ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY

PERSON-CENTRED CARE

SUBMISSION OF THE AUSTRALIAN NURSING AND MIDWIFERY FEDERATION

INTRODUCTION

1. This submission concerns person-centred care (PCC), advance care planning (ACP), and palliative care services delivered to people 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 Perth between Monday 24 June 2019 and Friday 28 June 2019. It addresses:
   - How aged-care services can be provided in a way which is person-centred, including care which values the identity, experience and autonomy of the person accessing care and promotes choice and control.
   - The factors that influence whether aged care services are delivered in a person-centred manner, including:
     - The relationships between the person accessing care, people providing support (including family and other members of the community) and the service provider.
     - Broader societal attitudes towards older people.
   - The perspective and experience of people who access aged care, including the ways in which aged care services are, or are not, person-centred.
   - Good practice care models for providing person-centred aged care.
   - The role of advance care planning to support the provision of quality aged care services.
   - The extent to which people accessing aged care services are able to access palliative care.
   - The quality of palliative care services available to people accessing aged care services.

3. This submission focuses on these issues from the perspective of Australian Nursing and Midwifery Federation (ANMF) members' delivery and/or involvement in aged care and in particular PCC, ACP, and palliative care in RACFs.

4. The ANMF conducted a national survey from 26 March 2019 to 12 April 2019 of staff working in aged care (2,775 participants) and community members with a relative or friend in aged care (354 participants). Relevant results from this survey are referred to in this submission. Staff members were asked to provide comment on their RACF's conversations with residents about ACP and end of life decisions. Staff and community members also provided qualitative data from which themes regarding PCC and palliative care arose. The staff survey report was provided to the Commission 3 May 2019, the companion report will be provided at a later date.

5. This submission identifies the problems that are experienced in the provision of PCC, ACP, and palliative care and then puts forward elements of what constitute good practice.

The AUSTRALIAN NURSING AND MIDWIFERY FEDERATION (ANMF)

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.[1]

BACKGROUND

11. The ANMF's position is that all residents of aged care facilities should have access to and experience safe, best practice care regardless of their location, health conditions, personal circumstances, and background.

12. Nurses and care workers are central to the provision of care encompassing all aspects of health care. This includes health promotion, prevention of illness and injury, care of the ill, disabled and dying. Care should be evidence-based and holistic in addressing physical, mental, social, and emotional wellbeing and should also be delivered in a manner that is appropriate and consistent with the individual preferences, values, and beliefs of each person.

[1] Care workers can be referred to by a variety of titles, including but not limited to 'assistant in nursing', 'personal care worker' and 'aged care worker'. In Australia, these staff are unregulated in contrast to registered nurses and enrolled nurses. For the purposes of this submission, workers who provide assistance in nursing care within RACFs are referred to as care workers.

Person Centred Care (PCC)

13. At its most basic, PCC is about focussing care on the needs of the individual person as opposed to the needs of the service. Person centred care acknowledges that each individual has their own needs, preferences, priorities, beliefs and views of how they would like (or not like) to be cared for.[2] These factors are also flexible and fluid; they may change over time. Person centred care has at its heart, the aim of enabling people to act as equal partners in the planning of their care and to always feel that their opinions and preferences are listened to and important. When a person is not able to make their own perspective known to staff, they may have a delegated person to make decisions and be involved in PCC on their behalf, this is discussed further below in relation to ACP. Person centred care is integral to the delivery of good practice care in RACFS and is the responsibility of all staff and organisations.

14. The ANMF and its members support and actively promote PCC. There are good practice models of PCC for RACFs that are led by or involve nurses. The ANMF and its members seek to improve PCC principles and address gaps in practice in line with the broader drive to enhance the delivery of PCC across all health and aged care contexts. The ANMF and its members value and understand the importance of the relationship between residents, their relatives/loved ones, and staff members and seek to work in partnership with them to deliver good practice PCC.

15. Known barriers to the provision of PCC include the related burdens of lack of time and lack of staff, as well as lack of organisational support, resources, and training.[3] A focus on ensuring sufficient staffing and skills mixes in RACFs as well as the provision of improved resources, training, and organisational support for the delivery of and mechanisms that support PCC is vital.

16. Person-centred care has demonstrated benefits among RACF residents with dementia including upon ability to perform activities of daily living and quality of life.[4,5] Cost-savings for RACFs may also be realised via the implementation of PCC.[6]

17. Person-centred care is also about ensuring that individuals, their relatives and loved ones are able to make informed decisions and choices regarding their care; now and

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[2] McCormack, B., and McCane, T. (Eds) (2016) Person-centred practice in nursing and health care: Theory and Practice. John Wiley and Sons. Chichester, West Sussex.

