Clinical Practice Guidelines: Other/Palliative care

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Palliative care

Over the past several decades, palliative care has evolved from a philosophy of care that focused on the end of life, to a multidisciplinary speciality that delivers comprehensive and holistic health care to patients with an active, progressive, and life-limiting illness throughout the trajectory of the disease. Palliative care is tailored to the patient's individual needs (adults and children) and their families, and may include physical, emotional, spiritual, and social interventions.[1,2]

There are five main delivery models of palliative care which include: outpatient palliative care clinic; inpatient palliative care consultation; acute palliative care inpatient unit; community based palliative care in the home; and hospice care. Community based care in the home is often the patient's preferred place in which to receive palliative care, and when approaching the end stage of their illness, it is often their preferred place of death.[3]

A palliative care health professional, a personal carer, or a family member involved in the delivery of various aspects of palliative care may request ambulance assistance in circumstances where the patient's condition deteriorates, or where they may be experiencing unexpected symptoms.

This Clinical Practice Guideline (CPG) provides both information and recommendations for ambulance clinicians when responding to a patient who is receiving palliative care.

In this CPG, the following topics are addressed:

- Management guidelines
- Management of common health problems associated with a life-limiting illness
- Administration of medicines in palliative care
- Advanced care planning
- Legal and ethical framework – palliative care

Key Management Principles

The principal aims of management when providing palliative care or responding to a patient who is receiving palliative care, is to ***provide relief from pain and other distressing symptoms;*** to ***maximise the quality of life;*** and to ***facilitate psychosocial support for the patient and family*** during the patient's illness and in their subsequent bereavement.

Management guidelines

A request to attend a patient receiving palliative care may occur in one of the following circumstances:

- The life-limiting illness for which they are receiving palliative care deteriorates or changes unexpectedly; or
- The patient requires urgent assistance following a medical incident or accident that is not directly related to the condition for which the patient is receiving palliative care; or
- The patient requires transport to a facility for ongoing provision of palliative care.

The ambulance clinician must first ***ascertain the reason for requesting ambulance services*** i.e., is it related to the life-limiting illness for which the patient is receiving palliative care; or another condition; and what are the patient's wishes?

Related to the life-limiting illness

If the reason is ***related to the life-limiting illness*** for which the patient is receiving palliative care, the clinician should consult with the patient, the patient's carer, and if necessary and practical, the patient's palliative care health practitioner to determine the most appropriate course of action (see below for a list of common health problems associated with life-limiting illnesses).

If the patient ***requires pain relief*** for the illness for which the patient is receiving palliative care, the ambulance clinician should refer to the patient's palliative care plan for direction.

The clinician should familiarise themselves with the palliative care plan/pain relief regime and *consult a medical practitioner* if additional analgesia above that which is prescribed in the palliative care plan, is required. These cases should be discussed with a QAS Medical Officer via the *QAS Clinical Consultation and Advice Line* for case specific management advice.

Unrelated to the life-limiting illness

If the reason is ***unrelated to the life-limiting illness*** for which the patient is receiving palliative care, the clinician must conduct a thorough clinical assessment and implement, with consent, appropriate treatment in accordance with relevant guidelines and procedures in the *Digital Clinical Practice Manual (DCPM)*.

If the patient ***requires pain relief*** for an unrelated condition, the ambulance clinician must first obtain information regarding the patient's palliative care analgesia regime and thereafter, determine the most appropriate analgesia and appropriate dose, having regard for the clinician's scope of practice, and other medicines that are being administered. The clinician should seek advice from the QAS Medical Officer via the *QAS Clinical Consultation and Advice Line* for case specific management advice.

Patient's wishes

The ambulance clinician must also ***ascertain the patient's wishes*** with respect to ambulance treatment and transport.

If the patient can communicate effectively and has the requisite decision-making capacity to make decisions regarding treatment and transport, ***consult directly with the patient*** and obtain the patient's consent before any treatment and/or transport is provided.

If the patient lacks the decision-making capacity to make decisions regarding treatment and transport, the clinician must inquire as to what ***health care plans and advance care planning measures*** are in place (see below for information relating to health care plans and advance care planning and consent for treatment). For example:

- Has the patient's medical practitioner recorded information regarding the patient's illness and current treatment regime?
- Has the patient prepared an *Advance Health Directive* detailing their wishes with respect to treatment for their current illness?
- Are there *other documents* available, the content of which may inform the ambulance clinician's decision making?
- Is there another person (guardian, attorney, or statutory health attorney) appointed/authorised to make decisions for and on behalf of the patient?

