



National Partnership Agreement: Comprehensive Palliative Care in Aged Care

WA Deep Dive Impact Evaluation **SUMMARY REPORT**

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For Further Information:
Professor Samar Aoun
samar.aoun@perron.uwa.edu.au

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INTRODUCTION

The Perron Institute was commissioned by the Western Australian Department of Health End-of-Life Care Program (EOLCP) to conduct an independent 'deep dive' evaluation on the impact of palliative and end-of-life (EOL) care initiatives in Residential Aged Care Homes (RACH), from the perspectives of consumers and service providers. This summary report is a consolidated version of the separate full report which describes the implementation and analyses of three phases of the evaluation in further detail. [Appendix 1](#) in this document outlines the key terms used in both reports and [Appendix 2](#) recognises the contribution of the research team and reference group.

Objectives

The aim of the independent deep dive impact evaluation was to understand the broader impacts of the WA National Partnership Agreement for Comprehensive Palliative Care in Aged Care (NPA) projects on residents, families, carers and service providers and to provide recommendations for long-term planning. The specific objectives were to: (i) gain a consumer perspective on palliative care in RACHs, (ii) identify key challenges/gaps in the provision of EOL care from consumer and provider perspectives and (iii) determine how service delivery can adapt and improve to meet community needs and expectations.

This was achieved by undertaking:

Phase 1: A survey on perspectives of consumers (bereaved carers) of people who died in RACHs in WA, between 2021 and 2024.

Phase 2: Consultations with service providers around the findings of the consumer survey.

Phase 3: A survey of service providers comparing outcomes from RACHs who had implemented NPA initiatives versus those RACH sites who had not.

Community & Aged Care Sector Engagement

This independent evaluation has been informed by 428 people across WA. This included 317 bereaved carers, each telling us about a relative who was a resident in a RACH in WA and died between 2021-2024. It also included 111 current employees from the aged care sector who worked in RACHs in various capacities, both clinical and non-clinical.

PHASE 1- CONSUMER SURVEY

A cross-sectional consumer survey was designed by Aoun et al. (2021) to explore indicators of the quality of care or experience, called 'quality indicators', related to the six priorities of the WA End of Life and Palliative Care Strategy for 2018-2028 (the Strategy) for developing and improving palliative care services across WA (Department of Health WA, 2018). It was adapted to the aged care setting in 2024 for this evaluation. The six priorities are:

1. Care is accessible to everyone, everywhere.
2. Care is person-centred.
3. Care is coordinated.
4. Families and carers are supported.
5. All staff are prepared to care.
6. The community is aware and able to care.

More than half of the 317 bereaved carers who completed the survey identified as female (63%), with a median age of 51 years. Almost half of carers were university educated (47%). A third of carers identified as their relative's main carer (30%), over half reported their relationship to the deceased as being a female relative such as daughter/granddaughter (55%), and 84% of bereaved carers lived in the metropolitan area. Less than half of carers (41%) reported their relative accessed palliative care services (PC user) whilst a resident in the RACH, less than one third (30%) reported their relative did not receive palliative care services (non-PC user), whilst the remainder of carers reported they were not sure (29%).

Just over a half of deceased residents were female (55%) with a median age of 86 years, and 84% lived in a RACH located in a metropolitan area. Almost half of residents were reported as having a dementia diagnosis (46%) and co-occurring frailty due to old age (49%). Residents spent a median of 1.8 years in the RACH before their death, and 78% died there. The 317 survey responses were attributable to 46 RACH 'organisations' across WA. It is important to note the distinction between the 'organisations' who operate RACH services from the individual RACH 'sites' of these organisations. Despite the consumer survey questions asking respondents for RACHs' name and postcode so sites can be quantified, these details were not consistently disclosed by all participants and therefore cannot be used to draw an accurate conclusion about the number of individual RACH 'sites' involved in the consumer survey.

This study sample was comparable to the general Australian RACH population in the following variables: the age distribution of residents; proportions living with dementia; proportion living in Country WA (rural); proportion dying in RACH and median length of stay at RACH.

Good quality indicators were seen across priorities, highlighted in the following reports from bereaved carers:

- 88% reported staff considered residents' EOL wishes if they were documented.
- 86% perceived staff as competent.
- 84% recalled staff treating residents with compassion, kindness, respect and dignity.
- 80% reported that care was coordinated between the RACH staff, the visiting palliative care team, if used, and the General Practitioners (GPs).
- 79% reported the quality of care as excellent or good.
- 74% reported residents' values were respected and considered.
- 72% reported the quality of end-of-life care as excellent or good.

There were also a number of indicators suggesting lower quality of care or experience. These occurred mostly in Priority Two (care is person-centred) and Four (family and carers are supported), with care around bereavement being especially noted as insufficient to meet carers' needs. Only half of respondents reported receiving as much support as wanted overall and at the time of death from RACHs, and even less (42%) received as much support as wanted after the resident's death. By contrast, family carers highly rated the informal support they received from their social networks and not-for profit organisations.

For most of the indicators in all priorities, PC users reported higher quality than the other two groups. Palliative care services made the experience of residents and families considerably better in most aspects of care.

This consumer survey is the first to report on the experiences of bereaved carers from WA RACHs as they reflect on the care, they and their loved ones received. The survey provides useful feedback to services as to where they are meeting the six priorities of the Strategy and where there are still unmet needs as experienced by their consumers. This study is particularly useful in that it now gives a baseline for experience of care across the six priorities which can be re-examined in future years as new initiatives are implemented across the sector. The reports from carers who self-reported as PC users are also used to define a subgroup likely to have been exposed to metropolitan visiting specialist palliative care services under the NPA initiatives, which contributes to understanding the NPA impacts.