[3] West, E., Barron, D.N., and Reeves, R. (2005). Overcoming the barriers to patient-centred care: time, tools and training. *Journal of Clinical Nursing.* 14(4):435-443. Available online: https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2702.2004.01091.x

[4] Sjögren, K., Lindkvist, M. and Sandman, P.O. et al. (2013). Person-centredness and its association with resident well-being in dementia care units. *Journal of Advanced Nursing.* 69(10):2196-205. Available online: https://onlinelibrary.wiley.com/doi/full/10.1111/jan.12085

[5] Chenoweth, L., Stein-Parbury, J., and Lapkin, S. et al. (2019). E ffects of person-centered care at the organisational-level for people with dementia. A systematic review. *PLoS One.* 14(2):e0212686. Available online: 10.1371/journal.pone.0212686

[6] Ballard, C., Corbett, A. and Orrell, M. et al. (2018) Impact of person-centred care training and person-centred activities on quality of life, agitation, and antipsychotic use in people with dementia living in nursing homes: A cluster-randomised controlled trial. *PLoS Med.* 15(2):e1002500. https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002500

in the future. Ensuring that ACP is undertaken in collaboration between staff and residents and/or a designated relative or loved one is one example of this.

18. Another example is ensuring that people are able to make decisions regarding their care based on information about a RACF prior to entering the facility as a resident; to ensure that the type and nature of care they will receive is in line with their needs and preferences. There is an absence of information for consumers regarding staffing and skills mix of RACFs to be able to assess whether a particular RACF is suitable for providing the type of care that a resident may want. For example, the skills and staffing mix of a RACF is not readily available to consumers, so currently people are hampered in their choices regarding selection of a suitable RACF.

19. Person-centred care must recognise the diversity of RACF residents including but not restricted to; culturally and linguistically diverse, Aboriginal and Torres Strait Islander, gender and sexually diverse (LGBTQI+) people. People from these groups (or who belong to intersecting groups) may or may not share common preferences, values, or beliefs regarding their care including in relation to palliative care, ACP, and end of life care. It is vital that staff are trained, supported, and have the time to engage individually with each resident and/or their relatives and loved ones to enable good practice PCC.

20. Patient-centred care (a closely related concept to PCC more attuned to acute care contexts with hospital patients) is an expectation of nursing that recognises the person or designated representative of that person (e.g. a designated relative or loved one) as a partner in the coordination of care based upon that person's wishes. As with PCC, patient-centred care is especially important at the end of life and requires expertise and a range of skills expected of and within the scope of practice of nurses.[7,8]

21. Evidence-based practice and PCC has been argued to be challenging to reconcile.[9] This is apparent where the available clinical evidence underpinning care planning for a resident may be at odds with the personal and potentially unique preferences for care held by that person and/or their relatives or loved ones. More recent advances in technology, research, and the approach to care however is increasingly enabling the complementary delivery of evidence-based practice and PCC.

22. Aged care staff must be aware of key ethical principles to ensure that residents, relatives and loved ones are provided with clear, evidence-based information they require to make informed decisions in line with their own preferences, values, and beliefs. Staff must also be able to support residents and relatives through decision

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[7] Ferguson, R. (2018). Care coordination at the end of life: the nurse's role. *Nursing.* 48(2): 11-13. Available online: https://oce.ovid.com/article/00152193-201802000-00004/HTML

[8] Royal College of Nursing (RCN). (2016). Fundamentals of end of life care: Roles and responsibilities. RCN. Available online: https://rcni.com/hosted-content/rcn/fundamentals-of-end-of-life-care/roles-and-responsibilities

[9] Weaver, R.R. (2015). Reconciling evidence-based medicine and patient-centred care: defining evidence-based inputs to patient-centred decisions. *Journal of Evaluation in Clinical Practice*. 21(6):1076-1080. Available online: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5057360/

making processes. Person-centred care in combination with evidence-based health care practices can yield outcomes benefiting both recipients of care and organisations.[10]

23. Beyond the benefits for residents of RACFs, PCC is also known to improve outcomes for staff, such as job characteristics and job-related well-being, particularly for staff members who feel supported.[11] As workforces who engage in PCC feel more competent, further implementation of PCC may have a positive impact on the attractiveness of RAFC employment.

