hygiene can be difficult to begin with for people with dementia.[56] Pain, fear, anxiety (particularly about falling or slipping), fatigue, and embarrassment[57] are just some of the barriers to meeting people with dementia's hygiene needs; as this population are often unable to articulate these feelings, the most common responses are aversion, aggression, and combative behaviours.[58] It is vital that carers (in whatever setting) approach meeting hygiene needs with consideration and empathy. Common barriers include insufficient privacy, physical discomfort (the room being cold or small), too much verbal and physical information, altered

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[50] Warren, J.L., Bacon, W.E., Harris, T, McBean, A.M., Foley, D.J. and Phillips, C. (1994) The burden and outcomes associated with dehydration among US elderly, 1991 *American Journal of Public Health* 84(8):1265-9

[51] Kurrle et al. op. cit.

[52] Ibid.

[53] Van Lancker, A., Verhaeghe, S., van Hecke, A., Vanderwee, A., Goossens, J., and Beeckman, D. (2012) The association between malnutrition and oral health status in elderly in long-term care facilities: A systematic review *International Journal of Nursing Studies* 49(12): 1568–1581 https://doi.org/10.1016/j.ijnurstu.2012.04.001

[54] Foley, N.C., Affoo, R.H. and Martin R.E A (2015) Systematic Review and Meta-Analysis Examining Pneumonia-Associated Mortality in Dementia *Dementia and Geriatric Cognitive Disorders* 39:52-67 https://doi.org/10.1159/000367783

[55] Goldberg, L.R., Westbury, J.L., Langmore, S.E., Crocombe, L.A., Kent, K. and Heiss, C. (2018) Oral health screening may decrease aspiration pneumonia risk for adults with dementia in residential aged care American Speech-Language-Hearing Association (ASHA) Convention, 15 - 17 November 2018, Boston, USA

[56] Hamdy, R.C., Kinser, A., Culp, J.E., Kendall-Wilson, T., and Depelteau, A. (2018) Agnosia interferes with daily hygiene in patients with dementia *Gerontology and Geriatric Medicine* 4(1):213 https://doi.org/10.1177/2333721418778419

[57] Rader, J., Barrick, A.L., Hoeffer, B., Sloane, P.D., McKenzie, Da., Talerico, K.A., and Glover, J.U. (2006) The bathing of older adults with dementia: easing the unnecessarily unpleasant aspects of assisted bathing *American Journal of Nursing* 106(4): 40-8

[58] Konno, R., Stern, C. and Gibb, H. (2013) The best evidence for assisted bathing of older people with dementia: a comprehensive systematic review *JBI Database of Systematic Reviews and Implementation Reports* 11(1):123-212

perception of water temperature and/or sensation, and fear of drowning or submersion (particularly in showers and with hair washing).[59]

Member responses in the 2019 ANMF survey also identified that hygiene and continence care can be compromised because of inadequate resources:

- Lack of resources to provide care needed. Often have nil stock of Resource Nutrition supplements, nil stock of wound management supplies, sick leave is often not covered. Incontinence aids used are the cheapest - will use liner type pads and net pants instead using pull up type pads. Pull up type pads are more suitable for use in dementia residents - they will more likely use these the liners and net pants, but management don't care and insist use of cheapest options and not what would be most suitable for the resident. Best practice strategies seems not to be important for management.

-A woman with late stage dementia whose dignity is not respected because she is made to wear ill-fitting incontinence pads that end up down around her knees inside her trousers or which she pulls down and walks around with her pants around her knees because she is wet and there are not enough staff to change her in a timely manner.

e. Wound care: the effects of dementia briefly discussed above (higher rates of concomitant health conditions, impaired nutrition, hydration, and hygiene), combined with reduced capacity to experience, recognise or express pain,[60] means PWD are at higher risk of wound development than other populations.[61]

f. Health care: due to the symptoms of dementia, other health issues may be masked, difficult to detect and difficult for people with dementia to communicate.[62] This increases the risk of both preventable complications[63]missed or inadequate treatment for other health issues. Risks

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[59] Ibid.

