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The role of paramedics in palliative and end of life care

Scoping report

OFFICIAL

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Introduction

Palliative and end of life care supports individuals with a life-limiting or life-threatening illness to live well until the end of their life. Palliative care can be delivered across several healthcare and community settings by specialist and non-specialised services. While palliative care is seen to be everyone's business, enhancing collaboration between healthcare professionals and their services is known to increase the probability that a person, with their caregivers, can be supported in their home and community, as their preferred place of care, and fulfill their wish that home will be their anticipated place of death¹.

Traditionally, ambulance services and paramedical staff have provided valued and trusted community-based responses to people experiencing healthcare emergencies. However, the changing nature of healthcare systems and newer models of healthcare delivery that focus on continuity of care for a person within their community setting has seen the emergence of community-based paramedicine, beyond emergency health responses, to contribute to broader preventative, restorative, palliative and end of life care².

Health systems are continually looking for ways to do things more effectively and efficiently. This scoping report focuses on the increasing role that paramedic staff and their services can play in the provision of palliative and end of life care for the Victorian community. This report will support the opportunity for improvement work commencing with Safer Care Victoria's Centres of Clinical Excellence to explore more deeply and apply their continuous improvement methodology to work towards system change for palliative care and paramedics to collaborate to improve peoples' end of life care outcomes³.

From the literature

Palliative care

Australia is seen as one of the world leaders in the provision of palliative and end of life care, with its relatively well developed and maturing federal, state and territory-wide systems, standards, services and supporting educational and training endeavours⁴.

While peak bodies, such as the Grattan institute and Palliative Care Australia, highlight the limitations and unmet needs within our systems^{5,6}, increased understanding of what palliative care can achieve, a broadening awareness of who should be considered part of a palliative care team – including paramedics and the expectations for people to receive community based services, irrespective of location – is driving demand that requires a more integrated, collaborative and inclusive approach to healthcare delivery, particularly in sustaining people with care based within their community⁷.

Paramedicine

Paramedical response services are a universal and integral part of all healthcare systems, notably known for their urgent community responsiveness in triaging from community to hospitals at the time of a healthcare emergency. The systematic engagement and inclusion of paramedicine in the provision of community-based care beyond the emergency response has been a growing and evolving area of development in many countries.

The context of this care has increasingly focused on supporting those with chronic progressive and advancing illness by responding to an urgency of need call with a focus on de-escalation, stabilisation and supporting care in the home. This has meant that, increasingly, paramedics are present at community situations where the progression of response sees dying at the person's home as a possible or inevitable outcome, and their role needs to support this process⁸.

International developments

Canada and the United States are world leaders in the strategic and systematic developments that build capacity and capability in the role of paramedicine in community-based home and residential aged care facilities, palliative and end of life care⁹. Paramedics have a trusted position that opens the potential for them to assist in facilitating people to fulfill their desire for their end of life at home.

Even with such development, the role of paramedics in adapting and expanding their clinical experience and expertise, their integration with other supporting community services, as well as the education and training support for this refocus, has not been without issue¹⁰. Paramedics report feeling relatively underprepared to contain triaging to the home base, nor do they specifically know how to be present to a dying person and their caregivers, if preparatory work surrounding advance care planning, medication provision, or connection to specific palliative care services are not in place to support this role¹¹.

The Australian picture

New South Wales and South Australian jurisdictions have adopted some relevant practice changes since the early 2000s, while Ambulance Victoria (AV) has more recently begun working in this arena. Overall, however, states and territories in Australia have been slower to adapt to this changing environment in a system-wide and strategic way, with significant jurisdictional, legislative, organisational, industrial and attitudinal barriers seeing considerable variation in how systems have been developed and sustained, or not considered at all.

