



## *General principles*

- Palliative care is a fundamental component of general practice.
- Most people die from chronic diseases that progress along one of three typical illness trajectories to the end of life, which are:
  - cancer (short decline)
  - non-malignant organ failure (intermediate decline with acute episodes)
  - frailty, dementia (gradual dwindling).
- Patient care along the illness trajectory can ideally transition smoothly from chronic disease management to treatment of advanced illness, to a palliative approach, end-of-life care and terminal phase:
  - A palliative approach shifts the primary focus from life-prolonging treatments towards symptom treatment and quality of remaining life.
  - End-of-life care is focused on providing increased services and support for the person's physical, emotional, social and spiritual/existential issues as they approach death.
  - The GP's role in end-of-life care includes a terminal care plan, care after death and bereavement support for patients and their families.
  - GP self-care and support of colleagues is important to prevent stress, burnout and compassion fatigue.

## Practice points

Practice points	References	Grade
Initiate advance care planning early when patients have capacity to express their wishes and directives for care if they become too ill or cognitively impaired to make decisions	28–31, 38	Consensus-based recommendation
General practitioners (GPs) can use a proactive, systematic approach to anticipate and provide person-centred care to the end of life and a 'good death' by: <ul style="list-style-type: none"> <li>• initiating advance care planning early to document patient wishes and directives</li> <li>• anticipating and assessing escalating palliative care needs early along the illness trajectory</li> <li>• establishing clinical care goals and treatment decisions with the patient/medical decision maker</li> <li>• reviewing clinical care plans frequently to address symptoms and physical, psychosocial and spiritual/existential issues</li> <li>• coordinating and participating in the provision of team-based end-of-life care.</li> </ul>	–	Consensus-based recommendation
Early identification, assessment and management of escalating palliative care needs are important to relieve symptoms, avoid suffering, reduce need for hospital care, and improve quality of remaining life and the death experience	13	Consensus-based recommendation
Recognise escalating palliative care needs at major transition points along the illness trajectory to initiate timely: <ul style="list-style-type: none"> <li>• palliative approach</li> <li>• end-of-life care</li> <li>• terminal care, including after-death and bereavement support</li> </ul>	13	Consensus-based recommendation
Indicators such as the 'surprise question' and the Supportive and Palliative Care Indicators Tool (SPICT) can help identify patients early when considering whether a person may benefit from a palliative approach	5, 6, 44, 47	Consensus-based recommendation
Consider using symptom assessment tools, which can be valuable in identifying symptoms, scoring their severity and monitoring the effectiveness of treatments	34	Consensus-based recommendation

## Introduction

An Australian man aged 65 years in 2009 could expect to live an average of 8.2 years without disability, and another 10.5 years with disability, including 3.5 years with severe or profound activity limitation. An Australian woman aged 65 years in 2009 could expect to live an average of 9.7 years without disability, and another 12.1 years with disability, including 5.6 years with severe or profound activity limitation.<sup>1</sup>

About two-thirds of Australians die between 75 and 95 years of age.<sup>1</sup> In 2005, 54% of people aged >65 years died in hospital, 32% in residential aged care facilities (RACFs), and 14% elsewhere (eg home).<sup>2</sup>

Chronic diseases are responsible for 90% of deaths,<sup>3</sup> and about 70% of deaths are 'expected' due to advanced disease,<sup>4</sup> predominately cardiovascular diseases (eg coronary heart disease, stroke), dementia and Alzheimer's disease, chronic respiratory disease and lung cancer.

Death is often preceded by a period of significant disability, interspersed by life-threatening events. Patients with advanced diseases have an average of eight hospital admissions in their last year of life.<sup>5</sup> Many of these involve

treatments that are of little or no benefit, or may cause more harm than benefit,<sup>6</sup> and patients often do not have the capacity or opportunity to discuss their wishes for care.<sup>7</sup>

## Clinical context

The current Australian healthcare system does not meet patient preferences for care at the end of life.<sup>4</sup> For instance, the low proportion of people dying at home is at odds with the stated preferred place of death of patients; and is half that of comparable countries such as New Zealand, the US, Ireland and France.<sup>4</sup> Place of death is a key indicator of quality end-of-life care.<sup>8</sup> Preferred place of death is influenced by many factors, including:<sup>9</sup>

- connectedness to community
- family
- availability of services and equipment
- complexity of caregiving and decision making.

Preference for receiving care at home is stronger for end-of-life care during the last months of life than for death at home. Transfer from home may occur in the last few days due to rapidly escalating patient care needs, patient safety risks or carer exhaustion.

Principles of a 'good death' have been summarised from surveys of people approaching death and their relatives. Patient priorities for end-of-life care include:<sup>10,11</sup>

- knowing when death is coming and what to expect
  - reasonable control of what happens
  - ensure wishes are respected
  - choice to leave when it is time
  - avoid prolonging dying
- choice and control over where death occurs
  - who is present and who shares the end
  - time to say goodbye
  - arrange important affairs
- access to
  - 'hospice-style' quality care in any location
  - necessary information and expertise
  - control of pain and other symptoms
  - dignity and privacy
  - spiritual or emotional support
- strengthening of relationships, and relieving burdens placed on the family.

Australia's healthcare system is facing the challenge of shifting away from a hospital-centric provision of treatment at the end of life towards better support for people who wish to receive care within their community during their last months of life.<sup>4,12</sup>

## Palliative care

Palliative care, while originally associated with cancer care, is appropriate for anyone with life-limiting illnesses, including non-malignant degenerative diseases, and dementia (refer to Part A. Dementia). In the past decade, palliative care has become available within almost every healthcare setting, including general practices, RACFs, acute hospitals and generalist community services.<sup>12</sup>

Each year in Australia, about 160,000 people die, and around 100,000 of these deaths are predictable. Of those, 40,000 patients receive specialist palliative care and 60,000 do not. Patients may receive palliative care for years, months, weeks or days before death.<sup>1</sup>

People receiving palliative care have fewer episodes of hospitalisation, shorter lengths of stay when they are hospitalised, and reduced visits to emergency departments. Those who receive palliative care at home have been shown to have increased quality of life and reduced need for hospital-based care.<sup>12</sup>

Box 1 provides definitions of palliative care; there is no clear demarcation point between curative and palliative intent, or at the transition between phases of palliative care.