[60] Cunningham, C., MacLean, W., and Kelly, F. (2010) The assessment and management of pain in people with dementia in care homes *Nursing Older People* 22(7): 29-35 doi: 10.7748/nop2010.09.22.7.29.c7947

[61] Aminoff, B.Z. (2011) End-stage dementia: Aminoff suffering syndrome and decubitus ulcers *Dementia* 11(4):473-81 https://doi.org/10.1177/1471301211421224

[62] Bauer, K., Schwarzkopf, L., Graessel, E., and Holle, R. (2014) A claims data-based comparison of comorbidity in individuals with and without dementia *BioMed Central Geriatrics* 14:10 https://doi.org/10.1186/1471-2318-14-10

[63] Bail, K., Berry, H., Grealish, L., Draper, B., Karmel, R., Gibson, D., and Peut, A. (2013) Potentially preventable complications of urinary tract infections, pressure areas, pneumonia, and delirium in hospitalised dementia patients: retrospective cohort study *BMJ Open* 3(6):1-8 doi:10.1136/bmjopen-2013-002770

around providing medication may also be increased due to the effects of dementia.[64,65]

45. Pain[66] and distress may be expressed in violent, agitated, or aggressive behaviour towards staff and other residents.[67] Erratic behaviour, such as wandering, inappropriate contact or socially unacceptable behaviour is also common.

46. People with dementia commonly experience mental health problems, such as depression, anxiety or delusions. Other mental health conditions may also be present. Expertise is required to distinguish, treat and manage mental health problems in conjunction with dementia and can be overlooked for people with dementia.

47. While the above concerns in relation to health and wellbeing may be of varying relevance for people with dementia in residential aged care, the range of potential concerns highlights the need for trained staff who have the skill to understand and respond appropriately to these issues. Where staffing levels and skills mix is inadequate all of the concerns in paragraphs 44-46 can pose significant and unacceptable risk to the health and wellbeing of people with dementia.

Inappropriate or overuse of chemical and physical restraint

48. In under- resourced RACF's whether in terms of staffing numbers or staffing at appropriate skills mix and training levels, behaviours of concern are sometimes inappropriately managed with physical and chemical restraint.

49. Inappropriate restraint practices are unacceptable on many levels. People with dementia should be treated and cared for with respect for their human rights and be provided care that allows and encourages optimal engagement in life and wellness.

50. Use of practices that are not clinically justified due to work pressure arising from lack of staffing and lack of suitably skilled staff to deliver quality care is an issue of great concern. This problem may arise particularly where people with dementia behave violently, which may be physical, verbal or sexual violence, towards staff, visitors or other residents. The risk of self-harm or injury may also be inappropriately managed by physical or chemical restraint.

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[64] Barber, N.D., Alldred, P., Raynor, K., Dickinson, R., Garfield, S., Jesson, B., Lim, R., Savage, I., Standage, C., Buckle, P., Carpenter, J., Franklin, B., Woloshynowych, M., and Zermansky, A.J. (2009) Care homes' use of medicines study: prevalence, causes and potential harm of medication errors in care homes for older people *British Medical Journal Quality and Safety* 18(5):341-6 doi:10.1136/qshc.2009.034231

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[66] Cunningham et al. op. cit.

[67] Konno et al op. cit.

51. The issue of balancing the need for safety for all residents, visitors and staff and ensuring people with dementia are not excessively or inappropriately restrained is ongoing and difficult.

52. The problem can result in unreasonable pressure on doctors to prescribe medication outside of clinical best practice. Staff may resort to the use of restraint as the only measure available to prevent injury to themselves and others. Families are faced with the distress of seeing loved ones either restrained or exposing themselves or others to harm.