The poverty of consideration of this area of development is starkly highlighted in the review of the national and individual state and territory government's end-of-life and palliative care strategies, frameworks, or service review documents. Only Tasmania's current strategic documents specifically refer to ambulance services in the context of palliative care. A similar process for each jurisdiction surrounding government ambulance and paramedical service strategies relating to work in the community around chronic illness, palliative or end of life care showed it was again only Tasmania that made any reference. No subsequent planning or implementation work has occurred since endorsement in 2017¹².

Notably, in 2007 New South Wales Ambulance established an Extended Care Paramedic (EPC) and a Coordinator of Palliative and End of Life Care roles, subsequently implementing the Authorised Palliative Care Plan (APCP), which provides NSW Ambulance paramedics an advance care treatment plan that pre-authorises and supports a paramedic to respond to the patient's end-of-life wishes beyond usual paramedic protocols. Similarly, in 2008, South Australian Ambulance Services established the EPC role (EPC), training clinicians to be able to work above the normal scope of paramedic practice, collaborating with other healthcare teams to manage and treat people in their home or residential care facility. Unfortunately, no published reviews or evaluations of these services are available.

Lord et al's publication in 2019, from a retrospective cohort study undertaken in Victoria in 2015-16, concluded that 'paramedics have a significant role in caring for patients receiving palliative care'. These results should inform the design of integrated systems of care that involve ambulance services in the planning and delivery of community-based palliative care. It is also noted that, other than more recent Ambulance Victoria initiatives, no other Australian Ambulance Clinical Practice Guidelines (CPGs) make any reference to palliative care practice, other than legal aspects of advanced care planning.

Interestingly, the Tasmanian Government's 2017 Strategic plans for end of life care and ambulance services highlights that end of life care across health services, the community and ambulance services are in significant need of the development of consistent policies, procedures and practices across the service system, including education and training on palliative care, communication skills and the legality of end of life care tools such as advance care directives and goals of care forms¹⁴.

Developments in Victoria

Momentum for development and change, while lacking explicit governmental strategic oversight or drivers, appears, in retrospect, to be driven by the community's needs, demands and expectations, as well as local initiatives within both Ambulance Victoria and Palliative Care Services responding to the communities they work in.

Advance care planning and directives

The increased awareness of and utilisation of documentation that represent a person's health-related decision making with advance care planning has challenged traditional approaches to decision making and approaches to care pathways to respond around community-based end of life care. Community-based services' awareness of healthcare practitioners' responsibilities have been further challenged with the implementation of Victoria's legislative change in 2018 with *The Medical Treatment Planning and Decisions Act 2016*, which gives statutory recognition to advance care directives contemporising laws relating to medical treatment decision making for people who no longer have decision making capacity¹⁵.

Under the Victorian Act, clear obligations now exist for all health practitioners, including paramedics, caring for people who no longer have decision making capacity but have nominated a substitute decision maker or have an advance care directive. These changes have cemented legislated recognition of a person's desire for a home-based death to be respected, even when a call to paramedic services may trigger an initial health emergency triaged response.

The Victorian end of life and palliative care framework

Victoria's End of life and palliative care framework has presented a vision for people, and their caregivers, to receive the best possible end of life care, placing the person receiving palliative and end of life care at the centre. The preferences and values of the person are to be respected and recognised, particularly at their end of life. Wherever possible, people could choose to be cared for and die in their place of choice, which may change in time and circumstance, but if possible, in their place of residency in the community¹⁶.

Built upon successive state government strategic plans and policy initiatives, explicit relational initiatives to connect the work of paramedics to the designated metropolitan and regional palliative care service systems have not previously been made. However, there have been initiatives driven by the most recent framework and funding to achieve more equitable support for people in their place of residence, and more capacity for health services to rapidly return people to their residence, if able, from hospitals.

However, significant variability remains, especially from the operationalisation of 'in' and 'out' of hours palliative care services' responses when care is deemed urgent and necessary by a person and their family. This variability can affect outcomes in situations where a well-coordinated response may

achieve an 'at home' paramedic supported response, avoiding an unwarranted and preventable hospital admission.