ADVANCE CARE PLANNING (ACP)

24. Advance care planning (ACP) is an important component in the provision of high-quality end-of-life care. It is undertaken to support an individual who is at any stage of health, and maintains a decisional capacity, to plan for their future care. This planning requires that an individual understands and shares their personal life goals, values and preferences across physical, psychological, social, and spiritual domains between themselves, their family, and healthcare providers.[12]

25. The goal of ACP is to ensure the individual receives best-quality care consistently aligned to these criteria. Should the individual's criteria shift then revision of the care plan may be required to ensure they continue to receive the best-quality care. The ACP may also include the appointment of a trusted person to make medical decisions on behalf of the individual should they lose the capacity to do so.[13]

26. Advance care planning in RACFs refers to discussions between residents, families, and healthcare professionals on future healthcare decisions, in advance of anticipated impairment in decision-making capacity. Advance care planning improves satisfaction and end-of-life care, while respecting individual resident autonomy. A written advanced care directive (ACD) may be developed based on ACP.[14, 15]

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[10] Delaney, L.J. (2018). Patient-centred care as an approach to improving health care in Australia. *Collegian*. 25:119-123. Available online: https://www.collegianjournal.com/article/S1322-7696(17)30042-2/pdf

[11] Willemse, B.M., De Jonge, J., and Smit, D., et al. (2015). Staff's person-centredness in dementia care in relation to job characteristics and job-related well-being: a cross-sectional survey in nursing homes. *Journal of Advanced Nursing*. 71(2):404-16. Available online: https://onlinelibrary.wiley.com/doi/full/10.1111/jan.12505

[12] Sudore, R.L., Lum, H.D., and You., J.J. et al. (2017) Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. *Journal of Pain and Symptom Management*. 53(5): p. 821-832.e1. Available online: https://linkinghub.elsevier.com/retrieve/pii/S0885-3924(16)31232-5

[13] Shepherd, J., Waller, A., and Sanson-Fisher, R. et al. (2018). Knowledge of, and participation in, advance care planning: A cross-sectional study of acute and critical care nurses' perceptions. *International Journal of Nursing Studies*. 86:(Oct):74-81. Available online: https://www.sciencedirect.com/science/article/pii/S0020748918301433

[14] Weathers, E., O'Caoimh, R., and Cornally, N., et al. (2016). Advance care planning: A systematic review of randomised controlled trials conducted with older adults. *Maturitas*. 91(September):101-109. Available online: https://www.sciencedirect.com/science/article/pii/S0378512216301487

[15] Rietjens, J.A.C., Sudore, R.L., and Connolly, M. et al. (2017) Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *The Lancet Oncology*. 18(9): e543-e551. Available online: https://linkinghub.elsevier.com/retrieve/pii/S1470-2045(17)30582-X

27. Nurses can have important roles in ACP both in acute healthcare and primary care (e.g. general practice) as well as within RACFs and there is a growing understanding of the responsibilities that nurses can take in terms of advocating on behalf of residents and ensuring that ACP is undertaken sensitively and collaboratively with residents and their relatives/loved ones.[16]

28. In Australian RACFs, prevalence rates of ACDs appear to be generally higher than for people in the community or hospital, with 48% of residents having one or more ACD. However, there are likely to be unmet needs regarding ACP, as only 4% of all people rated as being "completely disabled" were noted to have a statutory directive for preferences of care and only 14% had a formally appointed substitute decision-maker in a statutory directive.[17,18]

29. The ANMF supports ACP whereby individuals consider end-of-life decisions while they have the capacity to do so, and to provide instructions about their wishes for future treatment as direction for their family and health professionals.[19] Adequate time, training and education, sufficient staffing, and skills mixes are required to work collaboratively with residents and their relatives/loved ones regarding ACP and to ensure that residents and relatives feel supported and listened to throughout the process.

30. Person-centred care is an important factor for good-practice delivery of ACP in RACFs, where person-centredness is a known facilitator for better ACP where nurses play a key role in eliciting individual preferences, values, and beliefs. A person-centred approach to ACP is important to lessen the challenging and sometimes taboo nature of frank, open discussions regarding death and dying for some older people as it can be empowering and aid in better decision-making.[20,21]

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[16] Izumi, S. (2017). Advance Care Planning: The Nurse's Role. *American Journal of Nursing*. 117(6):55-61. Available online: https://oce.ovid.com/article/00000446-201706000-00028?relatedarticle=y

[17] A statutory directive is a legislated State-based ACD used to outline a person's preferences of care and/or appoint a substitute decision-maker who can be called upon to make medical treatment decisions on behalf of a person whose decision-making capacity is impaired (Definitions from Buck, K., Detering, K., Sellars, M., et al. (2017) Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services, Short Report. Advance Care Planning Australia, Austin Health, Melbourne. Available online: https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/2018-prevalence-study/report-prevalence-of-advance-care-planning-document-2017_summary-final.pdf?sfvrsn=2