53. This problem highlights that inadequate staffing and skills mix is a significant barrier to ensuring that chemical and physical restraint is only used as a last resort and as part of agreed care plan.

54. It must also be acknowledged that restraint is sometimes necessary and effective. Inappropriate use of chemical and physical restraint is an indicator that appropriate behaviour management, pain management or other forms of care have not been adequately provided.

Models of care and workplace design

55. The location and or place and model of care needs to recognise diversity of residents for example, CALD, Aboriginal and Torres Strait or LGBTQI people. As the symptoms of dementia advance, care that is provided in the language, place and culture of the person with dementia grows more important.

56. The physical layout and design of RACF's may not always meet the needs of people with dementia. A lack of well- designed, purpose built facilities that provide safety, security and spaces that are suitable for the needs of people with dementia reduces the capacity to provide optimal care.

57. A worker described a secure dementia care unit as follows in the 2019 ANMF l survey:

    There is also a need for better Dementia facilities particularly better designed buildings. I work in a secure Dementia wing but there are no quiet areas, gardens are a disgrace ...

Poor integration with other aspects of health care

58. If care is not provided in an integrated context utilising the knowledge and skills of a range of health professionals, including nurses, care workers, doctors and other allied health professionals, care can be missed, not delivered in a timely fashion or best health outcomes are not achieved.

59. The provision of care provided within a RACF must also be closely integrated with other healthcare providers, such as local general practitioners, hospital and respite care. Where there is inadequate or failed communication between healthcare providers the risk of errors and missed care increases considerably. People with dementia are particularly vulnerable to the risks of failed or inadequate communication.

60. Access to health care services can be difficult for people with dementia. Transfer to hospital, medical clinics or specialist medical appointments can be difficult and traumatic in some circumstances. This may result in missed or inadequate care.

61. A worker provided an example of a breakdown in provision of care and the harm it did a person with dementia in the 2019 ANMF survey:

    A patient sent in from a nursing home during an evening shift at the hospital after a "supposed fall" with no history or specific details relating to the incident. The ambulance had minimal information. Doctors tried and failed on several occasions to contact the facilty for more information, but were unable to get through. The patient in question suffered from severe dementia, so staff were unable to help them in anyway, as they became increasingly agitated when approached. After sometime the patient was found to have no injuries and deemed stable, were returned to the nursing home. The sadness of this situation was the fact that this person had been put under increased stress for no apparent reason.

What is needed to provide best practice dementia care?

Workforce support

62. Mandated staffing levels with the capacity to deliver the care required under assessed needs and skills mix must be introduced.

63. The aged care workforce should be trained in dementia care- whether at Certificate, Diploma or degree level. Training, mentoring and professional development should be ongoing and reflect evidence based best practice.

64. The workforce should be recognised and rewarded comparable to state government public hospital rates and conditions and career pathways developed to grow the workforce to cater for future demand.

65. Care should be provided as much as possible by a stable and familiar workforce, where the use of casual and agency staff is kept to a minimum.

66. To meet the needs of the growing population of people with dementia living in residential care the workforce needs to increase. Work conditions, wages and career structures should be in place to attract suitably qualified people to work in the area of dementia care.

67. Care workers should be regulated via a licensing system that ensures fitness and suitability to work in aged care.

68. Occupational violence and aggression in aged care must be treated as unacceptable and strategies and policies should aim for the elimination of risk in RACF's. Workers in aged care should not view injury, assault and aggression as 'part of the job'. Significant cultural change in how occupational violence is viewed and responded to must be encouraged. Staffing levels and skills mix are key to eliminating the risk of workplace violence and aggression.

Regulatory standards

69. The new Aged Care Quality standards will become operational on 1 July 2019. These standards are welcomed, however in regards to staffing and skills mix for residential care they still do not go far enough. They do not provide minimum staffing and skills mix requirements for residential providers to be assessed against. It is also important that ongoing evaluation is completed with the introduction of these new standards to ensure they are meeting their intended requirements.