### **Box 1. Definition of phases of palliative care**

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Palliative care:

- World Health Organization – Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems – physical, psychosocial and spiritual.<sup>13</sup>
- Palliative Care Australia – Palliative care is person-centred and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.<sup>14</sup>

Palliative approach:

- A palliative approach recognises that death is inevitable and focuses on the care rather than cure of a person with multiple chronic conditions, frailty and/or a life-threatening or life-limiting illness. The goal of a palliative approach is to improve or optimise a person's level of comfort and function and to offer appropriate treatment for any distressing symptoms. A palliative approach addresses a person's psychological, spiritual, social, emotional and cultural needs. Families are welcomed as partners in this approach. A palliative approach recognises that for older people with multiple chronic conditions, frailty and/or a life-threatening or life-limiting illness, that this is often the last chapter of their life, the length of which is unknown.<sup>15</sup>

End-of-life care (and terminal phase):

- End-of-life care is the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death. The needs of patients and carers are higher at this time.
    - This phase of palliative care is recognised as one in which increased services and support are essential to ensure quality, coordinated care from the healthcare team is delivered.
    - This takes into account the terminal phase or when the patient is recognised as imminently dying, death and extends to bereavement care.<sup>14</sup>
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For definitions and up-to-date information on legal issues that can arise with palliative medicine (eg double jeopardy) and end-of-life decision making, refer to [End of Life Law in Australia](#).

At the time of writing, euthanasia is illegal in all Australian states and territories. Since 19 June 2019, voluntary assisted dying (VAD) became legal in Victoria and is being considered in other states. VAD involves administering a medication for the purpose of causing death in accordance with the steps and processes set out through legislation. VAD must be voluntary, and will usually be self-administered by the individual.

In Victoria, the *Voluntary Assisted Dying Act 2017* (Vic) (the Act) sets legal criteria for an individual to be eligible for VAD, for health practitioners to be involved with VAD, and for the VAD processes overall. The Act provides for, and regulates, access to VAD, defined as 'the administration of a voluntary assisted dying substance, and includes steps reasonably related to such administration'.<sup>16</sup> Health practitioners can conscientiously object to being involved with VAD, and in Victoria, cannot raise the issue of voluntary assisted dying with patients (even indirectly).

The process for an individual to request and access VAD is separate from, and cannot be included in, advance care planning or palliative care. Once a person requests information about VAD, knowledge of best practice for end-of-life discussions is an important part of communicating about VAD. A patient receiving palliative care, if eligible, can concurrently request and have access to VAD through a separate pathway.

Further information on Victoria's VAD is available on the [Department of Health and Human Services website](#).

The National Palliative Care Strategy (the Strategy) highlights a focus on 'living well with chronic illness' and maximising quality of life, and six guiding principles:<sup>12</sup>

- Palliative care is person-centred care
- Death is a part of life
- Carers are valued and receive the care they need
- Care is accessible
- Everyone has a role to play in palliative care
- Care is high quality and evidence based

Specialist palliative care services usually include doctors, nurses, physiotherapists, occupational therapists, social workers, clinical pharmacists, dietitians, speech therapists and pastoral care workers. Specialist palliative care services may be available to support general practitioners (GPs) and patients by providing help with:<sup>18</sup>

- complex problems, symptom control, admission to hospice or hospital
- advice on ethical dilemmas (eg nutrition, hydration)
- spiritual issues, concerns held by the patient or carers, sense of therapeutic partnership
- resources for bereavement management.

The Strategy recognises that GPs play an essential role in advance care planning and providing palliative care for patients with terminal illnesses living in the community and RACFs.<sup>12</sup>

## GPs' role at the end of life

As patients approach the end of life, the GP's role is to apply the principles and approach to care of older people presented throughout this Silver Book. There is a sharper focus on:

- person-centred care to support wellbeing and quality of remaining life, and to respect the person's values, goals and treatment choices
- proactive clinical care planning to anticipate and provide care as the person's clinical condition deteriorates, and as goals of care shift from treating illness towards comfort and managing death.

All GPs who care for older people are engaging with issues their patients face towards the end of life. Even small shifts in emphasis towards anticipating and planning to minimise the effect of predictable problems can improve the care offered, and the quality of life experienced by patients and carers. For example, a high-quality handover to the GP who will care for the patient on admission to an RACF can enhance continuity of care and future care planning.

Rural GPs can often continue providing care for patients as they move between home, RACFs or rural hospitals. They may also be required to fill in for lack of patient access to community nursing, specialist palliative care services and equipment for home care.

Chronic disease prevention and management are already established as major routine parts of general practice. The rationale is compelling for GPs to extend management of progressive chronic diseases to meet patients' needs for community-based end-of-life care and a 'good' death.

The number of patients seeking GP care at the end of life is increasing because of multiple interacting factors, including:

- an ageing population
- technological advances that prevent premature death and extend life
- a growing number of general practice patients with progressive chronic life-limiting diseases, and associated disability and cognitive impairment
- patients seeking to avoid medical and hospital treatments that are of limited benefit and not wanted at the end of life
- a greater proportion of the population selecting palliative care at home or in RACFs
- the current gaps in services for end-of-life care in the community (ie inequality of access and service provision, lack of integration and communication between services)

- increased patient awareness of advance care planning for voicing their preferences for end-of-life care and place of death.

GPs have many of the skills required to provide advanced disease management and palliative care through to the end of life. These include:

- systematic chronic disease management
- person-centred care and communication
- shared decision making and goals of care
- supporting carers and family
- dealing with uncertainty
- anticipating likely events
- clinical care planning, including crisis planning
- team care participation and coordination
- using tools and resources to supplement knowledge and skills
- referrals and shared care with specialists and local team-based support services
- use of peer support and training.