If any of the documents listed above exist, the ambulance clinician is entitled to request that the document/s be produced so that the clinician can examine the contents. See below for details regarding Advance Care Planning Documents.

Management of common conditions associated with advanced life-limiting illness

Pain

Pain is often associated with life-limiting illnesses and is commonly treated with opioid analgesia, including medicines such as *fentanyl, morphine, oxycodone, or hydromorphone*. The pain is proactively managed with patients receiving baseline pain relief, and the use of breakthrough medicines for relief of acute pain.

If the patient is experiencing pain, it is important that the ambulance clinician assess if the pain is related to the illness for which the patient is receiving palliative care, or another underlying cause.

Nausea and Vomiting

Nausea and vomiting can be related to a range of factors including:

- The patient's medication (particularly opioid analgesia)
- Severe and persistent pain
- The life-limiting illness with which the patient is afflicted
- A medical condition that is unrelated to the life-limiting illness

Nausea and vomiting can be extremely distressing for the patient and the cause should be identified. A patient may be receiving both regular and/or breakthrough medicines to manage their nausea and vomiting secondary to their life-limiting illness. These can include *metoclopramide, levomepromazine, cyclizine, dexamethasone, haloperidol,* and others.

Single measures that may be helpful in reducing or alleviating nausea include:

- Increasing the patient's access to fresh air
- Changing the patient's body position
- Removing offensive odours from the patient's environment
- Offering the patient sips of carbonated beverages such as lemonade or soda water.

The ambulance clinician should also consider the administration of *ondansetron* or other medications as recommended, however, prior to doing so, it is important that the patient's current medications be assessed to determine if the patient is already receiving anti-emetic agents.

Constipation

Constipation is not uncommon in patients that are receiving opioid medications, are immobile due to illness, and have a reduced oral intake. Patients may be taking medicines either regularly or when required to manage constipation. These can include medicines such as *docusate, senna, macrogol, lactulose* or *sodium picosulfate.*

The paramedic should ascertain when the patient last evacuated their bowel and if this has been greater than three days, consider contacting their palliative care practitioner.

Dehydration

It is not uncommon for a patient suffering from a life-limiting illness, to reduce their oral fluid intake and subsequently, become dehydrated. If severe dehydration is evident, the ambulance clinician should consult the patient's palliative care practitioner.

The patient should be encouraged to drink water if the patient is able to swallow. It may also help to offer ice chips and swabs soaked in ice water, both of which will help to keep the patient's mouth moist.

Loss of Appetite and Loss of Weight

Loss of appetite and loss of weight during the advanced stages of a life-limiting illness is common. Other than offering support, interventions are limited.

Weakness

Generalised weakness and lethargy are common during the advanced stages of a life-limiting illness. The ambulance clinician should assess the patient to determine if the weakness is related to the illness or to an unrelated condition.

Confusion, Agitation and Terminal Restlessness

A patient suffering from a life-limiting illness may, during the advanced stages of the illness, suffer from varying levels of confusion. Patients may also present with anxiety, agitation, or restlessness during the final stages of their illness. Confusion can be related to medications or the patient's underlying terminal illness. Patients may be receiving medicines to manage agitation and terminal restlessness. These can include medicines such as *clonazepan, midazolam, haloperidol, levomepromazine*, and others.

Dyspnoea

A patient may be suffering from dyspnoea during the terminal stages of their illness, particularly if the patient has heart failure or chronic obstructive pulmonary disease. Patients may be receiving medicines such as *morphine* or *fentanyl,* or *midazolam* to manage dyspnoea.

Secretions

During the terminal phase of an illness the patient may have increased respiratory tract secretions, which can sound distressing to family and others who may be caring for the patient. In addition to positioning and oropharyngeal suctioning, patients often receive medications such as *hyoscine-N-butylbromide*, *hyoscine, hydrobromide* or *glycopyrrolate* and others to reduce distress related to respiratory secretions.

Administration of medicines in palliative care

Patients can receive palliative care medicines via different routes depending on the stage of their illness. In patients with an advanced terminal illness, combinations of medicines can be administered via a continuous subcutaneous infusion to provide relief of pain, nausea and vomiting, secretions and terminal restlessness (for example, *morphine + midazolam + metoclopramide*). Breakthrough doses may be administered via the subcutaneous route if required.

Administration of any medicines related to the care of patients receiving palliative care must occur in consultation with a medical practitioner. It is essential that all management plans are discussed with the *QAS Clinical Consultation and Advice Line* and/or the PallConsult Service. *(see below)*

PallConsult is a specialised palliative care support line that is available to ambulance clinicians and other health providers seeking advice in relation to the management of a patient with a diagnosed life-limiting disease. The service is **not** limited to patients who are receiving palliative care at the time or are known to a palliative care team.

