

# Principles of engagement

## We are Ambulance Victoria Engaged (WAVE) project

The WAVE project seeks to improve engagement between palliative care services and paramedics in the provision of end-of-life care. This document outlines each principle and provides some practical suggestions for change ideas at the individual, local and state level.

### Summary

We gathered feedback from working groups to inform six key principles. The working groups provided expertise and comprised a diverse representation of consumers, clinicians and other staff from palliative care services and Ambulance Victoria.

#### Our key principles

We are a team, including people receiving palliative and end-of-life care, their families and caregivers, as well as paramedics and palliative care providers.

1. **Shared decision making and person-centred care** are priorities
2. We are an integrated team where everyone **recognises, understands and values each role**
3. We **foster local connections** to meet needs
4. We have known **channels of communication**
5. We have a **unified approach to palliative and end-of-life care** in the home
6. We can **support the person's preferred care plan and venue, including home-based care** when this is their preference

### 1. Shared decision making and person-centred care are priorities

The person, caregiver and family are **recognised as members of the team**. They are:

- respected and included in conversations and decisions about care
- included in decision making and encouraged to elicit and understand the person's wishes, and these wishes are taken into consideration, including location wherever possible
- supported in ways relevant to cultural, social, physical and emotional needs and choices
- enabled to have more quality time together by reducing stressful experiences through preparation and integrated team experiences.

## 2. We are an integrated team where everyone recognises, understands and values each role

'The team' includes all connections to a person's care regardless of geographical setting. For example, a person may live in rural Victoria and see (virtually or in-person) their local general practitioner, district nurse and a specialist service that is based in metropolitan Melbourne.

There is a **shared definition and acceptance** of the value of each role in the team, including recognising:

- the person, caregiver and family as members of the team
- the local health network providing palliative and end-of-life care comprising nursing, medical including general practitioners, allied health, aged care and residential services
- the role of Ambulance Victoria including triaging, paramedic attendance and as referrers
- specialised palliative care services.

## 3. We foster local connections to meet needs

We acknowledge there are challenges aligning practices due to different service models and internal processes across metropolitan, regional and rural Victoria. We will work to develop relationships with local services to:

- understand local team members and services, including abilities and limitations such as service hours or local emergency demand
- identify options to bridge 'gaps' between services and specify local solutions when outside hours/region of a specialised care service
- adapt and share resources for local context, including consumer health information, health care services contact details and hours of access, and staff opportunities for support, education or palliative care experience
- find ways to build connections and reduce silos between clinical groups to improve teamwork, and ensure these connections can endure through workforce movement
- find local solutions to improve referral pathways and access issues for medications, equipment and ancillary and allied health services.

## 4. We promote open channels of communication

We advocate **24/7 access to expert palliative advice** that is consistent and reliable for symptom management, trouble shooting, and information regarding treatment options and plans.

- First line of access should be directly to the linked palliative care service – with details immediately accessible in the home (including which service, phone contact, hours of service)
- Second line of access for when the palliative care service linked with the person is unavailable could be the Palliative Care Advice Service (phone: 1800 360 000, email: [www.pcas.org.au](http://www.pcas.org.au)).

There is improved **flow of patient-specific information** between paramedics, palliative care services, and emergency departments.

- Emergency staff including paramedics should be able to access ‘need to know’ information such as whether palliative care service is involved, that service’s contact details and hours of access, patient goals of care or end-of-life wishes, anticipatory medicines and orders. Consider mechanisms to communicate after paramedic callouts regarding individual outcomes or referral acceptance.

## 5. We encourage a unified approach to palliative and end-of-life care in the home

Working together supports the best outcome for the person, caregiver and family. We seek opportunities to **systemise care** across Victoria and **avenues to support engagement** between services, including:

- identifying where standardised or shared practices, protocols, tools or guidelines can be used including expectations of care
  - seek endorsement where appropriate
- identifying ways to communicate when other services are involved
- creating an interprofessional forum to share learnings across services including reviewing engagement and consumer experiences
- seeking executive support where necessary for agreed avenues to invest time and resources
- identifying and engaging with other key members including general practitioners, aged care and residential facilities.

We acknowledge system issues that need ongoing advocacy including resourcing, access to anticipatory medications, timeliness of referrals to enable care planning, and capacity to respond to after-hours referrals to palliative care services.

## 6. We support the person’s preferred care plan and venue, including home-based care when this is their preference

The **person, caregiver and family are empowered** regarding home-based care where appropriate and feasible to do so. This includes wherever ‘home’ is for the person, including permanent or temporary accommodation, as well as supported residential or disability homes. Home-based care should include early planning that is flexible to change at short notice with specific person-centred supports available at any time of day.

We support:

- developing a care plan with caregivers and families, including when they may consider calling an ambulance
- sharing resources that clearly address the barriers for dying at home, and help clarify when home may no longer be an appropriate setting
- providing education and support for caregivers and family for what to do after death has occurred.

**Paramedics are enabled** to use a palliative care approach rather than an acute lifesaving response.

- Paramedic guidelines and treatment protocols are flexible and can:
  - include the opportunity to seek and follow a care plan during an episode of distress
  - provide home-based care without triggering unnecessary transfers
  - can use principles of palliative care to administer therapeutic agents (for example, subcutaneous routes, off-label uses such as haloperidol or cyclizine for nausea)
- Paramedics have immediate access to relevant patient-specific information within and after hours and are empowered to contact and refer to health teams.