PHASE 2- SERVICE PROVIDER CONSULTATIONS

The aim of this second phase of the evaluation was to assess RACH service providers' perceptions of the bereaved carers survey.

Three focus groups were conducted with 22 participants from 12 metropolitan RACHs. A variety of professional groups were represented, including staff in leadership positions, allied health, nurses, pastoral care, and care workers.

This analysis of the service provider's focus groups identified what was working well and existing challenges to palliative care services at RACHs. All service providers in the focus groups reported using the visiting specialist palliative care service, the Metropolitan Palliative Care Consultancy Service (MPaCCS), and described that the MPaCCS service worked well with the RACH for residents who were more medically complex at EOL. They described the role of MPaCCS as empowering the RACH to manage issues that arose.

In response to the bereaved carer survey results, service providers described multiple challenges in line with carer experiences: staff knowledge and confidence in providing palliative care; limited communication between the hospital, RACH, staff, and family carers; and limited GP services impacting care provision.

Participants described the following recommendations for improving palliative care in RACHs:

- Ongoing RACH staff training
- RACH Staff access to GPs, medication, and allied health
- Improved communication between family carers and RACH staff
- Grief and bereavement support

PHASE 3- RESIDENTIAL AGED CARE HOMES STAFF SURVEY

This third phase of the evaluation aimed to assess RACH staff perceptions of the impact of the NPA initiatives on their practice, guided by the 'National Outcomes and Indicators' established by Nous (2021) as a means of measuring progress against the NPA's goals and aims. Eighty-nine RACH staff completed the survey. The analyses focused on comparing outcome indicators for two groups: those who had engaged with an NPA initiative (72%) and those who had not (28%). Seven out of the nine NPA initiatives were represented, and the top three NPA initiatives reported on were: MPaCCs (58%), the Residential Care Line (RCL) (53%) and residential goals of care (RGoC) (47%). This sample of respondents had a median of five years' experience in their current role, with a third having been employed by their organisation for over five years. Over a half of respondents were employed in a clinical role followed by 29% in a managerial or leadership role.

While this sample of respondents may not be representative of the total population of RACH staff in WA, the positive impact of the NPA initiatives on practice was evident from the consistent trend in the comparisons between the two groups and the significant differences in many of the indicators. The following results are reported in Table 21 of the full report.

Outcome 1: More End-of-Life Care Discussions, Decisions and Documentation

There were significant differences between the two groups with NPA sites having better outcomes in terms of "more discussions about EOLC decision making (75% vs 44%, $p < 0.01$); EOLC documentation requested by RACH (98% vs 76%, $p < 0.01$); and documents utilised to recognise and respond to clinical deterioration (83% vs 44%, $p < 0.001$). Only about 50% of RACHs reported an increase in numbers of residents who have advance care planning (ACP) documents, Advance Health Directives (AHDs) or Residential Goals of Care (RGoC), and about 40% reporting EOLC plans being reviewed 3-6 months, and the difference between the two groups was not significant.

Outcome 2: Improved Access to Information About Palliative and End of Life Services

Significant differences existed between the 2 groups for families being provided with information about EOL planning (88% vs 56%, $p < 0.01$) and RACHs holding MDT case conferences about palliative care (77% vs 44%, $p < 0.01$), with NPA sites performing much better.

Outcome 3: Improved Recognising and Responding to Residents' Palliative Care Needs

All four indicators showed a significant difference between the 2 groups, with NPA sites performing significantly better in terms of: residents emotional/spiritual/cultural needs being met at EOL (88% vs 60%, $p < 0.01$); staff are supported to participate in PC education/training (84% vs 48%, $p < 0.001$); staff have access to assessment tools to identify clinical deterioration (84% vs 56%, $p < 0.01$); residents can access appropriate medication when changes occur at EOL (92% vs 68%, $p < 0.01$).

Outcome 4: Improved Access to Visiting Palliative Care Teams

The NPA sites performed significantly better regarding residents being able to access palliative care services in a timely manner (84% vs 48%, $p < 0.001$).

Outcome 5: Improved Quality of Palliative Care in RACHs

All three indicators showed a significant difference between the 2 groups, with NPA sites performing better: Residents are referred to specialist palliative care services if required (84% vs 52%, $p < 0.01$); Staff have access to timely clinical advice if a resident's condition changes (89% vs 56%, $p < 0.001$); Staff feel more confident in their understanding of palliative care (86% vs 56%, $p < 0.01$).

Outcome 6: Residents Dying in Their Preferred Place of Death

All three indicators showed a significant difference between the 2 groups, with NPA sites performing better: Residents preferred place of death is documented by the RACH (77% vs 44%, $p < 0.01$); Staff know how to utilise information about residents preferred place of death (64% vs 36%, $p < 0.05$); Less residents are transferred to hospital for symptom management at end of life (72% vs 44%, $p < 0.05$).

Outcome 7: Coordination Among Primary, Acute and Specialist Care

Although indicators were on the lower side for both groups than indicators in earlier outcomes, there was a statistical difference between the 2 groups in terms of: improved coordination between GPs, hospitals and PC Teams (63% vs 24%, $p < 0.01$); and between GPs and RACH staff (59% vs 28%, $p < 0.01$). There was no difference between the two groups as to RACH staff supporting GPs to coordinate case conferencing.