However, GPs have reported that a major barrier to providing advance care planning and palliative care is their uncertainty and lack of knowledge about prognosis, illness trajectory and terminal phase of advanced chronic diseases<sup>19,20</sup> (eg cancer,<sup>21</sup> heart failure,<sup>21</sup> dementia).<sup>21,22</sup>

GP awareness of illness trajectories allows anticipation of likely events and practical planning for end-of-life care.<sup>23</sup>

## *In practice*

### Anticipating patient needs

The key to GP care of patients through to the end of life is a proactive systematic approach based on anticipating patient clinical needs and care preferences. Three important concepts have been developed, which can help clinicians anticipate, discuss and plan clinical care to meet patient needs, and also help patients and carers understand and cope with their situation:<sup>24,25</sup>

- Typical illness trajectories for chronic conditions
- Advance care planning
- Early identification of palliative care needs

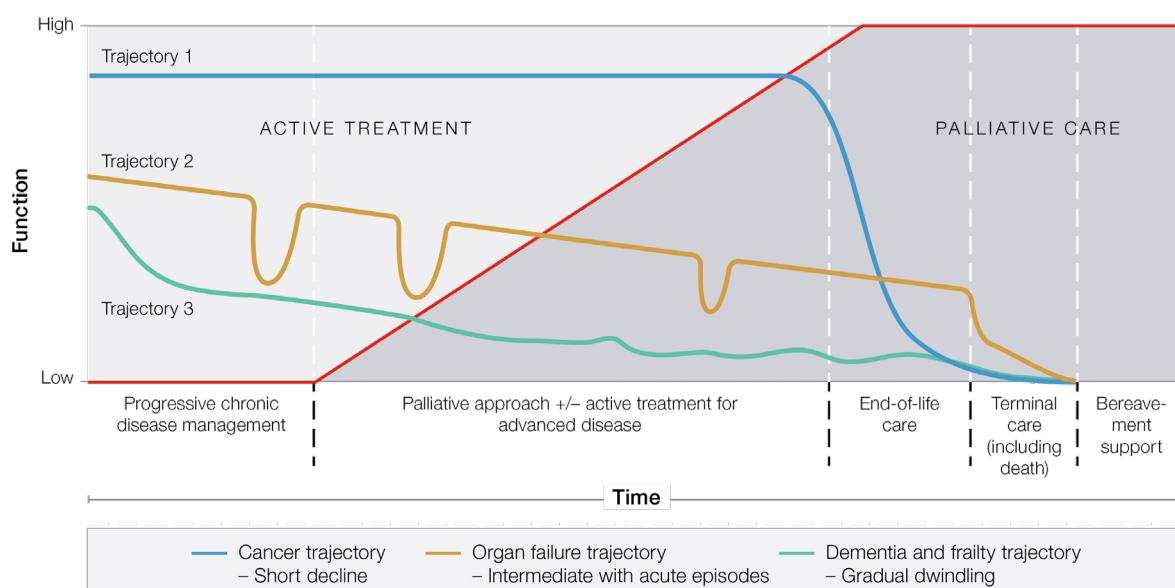
### Illness trajectories

Three typical illness trajectories have been described for people with progressive chronic illness, which are:<sup>23</sup>

- cancer (short decline)
- organ failure (intermediate with acute episodes)
- frailty or dementia trajectory (gradual dwindling).

Patients with specific progressive chronic diseases often have common patterns of experiences, symptoms and palliative care needs.

Figure 1 illustrates the typical illness trajectories for chronic conditions,<sup>23</sup> juxtaposed with the phases of palliative care towards the end of life.

**Figure 1. Typical illness trajectories and palliative care phases towards the end of life**

### Trajectory 1 – Cancer (short decline)

In trajectory 1 (typically cancer), there is steady progression with a slight decline in physical health over months to years with periods of positive or negative effects of cancer treatment. This is followed by a short period of evident decline with a clear end-of-life phase of increasing symptoms and rapid decline in weight and functional status in the last weeks or months of life.

### Trajectory 2 – Organ failure (intermediate with acute episodes)

Trajectory 2 typically occurs in non-malignant, life-limiting illness with organ failure (eg advanced heart disease, lung disease). There is an intermediate rate of decline in function over years with long-term limitations and acute, often life-threatening exacerbations and hospital treatment, followed by further deterioration. Death often seems 'sudden' and may occur at any time along the trajectory, with symptoms of end-stage organ failure.

### Trajectory 3 – Frailty or dementia (gradual dwindling)

Trajectory 3 is a gradual dwindling decline of physical and/or cognitive function, which typically occurs in frailty or dementia. People with dementia have a long, variable disease course up to six to eight years prior, early impairment of memory and reduced capacity for decision making and communication (refer to Part A. Dementia). People with frailty, a syndrome of general physiological decline that occurs in later life, often lack a specific disease diagnosis (refer to Part A. Frailty). The last year of life is characterised by a steady slow decline in overall function, rather than a sudden decline in any one domain. Frailty and dementia together predict a more rapid decline.

Each of the three illness trajectories has physical and associated psychological, social, and spiritual/existential domains.<sup>23</sup>

Multimorbidity, polypharmacy and the patient's wishes and directives also have the potential of altering the patient's illness trajectory and should be considered when planning clinical care.

Discussion of the likely disease trajectory at the time of advance care planning and clinical care planning can help patients and carers:<sup>23,24</sup>

- clarify the person's goals of care and treatment preferences
- improve quality of life and symptom control
- reduce distress



- plan for a good death, including preferred place of death
- avoid unwanted hospital admission
- contribute to informed decision making and care delivery (whether at home, RACF or hospital).

## Advance care planning

Advance care planning is an essential tool for end-of-life care that is person centred. It is a process where a person discusses their values and healthcare preferences with their family, friends and healthcare team. Ideally, advance care planning will result in a formal, written advance care directive (addressing values and/or instructions) to help ensure the person's preferences are respected. As a part of their advance care directive, a person can choose a 'medical decision maker', who would make decisions for the person if they were not able to communicate.<sup>26</sup>

Advance care plans have been shown to:

- improve patients' quality of end-of-life care<sup>27,28</sup> and death experience
- improve adherence to patients' wishes<sup>29</sup>
- improve patient and family satisfaction with care<sup>29,30</sup>
- initiate earlier provision of palliative care<sup>31</sup> with prolonged survival<sup>32</sup>
- increase chance of dying in place of choice (eg RACF with palliative care, rather than death in hospital)<sup>33</sup>
- reduce hospital length of stay for people aged >65 years admitted from an RACF<sup>34</sup>
- promote communication, make palliative care easier and more efficient, and reduce distrust and conflict between family, friends and healthcare practitioners.<sup>35</sup>

## When to initiate advance care planning

Given their longstanding, trusted relationships with patients, GPs are well placed to initiate and implement an advance care plan.<sup>33</sup> An advance care planning conversation fits well with giving advice on healthcare options for any current diagnosis and realistic assessment of prognosis.<sup>36</sup>

Many patients will have limited or no capacity to communicate their preferences and make decisions personally when their health deteriorates at some points along their illness trajectory. For example, this may occur:

- when ill during cancer treatment or near the end of life on trajectory 1
- when suffering an acute life-threatening illness or advanced organ failure on trajectory 2
- early in dementia on trajectory 3.