## Practical suggestions

### Individual level

Palliative care providers should consider:

- empowering the person, caregiver and family by including them in conversations about care
- fostering conversations that help understand end-of-life wishes, including location of care, and realise these may be different between person, caregiver and family
- developing a clear care plan outlining in-person or phone support available at any time of day. This should include when to consider calling an ambulance, what to say on the phone, and what to say to the paramedic on arrival. Address any assumptions of calling an ambulance including fear of unwanted hospital admission, and the 'instinct' to call when in crisis mode. Review and update this plan regularly
- providing education, including basic manual handling and techniques for reassurance and symptom management to families
- sharing resources that clearly address barriers for dying at home, what to do after death, and help clarify when home may no longer be an appropriate setting. Suggestions include:
  - Support for carers: [www.carerhelp.com.au](http://www.carerhelp.com.au)
  - A guide for after death has occurred: [www.betterhealth.vic.gov.au/health/servicesandsupport/what-to-do-after-someone-dies#bhc-content](http://www.betterhealth.vic.gov.au/health/servicesandsupport/what-to-do-after-someone-dies#bhc-content)
  - Advance Care Planning Australia advice: [www.advancecareplanning.org.au/create-your-plan/create-your-plan-vic](http://www.advancecareplanning.org.au/create-your-plan/create-your-plan-vic)
- a diary or logbook kept in the person's home so that caregivers and family can be easily updated
- providing comprehensive carer support including bereavement services
- reaching out to form local connections (see local level below)
- including paramedics in home-based admission orientation and checklists.

## Local level

Form a group with representatives from local palliative care and paramedic services to review local practice. Include consumer representation and relevant primary health or general practitioners. Build connections to improve teamwork and reduce clinical silos. Consider how any changes will endure through workforce movement.

- Develop a clear outline of each team members role and responsibilities so that limitations to care are known and understood
- Develop, adapt or share resources for local context including consumer health information, health care services contact details and hours of access
- Understand local variations to practice, and consider which work well and where there is room for improvement, for example, referral pathways, access to equipment, anticipatory medicines, ancillary or allied health services
- Outline local options to bridge gaps between services and local solutions when outside hours or region of a specialised care service. Specify in-person support options and access to expert palliative advice, including hours of access of palliative care services or the Palliative Care Advice Line
- Agree and use consistent methods for paramedics to identify in real time if a person is already linked with a palliative care service, contact details, end-of-life wishes, advance care plans, anticipatory medicines and orders. For example, a summary of 'need to know' information in a home care folder that also has space for a paramedic to record a visit; magnet on fridge with palliative care service details; local geo-flagging in Ambulance Victoria system
- Develop collaborative feedback mechanisms for after paramedic callouts regarding individual outcomes and review processes. For example, within existing meeting structures or follow up processes
- Develop a network to review and improve person experience and service delivery, including:
  - a regular opportunity to share case studies and learnings from when things go well and not so well
  - review of existing orientation/training resources to effectively include paramedics and palliative care providers, for example, checklists, communication prompts
  - share staff opportunities for support, education or palliative care experience
  - identify and address further needs for upskilling, for example, mentoring between palliative care and paramedics for secondary triage communication for end-of-life.

## State level

Form a statewide network utilising existing channels such as the palliative care consortia. This network would seek opportunities to systemise care across Victoria and support engagement between services. Executive support is key for services to engage in this network and contribute to change.

- Develop a state-wide definition of roles of team members
- Create a visualisation or map of paramedic and palliative care provider regions

- Identify where standardised or shared practices, protocols, tools or guidelines can be used, including expectations of care. Seek endorsement where appropriate and use consistent and aligned terminology
- Ensure regular review of mechanisms to avoid unintended consequences such as appropriate calls being deprioritised after being identified as palliative
- Review paramedic guidelines and treatment protocols to ensure flexibility to provide a palliative care approach where appropriate
  - include the opportunity to seek and follow a care plan during an episode of distress
  - allow provision of home-based care without triggering unnecessary transfers
  - allow use of principles of palliative care to administer therapeutic agents (for example, subcutaneous routes, off-label uses such as haloperidol or cyclizine for nausea)
- Consider electronic platforms that could be used to aid communication
  - Ambulance Victoria location of interest functionality or 'flagging' geolocations
  - online platform for palliative care referrals and care plans, with access by Ambulance Victoria to support paramedics (similar to My Aged Care) or if an existing platform (for example, Palcare) could be used to alert palliative care services
  - review secondary triage questioning and consider palliative care related questions
  - consider if a phone number other than 000 could be used to speak with a paramedic rather than an operator where reasons for visit and goals of care can be discussed
- Collaboratively review critical incidents to prevent future errors
- Consider learnings and recommendations from initiatives such as palliative care at home pilot programs and evaluation of care of the dying person. Reflect specifically on impacts to paramedics
- Create an interprofessional forum to share learnings across services, including reviewing engagement and consumer experiences
- Acknowledge and continue to address system issues including resourcing, access to anticipatory medications, timeliness of referral to palliative care to enable planning, capacity of palliative care services to respond to referrals after hours and inclusion of Advance Care Planning in accreditation standards.