Outcome 8: Integrated Health and Aged Care Systems

Improved coordination of care from hospital discharge to RACH was the lowest rated indicator and showed no difference between the 2 groups (42% vs 24%, not significant).

Outcome 9: Participation in Palliative Care Quality Improvement Initiatives

While "participation in audits or quality improvement initiatives" was better for the NPA group, this indicator was on the lower side for both groups, although 36% of respondents reported they did not know if their RACH participated in such initiatives.

Conclusion: More attention regarding better quality practice is needed where indicators scored lower, namely coordination among primary, acute and specialist care (Outcome Seven); integrated health and aged care systems (Outcome Eight); and participation in palliative care quality improvement initiatives (Outcome Nine).

Major positive outcomes: Compared to non-NPA sites, NPA sites staff reported:

- A decrease in residents transferred to hospital for symptom management.
- An increase in preferred place of death being documented.
- An increase in utilising documented information about preferred place of death.
- An improvement in staff confidence in their skills and understanding of Palliative Care.
- More residents and families were provided with information about end-of-life planning.
- More utilisation of care documents to recognise and respond to clinical deterioration.
- Improved coordination between GPs/hospitals/PC teams.
- More staff are supported to participate in palliative care training and education.
- More staff have access to timely clinical advice if a resident's condition changes.

TRIANGULATION OF RESULTS USING FRAMEWORK OF WA NPA PROJECT LOGIC MAP

The findings from the three phases of this evaluation confirm what has been reported in the literature: bereaved carers called for a more person-centred care system that encompasses the residents’ needs in the physical, psychological, emotional and spiritual domains. Carers requested more timely information and appropriate resources to feel supported and needed to be more involved in care decisions undertaken within the RACH. They pointed to challenges in workforce capacity and capability and accessing health services. Staff reported needing access to ongoing education and training as identifying and communicating about residents’ palliative care needs has been highlighted as a consistent service gap. This is compounded by health interface challenges, these being access to primary, secondary and tertiary health care services.

While these gaps and challenges are not particular to WA, this evaluation has been able to shine a light on the cumulative impact of the NPA initiatives, using this deep dive methodology. One primary and common aspect of the palliative care in aged care model adopted in WA is the integration of specialist palliative care into RACHs in metropolitan areas. The impact of this integration has been evident in reports from both bereaved carers and staff:

- 1) Overall, bereaved carers reported that residents utilising palliative care services resulted in improved experiences for both residents and their family carers in most aspects of care as compared to residents who did not access palliative care services.
- 2) Staff from sites with NPA initiatives reported practices with higher quality indicators than those working in sites with no NPA initiatives.

The following discussion uses the impacts headings of the WA Project Logic Map (Appendix 7 in full report) to discuss the differences in responses between residents/carers who did or did not receive specialist palliative care and RACHs that did or did not engage with NPA initiatives. A way forward and recommendations will then follow.

Health and Quality of Life

Impacts in WA NPA Logic Map	Bereaved carers	RACH staff
Health and Quality of Life. <i>Reduced resident symptom burden and inappropriate/unnecessary procedures, hospital referrals, admissions and length of stay.</i> <i>A better experience of death and dying for residents and families/carers.</i> <i>Increased resident, family/carer and staff satisfaction.</i>	PC users reported better outcomes than non-PC users in: -Good pain and symptom management. -Palliative care accessed as soon as needed. -Cultural, spiritual background respected. -Non-PC users reported: Lower satisfaction for pain and symptom management.	NPA sites rated higher than non-NPA sites in: -Used assessments to track clinical deterioration. -More discussions on EOLC decision making. -Higher number of multidisciplinary case conferences. -Emotional, spiritual, cultural needs of residents better met.

	-Both carer groups reported being not well supported by staff at the time or after resident's death.	
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It seems grief and bereavement support were not factored in this current model of care investment. A recent systematic review reported that “families of people entering and living in residential and aged care settings have complex and dynamic bereavement care needs. The quality of care provided to an older person at the end of their life and after death care can influence family caregivers’ grief reactions”. Future initiatives need to address grief and bereavement support for staff and family carers. However, supporting family carers pre- and post-death needs a more sustainable and collaborative model of care that involves supportive informal networks and referral pathways from RACHs to community-based not-for-profit organisations. This could be achieved through a collaborative Compassionate Communities model of care. A community development approach could facilitate RACHs in accessing and developing resources available in their local communities.

Access and Choice

Impacts in WA NPA Project Logic Map	RACH staff
<p>Access and Choice. <i>Increased access to quality care options informed by regular assessments, ACP and Goals of Patient Care planning.</i> <i>A higher proportion of RACH residents die in their place of choice.</i></p>	<p>NPA sites rated higher than non-NPA sites in:</p> <ul style="list-style-type: none"> -Frequency documenting preferred place of death. -Utilising documentation on preferred place of death. -Dying in preferred place of death. <p>NPA/non-NPA sites rated similar:</p> <ul style="list-style-type: none"> -Rates of AHD, RGoC and ACP document completion. -Regular review of EOL care plans.

Seventy eight percent of residents died in RACHs and 18% in hospitals. While RACH was the stated preferred place of death for only 21% of residents, there were 27% who stated no preference and 22% whose preference was not discussed, bringing the total to 70% which is close to the actual RACH place of death proportion, reported in phase 1.