Advance care planning is ideally discussed early, when patients are well and have capacity to anticipate, discuss and plan for preferred treatment when they become too ill or cognitively impaired to express their wishes.

Initiating advance care planning and documentation of an advance care directive is recommended routinely in the 75+ health assessment, progressive chronic disease management, early dementia or frailty, or at entry into RACFs.

Forms and requirements for advance care plans vary between states and territories. Resources are available for competent adults and those who lack decision-making capacity to undertake advance care planning. Further information and forms for each state or territory can be found at [Advance Care Planning Australia](#).<sup>37</sup>



## Assessment of decision-making capacity

A person is assumed to have decision-making capacity unless there is evidence to indicate otherwise. Competence or lack of competence can fluctuate over time and for different levels of decision making, and is specific to the issues, actions or decisions at hand. People should always be involved in decisions that concern them to the maximum extent possible.<sup>37</sup> Refer to [Advance Care Planning Australia](#) for more information.

Assessment of capacity should take place as close as possible to the time the decision is required. A person with capacity should:<sup>37</sup>

- know the decision facing them
- know the possible options
- know the reasonably foreseeable outcomes of the options available
- be able to provide a rationale for decisions they have made and therefore demonstrate ability to consider the information, balance the risks and make a choice.

If a person lacks capacity to make medical treatment decisions themselves, there are three ways in which decisions can be made by, or for them:<sup>25</sup>

- An advance care directive made by the person before they lose capacity can provide directions about medical treatment.
- A substitute decision maker can make the decision, based on what they believe the person would want and their best interests.
- A tribunal or the courts can provide consent or make a treatment decision.

## Person-centred care

Dying is a multidimensional experience with physical, psychological, social, and spiritual or existential aspects.<sup>38</sup> Each patient has a unique life journey, with their own combination of personal character and strengths, relationships with others, cultural background, values, work and life experiences, and physical and mental health comorbidities.

GPs provide medical care throughout life to a diverse range of people, and are therefore well placed to understand patients' views of their situation and expectations, and to be responsive to the personal influences of cultural and life experiences.

Box 2 illustrates factors to consider when providing end-of-life care for people from diverse backgrounds.<sup>12,39</sup>

### Box 2. Personal factors to consider when providing end-of-life care to patients from diverse backgrounds

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Cultural differences:

A patient's beliefs, values and traditional healthcare practices are relevant at the end of life for them and their families. Other cultural considerations include:

- communication issues
- modes of decision making
- role of advance care planning
- concepts of disease, death and dying in relation to the rest of life
- customs surrounding death, burial or cremation and bereavement
- meaning of pain and other symptoms
- attitudes to medication and nutrition
- privacy issues
- spiritual and religious issues and rituals.

**Aboriginal and Torres Strait Islander peoples:** When caring for Aboriginal and Torres Strait Islander people, it is important to work in partnership with Aboriginal health workers and carers, and be sensitive to the cultural and spiritual meaning of dying, death and place of death, and the effect of earlier experiences of loss and historical shared community heritage of loss.<sup>40</sup>

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**Lesbian, gay, bisexual, transgender, intersex (LGBTI) people:** Be aware that many LGBTI people may have experienced prejudice and discrimination in healthcare settings. Care for the person at the end of life includes respect and support of their self-designated family, substitute decision maker and chosen carer/s.

**People with severe mental health conditions:** People with severe mental health conditions may have had delayed diagnosis and care of their life-limiting illness, and poorly met social, housing, income and support needs. Consider extra support from mental health services.

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## Early identification of palliative care needs

Awareness of illness trajectories enables early identification of needs and practical planning for palliative care. Figure 1 illustrates the phases of palliative care juxtaposed with typical illness trajectories for chronic conditions. Three major transition points can occur along the illness trajectory and if recognised, can enable better palliative care:

- Early identification of palliative care needs and initiation of a palliative approach
- Reassessment of palliative care needs and initiation of end-of-life care plan
- Identifying dying and initiation of terminal care plan, planning for after-death care and bereavement support

GPs caring for patients with a life-limiting illness can consider, discuss and agree on a palliative approach at any point on their illness trajectory. Early palliative care may prolong life for patients, and improve quality of life for patients and carers, by promoting realistic medicine and preventing ineffective burdensome treatment.<sup>38</sup>

Early palliative care needs are different for people with different conditions. The three illness trajectories and their physical, psychological, social and spiritual/existential domains can be applied in early palliative care planning to prevent distress, as shown in the four-minute video [Palliative care from diagnosis to death](#), and are outlined below:<sup>41</sup>

- Trajectory 1 – Social decline may occur at the same time as physical decline. However, people with cancer may need an early palliative approach even when they are physically well to acknowledge psychological symptoms (eg anxiety) and spiritual or existential distress and questioning that may peak at diagnosis, hospital discharge or cancer recurrence, as well as during the physical decline and terminal phase.
- Trajectory 2 – Social and psychological decline often run in parallel with physical decline and life-threatening exacerbations followed by partial recovery. Emotional and spiritual or existential distress may increase steadily in people with organ failure because of a loss of physical capacity and independence. An early palliative approach that addresses psychological and social issues and physical aspects may be more effective in preventing distress.
- Trajectory 3 – For people with frailty or dementia, gradual physical and cognitive decline may cause parallel loss in activities of daily living with early social withdrawal, emotional and spiritual or existential distress (refer to Part A. Frailty; refer to Part A. Dementia). An early palliative approach can:
  - support physical health as well as enable social and psychological resilience and a sense of purpose
  - address anxiety and fears of loss of independence, dementia or becoming a burden.