Recently available data indicates that 70 per cent of people express a preference to die at home; however, only 14 per cent do. In Victoria, only approximately 50 per cent of people with designated community palliative care service who want to die at home do so¹⁷.

While the Victoria-wide palliative and end of life advice line (2020) has added a new capability for patients, families and care providers, including paramedics and general practitioners, to gain more immediate advice, the variability of a patient or family's knowledge of the unwell person's goals of care, their local designated palliative care provider's triage processes and the practical responses, including the rationale for the use of paramedic services, remains underdeveloped.

The framework's implementation, evaluation and monitoring strategy, from 2016 to 2026, indicates that leverage for change and its aim for improved outcomes for patients, families and health services for palliative and end of life care can be driven by many sources. This includes incidents and consumer feedback, patient/carer surveys, sector clinical and consumer drivers, outcome data, project level reports and evaluations¹⁷, which accounts for the grass roots building momentum for the palliative care services and paramedical interface.

The improvement work begins

The Palliative Care Clinical Network

The Palliative Care Clinical Network was established within the Department of Health and Human Services (DHHS) in 2010 to provide clinical leadership in the implementation of policy directions and program initiatives in Victoria. While not an explicit direction, work surrounding the health services engagement in the development of the Victorian end of life and palliative care framework saw some preliminary meetings with Ambulance Victoria departmental representatives looking at palliative care engagement that occurred in 2015, without ongoing engagement or outcomes.

Just prior to the transition from the Palliative Care Clinical Network to the newly established Safer Care Victoria in 2017, its role shifted to focus on supporting health services in healthcare quality and safety improvement, innovation and leadership¹⁸. This resulted in the initial collaboration and engagement with Ambulance Victoria to review and endorse the establishment of the AV Clinical Practice Guideline palliative care section and its palliative care tool to calculate morphine equivalent dosing and its guidance for use for paramedics using (for the first time) subcutaneous medication delivery in late 2016.

The Ambulance Victoria Palliative Care Clinical Practice Guideline¹⁹

According to Lord¹⁸ in December 2016, Ambulance Victoria identified a need to provide paramedics with clinical guidelines for people registered with a community palliative care service who present with symptom issues and applied to people with advanced incurable disease who express a wish to stay at home. The guideline provides instructions for paramedic management of specific symptoms and authorises subsequent care at home, if the appropriate care is available, rather than transport to a hospital for medical assessment, which practically would reflect an available and appropriate advance care directive, available orders and medication for subcutaneous use and contactable palliative care medical and nursing. We created a pathway for care prior to arrival of the paramedics and removed the mandatory transport aspect of care.

An initial evaluation of the clinical practice guideline was conducted in 2018²⁰ and showed that, with the available data and reported experiences, its utility and benefit was positively demonstrated. The evaluation also commented on already mentioned concerns surrounding experience in working with non-emergency dying patients, communication issues, and skills to contextualise care surrounding interpretation of the voice of a nominated medical treatment decision maker and known advance care planning conversations and documents or legal documents such as advance care directives, when a person has lost decision making capacity.

Many of these issues were raised in background briefing meetings with Victoria's Chief Paramedic, the Nurse Coordinator of the Victorian Coronial Admissions and Enquiries Service, and the Nurse Manager of the recently established Victorian Palliative Care Advice Service. There were also direct email communications received from paramedics to the PCCN, concerning paramedic education, training and preparedness to manage such situations, confidence in the recognition and responding appropriately to

the needs of a dying patient and their families, as well as having the appropriate skills training around secondary triage communications to manage the clinical situation at a person's home.

One important component also raised was the apparent variability in the awareness and engagement of the palliative care services to prepare families for AV engagement and to have the right tools in place to appropriately respond.