70. Clinical quality indicator data will be required to be submitted from all Commonwealth funded residential aged care facilities from 1 July 2019. Providers must measure, monitor and report data on pressure injuries, use of restraint and unplanned weight loss. This measure is supported, however the data needs to be collected in a validated, consistent way enabling it to be appropriately compared and analysed to improve care outcomes.

71. Greater regulatory requirements and oversight must be supported by government in the funding and staffing of those regulatory bodies, including engaging people with appropriate clinical expertise.

72. The increase to regulatory oversight and standards must be met with commensurate increases to staffing levels and skills to ensure those regulatory requirements can be met. Any failure to meet standards must be looked at from a systemic rather than an individual level.

Best practice health care

73. Wherever possible, people with dementia should have developed advanced care plans in conjunction with loved ones. Plans should identify agreed treatment, behavioural strategies and wishes of the individual. This may, where warranted, include the use of restraint, surveillance and end of life planning.

74. Care plans setting out health and wellbeing goals should be in place and reviewed regularly. Plans should reflect the individual's wishes and balance dignity of risk with the capacity to ensure the safety and wellbeing of others.

75. Risk management and behaviour management should be discussed, documented and reviewed regularly.

76. Facilities should be built or designed for the purpose of providing dementia care that offer secure, safe spaces and reflect best evidence based practice- such as providing sensory and calm areas.

77. Care should be provided in settings that acknowledge diversity. Cohorts of people with dementia such as CALD groups, LGBTQI people, younger people and forensic residents have different care needs that will be best met in tailored settings.

78. The development and building of Specialist Dementia Care Units, such as those recently built in Caulfield in Victorian and Glenvale in Tasmania, is welcome and should continue to be supported.

79. A model of nurse-led dementia care should be considered. Nurse practitioners can play a leading role in co-ordinating dementia care that would result in better quality care and more accessible care, particularly for people in regional and remote areas.

80. The capacity of nurse practitioners to fill unmet demand for assessment, co-ordination and delivery of health care should be expanded and explored. Nurse practitioners are highly skilled and capable of meeting this demand.

81. The work of nurses and care workers should be supported and complimented by allied health professionals.

82. There should be a multi-disciplinary integrated approach to healthcare of people with dementia both within their residence and when accessing acute, specialist or respite care.

83. RACF's should be encouraged to form health partnerships with acute health care providers, such as medical centres and hospitals and with palliative care providers to maximise health care capacity and integration.

84. Technology should be utilised creatively and to minimise unnecessary transfer and movement of people with dementia. For example, teleconferencing within RACF's to other health care providers, such as nurse practitioners or specialists, will both reduce distress for people with dementia and increase access to health care.

85. Individuals must be treated with dignity and respect. At all times any intervention should be in accordance with agreed care plans, subject to medical and clinical review both in establishment and ongoing – and be person centred and recognise diversity and needs of the individual and their family members.

86. A cultural shift to viewing the provision of aged care as providing health care should be encouraged. Care for people with dementia should be integrated into the whole range of aged care services- from care support in the home, to residential care, from

mild to severe dementia and end of life care. At all times the experience of the person moving through the health care system should be central.

87. Shifting to a perspective of dementia as a life-limiting condition[68, 69] focusing on supportive rather than curative interventions[70] will address some of the issues around treatment of both acute and exacerbated health concerns, including the distress associated with transfer to acute facilities.[71] As with other forms of palliative care, the focus should be on interventions that improve quality of life[72] rather than distressing procedures that cause distress without substantially affecting outcome.[73]

Sufficient funding

88. Government must ensure there is sufficient funding to meet the growing demand for dementia care in RACF's. This must be considered in the short, medium and long term. Real and lasting cultural change and health care improvements will not be achieved in dementia care in the absence of appropriate funding for mandated staffing levels and skills mix.

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