Areas that show a need for improved performance and for which there is no statistically significant difference between the NPA and non-NPA sites was in numbers of residents who have ACP documents, AHDs and RGoC, and whether residents’ EOL care plans are reviewed every 3-6 months.

This may warrant developing systems that support revisiting care plans. One example of a successful program addressing the discussion and documentation of resident care needs runs monthly palliative care needs rounds for residents with high symptom burden as described in the recommendations section. While ACP documents are often considered around the time of admission to RACH, the findings of consistent challenges and barriers highlight that advance care planning discussion and documentation is best completed in the

community. Work has been happening in this space, but it needs to be better supported for a much wider population reach.

Understanding

Impacts in WA NPA Project Logic Map	Bereaved carers	RACH staff
Understanding. <i>Improved resident and family/carer understanding of EOL&PC, informing planning and decision making.</i>	PC users reported being included in EOLC decision-making more than non-PC users.	NPA sites rated higher than non-NPA sites in: -Residents/carers provided with more information on EOL planning. -Staff more confident in their understanding of palliative care.

It is worth noting that the unsure group (29% of total sample) had significantly more rural respondents than the groups who did know if they received or did not receive palliative care, highlighting the need to expand and raise awareness of specialist palliative care models in country WA.

Capability and Capacity

Impacts in WA NPA Project Logic Map	Bereaved carers	RACH staff
Capability and Capacity. <i>A higher proportion of RACH, primary care and hospital staff have the necessary knowledge, skills and confidence to provide quality EOL&PC, within scope of practice.</i>	-Both groups of carers reported that staff appeared to have limited skills and confidence when providing EOLC. -PC users rated staff competence higher compared to non-PC users.	-Both groups of staff reported limited skills and confidence when caring for people at EOL, pointing to low death literacy. - Non NPA sites scored significantly worse than NPA sites in supporting staff to participate in palliative care training and education.

Service providers suggested increased use of professionals such as spiritual care, social work, occupational therapy, and physiotherapy to optimise quality of life at end of life. This may assist with a better experience of dying and death for residents and their carers.

Care Coordination and Communication

Impacts in WA NPA Project Logic Map	Bereaved carers	RACH staff
Care Coordination and Communication. <i>Improved coordination and communication among and between RACH, primary care and hospital staff, and improved integration of the health and aged care systems.</i>	-Both groups reported challenges accessing GPs for dying residents. PC users reported: -Higher ratings than non-PC users on RACH working well with the GP. -Out of hours care plans in place if residents' condition deteriorates.	-NPA sites rated higher than non-NPA sites in: Access to appropriate medication in a timely manner. Both groups rated similar in: -Challenges accessing GPs. -RACH supporting GPs with coordination of case conferencing. -Coordination of care from hospital discharge to RACH. -EOL care plan review audits.

There is a need to improve partnerships across the sector within the context of the poorly integrated system that exists. Future research could do a deep dive into RACHs that have good GP services versus those that do not, identifying what makes it work well and how can these factors be systematised to improve overall access to and care from GPs. The issue of variable access to GPs and medications was not significantly impacted by the current NPA initiatives and calls for further work.

System

Impacts in WA NPA Project Logic Map	Bereaved carers	RACH staff
<p>System. <i>Reduced inappropriate/ unnecessary procedures/ treatments, hospital referrals, transfers and admissions.</i> <i>Reduced demand for specialist EOL&PC services.</i> <i>Improved RACH workforce staffing levels and retention.</i> <i>Enhanced community confidence in the EOL&PC provided to RACH residents and their families.</i></p>	<p>PC users reported more: -Helpfulness of ED visits. -13% of PC users and 22% of non-users reported unwanted decisions made by RACH staff (similar to UK reports-about 20%).</p>	<p>NPA sites rated higher than non-NPA sites in: Less residents were transferred to hospital for symptom management.</p>

Research has long supported that a palliative approach should be offered earlier in the disease trajectory rather than reactive end-of-life care. A palliative approach to care can facilitate addressing residents needs in a proactive rather than reactive manner, as factors such as disease progression and symptom management are discussed earlier on in the trajectory. This approach reduces the reactive responses to poorly managed symptoms, such as through conducting proactive medication management reviews and ensuring an out of hours care plan is developed.

STRENGTHS AND LIMITATIONS OF THE STUDY

Consumers

The consumer survey sample may not be representative of the general RACH population because of the sampling framework where we could only rely on social media and several consumer and service provider networks to recruit bereaved carers. However, there were important similarities in several variables between this study sample and the general RACH population as cited in several official reports and detailed in Phase One of the full report: the age distribution of residents, proportions of residents living with dementia, proportion of rural residents, proportion of residents dying in RACHs, and median length of stay at RACHs. These similarities in the demographic and clinical profile of residents gives more weight to the consumer feedback and by consequence the conclusions and recommendations from this study. Furthermore, the experiences of bereaved carers echo those in other literature calling for a more person-centred care system that encompasses the residents and carers support needs in the psychological, emotional, and spiritual domains.

It is worth noting that even with the lay-friendly definition of specialist palliative care 'Visiting Palliative Care Team' (as recommended by the reference group), there was confusion amongst consumers about whether their relative resident at RACH had engaged with palliative care services.