Access to PallConsult is via the *QAS Clinical Consultation and Advice Line* (1300 315 280 › Option 4 Palliative Care › Option 2 Adult Palliative Care). The clinician MUST:

- Confirm they have contacted the PallConsult Service.
- Identify themselves as a 'QAS paramedic' and the QAS district in which they are located.
- State they are seeking advice regarding a palliative care patient they are currently treating.

Decisions regarding ongoing management and administration of medicines MUST follow existing QAS policy. If instructions provided to a QAS clinician are inconsistent with, or outside the scope of QAS clinical policy, the clinician must contact the QAS Medical Officer via the *QAS Clinical Consultation and Advice Line*.

Table 1: Common Medications used in Palliative Care

MEDICATIONS	INDICATIONS
Morpine, Fentanyl	Pain, dyspnoea
Hydromorphone, Oxycodone	Pain
Metoclopramide, Cyclizine, Dexamethasone	Nausea and vomiting
Levomepromazine	Nausea and vomiting, terminal restlessness, dyspnoea
Midazolam	Agitation, terminal restlessness, dyspnoea
Haloperidol	Nausea and vomiting, agitation, terminal restlessness
Clonazepan	Agitation, terminal restlessness
Hyoscine, Glycopyrronium, Hyoscine-N-Butylbromide, Hydrobromide	Respiratory secretions
Macrogol, Docusate, Sodium Picosulfate, Lactulose, Senna	Constipation

Advanced Care Planning

Advance Care Planning (ACP) is not limited to making decisions regarding end-of-life care and identifying a substitute decision-maker; it is much more. ACP involves a patient-centred approach to planning health and personal care that is consistent with the person's beliefs, values and personal goals, and should be part of the role of all health professionals.[4] The ACP process is collaborative and should be initiated well before the patient experiences a deterioration due to their life-limiting illness.[5]

While any person can participate in the ACP process, even those that are healthy, people who are most likely to benefit from ACP include those that:

- Are diagnosed with a life-limiting illness
- Have multiple comorbidities and are at risk of deterioration
- Have early cognitive impairment
- Are frail
- Are living with chronic progressive deterioration of disease
- Are approaching the end of life.

The **benefits of ACP** are well documented and include:

- A reduction of unnecessary and aggressive treatments at the end of life stage[6,7]
- Patients' wishes in relation to treatment delivered during the final days; the place of death; and funeral arrangements are respected[7]
- Reduced hospitalisations for patients at the end of life[7]
- Increased likelihood that health care professionals and family members will comply with the person's wishes[8]
- Early initiation of appropriate palliative care that improves symptoms and the quality of life[9,10]
- Reduction in the level of anxiety and stress in surviving relatives[9,10]

ACP typically results in the preparation and sharing of the following documents:

- Making an Advanced Health Directive (AHD) in which the patient can provide directions about health matters that may be required at some future time.[11]
- Appointment of a substitute decision-maker to make decisions for the patient at a time when they lack the decision-making capacity to do so.[12,13]
- Providing copies of these enduring documents to relevant health care providers where they may be uploaded/available on the Queensland Health Viewer, and available to family members and carers.

Advanced Health Directive

An AHD is an enduring document in which a person can provide details regarding their views, wishes and preferences in relation to health matters, and specific directions about life-sustaining treatment and other health care that may be considered.[11] An AHD is legally recognised, however, the document must be:

- in writing;
- signed by the patient;
- signed and dated by an 'eligible witness'; and
- signed and dated by a medical practitioner (not the witness) who must also certify that the patient had decision-making capacity to make an AHD at the time.[14]

A patient's AHD will only operate if and when the patient loses the capacity to make a decision.[15]

Substitute decision-makers

A substitute decision-maker may include:

- a guardian appointed by a court or tribunal;[16]
- an attorney for health matters appointed under an enduring document such as an Enduring Power of Attorney (EPOA) or AHD; or [17]
- a statutory health attorney authorised under the provisions of the *Powers of Attorney Act 1998* (the person's spouse or a close friend or relative who is over 18 yrs and is not a paid carer or the person's health provider).[18]

The authority to make decisions about health care for, and on behalf of another person is not activated unless and until the person suffers from impaired decision-making capacity.[18]

