



# Palliative care for the patient without cancer



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## Background

Palliative care aims to improve quality of life for patients with life-limiting illnesses. It is often linked to the care of people with cancer; however, patients with non-cancer end-stage conditions also have significant needs.

## Objectives

The aims of this paper are to discuss common trajectories of deterioration in non-malignant conditions, consider possible barriers to palliative care referral, review the principles of the palliative care approach and illustrate specific factors relevant for common non-cancer conditions.

## Discussion

The symptom burden and care needs for patients with end-stage, non-malignant illnesses are similar to those of patients with advanced cancer. These patients benefit from a palliative approach, comprising management of the underlying condition and attention to symptoms, psychosocial needs and carer support. Advance care planning provides an opportunity to prepare for future illness episodes, including provision of end-of-life care. General practitioners are well placed to provide palliative care for patients with advanced non-cancer illnesses.

**PALLIATIVE CARE** aims to improve quality of life for patients and families experiencing life-limiting illnesses. This is best achieved through the use of a multidisciplinary team and requires effective and timely communication between primary, secondary and tertiary healthcare providers. Important elements of this approach include the management of physical symptoms, psychosocial care, support for families and carers, and bereavement follow-up. Palliative care is often linked to the care of people with cancer for whom symptom burden and illness trajectory have been largely predictable, with a time of functional preservation being followed by a rapid terminal decline.<sup>1</sup> In Australia, people with advanced cancer often have access to palliative care services. An Australian study of patients in their last year of life showed specialist palliative care (SPC) was provided to 68% of patients whose deaths were related to cancer.<sup>2</sup>

Patients with non-cancer life-limiting illnesses have comparable symptom burden and care needs to patients with cancer but are less likely to access palliative care supports. In the above study, while 40% of deaths were related to non-cancer illnesses, only 14% of these patients accessed SPC services.<sup>2</sup> The classic trajectory of chronic non-malignant conditions (including end-stage renal failure [ESRF] and chronic obstructive pulmonary disease [COPD]) is one of progressive but variable clinical and functional decline, marked by exacerbations and

recoveries and eventually a deterioration that results in death.<sup>1</sup> The heterogeneity of these conditions means that the needs of patients and families will vary significantly. A palliative approach for the patient without cancer includes symptom management, attention to expectations and fears, and advance care planning. This can occur concurrently with treatments that are directed at optimising health, preventing exacerbations or restoring function.

Patients with life-limiting non-malignant illnesses usually have an ongoing relationship with their general practitioner (GP) and may have long-term connections to a specialist team. Generalist skills in palliative care are the domain of all medical practitioners.<sup>3</sup> GPs, who often have a thorough knowledge of their patients' broader health and psychosocial circumstances, are well placed to provide palliative care.<sup>4</sup> As Australia's population continues to age, and with ongoing rates of chronic illness, it is important that GPs are supported to remain the cornerstone of palliative care provision. With population data suggesting most Australians desire their management, including end-of-life care (EOLC), to occur at home, the interface between GPs and community palliative care (CPC) services is especially pertinent.<sup>5</sup> CPC services are predominantly nursing-led and vary in structure and process, depending on location. These services aim to support patients and families at home through the provision of SPC assessment and management. Ideally, a

CPC team includes occupational therapy, physiotherapy, psychology, pastoral care and social work, in addition to specialised nursing and medical support.

A range of barriers to palliative care referral have been identified for people with advanced non-malignant diseases (Box 1). These include discomfort in discussing palliative care, fear of taking away hope, patient fear of abandonment by their usual clinician, and a focus on the disease rather than the needs of the person.<sup>6-8</sup> There are also significant challenges inherent in prognostication for non-malignant conditions, which may cause difficulty in determining the optimal timing of palliative care referral.<sup>8</sup> Clinical factors that may help identify those for whom a palliative approach is appropriate include deteriorating functional capacity with increasing care needs, recurrent or unplanned hospital admissions and refractory symptoms despite optimal management. Additionally, a range of tools are available to aid decision making, including the 'surprise question', which asks whether it would be a surprise if the person died in the next specified time period,<sup>9</sup> and the Supportive and

Palliative Care Indicators Tool (SPICT), which includes disease-specific markers of deterioration.<sup>10</sup> The timing of referral for people with advanced dementia or those with generalised frailty can be particularly problematic, as the usual signs of deterioration, such as poor oral intake or limited functional status, are common long-term features of these conditions. An additional consideration affecting palliative care service provision for patients with non-malignant life-limiting conditions is adequate resourcing and funding – especially for residential aged care facilities (RACF). Ongoing education, networking and development of innovative models of care that integrate generalist and SPC providers may assist in overcoming some of these barriers.