The Ambulance Victoria Regional/Rural Local Government Area (LGA) Paramedic Community Support Coordinators (PCSC)

The role of the AV Paramedic Community Support Coordinators (PCSC) was established in 2018 and is available to LGAs across Victoria, excluding metropolitan Melbourne and Greater Geelong. They are professional paramedics whose work goes beyond the traditional role of responding to emergency cases. In addition to supporting emergency responses, a key focus of their role is working with other local health services in the provision of primary care, as well as training and supporting local ambulance services to meet their community's health-related needs. See Appendix 1.

The initiative began to see PCSCs engaging community palliative care providers around the people receiving palliative care and end of life care services in their community. They took on a practice and ongoing role in getting to know and work with a patient, their family and care services – away from being urgent responders – and preparing a family as to when the need for an urgent call arose, they could see the patient in a broader context of the person's home care.

Jo Brooks, the Hume Region's Paramedic Community Support Coordinator for Wodonga, Towong and Indigo, described in her report *The Mitta Project* the collaboration between paramedics, palliative care and other district support workers. From the Mitta Project, the PCSC partnered with Palliative Care Wodonga and the Tallangatta District Nursing Service so that the palliative patient received visits from all three services with the PCSC becoming the 'eyes and ears' within the community, especially as the patient moved into their final days. Visits to support the patient and family were shared between all three services, ensuring that the family saw a service every couple of days. The AV services were able to respond to non-emergency calls, support any necessary home to hospital transfers, provide falls support in the home and safe manual handling advice to families, as well as utilise the AV clinical practice guideline for palliative care to provide medication breakthroughs when required for more problematic symptom issues, support the dying process if necessary and verify the death once occurred.

What is of interest in the regional locations is that paramedic community support staff were often closer to the person than specialist palliative care or community nursing services. This meant that they could support a coordinated, local, timely and patient-centred level of care for people who live in rural and remote locations and move from 'reactive emergencies to proactive healthcare'.

The WAVE Project (We are Ambulance Victoria Engaged)

This work of the rural/regional PCSCs soon came to the attention of the PCCN from the PCCN's engagement across the sector, and through being a member of the state's palliative care consortia managers meetings²². During 2019, the PCCN co-organising two regional palliative care fora, held in Loddon Mallee and Gippsland regions, and a subsequent discussion with members of the Hume Region Palliative Care Consortia and their Clinical Advisory Group. These meetings highlighted that the role of paramedics had evolved within their own local health areas and gave both paramedics and palliative care staff the opportunities to discuss the benefits of increased collaboration and possibilities of more systematic approaches across LGAs. It also gave an opportunity to reflect on the barriers and problems that had arisen. See Appendix 2.

These conversations, with the positive benefits of the PCSC roles and activities surrounding local community service engagement, brought into focus perceived system disparities between metropolitan Melbourne and Greater Geelong where the PCSC role does not exist, and the structures of response remain limited to a reactive approach to urgent care calls to AV services.

By late 2019, planning began to establish a Safer Care Victoria endorsed project to build on the work of the regional PCSCs, which later became The WAVE project. The project was centred in its design and ambition within the SCV continuous improvement methodology; sectoral engagement was essential in bringing clinical and organisational experts together to 'jump start' a sequence of smaller changes in a process that would enable broader change across both AV and palliative care systems, to benefit a person and their caregivers' outcomes²³.

For paramedics, there needed to be a more systematic approach to the care pathways that could integrate core practices and principles into such services. Further support and education were also required to build capability for paramedics in effectively utilising the clinical practice guidelines for palliative care and ensuring that a similar systematic approach with speciality community palliative care providers could be taken to proactively work with families to educate and have in place the tools that would help families to feel engaged with AV and see them as an integral part of their palliative care team.

It was also important to understand what key components could be applied to metropolitan Melbourne and greater Geelong, recognising the system differences in capacity building between these centres and their regional/rural services.

While meetings from the PCCN established connection with key AV quality and patient safety personal in January 2020, and the Clinical Lead for SCV's PCCN developed proposal secured sabbatical leave funding, the COVID-19 pandemic, with the pivot of SCV activity to the pandemic and health provider engagement no longer available, a 12-month hiatus has ensued.