The current model of RACHs engaging with and referring their residents to 'specialist palliative care services' namely MPaCCS, who visit their premises but mostly meet with RACH staff and not the families, was not always obvious for consumers. Where 'generalist' palliative care was provided to residents by existing RACH staff including the GP and nursing team, consumers may have perceived this as a 'visiting palliative care team'.

Service Providers

Similarly, the sample of the RACH staff survey may not be representative of the general RACH staff population, however their feedback reflects already-known challenges, as do their suggestions for improvement.

It should be noted that disruptions due to COVID-19 restrictions across WA meant that RACHs could not implement NPA pilot projects according to schedule. In addition, not all RACHs or service providers engaged in NPA initiatives completed the phase 3 survey which may have influenced results.

Competing surveys in the same timeframe as this study

Recruiting for the two surveys was challenging in a time where both consumers and service providers have been targeted to participate in surveys and other forms of consultation. At the time of conducting this study, bereaved carers (Next of Kin) and RACH staff were both over surveyed populations due to the number of submissions prepared for the Royal Commission into Aged Care Quality & Safety, improvement initiatives, independent evaluations being conducted by public and private organisations, and an increase in RACH regulation and compliance.

In addition, Commonwealth and WA Departments of Health both simultaneously conducted online surveys and/or facilitated online education and training sessions for RACH staff. Going forward, collaboration with the various teams involved in EOL&PC in aged care initiatives would avoid duplication and unintended reduction of opportunities to engage with potential participants. For example, some NPA project teams conducted their own evaluations based on each initiative. The RACH survey and focus groups that formed the independent evaluation brief may have had more uptake if duplicate requests from various teams did not occur.

RECOMMENDATIONS

SERVICE IMPROVEMENT

The following recommendations are based on evidence from analyses in Phases One, Two and Three detailed in the full report and on key suggestions by consumers and service providers for service improvement. Some recommendations are within the realm of the Western Australian Department of Health while others would be within RACH usual business, and some would be potentially addressed to WA Primary Health Alliance (WAPHA), private community GPs and community pharmacies.

1. Build Workforce Capacity and Capability

Capacity

- Address Workforce Retention Issues: Identify key concerns among RACH employees that are influencing high staff turnover within RACHs across WA. These issues relate more broadly to aged care at the federal level, such as recruitment, retention, salaries and conditions of aged care staff.
- Improve access and expand awareness of specialist palliative care services available to RACHs for communities in country WA.

Capability

- Increase the flexibility of training schedules: High staff turnover within RACHs may require a more flexible schedule for educational offerings including training and workshops. There are limitations associated with set curriculum timelines and alternatives are required.
- Provide training opportunities for non-clinical Staff: Personal Care Attendants (PCAs) provide the majority of face-to-face care in RACHs, and educational programs designed specifically for this group warrant further attention around end of life and palliative care programs.
- Provide Dementia-specific education for all clinical and non-clinical RACH staff to improve their care of residents who are diagnosed with dementia and cognitive decline.
- Provide death literacy and grief literacy education to clinical and non-clinical RACH staff to improve skills and confidence in caring for people at end of life and in supporting their families (such as recognising and responding to clinical deterioration).
- Provide mentorship between more senior or qualified RACH staff within individual sites or across RACH providers that may assist in minimising staff burnout.
- RACHs to appoint specific end of life care champions across individual sites to support an organisation-wide cultural shift towards a palliative approach to care for residents, aligned with their advance care planning documentation.

EOLCP have the following [NPA Initiatives](#) in progress in this domain: MPaCCS Expansion, Cancer Council WA RACEPC Communicate, WAPHA GP Case Conferencing Coordinator and RCL Expansion.

2. Improve Coordination of Care

Care Planning

- While advance care planning (ACP) documents are often considered around the time of admission to RACH, the findings of consistent challenges and barriers highlight that ACP discussion and documentation are best completed in the community. Work has been successfully happening in this space by Palliative Care WA and groups of compassionate communities, but it needs to be better funded for a much wider and faster population reach. In addition, there is a need to continue innovation and new models of facilitation and support to improve the reach into key population groups.
- The 'care plan for the dying person' is a resource developed by acute and subacute healthcare services in Australia, often at a state level. There is a need to consider the development of a care plan for the dying person tailored for the aged care setting in WA, along with implementation support and ongoing resources. The care plan supports a model of care that combines frequent assessments, critical thinking, individualised care planning, shared decision-making and continuous review to ensure the focus of care is on the dying person and those close to them.
- Residential Goals of Care (RGoC) is a document and process adapted for RACHs from the Goals of Patient Care document and process currently used in WA hospital settings. The tool supports clinical care, provides common language across settings, and complements consumer-led ACP documents. It promotes conversations about goals of care, limits of escalation of care, whether the resident wants to go to hospital and may trigger ACP. Continued implementation of this new model is warranted across WA RACHs.

EOLCP have the following [NPA Initiatives](#) in progress in this domain: EMHS Transition Support Officer, SMHS Care Coordinator, NMHS Transition Support Navigator, WACHS Residential Goals of Care, MPaCCS Expansion, WAPHA GP Case Conferencing Coordinator.

Access to GPs

- Develop sustainable models of delivering primary care in RACHs in collaboration with GPs to better understand how additional resourcing may improve quality care for residents, as much of primary care is palliative care in this setting.
- Need a proactive approach to prescribing medications at end of life to minimise wait times for residents and distress for family carers related to poor pain and symptom

management e.g. through promoting the National Core Medication List in primary care and community pharmacies.