## Indicators of foreseeable decline towards death

End-of-life processes are multifactorial, so each person's prognosis will imply a degree of uncertainty. Patients may follow none or several of the three trajectories, progress at different rates and die at any point.<sup>23</sup>

Many people, particularly if they have organ failure or multimorbidity, are identified too late to benefit from a palliative approach that is integrated with appropriate treatment of their underlying illnesses.

An important step in early recognition of patients with palliative care needs is anticipating and looking for foreseeable deterioration to death. GPs can then plan care as soon as it might be of benefit, rather than only in the last few weeks or days of life.

Indicators that a person might be nearing the end of life include:<sup>18</sup>

- answering 'no' to the 'surprise question' – 'Would I be surprised if this patient were to die in the next few months, weeks, or days?'<sup>42</sup>
- general features of decline including deterioration in health status, increasing need, or choice for no further active life-prolonging treatments

- specific clinical indicators related to disease progression
- the use of tools such as the [Supportive and Palliative Care Indicators Tool \(SPICT\)](#) to identify people whose health is deteriorating<sup>43</sup>
- considering what can realistically be achieved for the patient.

The 'surprise question' is intended to be used to consider death in the foreseeable future and help identify patients who might benefit from a palliative approach.

General factors are more reliable end-of-life prognostic indicators than disease-centred variables, particularly for older patients with multiple chronic conditions. General factors include:<sup>23,24</sup>

- functional, nutritional and cognitive impairment (eg weight, mobility, activities of daily living, communication, interactions)
- emotional problems
- geriatric syndromes (eg delirium, dysphagia, pressure ulcers, repetitive falls) occur when the accumulated effects of multiple risk factors and impairments in multiple systems render an older person vulnerable to situational challenges. 'Geriatric syndrome' is a poorly defined term that highlights unique features of common health conditions in older people; they are highly prevalent, multifactorial, and associated with substantial morbidity and poor outcomes
- symptoms (eg dyspnoea, anxiety)
- social vulnerability or use of resources (eg increased dependency, services, hospitalisations).

Dynamic decline of function, nutritional status, emotional distress and geriatric syndromes are additional prognostic indicators and are useful for identifying patients for a palliative approach in all three trajectories, and for transition to end-of-life and terminal care.<sup>23,24</sup>

Most tools for the early identification of patients with palliative care needs incorporate severity of general indicators of deteriorating health and some specific clinical indicators.<sup>23,24</sup>

SPICT was developed to identify patients with advanced chronic conditions who are at risk of deteriorating and dying. It includes six general factors of poor or deteriorating health, and clinical indicators of multiple life-limiting conditions. SPICT may assist the GP to identify patients with unmet supportive and palliative care needs for assessment and care planning earlier in the illness trajectory.<sup>44</sup>

## Proactive systematic care

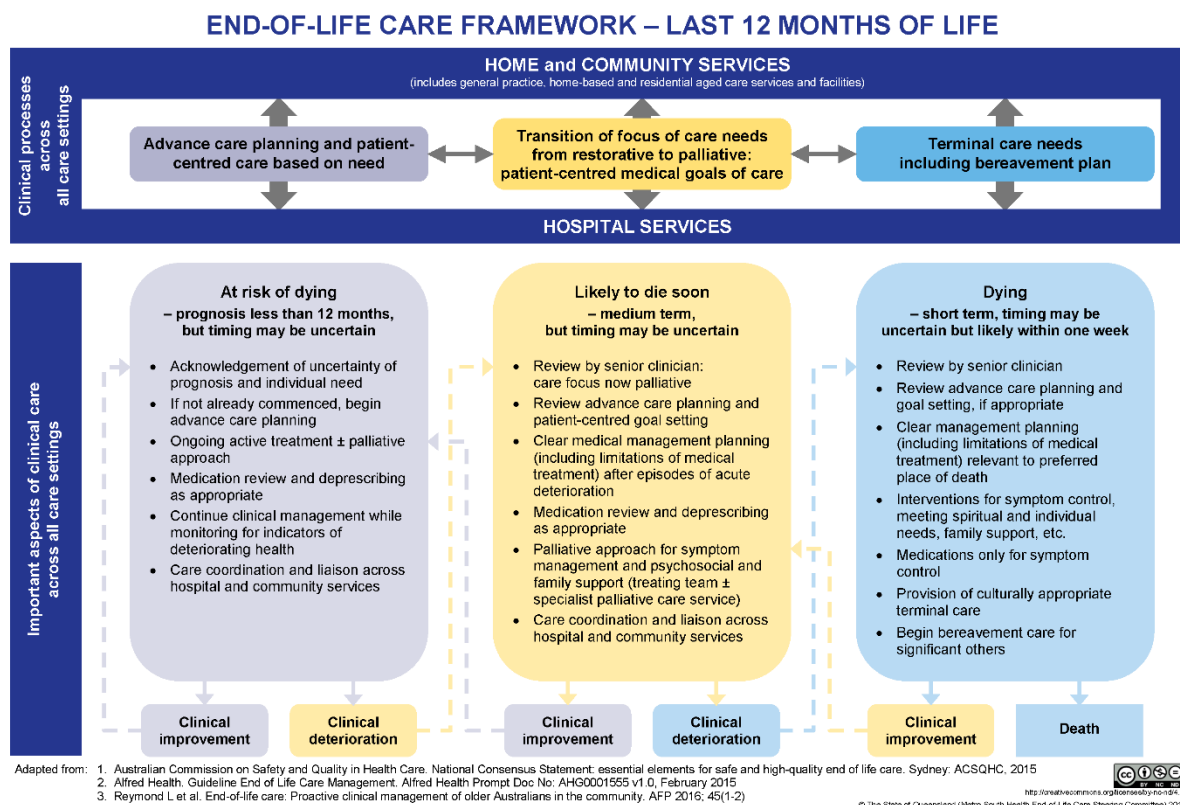
There comes a time in treating any patient with progressive chronic illness when death becomes likely in the foreseeable future, and the focus shifts from the illness to the person, providing the care they want and a good death. This may be considered at:

- routine assessment (eg 75+ health assessment, comprehensive medical assessment)
- advance care planning
- review of clinical care plan
- onset of advanced chronic disease or incurable cancer
- discharge from hospital treatment (eg acute episode of heart disease, lung disease)
- decline in functional capacity, cognition or geriatric syndromes
- admission into an RACF
- the request of patient and family.