The momentum for change: 2021

Pivoting back towards post pandemic business in late 2020, re-engagement in the project began. As part of the DHS and SCV restructures, the project now sits as a palliative care focused project within the newly established Centres of Clinical Excellence (CoCE), being the CoCE Older Persons team. With the business case approved, the following project team has been established:

- Project lead: A/Professor Mark Boughey
- Senior project officer: Sophie Jennings
- Project officer: Emmalee McArdle
- SCV improvement coach: Guinevere Kindley.

The timeliness of the project has seen significant engagement and response from clinical, organisational and academic personnel across Victoria and nationally. The recent tabling of the *Royal Commission into Aged Care Quality and Safety*²⁴ has specifically highlighted significant issues pertaining to palliative care provision with need to urgently increase capacity and capability of both palliative care services and the interdisciplinary approach to care assessment by medical, nursing and allied health teams, including paramedics. It has also highlighted the issues of unsupported and unnecessary transfers from homes, including residential care facilities to hospitals.

It appears the WAVE project and other work around Australia has a right time, right place feel to its timing. Let's hope significant outcomes can be achieved.

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Appendix 1

Envisaged roles of the regional Paramedic community support coordinator (PCSC) and their team of ambulance community officers (ACO)

Paramedic Community Support Coordinators are professional paramedics whose work goes beyond the traditional role of responding to emergency cases. In addition to supporting emergency response, a key focus of their role is working with other local health services in the provision of primary care and training as well as supporting local ambulance to meet the community's health needs.

Under PCSC supervision, Ambulance Community Officers, are first responders employed on a casual basis to provide advanced first aid in rural communities where the caseload is low, and the branch is not staffed full-time. ACOs have life-saving skills but can also provide a community focus.

This list of opportunities regional/rurally included the following:

1. Identify the community leaders in each town in the valley and meet to discuss their expectations of the health services in the community.
2. Follow up on every ambulance patient by the PCSC. A visit to the patient's home allowed the team to understand the potential for ongoing health needs and to put patients in touch with other services to aid their recovery at home.
3. ACOs became community champions in their 'patch' of the valley. Residents were encouraged to approach the ACO if they had concerns about neighbours or friends, and a home visit was carried out by the PCSC.
4. My Age Care referrals are initiated for all ambulance patients over the age of 65 years who required an in-home assessment.
5. The team have partnered with the only health service in the Mitta Valley – District Nursing, and the PCSC and ACOs are the 'eyes and ears' of the community when the nursing staff were not present.
6. Community members who have returned home following surgery are followed up on by the PCSC to ensure that they were recovering and managing at home. Some are referred to their GP if a pain management review is required.
7. Palliative care patients are identified, and the patient and family visited by the PCSC, and often an ACO, as part of the support team made up of Palliative care and District Nursing. As the patient moves towards end of life, the PCSC visits will be scheduled so that at least one health service (Palliative care, District Nursing and AV) visits the family every 1-2 days. Opportunities such as manual handling skills are delivered to family members by training manual handling ACO's, falls response, verification of death.
8. Acute emergency defibrillators (AED)/Cardiopulmonary resuscitation (CPR) training in the community and school. Public AED's are now in each of the towns where previously no AED's existed.
9. Frequent callers are met, and management plans set in place for their medical needs. The PCSC and ACO's monitor these patients regularly to ensure that their plans are working. The motto of the team is to 'ensure patients can be the best they can be.'
10. A community engagement display is set up at every community event which is always busy and well attended.

Appendix 2

Considerations for the interface between palliative/end of life care services and paramedical care

Clinical needs and collaborations

The single greatest improvement would be that every patient with palliative or end of life illness has the appropriate documents/letter indicating that they are palliative/end of life and there is a wish for this to be at the home setting, with the name of their treating service available in and after hours. This opens the door for the AV palliative care guidelines to be used by the paramedics.