[18] Buck, K., Detering, K., Sellars, M., et al. (2017) Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services, Short Report. Advance Care Planning Australia, Austin Health, Melbourne. Available online: https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/2018-prevalence-study/report-prevalence-of-advance-care-planning-document-2017_summary-final.pdf?sfvrsn=2

[19] Australian Nursing and Midwifery Federation (ANMF). Assisted Dying: ANMF Position Statement. Available online: http://anmf.org.au/documents/policies/PS_Assisted_Dying.pdf

[20] Batchelor, F., Hwang, K., and Haralambous, B., et al. (2019). Facilitators and barriers to advance care planning implementation in Australian aged care settings: A systematic review and thematic analysis. *Australasian Journal on Aging*. [Early View Version]. Available online: https://onlinelibrary.wiley.com/doi/full/10.1111/ajag.12639

[21] Sellars, M., Chung, O., and Nolte, L., et al. (2018). Perspectives of people with dementia and carers on advance care planning and end-of-life care: A systematic review and thematic synthesis of qualitative studies.

Palliative Care

31. Palliative care involves a person and/or family-centred approach that aims to improve the quality of life of people and their families facing the problems associated with life-limiting illness or conditions, through the prevention and relief of suffering by means of early identification, assessment, and treatment of pain and other problems, physical, psychosocial, and spiritual.[22,23]

32. In the present submission, the ANMF utilises the broadest definition of palliative care.[24] Palliative care may begin upon diagnosis or identification of a life-limiting or incurable illness or condition from which a person is unlikely to recover, and is focused upon ensuring that a person is able to live fully and comfortably. It is important to understand that palliative care is not just about end of life care; the provision of palliative care should be based upon individual need rather than prognosis.[25]

33. Palliative care involves treatment of individuals who have a serious illness or condition in which a cure or complete reversal is no longer possible. This is particularly the case for many residents of RACFs who, while not approaching the end of life more acutely (e.g. within the coming weeks or months), are unlikely to be 'cured' or to 'recover fully' due to the natural processes of ageing and decline. The purpose of palliative care is to assure the individual and those involved in his or her life experience, optimal quality of life both leading up to, and throughout end of life.

THE PROBLEMS

Lack of mandated minimum staffing levels and skills mix

34. Despite the recognition of the importance of the provision of PCC, APC, and palliative care for residents of RACFs, there are no mandated minimum staffing levels, skills mix, or models for aged care to ensure that staff can effectively provide these.

35. 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

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Palliative Medicine. 33(3): 274-290. Available online: https://journals.sagepub.com/doi/10.1177/0269216318809571

[22] Sepúlveda, C., Marlin, A., and Yoshida, T. et al. (2002). Palliative Care: The World Health Organization's Global Perspective. *Journal of Pain and Symptom Management*.24(2):91-96. Available online: https://www.sciencedirect.com/science/article/pii/S0885392402004402?via%3Dihub

[23] Ahmedzai, S.H., Costa, A., and Blengini, C. et al. (2002). A new international framework for palliative care. *European Journal of Cancer*. 40(15): p. 2192-2200. Available online: https://www.sciencedirect.com/science/article/pii/S0959804904004976?via%3Dihub

[24] World Health Organisation (WHO). (2019). WHO Definition of palliative care. WHO. Geneva. Available online: https://www.who.int/cancer/palliative/definition/en/

[25] Krau, S.D. (2016). The Difference Between Palliative Care and End of Life Care: More than Semantics. *Nursing Clinics of North America*. 51:ix-x: Available online: https://www.nursing.theclinics.com/article/S0029-6465(16)30027-5/pdf

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 PCC, APC, and palliative care in RACFs.

36. It is likely that low numbers of staff (i.e. low staff to resident ratios), under-resourcing, and inadequate organisational and business models significantly hamper RACF staff from providing quality PCC. A RACF's capacity to provide good personal and clinical care is strongly contingent on adequate staffing; both the number of staff and their qualifications and training.

37. The findings of the ANMF's National Aged Care Survey 2019 indicated that although end of life discussions did occur with residents and families at their workplaces, they were often problematic. Survey participant's responses highlighted the difficulty for many, both staff members, who are not trained in the process, and families and residents, in confronting and dealing with end of life issues. Because of a reluctance to discuss the pathways to 'dying well' participants also recognised that families' expectations can be unrealistic.