Figure 2 illustrates a framework for GPs providing palliative care for community-based older patients.<sup>45</sup> It supports GPs to:

- assess palliative care needs
- use available tools
- develop proactive person-centred management plans that reduce the need for decision making in emotionally charged situations.

Figure 2. Framework for GPs providing care for community-based patients



Reproduced with permission from Decision Assist. A framework for palliative care in community-based aged care patients. Dickson, ACT: The Australian & New Zealand Society of Palliative Medicine, 2017.

The framework begins by asking: 'Would I be surprised if my patient were to die in the next six to 12 months?'.<sup>45</sup> This can be answered by intuition, using clinical and personal knowledge of the patient, and/or clinical tools (eg SPICt) to identify people who are at risk of deteriorating and dying:

- If the answer is 'yes', continue progressive chronic illness management, and initiate or review the patient's advance care plan and clinical care plan.
- If the answer is 'no', assess the patient's palliative needs and symptoms, review and use the advance care plan in discussion with the patient +/- medical decision maker, and initiate a clinical care plan for
  - palliative approach: prognosis within 6–12 months
  - end-of-life-care: prognosis within weeks (<6 months)
  - terminal phase, after death and bereavement: prognosis <1 week.

### Proactive person-centred approach to palliative care

Identification of a patient's palliative care needs becomes the starting point for initiating a palliative approach or end-of-life care. A proactive person-centred approach to palliative care entails the following:

- Identify and assess escalating palliative care needs early
  - Identify position along illness trajectory
  - Does the patient need care for a palliative approach, end-of-life or terminal phase?
  - Consider any physical, psychosocial and spiritual/existential issues
  - Consider patient symptoms
  - Consider carer burden and needs (eg carer allowance and payment, self-care, respite)

- Regularly reassess clinical condition, symptoms, deterioration and palliative care needs
- Discuss and share decision making with the patient, medical decision maker and carer
  - Discuss illness trajectory with patient and carer so they understand what is happening, especially at transition to a palliative approach, end-of-life care or terminal care
  - Review advance care plan and patient values, goals and choices, including preferred location of care and preferred place of death
  - Include patients to the extent they can contribute to ensure their needs and dignity remain the primary focus
  - Address patient and family concerns (eg give honest answers when asked ‘How long have I got?’, ‘What will happen?’); family views and issues are important and need to be understood
  - Use family and team case conferences when needed; for example, some relatives and RACF staff may need GP support to accept a resident’s decision for a palliative approach
  - Establish clinical goals of care and treatment decisions with patient and medical decision maker
- Create a GP clinical care plan, tailored to address
  - location of care (at home or RACF)
  - any physical, psychosocial and spiritual/existential issues
  - clinical care and control of symptoms
  - medication management, including deprescribing (refer to Part A. Deprescribing) and rationalising medicines as clinical condition changes (refer to Part A. Medication management)
  - services needed, and avoidance of unwanted treatments
  - aids and equipment (eg assistance with activities of daily living, mobility)
  - crisis management, emergency and after-hours care
  - patient and carer education and support, respite
- Document and share the care plan, and review regularly and revise as needed for palliative approach, end-of-life or terminal phase
- Make team care arrangements
  - Different arrangements for care at different locations; some patients will transfer between locations for specific treatments or as needs change towards the end of life
  - Be familiar with [My Aged Care](#), Aged Care Assessment Service (ACAS) and funding arrangements for home supports and RACFs; refer early to allow for funding delays
  - Team members may include
    - practice nurses in general practice who can help with health assessments, advance care planning, care plans, clinical care, support for patients and family, liaison with other services
    - home-care community services (eg personal care, community nursing, occupational therapy, physiotherapy, palliative care, pharmacy)
    - RACF staff, pharmacist, allied health, pastor, specialist palliative and support services
- Engage other community services (eg after-hours doctors, ambulance service, medical specialists, hospice care, dementia advisory and hospital outreach services, funeral director, carer respite, informal care networks, service groups and Compassionate Community organisations)
  - GPs can coordinate or participate in case conferences,<sup>46,47</sup> shared care arrangements, and telehealth consultations
  - Ensure documentation (eg the appointed medical decision maker, advance care plan, advance care directive, care plan) is available for continuity of care between all care providers, including after-hours doctors and ambulance
- Ensure practice organisation is maintained
  - Work collaboratively with practice nurse, GP colleagues, general practice registrars, after-hours doctors, other specialist medical practitioners, and allied health professionals

- Establish a palliative care patient register
- Use medical software templates and reminder systems
- Use Medicare Benefits Schedule (MBS) item numbers for GP attendance (at practice, home or RACF; including after hours, emergency and telehealth consultations), health assessments, care plans, and case conferences
- Use clinical apps, tools and guidelines
- Store and share relevant documentation with other service providers as needed

## Clinical care plans

Table 1 illustrates the PEPSI COLA mnemonic from the National Gold Standards Framework, which covers most potential problems in palliative care for GP clinical care planning.<sup>25</sup> It provides a structure to consider a patient's holistic needs, which is helpful for assessments, promoting communication with the patient, and documenting the clinical care plans as the patient approaches death.<sup>14</sup>