- Improve out of hours access to GPs for RACH residents including weekends and public holidays. This approach would also minimise the need for unnecessary hospitalisations.

EOLCP have the following [NPA Initiatives](#) in progress in this domain: WAPHA GP Case Conferencing Coordinator, RACGP GP Information Resources and RCL Expansion. For Example, the GP Case Conferencing Coordinator pilot is designed to support place-based coordinator roles within RACHs that act as a conduit between GPs, RACH staff, specialist palliative care services and residents.

Continuity of Care

- Improve data sharing ability among RACH staff, GPs and hospital staff to ensure equal access to ACP documents, Goals of Patient Care to translate to RGoC documents, and residents' preferred place of death.

EOLCP have the following [NPA Initiatives](#) in progress in this domain: NMHS Transition Support Navigator, SMHS Care Coordinator, EMHS Transition Support Officer and MPaCCS Expansion. For example, HSP's Transitions of Care pilots are designed to support quality transfer of information at discharge from hospital to RACH, and MPaCCS' hospital liaison nurse to support transition from hospital to RACH and RACH to hospital for those with palliative care needs.

3. Improve the quality of end-of-life and palliative care

Multidisciplinary Teams

- Increase the number of Allied Health and Spiritual Care staff in RACHs including social workers, occupational therapists and physiotherapists to optimise the quality of end of life.
- Increase a person-centred focus on residents' physical, psychosocial, functional and spiritual needs.
- Introduce grief and bereavement support for resident and family carers, for example grief counsellors employed by RACHs or in specialist palliative care teams.

EOLCP have the following [NPA Initiatives](#) in progress in this domain: MPaCCS Expansion (Social Workers).

4. Enhance Communication with and Support for Family and Carers

- RACH staff need access to training in how to share prognosis, palliative care phase and care plans with family members as residents deteriorate and die.
- Undertake education for families and carers about end-of-life and palliative care literacy, in partnership with organisations such as Palliative Care WA.
- More liaison with not-for-profit organisations that can support family carers is needed, with RACHs taking a signposting role via making available a list of services that family carers can tap into. This could be achieved through a collaborative Compassionate Communities model of care.

EOLCP have the following [NPA Initiatives](#) in progress in this domain for RACH staff education and training: Cancer Council WA RACEPC Communicate, RCL Expansion, MPaCCS Expansion and WAPHA GP Case Conferencing Coordinator.

FUTURE WORK TO SUPPORT SERVICE IMPROVEMENT

- **Education in End of Life and Palliative Care**

Although there is a wide range of education and training opportunities available to aged care sector staff in WA (and more specifically through the NPA initiative RACEPC), there were repeated recommendations to improve and increase RACH staff training surrounding end of life and palliative care. Future research should explore why these educational opportunities are not being utilised, or alternatively, why the learnings are not successfully translating into practice. A focus on the need of CALD staff and PCAs is warranted.

- **Monitoring Changes in Quality Indicators Over Time**

This evaluation is particularly useful for providing a baseline for experience of care across the six priorities of the WA End-of-Life and Palliative Care Strategy which can be re-examined in future years as new initiatives are implemented across the sector to track their impact on residents/ family carers and RACH staff.

- **Expanding on Understanding GP and Hospital Staff Perspectives**

The lack of coordination among RACH staff, GPs and hospital staff as individuals and as key service providers to the aged care sector should be explored in more detail in order to gain a clearer understanding of how integration and cooperation could be improved. It would be particularly beneficial to identify RACHs where GP access and integration is well established, to understand key success factors and barriers to provision of palliative care.

To bolster the provision of generalist palliative care, further research with GPs needs to be undertaken to understand their perceived barriers and facilitators to provision of high quality and timely palliative care in RACHs.

- **Supporting Family Carers**

Supporting family carers pre- and post-death requires a more sustainable and collaborative model of care that involves supportive informal networks and building referral pathways between RACHs and community-based not-for-profit organisations. This could be achieved through a collaborative Compassionate Communities model of care. This community development approach would assist RACHs in accessing resources available in their local communities.

Another initiative that is gaining momentum in the US and the UK and that RACHs can facilitate is Help Texts which is a text messaging program that delivers twice-weekly text support, education, tips, and reminders to people who are grieving, as well as to their friends and family who want to support them. The program is designed to engage griever who may not be inclined to seek bereavement counselling but could benefit from additional support. Some hospices have included this initiative as part of their signposting with positive evaluation outcomes (<https://helptexts.com/>)

SECTOR IMPROVEMENT (MODELS OF CARE)

The following recommendations for sector improvement, including models of care, have been curated from a considered range of industry reports, academic research and case studies. It is imperative the aged care sector recognises the need for a cultural shift in end-of-life care.

Although the experiences and perspectives of bereaved carers and RACH staff have provided invaluable insights into how end of life and palliative care service provision may be improved in RACHs, it is imperative the aged care sector recognises the value of community networks.

An urgent whole of community response will be required to respond to the imminent impact of ageing in Australia, as collaboration between health care and social care becomes critical.

In building effective and sustainable models of end-of-life care, aged care providers must not only improve the provision of care but expand beyond healthcare systems into communities.

The cost and capacity of current clinical models of care in aged care are not sustainable and services must strive to provide person-centred meaningful care to residents at end of life.

Aged care systems are increasingly burdened by administrative tasks and less focused upon facilitating connections between residents and with the wider community, thus contributing to loneliness, learned helplessness, lack of self-agency and internalised ageism of residents.