38. The survey report included these comments from RACF staff members in relation to the above and the impact that high workloads and lack of adequate staffing levels have upon PCC, ACP, and palliative care:

    i. *"Time is an issue to have a proper discussion and assist families to fill in the form, especially when some families find the topic very sensitive.*
    ii. *The discussions are had and then rarely followed through as staff either don't have the time to put end of life wishes in place or do not have the experience required.*
    iii. *No end of life pathways in place that are satisfactory to meeting the needs of these residents and not enough trained staff and time to sit with the residents and their families to discuss these issues to provide the palliative care and comfort measures in the facility if the resident chooses to do so.*
    iv. *But it is often put off until the absolute necessary like when the resident is already dying and the family is already stressed and so they don't want to think about it and that leaves the staff in opposition quite often without advanced care directives because it gets left."*

Lack of specific training

39. The 2012 and 2016 Aged Care Workforce Surveys found that direct care workers in the aged care sector identified "palliative care" (and dementia) as one of the top two areas where they require further education and training.[26,27] In 2016, palliative

[26] King, D., Mavromaras, K., and Wei, Z., et al. (2013). National Institute of Labour Studies, Flinders University (2013). The aged care workforce 2012: Final report. Available online: http://www.agedcarecrisis.com/images/pdf/The_Aged_Care_Workforce_Report.pdf

[27] Mavromaras, K., Knight, G., and Isherwood, L., et al. (2017). National Institute of Labour Studies, Flinders University (2013). The aged care workforce 2012: Final report. Available online: https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/03_2017/nacwcs_final_report_290317.pdf

care, one of the most common areas of specialisation within the aged care workforce along with dementia care and mental health training, remains a high priority for future workforce training particularly in regional and rural areas where access to training is lower.

40. There is a lack of specialist trained nurses and care workers providing PCC, ACP, and palliative care. Residents, their relatives and loved ones should be able to be confident that staff are trained and supported to provide the type of care that is required and desired by residents. Generic training may not be sufficient for ensuring that palliative care is provided in a person-centred manner, or that ACP are carried out collaboratively and sensitively.

41. Nurses, particularly registered nurses, are vital to the provision of ACP in RACFs, where factors such as communication, leadership, and critical thinking skills are known to enable nurses to positively impact upon the uptake of ACP. Lack of knowledge and education regarding ACP reduces the confidence of RACF staff to engage in ACP discussions with residents and is associated with poor uptake of ACP. Additionally, low awareness, absence or complexity of written information, and difficulties with understanding the details of ACP among residents and families is a barrier to the uptake and successful implementation of ACP in RACFs. Nurses who are trained and supported to increase their knowledge and confidence with ACP enable improved uptake of ACP.[28]

42. Good practice ACP is supported by effective multi-disciplinary collaboration between health and aged care professionals with residents and their family members to explain medical and legal terms and lessen the burden for residents and family members and residents. The specific expertise of nurses and the presence of well-integrated, standardised processes and documentation for ACP in RACFs are also central.[29]

43. Staff training and ongoing professional development regarding ACP in the absence of adequate staffing levels is not effective on its own, as time constraints are a known barrier to ACP and these time constraints themselves are often due to lack of enough staff.[30,31] To deliver best practice ACP, there need to be enough trained staff available to have the necessary time to discuss ACP with RACF residents and family members.

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[28] Batchelor, F., Hwang, K., and Haralambous, B., et al. (2019). Facilitators and barriers to advance care planning implementation in Australian aged care settings: A systematic review and thematic analysis. *Australasian Journal on Aging*. [Early View Version]. Available online: https://onlinelibrary.wiley.com/doi/full/10.1111/ajag.12639

[29] Ibid.

[30] Ibid.

[31] Ampe, S., Sevenants, A., and Smets, T., et al. (2017). Advance care planning for nursing home residents with dementia: Influence of 'we DECide' on policy and practice. *Patient Education and Counselling.* 100(1): 139-146. Available online: https://www.sciencedirect.com/science/article/pii/S0738399116303524

Care workers, PCC, ACP, and palliative care

44. While nurses provide much of the necessary planning and care around palliative and end of life care including ACP due to their training and expertise, care workers are also greatly involved in the delivery of care for RACF residents.

45. Care workers are important members of the care team in RACFs and have a valuable role in the delivery of PCC.[32] It is important to note however, that many care workers have not undertaken the same level and type of education and training as nursing staff, so may not have the same advanced skills and understanding of the concepts and practical aspects of the delivery of PCC.

46. While nurses are regulated - providing 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.

47. Care workers who lack training and education in PCC and end of life care including ACP and palliative care may not enable the best-practice delivery of these vital features of care in residential facilities. Care workers in Australia have been found to have a reasonable but relatively superficial understanding of PCC.[33] One reason for this may be a global gap in PCC education for care workers.[34]

48. Despite the absence of specific PCC education for care workers, they do have understandings of the practice dimensions of caring for people at the end of life and themselves require effective support, for example to assist with the emotional challenges of caring for dying residents and their families with whom close emotional attachments have formed.[35]

49. As experienced by nurses, lack of time to spend with residents in a psychosocial context is a noted barrier to the provision of PCC by care workers.[36] Teamwork is a key enabler of PCC among care workers and is based on findings that many care tasks require multiple staff to work together and to support one another to deliver safe, effective care.[37] To support teamwork, there must be a sufficient number and skills mix present to ensure that care workers can work collaboratively and be supervised and coordinated by skilled and experienced nursing staff with specific training and education in PCC, ACP, and palliative care.