The predominant physical symptoms experienced by people with non-malignant conditions often correlate with the affected organ system. While an in-depth analysis of all possible non-malignant diseases is beyond the scope of this paper, some examples of conditions where palliative care is often involved are discussed below. A discussion of the important role of advance care planning and general EOLC management principles are also provided.

### Box 1. Potential barriers to palliative care referral for people with advanced non-malignant diseases<sup>6-8</sup>

- Clinician, patient or family discomfort in discussing palliative care
- Previous poor experience with palliative care
- Uncertainty regarding the role of palliative care (from both patients and clinicians)
- Cultural considerations around discussing death and dying
- Unclear triggers for referral
- Limited clinician time
- Fear of taking away hope
- Lack of recognition of the impact of symptoms on quality of life
- Patient fear of abandonment by their usual clinician
- A focus on the disease rather than the needs of the person
- Limitations in the availability of palliative care services, especially in more rural and remote areas

### Chronic obstructive pulmonary disease

Severe COPD is a progressive life-limiting condition. Patients with severe COPD have a high symptom burden and diminished quality of life comparable to patients with advanced cancer.<sup>11,12</sup> A palliative approach to severe COPD involves optimisation of disease-specific management (including appropriate inhaler therapies), attention to symptom management, support for smoking cessation, action plans for the management of exacerbations, consideration of routine vaccinations, attention to comorbid conditions (including depression and anxiety), and interventions such as pulmonary rehabilitation. GPs are well placed to provide this care in conjunction with specialist and community supports. Where available, models of integrated respiratory and palliative care represent additional

resources for comprehensive care and have been associated with improved outcomes.<sup>13</sup>

Patients with severe COPD almost universally experience breathlessness; however, the symptom is often under-recognised and under-treated.<sup>14,15</sup> Episodes of breathlessness may be severe and distressing, with associated panic and resultant emergency department presentation. Education and provision of written plans empowers self-management. Non-pharmacological strategies for breathlessness include positioning, provision of a hand-held fan, breathing techniques, distraction and activity pacing.<sup>16</sup> While there are no medications licensed for use for dyspnoea, there is some evidence that low-dose morphine can be safely and effectively used to treat refractory breathlessness in patients with severe COPD.<sup>17</sup> When providing opioids for breathlessness, consideration should also be given to prevention of adverse effects including constipation. There is a lack of evidence to support the use of benzodiazepines for the relief of breathlessness in COPD; however, they may be considered if there is associated anxiety, and breathlessness management strategies have been unsuccessful.<sup>18</sup> There is also a lack of evidence for the use of oxygen for relief of breathlessness in patients who are not hypoxic.<sup>19</sup>

### End-stage renal failure

Patients who are treated conservatively for ESRF and those considering cessation of dialysis are likely to benefit from a palliative approach. Patients with advanced renal disease experience distressing symptoms and impaired quality of life at a rate similar to patients with terminal cancer.<sup>20</sup> Common symptoms in ESRF include fatigue, breathlessness, pain, nausea, poor appetite, fluid overload and itch.<sup>20</sup> These patients have a limited life expectancy, and advance care planning may assist with ensuring that care delivered is concordant with the patient's values. Discontinuation of dialysis involves discussions with the patient, carers and treating team regarding the venue of care, expected disease course, management

of symptoms and wishes for end of life, with consideration for SPC referral as appropriate. These discussions are best executed in a planned and unhurried manner and often over a series of consultations.

### Cardiac failure

Cardiac failure represents a diverse syndrome with variable patient trajectories. The symptom burden in advanced cardiac failure is again comparable to that of advanced cancer<sup>21</sup> and includes breathlessness, fatigue, nausea and constipation.<sup>22</sup> Patients with advanced heart failure may have access to a heart failure management plan and an interdisciplinary care team, and benefit from continued close medical management alongside a personalised palliative approach.<sup>23</sup> Symptom management of breathlessness is similar to the approach taken in severe

COPD, and low-dose opioids may be considered. Careful discussion between the GP, cardiologist and patient regarding the patient's wishes and advance care planning is important and may include consideration of deactivation of devices such as automated implantable cardioverter-defibrillators. Patients with refractory symptoms and poor prognostic features may benefit from SPC input, and support for carers is essential.

### Progressive neurological conditions

Progressive neurological conditions include a range of progressive and life-limiting diseases such as motor neurone disease, Parkinson's disease and dementia. The symptoms are individual and complex, and the involvement of a multidisciplinary team is essential.<sup>24</sup> Advance care planning is again critical and presents an opportunity to prepare

for foreseeable future events such as difficulty swallowing or respiratory changes. Depending on the type and stage of disease, SPC can assist in supporting patients, carers and clinicians.