**Table 1. The PEPSI COLA structure for palliative care clinical planning**

Domain	Issues to consider
Physical	<ul style="list-style-type: none"> <li>• Symptom control</li> <li>• Medication – regular and as needed</li> <li>• Compliance/stopping non-essentials</li> <li>• Complementary therapies</li> </ul>
Emotional	<ul style="list-style-type: none"> <li>• Understanding expectations</li> <li>• Depression and adjustment</li> <li>• Fears/security</li> <li>• Relationships</li> </ul>
Personal	<ul style="list-style-type: none"> <li>• Spiritual/religious needs</li> <li>• Inner journey</li> <li>• Quality of life</li> <li>• Patient/carer agenda</li> </ul>
Social support	<ul style="list-style-type: none"> <li>• Benefits/financial</li> <li>• Care for carers</li> <li>• Practical support</li> </ul>
Information/communication	<ul style="list-style-type: none"> <li>• Within team</li> <li>• Between professionals</li> <li>• To and from patient</li> <li>• To and from carers</li> </ul>
Control	<ul style="list-style-type: none"> <li>• Choice, dignity</li> <li>• Treatment options/management plan</li> <li>• Advance directive</li> <li>• Place of death</li> </ul>
Out of hours/emergency	<ul style="list-style-type: none"> <li>• Continuity</li> <li>• Provision of out-of-hours care to patients/carers</li> <li>• Carer support</li> <li>• Medical support</li> <li>• Drugs and equipment</li> </ul>
Late	<ul style="list-style-type: none"> <li>• End-of-life/terminal care</li> <li>• Stop non-urgent treatment</li> <li>• Patient and family aware</li> <li>• Comfort measures/spiritual care</li> <li>• Rattle, agitation</li> </ul>

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<b>Afterwards</b>	<ul style="list-style-type: none"> <li>• Bereavement follow-up/others informed</li> <li>• Family support</li> <li>• Assessment/audit</li> <li>• Support team</li> </ul>
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As described in Box 1, there is ideally a shift in focus of clinical care as the patient progresses along the illness trajectory and approaches death. Regular patient reassessment can lead to early recognition of escalating palliative care needs and reduce patient distress by enabling a smoother transition to palliative approach, end-of-life and terminal phase.

## Palliative approach

The focus of care in the palliative approach shifts from life-prolonging treatments towards symptom treatment and quality of remaining life. In the palliative approach, GPs should:

- discuss the trajectories (physical, social, psychological, spiritual/existential) with patients and carers
- provide palliative care ongoing with disease management
  - anticipate and manage symptoms, illness exacerbations, and acute events
  - introduce interventions to optimise the person's level of comfort, function and wellbeing
  - address personal values and advance care planning for future care
  - make early referrals and team care arrangements
  - use case conferences to agree on issues and goals, and coordinate care between service providers
  - monitor for deterioration and escalating needs
- avoid unwanted non-beneficial interventions or hospitalisation
  - non-beneficial interventions that will not be effective in treating a person's medical condition or improving their quality of life may include diagnostic tests, medications, artificial hydration and nutrition, intensive care, and medical or surgical procedures. Non-beneficial treatments are sometimes referred to as 'futile' or 'inappropriate'; however, these are not the preferred terms<sup>48,49</sup>
- address carers' needs
  - carers are often the main care providers of palliative care patients while living at home. Identifying and supporting carers is important. Carers' needs and burnout are substantial, and often overlooked because they are not the ill person<sup>50</sup>
  - the Needs Assessment Tool for Carers of people dying with cancer (NAT-C) and non-cancer (NAT-CC) are available as self-completed checklists. NAT-C improves outcomes for carers, particularly those with anxiety or depression.<sup>51</sup>
- regularly review symptoms and changes in clinical condition.

## End-of-life care

The focus of end-of-life care is on providing increased services and support for the person's physical, emotional, social and spiritual/existential issues as they approach death. It entails:

- different arrangements according to preferred place of care and death
- frequent symptom reviews and changes in treatment as the person's health deteriorates
- preparing for the terminal phase
- support for patient, family and carers
  - communicate prognosis
  - respect the patient and their family's wishes, and review patient values, advance care plan, and advance care directive



- listening to carers and family experiences and bereavement arrangements will help carers and family members achieve peaceful closure
- enable carers, friends and family to be present before and at time of death if this is the desire of the patient
- if wanted, help arrange spiritual or religious support in a timely manner
- rationalising medicines
  - review medicines and deprescribe medicines that are of no short-term benefit (refer to Part A. Deprescribing).
  - consider anticipatory prescribing for common symptoms and acute/crisis events
  - consider use of subcutaneous drug administration if patient is unable to swallow
  - use tools (eg [palliAGEDgp app](#), [palliMEDS app](#), [Opioid Calculator app](#))
- turning off implantable defibrillators (if patient is known to have one) so as not to discharge upon death. For advice, contact the manufacturer or cardiologist.

## Care at home

Patients need to have their symptoms well managed for them to be able to stay at home for as long as possible, and to die at home. Anticipate the possibility that the person may be cared for at home for all but the last few days of life, when transfer may occur because of rapidly escalating care needs not able to be met at home, patient safety risks or carer exhaustion.

Make arrangements for care at home and empower carers by providing the necessary knowledge and tools, including:

- how and when to contact service providers, including after-hours care (eg palliative care, community care, GP, locum doctor, pharmacist, ambulance service, funeral director)
- arranging or checking equipment needed (eg diet, dressings, rails, commodes, personal medical alert alarm and system)
- training and giving confidence to carers to administer subcutaneous medication for prompt management of pain and other symptoms
  - assist in educating family on care and use/administration of medicines (eg via [caring@home](#))
  - ensure backup, supply, and equipment for administration of medicine
- arranging for collection of equipment and removal of medications (including Schedule 8 drugs and sharps) after death
- ensuring death-at-home documentation is available (eg advance care plan, advance care directive, 'not for resuscitation' orders).