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[32] Kadri, A., Rapaport, P., and Livingston, G. (2018). Care workers, the unacknowledged persons in person-centred care: A secondary qualitative analysis of UK care home staff interviews. *PLoS One.* 13(7):e0200031. Available online: doi: 10.1371/journal.pone.0200031

[33] Oppert, M.L., O'Keefe, V.J., and Duong, D. (2018). Knowledge, facilitators and barriers to the practice of person-centred care in aged care workers: a qualitative study. *Geriatric Nursing.* 39(6):683-688.

[34] Colomer, J., and de Vries, J. (2016). Person-centred dementia care: a reality check in two nursing homes in Ireland. *Dementia*. 15(5):1158-1170. Available online: https://journals.sagepub.com/doi/10.1177/1471301214556132

[35] Vandrevala, T., Samsi, K., and Rose, C., et al. (2016). Perceived needs for support among care home staff providing end of life care for people with dementia: a qualitative study. *International Journal of Geriatric Psychiatry*. 32(2): 155-163. Available online: https://onlinelibrary.wiley.com/doi/full/10.1002/gps.4451

[36] Ibid. 33.

[37] Ibid. 33.

50. The average stay in an RACF is 2.5 years and more than 80% of exits from RACFs are due to death, further around 56% of people who exit from home care enter RACFs.[38] It is clear then, that many people should receive palliative and end of life care within RACFs. Good person centred practice for end of life care involves careful symptom assessment and management, skilled management of pain, discomfort, and distress, and compassionate and collaborative engagement with residents and their relatives regarding ACP.[39] As noted by the Australian College of Nurses:[40]

> *"This is clearly the domain of nurses, and patients who are in need of this level of care require specialised* [registered nurse] *input, supervision and support. However, senior Australians are receiving* [end of life] *care by* [unregulated healthcare workers] *with no or minimal training in dignified* [end of life] *care to ensure the wishes of these individuals are respected (i.e. advanced care directives)."*

51. This issue 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 (emphasis added):

> *"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 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."*

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[38] Australian Institute of Health and Welfare (AIHW) GEN Aged Care Data. (2019). People leaving aged care. Australian Government. Available online: https://www.gen-agedcaredata.gov.au/Topics/People-leaving-aged-care

[39] Schroeder, K. and Lorenz, K. (2018) Nursing and the future of palliative care. *Asia Pacific Journal of Oncology Nursing.* 5(1):4-8. Available online: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5763437/

[40] Australian College of Nurses (ACN). (2019) White Paper: Regulation of the unregulated health care workforce across the health care system. Australian College of Nurses. Available online: https://www.acn.edu.au/wp-content/uploads/white-paper-regulation-unregulated-health-care-workforce-across-health-care-system.pdf

Lack of access to palliative care in RACFs

52. Access to palliative care in Australian RACFs can be poor, especially for people with dementia who may have challenges effectively participating in person-centred, collaborative end of life care such as palliative care and ACP discussions. They may be particularly at risk of poorer access.[41]

53. A recent Productivity Commission Report highlighted the poor state of palliative care and end of life care in many RACFs and noted that this concern was shared by both Alzheimers Australia and Palliative Care Australia.[42] Unmanaged, severe pain is a frequent problem where without 24-hour nurse cover, residents may wait hours for proper pain relief. This report also noted that RACFs can be 'reluctant' to accept new residents who are dying due to an inability to provide care due to there being too few registered nurses. Additional staff and more training is urgently required to ensure that palliative care and end of life care are improved. Indeed, Palliative Care Australia noted that in RACFs, the '*structure and staff mix is heavily weighted in the lower paid unregulated staff (PCAs) [personal care assistants] with inadequate levels of qualified healthcare staff especially outside standard business hours*'.

Poor integration with other aspects of health care

54. 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 allied health professionals, care can be missed, not delivered in a timely fashion or best health outcomes are not achieved. This is particularly pertinent for palliative and end of life care.

55. The provision of care provided within a RACF must also be closely integrated with other healthcare providers, such as local general practitioners, specialists (e.g. in palliative care) hospital, and respite care. This is of particular importance in the context of palliative care, end of life care, and ACP where involvement of other healthcare professionals can become increasingly necessary. Where there is inadequate or failed communication between healthcare providers the risk of errors and missed care increases considerably. People at the end of their lives, and especially those with dementia, are particularly vulnerable to the risks of failed or inadequate communication.