A systemic cultural change requires commitment, resources and a process which places residents stated needs and aspirations at the centre, so residents are not merely 'cared for' but also 'cared about'.

Suggested Models of Care

- **Network Centred Aged Care**

This approach is underpinned by community development with a focus on meaningful relationships and network centred aged care. As an example, the 10K initiative focused on the maintenance and development of social networks and relationships for a group of elders who lived in an aged care home in the Western Suburbs of Sydney (Rahn et al, 2020). The role of the community development worker was to engage with the resources and networks within a 5-kilometre radius of the home. At the same time there was a focus on developing the agency of people (staff and residents) within the home so that they took collective action/s to solve problems such as loneliness and overcome barriers such as an overreliance on clinical approaches to care provision. Although the project was conducted with residents in Sydney NSW, the approach is likely to be adaptable to other similar aged care settings (Rahn et al, 2020).

- **Compassionate Connectors Program**

Building effective and sustainable models for EOL care means improving how care is provided as well as expanding models beyond the healthcare system to include the community. The Compassionate Connectors Program was trialled for terminally ill older people living at home in the South West of WA. Connectors supported patients and their family carers referred by the health service to identify networks of care that can meet their practical and social needs. The program significantly improved social connectedness, reduced social isolation and reduced hospital admissions and lengths of stay (Aoun et al., 2023; Aoun et al., 2022). Such model of care needs considering how it can be adapted in RACHs, where RACH residents can be supported to maintain and enhance their social networks within and prior to their entry to their RACH, and RACHs could engage with, contribute to, and draw upon their local communities.

- **Wellness Hubs**

Bupa is piloting a wellness hubs initiative in six of its aged care homes in regional areas of Queensland, where there is a shift from an illness and reactive approach of care to a restoration and wellbeing-centred care model and a care delivery program with a holistic focus. The Bupa wellness hubs are led by nurse practitioners in partnership with general practitioners and allied health teams who review and manage multidisciplinary care – including telehealth. The Wellness Hubs are already having a positive impact on resident outcomes. These include proactive healthcare management, enhanced admission experiences, smoother care transitions, reduced hospital transfers, and improved clinical indicators (ARIIA, 2023).

These suggested outward looking models of care require different perspectives and skills in addition to those gained through clinical training. Public health perspectives and community

development skills need to be added to the aged care team, through revising staff profiles, arranging secondment from community services, or seeking the necessary skills from volunteers. However, it takes time and a concerted effort to recognise that change is needed and desirable. A combination of behavioural, cultural and systems change is required and resistance to such changes will be encountered along the way.

- **INSPIRED Model of Care**

The INSPIRED model has been promoted as an effective evidence-based approach to provision of end-of-life care for residents at RACHs (Chapman et al., 2018; Forbat et al., 2019; Forbat et al., 2024; Rainsford et al., 2020). Research has found that this model's use of monthly needs rounds with RACH staff and specialist palliative care facilitates care planning for residents with high symptom burden or complex needs at end of life. An economic evaluation highlighted that an investment of \$75 million for increase nurse practitioners and multidisciplinary services would result in between \$135 and \$310 million reduction of costs due to hospitalisations and emergency services (Forbat et al., 2020; Palliative Care Australia & KPMG, 2020).

However, it is worth noting the resources required by such initiatives may impose limits on their relevance and sustainability if the resources to enact the program are not provided, as many require the participation and/or supervision of nurse practitioners, not always available to aged care services, while care in practice is provided overwhelmingly by staff at Personal Care Assistant (PCA) level. Programs that equip and support PCAs through training and mentoring (rather than primarily focusing on registered nurses) also warrant further attention.

CONCLUSION

Provision of quality palliative care services for residents of RACHs can facilitate quality of life at end of life and foster a good death for the resident, their family and RACH staff. To do so, additional training and increased capability of staff is required, care should be effectively planned and coordinated, communication between RACH staff, residents, families and other agencies needs to improve, and the quality of care provided should allow the resident to live and die with dignity.

Current systems are geared to doing tasks (with ever-increasing burdensome administration) rather than facilitating connections between residents and with the wider community, thus contributing to loneliness, learned helplessness, lack of self-agency and internalised ageism of residents. This change in culture requires commitment, resources and a process which put residents stated needs and aspirations at the centre, so residents are not merely 'cared for' but also 'cared about'. The scale and imminent impact of ageing we are soon facing requires a whole of community urgent response and collaboration across health and social care is critical.

Ultimately, to achieve an effective, affordable & sustainable end-of-life care system, a public health approach based on a close partnership between clinical services and communities/civic institutions is the optimal practice to be infused in any model of care (Figure). "The New Essentials concept proposes a way of integrating the processes and operations of the four basic components— specialist palliative care, generalist palliative care, compassionate communities and civic end-of-life care—that make up palliative and end-of-life care" (p.4, Abel et al, 2018).