Many people are referred to community services in the last days and weeks of life, so developing a written and signed advance care plan places undue and unwanted pressure on a deteriorating/dying person. Determining who takes on the role of medical treatment decision maker when a person no longer has capacity to make medical decisions remains an important question to ask and document.

It remains that while the aim and wish of a person to be at home may be intended for, it is important to recognise that a person's home may relate to a variety of locations and situations. Contextualising what can be achieved in a 'home' may indeed be problematic depending on location, resources, safety issues, accessibility and cultural impacts. This needs to be discussed in planning phases of care.

There should be a weekly hand over between palliative care and local ambulance teams so that complex palliative care or dying patients can be identified, particularly those who are likely to call an emergency response and/or after hours.

Timely access to anticipatory medications, hence proactively organised from hospital discharge or by palliative care team/the coordinating paramedic could raise this at a meeting. This is also true for those accessing Voluntary Assisted Dying (VAD) as well because they are still dying and can have unanticipated end of life symptom issues if medication works slowly, especially for people in regional and remote areas. Also, a patient in the region had struggled to access VAD which resulted in the patient being distressed, hospitalised and receiving palliative sedation therapy – rather than having palliative care engaged earlier at home.

Rural emergency departments have found that bed block is caused by poor management of residential aged care patients with palliative care needs. This highlights the importance of care plans being developed in consultation with family and a GP/palliative care service so patients can be treated in their chosen place of preference, where possible, rather than being transferred to the emergency department.

Potentially a more coordinated response to after-hours support for clients living in rural areas either in their own home or residential care facilities, particularly for those clients in the terminal/dying phase where after-hours medical and nursing visits are unachievable, but we would need to talk to a specialist support service member.

Ambulance noted it is difficult when patients need to be transported to hospital but this conflicts with the patient's wishes to be treated at home. In these situations, it should be clearly communicated to families and where possible the patient should be transported back to their residence as soon as possible.

Half of the ambulance workforce in the region are volunteers. Volunteers hold a certificate 2 in emergency response and receive 30 hours training per year. They are paid for 'case jobs' and can provide care at a similar level as first responder or first aid. Their training should be a priority as well. Issues with resourcing, access and a predominate volunteer workforce has caused barriers to provide a wait and return service for palliative care patients after hospital presentation.

Organisational needs

Ambulance Victoria

We created a pathway for care prior to arrival of the paramedics and removed the mandatory transport aspect of care for known palliative and end of life care.

Triage questioning - changing the order of the questions asked by the ambulance call centre to include a palliative care question. It is hoped that this will mean the appropriate ambulance team will be dispatched.

Paramedics based in Wangaratta were trialling a 'tuck in' project with their palliative care patients in the region. It was temporarily ceased due to staffing issues however they are now proceeding with the project.

It would be helpful for paramedics to have access to the palliative care patient information portal. However, due to patient privacy issues, paramedics may not attain access to everyone's details. Currently after-hours palliative services have some data, however if the paramedic could also access this data it would assist with patient management in line with patient wishes when the after-hours advice has not been effective in managing patient concerns. Paramedics could also be involved with final 'wish' trips as well as final 'move' trips to the location that best supports their dying time.

Palliative Care Services

There is also demand for better education for family and carers in both the use of anticipatory medication and preparedness for end of life with ambulances often being called due to the lack of knowledge using anticipatory medication. They are not prepared or become overwhelmed during end stages of the person's life or they feel they need someone to take charge of the situation.

Education with carers when calling ambulance service could potentially help the correct level of ambulance response being dispatched rather than the MICA team being called in a palliative care or end of life situation.

Creating an organisational 'community of practice' forum to form local meeting time and space for feedback and reflection mechanisms between both paramedics and palliative care providers.

It was also suggested that the palliative care nurse can teach regional ambulance to use butterfly cannulas to enhance the ability of ambulance to provide palliative care.

For some regions there was a need for a registered community skill bank so the community can draw from known resources and skills in the area to provide care for palliative care patients in the region.



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