56. At the end of life, transfers between care settings (e.g. to hospital emergency departments) can be difficult and traumatic for both residents and their relatives/loved ones. As noted by the Productivity Commission, which noted that end of life care appears to be poorly provided in many RACFs:

> *"Too many people who, with appropriate support, could and would choose to die at home or in their aged care residence, die in hospital. Providing end of life care*

[41] Alzheimer's Australia (2013). Paper 37: Quality of residential aged care: The consumer perspective p 4. https://fightdementia.org.au/sites/default/files/20131112_Paper_37_Quality_of_Residential_Aged_Care.pdf
[42] Australian Government Productivity Commission. (2018). Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services. Report No. 85, Canberra. Available online: https://www.pc.gov.au/inquiries/completed/human-services/reforms/report

for these people where they live would better meet their clinical needs and reflect their choices."[43]

57. Unnecessary transfers at the end of life should be minimised, and staff collaboration and communication with residents and their relatives/loved ones is an important way that this could take place. Families often play a significant role in resident transfer decisions in reaction to changes in condition. Relatives' insecurities with RACF care; unpreparedness for end of life; absent/inadequate ACP; and lack of communication and agreement within families regarding care goals are often linked with relatives' desire to transfer residents from a RACF to a hospital at the end of life.[44] This was also identified by aged care staff members in the ANMF's 2019 Survey:

    i. *"But they [ACP] are not done frequently enough or in-depth enough, leaving residents and families with unrealistic expectations and RNs left with no alternative than to send to hospital even when they do not believe it would be of significant benefit to the resident."*

58. Improved communication and lack of access to appropriate and timely palliative care support and expertise in RACFs may contribute to frequent but potentially unnecessary and harmful transfers at the end of life. Improving palliative care within RACFs though improved staffing levels, skills mixes, training, and integration with multidisciplinary health care professional and specialists would improve the delivery of person-centred end of life care.

What is needed to provide best practice person centred care, advance care planning and palliative care?

Workforce support

59. Mandated minimum staffing levels and skills mixes with the capacity to deliver person centred palliative care and ACP must be introduced and published to ensure that consumers are able to make informed decisions regarding the choice of RACF before entering residential aged care and to be confident that there are enough staff with the right education and qualifications to deliver best practice person-centred care.

60. The aged care workforce should be trained in PCC, palliative care, and participating in ACP- whether at certificate, diploma or degree level. Training, mentoring, and professional development should be ongoing and reflect evidence based best practice.

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[43] Ibid.

[44] Stephens, C., Halifax, E., and Bui, N. et al. (2015). Provider Perspectives on the Influence of Family on Nursing Home Resident Transfers to the Emergency Department: Crises at the End of Life. *Current Gerontology and Geriatrics Research.* Article ID 893062. Available online: https://www.hindawi.com/journals/cggr/2015/893062/

61. In line with the Australian Productivity Commission's recommendations; aged care providers should be required to ensure that clinically trained staff hold ongoing conversations with RACF residents about their future care needs. This would ideally be part of the role of nurses or nurse practitioners employed in the RACF but could also be undertaken by general practitioners or as part of an arrangement with an external palliative care service. Care workers are also part of ACP, however, are not suitably trained and prepared to lead in this role.[45]

62. To meet the needs of the growing population of older people including people with dementia and people from diverse social and cultural backgrounds living in RACFs, the workforce needs to increase and itself become more diverse. Work conditions, remuneration, and career structures should be in place to attract suitably qualified people to work in RACFs who are able and qualified to provide PCC.

Regulatory standards

63. 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. Without including mandated minimum staffing and skills mix requirements, it will be impossible to ensure that the right staff are available to deliver upon the new standards.

64. It is also important that ongoing evaluation against the new Aged Care Quality standards is completed to ensure that RACFs are meeting their intended requirements. Along the same line, evaluation of RACFs to ensure that adequate minimum staffing levels and skills mixes are maintained is also required.

65. Clinical quality indicator data will be required to be submitted from all Commonwealth funded RACFs 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.

66. Further, beyond the basic monitoring, collection, and reporting of this data, robust examination and analysis must occur in order to identify the risk factors and causes that underlie these outcomes. This will be vital to future implementation of measures to reduce risk, improve outcomes and deliver on ensuring continuous improvements to care in RACFs.

67. 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.

[45] Ibid. 42.

68. 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 care

69. All residents of RACFs and/or their designated relatives or loved ones should have engaged in APCs with trained RACF staff. Plans should identify agreed care, treatment, behavioural strategies, and wishes of the individual. Where agreed with the resident or designated relative, ACP should also include person-centred palliative care and end of life planning.