Palliative Care – The New Essentials

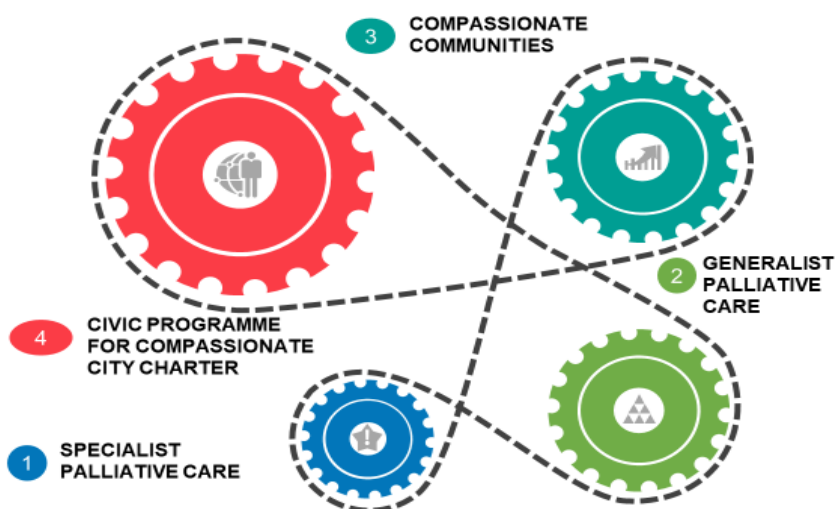


Figure: The New Essentials Palliative Care Model (Abel et al., 2018)

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APPENDIX 1: KEY TERMS AND DEFINITIONS

Palliative Care

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (WHO, 2024).

Palliative Approach to Care

A palliative approach to care emphasizes the need for a patient and family-centred care that focuses on the person and not only on the illness, the importance of therapeutic interactions between care providers and the patient and family, a clear communication all through the illness trajectory and it stresses in particular the importance of goals of care and advance care planning (Aoun, 2018; Palliaged, 2024).

End-of-Life Care

In the context of this report, 'end-of-life care' is used as an umbrella term to refer to the care provided to a RACH resident, rather than referring specifically to the final 12 months of life. It should be noted that the nuanced clinical distinction between palliative care, end of life care and terminal care have not been delineated for the purposes of this consumer survey.

Visiting Palliative Care Team

In the context of this report, there are no references to the term 'specialist' or 'generalist' palliative care services. In collaboration with the project reference group, the following definition of a 'visiting palliative care team' was provided to consumers:

Consumer Survey Q3.5: Was your relative seen by a 'visiting palliative care team' in the Residential Aged Care Home? [*In WA, there are specialist palliative care teams of doctors, nurses, social workers and other clinicians that visit Residential Aged Care Facilities and Nursing Homes to provide extra support to residents, families and staff. These visiting palliative care teams in WA include MPaCCS from Bethesda Palliative Care Unit, WA Country Heath Palliative Care and Silver Chain].*

Palliative Care Users (PC Users)

In the context of this report, the term Palliative Care User (PC User) is used to describe the group of bereaved carers who indicated their relative engaged with the 'visiting palliative care team' as indicated above and therefore accessed 'specialist palliative care services' at end of life. It should be noted the validity of this self-reported characteristic was reliant upon individual consumers understanding of palliative care services within the aged care home.

Consumers and Bereaved Carers

Throughout this report, the term consumers and bereaved carers is used interchangeably to describe the perspectives of those whose residents lived in a RACH in Western Australia.

Service Providers and RACH Staff

Throughout this report, the term service provider and RACH staff are used interchangeably to describe the perspectives of those who are employed by RACHs in Western Australia.

Rural and Country WA

Throughout this report, the terms Rural and Country WA are used interchangeably as a description of geographical location, in contrast to metropolitan Western Australia.

Death Literacy

Death literacy is knowledge about, and understanding of, the death system –which is all the things that are Death, Dying, Loss and Grief (DDLG) related in a society. Death literacy is our “know how” and includes 4 key things: 1) Knowledge about end-of-life planning, the end-of-life system and how it works, 2) Skills related to care and having conversations about DDLG, 3) Knowing how to take action–accessing community support and informal networks, 4) Experience –normalising DDLG, wisdom learnt through personal experiences (Noonan et al., 2016).

Grief Literacy

Grief literacy is defined as the multidimensional capacity to access, process, and use knowledge regarding the experience of loss: it comprises knowledge to facilitate understanding and reflection, skills to enable action, and values to inspire compassion and care. These dimensions connect and integrate via the interdependence of individuals within sociocultural contexts. Grief literacy extends beyond the individual person; instead, it is a broader concept that reflects the capacity and values of a community and society (Breen et al., 2022).

Residential Aged Care Homes (RACHs)

Throughout the course of this evaluation the aged care sector and government preferences in relation to terminology surrounding Residential Aged Care Facilities (RACFs) was altered to Residential Aged Care Homes (RACHs), and this has been reflected throughout the report. It should be noted that all bereaved carer and service provider quotes were not altered.

APPENDIX 2: PROJECT CONTRIBUTORS

Reference Group Members

- Deirdre Whitty – North Metropolitan Health Service, Residential Care Line
- Frances Arthur – Western Australian Department of Health, End-of-Life Care Program
- Bernadette Nowak – Bethesda Healthcare
- Janet Wagland – Brightwater Group
- Marta Mendiolaza – Bethanie
- Liz Behjat – Aged & Community Care Providers Association
- Clare Mullen – WA Health Consumers' Council

Research Team

- Professor Samar Aoun – Perron Institute/UWA and Chief Investigator
- Professor Kirsten Auret – Rural Clinical School of Western Australia and Co-Investigator
- Professor Bruce Rumbold – La Trobe University/Perron Institute and Co-Investigator
- Jennifer Lowe – Perron Institute Research Fellow
- Dr Julie Brose – Perron Institute Postdoctoral Research Fellow
- Denise Howting – Perron Institute Graduate Biostatistician