### Advance care planning

Formal advance care planning processes assist patients, families and clinicians to discuss and document preferences for future care. Focusing on patient values, preferences and cultural and spiritual needs can help frame these discussions, and identifying a substitute medical treatment decision maker is useful for future illness episodes. Patients may have clear preferences about the suitability of interventions, such as antibiotics, non-invasive ventilation, and more intensive levels of care. For patients with severe progressive disease, the treating team should determine which interventions are medically appropriate.

**Table 1. Medications at the end of life**

<b>General considerations</b>	Prescribe on the basis of the patient's symptoms, which should be regularly reassessed. The subcutaneous route is often least invasive and most reliable in the terminal phase. If regular doses are required, consideration should be given to a continuous infusion via syringe driver with doses as required for breakthrough symptoms.
<b>Pain</b>	Morphine 2.5–5 mg subcutaneous 2 hourly as required OR Fentanyl 25–50 µg subcutaneous 2 hourly as required (fentanyl is the preferred option in renal failure because of reduced risk of toxicity) OR Hydromorphone 0.5–1 mg subcutaneous 2 hourly as required
<b>Nausea and vomiting</b>	Metoclopramide 10 mg subcutaneous three times per day as required OR Haloperidol 0.5–1.5 mg subcutaneous two times per day as required
<b>Agitation and restlessness</b>	Midazolam 2.5–5 mg subcutaneous 2 hourly as required OR Clonazepam 0.2–0.5 mg oral (drops) or subcutaneous 4 hourly as required
<b>Shortness of breath</b>	Morphine 1.5–2.5 mg subcutaneous cut 2 hourly as required OR Fentanyl 25–50 µg subcutaneous 2 hourly as required OR Hydromorphone 0.25–0.5 mg subcutaneous 2 hourly as required
<b>Excessive secretions</b>	Hyoscine butylbromide 20 mg subcutaneous 2–4 hourly as required

*This table includes medications commonly used first line for symptom management at end of life. Doses need to be adjusted in patients who develop tolerance to opioids or benzodiazepines, and reviewed in the setting of renal and/or liver failure. The PalliAGED GP app is a useful resource for evidence-based information and prescribing<sup>25</sup> as is the electronic Therapeutic Guidelines (eTG) Guidelines for Palliative Care.<sup>26</sup>*

It is difficult to have these conversations with patients and families at the time of decompensation, and careful pre-emptive planning is superior. Knowledge of the patient's preference for care in the event of a significant deterioration optimises the chance of hospitalisation being avoided and comfort-based EOLC occurring at home if this is desired. In the absence of these discussions and plans, the default outcome is often for the patient to go to the emergency department. Advance care planning can help the patient, family and treating doctor provide the most appropriate care in the most appropriate venue.

## End-of-life care

The principles of EOLC management are similar for patients with malignant and non-malignant conditions and include attention to physical symptoms and psychosocial needs, attendance to personal care and support for families and carers. Many patients can be managed in their home environment (including RACF) if that is their preference. In facilitating this care, the GP may be supported by a palliative care consultation or involvement of a CPC team or residential aged care palliative care outreach worker. Important considerations as a patient deteriorates and nears the end of life include cessation of non-essential medications, avoidance of non-contributory interventions and investigations, pre-emptive prescription of symptom-relieving medications to ensure availability if urgently required (Table 1), mouth and pressure care, and support and education for families and carers. Increased respiratory secretions and agitation or restlessness are relatively common symptoms in patients who are dying and often distressing for families and loved ones. Empathic education addressing the possibility of these occurrences may reduce distress.

Some patients will require admission to an inpatient palliative care unit (PCU). This includes those with SPC needs (such as challenging symptoms, complicated nursing needs or complex psychosocial issues), and those whose preference is to avoid EOLC at home. If a GP's

assessment is that their patient requires PCU admission, this would ideally be facilitated with the hospital palliative care team, to ensure a smooth transition and to minimise the chance of death in an undesired location such as the emergency department.

There is increasing recognition of the significant physical and psychosocial symptom burden and distress associated with many advanced non-malignant conditions. The adoption of palliative care principles and practices can have a significant beneficial impact on the care of the patient without cancer through the alleviation of symptoms, support for families and carers, assistance with complex medical decision making and quality EOLC.

## Key points

- People with advanced non-malignant illnesses have comparable symptom burden and care needs to people with cancer, but are less likely to access palliative care supports.
- While symptoms are often disease-specific, problems such as pain, nausea, fatigue, breathlessness, anxiety and depression are frequent in both advanced malignant and non-malignant diseases.
- There are a number of clinical factors and specific tools available to help guide decision making regarding when to adopt a palliative approach and/or refer to palliative care services for people with advanced non-malignant illnesses.
- A range of barriers to the adoption of a palliative approach and/or referral to palliative care services exist for people with advanced non-malignant illnesses.
- Advance care planning can help to ensure that the most appropriate care is provided in the most appropriate venue.

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