70. Advance care plans setting out health and wellbeing goals regarding person-centred palliative and end of life care should be in place and reviewed regularly with the resident and/or their designated relatives or loved ones. Plans should reflect the individual's wishes and balance dignity of risk with the capacity to ensure the safety and wellbeing of others.

71. Facilities should be built or designed for the purpose of facilitating PCC that offer secure, safe spaces and reflect best evidence-based practice - such as providing home-like, comforting surroundings, sensory, and calm areas. It is important to note however that the diverse and increasing clinical needs of RACF residents must also be supported by sufficient clinical capacity and that to provide good practice palliative care in place, a RACF must also be considered to be a healthcare facility.

72. Person centred care must be provided in settings that acknowledge diversity. Cohorts of people with dementia such as CALD groups, LGBTQI+ people, younger people, and others have different care needs that must be considered, discussed, and met in collaboration with trained staff.

73. Evidence-based models of nurse-led palliative and end of life care should be considered. Nurse practitioners and registered nurses in RACFs can play a leading role in coordinating palliative and end of life care and also work collaboratively with other multidisciplinary healthcare professionals within and outside RACFs as required that would result in better quality care and more accessible care, particularly for people in regional and remote areas.

74. 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.

75. The work of nurses and care workers should be supported and complemented by general practitioners, geriatricians, allied, and specialist health professionals.

76. There should be a multi-disciplinary, integrated approach to person-centred, palliative and end of life care of people in RACFs and when accessing acute, specialist, or respite care.

77. Residential aged care facilities 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.

78. Technology should be utilised creatively and to minimise unnecessary transfer and movement of people for end of life care. For example, teleconferencing and telehealth services between RACFs 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. The Nurse Practitioner Reference Group to the Medicare Benefits Schedule Review Taskforce has recommended that telehealth consultations should take place via telephone where clinically appropriate (i.e. without requiring a video connection) which would also improve RACF access to broader healthcare professional support and services and be especially useful to rural, regional, and remote RACFs.[46]

79. Trained staff such as registered nurses and nurse practitioners should work collaboratively with residents and their relatives/loved ones to help explain palliative care and end of life so that person-centred care plans and decisions can be made such as those around transfers and ACP.

80. All individuals must be treated with dignity and respect. At all times any intervention should be in accordance with agreed PCC plans, subject to medical and clinical review both initially and ongoing and recognise diversity and the needs of the individual and their relatives/loved ones.

81. A cultural shift to viewing the provision of aged care as providing person centred health care should be encouraged. Where relevant, palliative care 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, along with that of their relatives/loved ones should be central.

82. With the right levels of staffing and skills mix within RACFs that also support and facilitate optimum multidisciplinary collaboration between healthcare professionals and partnership and involvement of residents and their loved ones or relatives in person-centred, palliative care the distress associated with transfer to acute facilities for end of life care that could otherwise be delivered within an RACF could be avoided.[47] Palliative care should focus on interventions that improve quality of life in

[46] Medicare Benefits Schedule Review Taskforce Nurse Practitioner Reference Group (MBS NPRG). (2018). Report from the Nurse Practitioner Reference Group. Available online: https://www.acnp.org.au/mbs-review
[47] Mitchell S.L., Teno, J.M., Intrator, O., Feng, Z., and Mor, V. (2007) Decisions to forgo hospitalization in advanced dementia: a nationwide study *Journal of the American Geriatrics Society* 55(3):432-438 DOI: 10.1111/j.1532-5415.2007.01086.x

line with a person's wishes,[48] rather than procedures that cause distress without substantially or meaningfully affecting outcome.[49] A point emphasised by aged care staff members in the ANMF's 2019 survey:

i. *"Palliative care is frequently not managed or poorly managed due to lack of staff and skilled registered staff. This poses extreme pressures on experienced registered staff as they will not be supported with decision-making, creating gaps in documentation, forcing residents to experience poor palliation or being transferred to hospital against their wishes."*

Sufficient funding

83. Governments must ensure there is sufficient funding to meet the growing demand for PCC, ACP, and palliative care in RACFs. 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 the absence of appropriate funding for mandated staffing levels and skills mix to deliver this vital care for RACF residents.

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[48] Ibid.

[49] Morrison, R.S., Ahronheim, J.C., Morrison, G.R., Darling, E., Baskin, S. A, Morris, J., Choi, C., and Meier, D.E. (1998) Pain and discomfort associated with common hospital procedures and experiences *Journal of Pain and Symptom Management* 15(2):91-101 https://doi.org/10.1016/S0885-3924(98)80006-7