Table 2: Advance Care Planning Documents

DOCUMENTS	TYPE	PURPOSE	USE
Advanced Health Directive (AHD)[19]	**Legal Document**	A **formal document** in which an *adult* provides direction about health matters which are to be followed should the person lose decision-making capacity. The document also allows for a person to nominate one or more people (attorney/s) to make decisions on their behalf.	The AHD is activated when the person loses decision-making capacity.
Enduring Power of Attorney (EPOA)[20]	**Legal Document**	A **formal document** in which an *adult* may appoint one or more people whom they trust, to make financial and/or personal decisions (including decisions about healthcare) on behalf of the person if/ when they are unable to make decisions for themselves.	The EPOA is 'enduring', which means that the power continues even if the person giving the EPOA loses the capacity to make decisions. EPOA for financial matters – the person can determine when the authority will activate (specific date). EPOA for health and personal matters will only activate when the person loses decision-making capacity. If there are more than one attorney appointed, the person must indicate how decisions are to be made (jointly; separately; or by majority).

DOCUMENTS	TYPE	PURPOSE	USE
Acute Resuscitation Plan (ARP)[21]	**Clinical Document**	A **medical order** that is designed to record the outcome of resuscitation planning following a discussion with a patient or their substitution decision-maker (if the patient lacks decision-making capacity) and members of the multidisciplinary team. The purpose of the ARP is to provide clinical direction and encourage compliance with relevant guardianship laws as they relate to the withholding and/or withdrawal of life-sustaining measures. The ARP is not a legal document and is not referenced in the guardianship legislation.	The ARP is intended to be used in an emergency to provide clinical direction to attending health providers responding to a patient's acute deterioration.
Statement of Choices (SoC)[22]	**Advance Care Planning Document**	A values-based advance care **planning document** that records a person's values and preferences in relation to health care that may be provided, including health care that is delivered at the end of life. The SoC is not a legal document and is not referenced in the guardianship legislation. **The SoC is available for adults and children/young people (under 18 years of age).**	The SoC is used to guide a conversation regarding advance care planning. The SoC also records the contact details of the person's substitute decision-maker and the existence of any legal documents in the case of an adult patient (AHD, EPOA) that may exist.
My Care Companion Decision Aid (CC)[23]	**Advance Care Planning Document**	A value-based **planning document** that records a person's values, preferences and health care decisions regarding treatment and care.	The CC is a planning document that is used to facilitate a conversation regarding advance care planning, and to record details of those conversations. The CC does not record contact details of substitute decision-makers.

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The Legal and Ethical Framework – Palliative Care

As stated above, one of the principal aims of management when providing palliative care or responding to a patient that is receiving palliative care, is to provide relief from pain and other distressing symptoms. The delivery of pain relief must occur within the following legal and ethical framework.

Consent for Treatment

Adult Patient

- Adult patient ***with decision-making capacity*** – with the patient's consent.[4]
- Adult patient ***with impaired decision-making capacity*** – in accordance with the patient's wishes recorded in an AHD, if one is available.[25]
- Adult patient ***with impaired decision-making capacity*** and no AHD – with the consent of the patient's substitute decision-maker (guardian, appointed attorney or statutory health attorney).[26]

Child

- Child patient – ***with the consent of the child's parent or guardian***.[27]

Young Person

- Patient between 13 and 18 years of age and assessed as Gillick competent – ***with the consent of the patient***.[28]
- Patient under 18 years of age and is not Gillick competent – ***with the consent of the patient's parent or guardian***.[28]

Medical Authorisation for Pain Relief

In the event a patient's death is hastened by the administration of palliative care pain relief, a doctor or someone **authorised by a doctor** will not be criminally responsible for the patient's death if the palliative care was:

- authorised by a doctor (**in writing**); and
- provided in good faith and with reasonable care and skill; and
- provided for the purpose of relieving the patient's pain and symptoms; and
- was reasonable having regard for the patient's clinical circumstances and state of mind at the time.[29]

Withholding or withdrawing of life-sustaining measures

See guidelines in: *CPG: Resuscitation General – Lawful directions to withhold or withdraw cardio-pulmonary resuscitation*.

CPG: Clinician safety
CPG: Standard cares

> ***Note:*** *Clinicians must only perform procedures for which they have received specific training and authorisation by the QAS.*

Condition RELATED to the patient's life-limiting illness

Pain relief required?

N

Manage according to:

- **Appropriate CPGs**
- **Patient Palliative Care Plan**

Y

Refer to patient's Palliative Care Plan and medication regime

Consult with patient's Palliative Care Physician OR QAS Clinical Consult Physician

Condition UNRELATED to the patient's life-limiting illness

Pain relief required?

Y

Refer to patient's Palliative Care Plan and medication regime

Consult with patient's Palliative Care Physician OR QAS Clinical Consult Physician

N

Manage according to:

- **Appropriate CPG**

Transport if required