## Terminal phase and after-death care

Recognising that death is imminent can sometimes be difficult, particularly if the person is declining gradually. Within hours to days of death, several of the following symptoms and signs (not explained by a reversible cause) may be present:<sup>52</sup>

- Increased trajectory of deterioration
- Peripheral shutdown and cyanosis, changes in respiratory patterns (eg Cheyne–Stokes breathing), retained upper airways secretions
- Drowsiness and reduced cognition (ie no response to verbal and/or physical stimuli)
- Uncharacteristic or recent restlessness and agitation
- Reduced or absent urinary content
- Cardiac signs (eg hypotension, tachycardia)
- Decreased mobility (eg bed bound)
- Decreased ability to swallow safely

The focus of care in the terminal phase is on enabling a 'good death' with dignity, relief from pain and other symptoms, and respecting the person's preference of place of death and who is present. Terminal care priorities are as follows:

- Provide support and communicate diagnosis of dying and likely course to the patient, family and service providers
- If the patient lives in an RACF, commence residential aged care end-of-life (terminal) pathway
- Monitor and address symptoms with nursing care and medications
- Cease non-essential medications, review anticipatory prescribing and ensure appropriate medications are available
- Discuss what to do after death
  - carers and family can have time alone with the person before contacting person to certify death, and the funeral director
  - arrangement of death certificate
  - bereavement support
  - document bereavement follow-up plan

### After death

After the death of a patient, the GP can ensure practical tasks are performed:<sup>18</sup>

- Oversee completion of legal requirements
  - death is to be verified by an authorised person – medical practitioner, nurse or paramedic
  - if the body is to be cremated, inform funeral director of hazards to be removed (eg implanted pumps, cardiac devices, radioactive isotopes, implants)
  - some deaths must be reported to the coroner; if in doubt, contact the state or territory coroners' office to discuss
  - death certificate is to be completed by medical practitioner (requirements vary by state or territory)
- Make sure carers and family are aware they can have time alone with the person before contacting the practitioner to certify death
- Offer to contact a funeral director or minister of religion (may be done by family member or RACF staff)
- Offer bereavement support
- Inform community nursing team or palliative care team; they can organise support for the family
- Organise collection of equipment, removal of medications, including Schedule 8 drugs and sharps
- Inform relevant health providers and health services

### Symptom control

Patients with life-limiting illness frequently develop symptoms because of progression, relapse or exacerbation of chronic diseases, treatments and/or intercurrent illness. Early identification, assessment and management are important to relieve symptoms and improve quality of life. Assess each symptom, its impact, cause and effect of previous treatments, and consider priorities for the patient.<sup>18</sup>

In a systematic review of general practice end-of-life symptom control, most GPs expressed confidence in identifying end-of-life care symptoms. However, they reported lack of confidence in providing end-of-life care at the beginning of their careers, and improvements with time in practice. They perceived emotional support as the most important aspect of end-of-life care that they provide. GPs felt most comfortable treating pain, and least confident with dyspnoea and depression. Observed pain management was sometimes not optimal. More formal training, particularly in the use of opioids, was considered important to improve management of both pain and dyspnoea.<sup>53</sup>

Symptom assessment tools can be valuable to identify symptoms, score their severity and monitor the effectiveness of treatments. A useful tool for GPs is the [Symptom Assessment Scale \(SAS\)](#), which is available in 15 languages for

completion by patients, their carer or RACF staff. It lists and scores severity on a scale of 0–10 for seven common symptoms (with ability to add extra symptoms) in palliative care:

- Difficulty sleeping
- Appetite problems
- Nausea
- Bowel problems
- Breathing problems
- Fatigue
- Pain (refer to Part A. Pain)

Physical issues and symptoms to be considered in palliative care for people with dementia include monitoring for non-verbal pain behaviours, falls (refer to Part A. Falls), vision, oral health, swallowing difficulties, seizures and withdrawal effects of deprescribing medication.

Refer to clinical guidelines (eg eTG Palliative Care,<sup>18</sup> CareSearch)<sup>54</sup> for detailed assessment and management of common physical symptoms and problems at the end of life, including pain, fatigue, gastrointestinal, respiratory, neurological and neuromuscular, psychological, dermatological, haematological, genitourinary, and emergencies.<sup>18</sup>

Many of the troubling symptoms of the terminal phase can be remembered under the mnemonic PANERO:<sup>52</sup>

- **P**ain
- **A**gitation
- **N**ausea (and vomiting)
- **E**mergencies (eg acute severe):<sup>18</sup>
  - vomiting
  - dyspnoea
  - airway obstruction
  - superior vena cava obstruction
  - agitation and altered mental state
  - haemorrhage
  - seizures
  - spinal cord compression
- **R**espiratory symptoms (eg noisy breathing)
- **O**ther symptoms (related to the specifics of the terminal illness)

Principles of symptom management include the following:<sup>18</sup>

- Closely monitor patients' symptoms and individualise treatment as needed
- Minimise the burden of treatment and number of medications
- Communicate and document plan to patient, carer and treating health providers
- Frequently review symptom and management

## Medication management in palliative care

### Principles

Issues to consider for safe use of medicines in palliative care include:<sup>55</sup>

- monitoring for effectiveness and adverse effects
- minimising burden on patients
- polypharmacy (refer to Part A. Polypharmacy)
- deprescribing (refer to Part A. Deprescribing)
- safety of opioid use and disposal
- complexities of opioid prescribing.

Key principles for medication management at the end of life are as follows:<sup>18</sup>

- Assess and closely monitor patients and individualise treatment as needed
- Continue current medicines if needed for symptom control
- Stop unnecessary, burdensome or harmful medicines
- Consider anticipatory prescribing
- Prescribe regular medicines for ongoing symptoms and as required for intermittent or breakthrough symptoms
- Keep the patient comfortable by ensuring adequate doses
- Administer medicines subcutaneously or sublingually
- Consider practical aspects of subcutaneous administration (eg injection volumes, medicine compatibility, skill of carers)
- Monitor effects and adjust dose
- Seek palliative care advice if a patient is distressed or does not settle despite adequate doses

Alleviating suffering and ensuring a patient can maintain their dignity and some sense of control as their life comes to an end is the essence of good palliative care.<sup>18</sup> However, in the terminal phase, GPs may be concerned that they could prescribe or administer a medicine that will unintentionally lead to a patient's death.<sup>25</sup>

In Australian law, the 'doctrine of double effect' recognises that giving medicines (usually by a health professional) to a patient to relieve pain is lawful, even if it could hasten death. The two critical elements of 'double effect' are intention and that the patient's death is imminent. If the primary intention is to relieve pain and symptoms, not cause death, the person who gave the medicine will not be criminally responsible for a death which follows, even if it is foreseen. For further information, refer to 'Palliative Medicine' on the [End of Life Law in Australia](#) website.

### Deprescribing

Deprescribing is the withdrawal of medicines that are no longer beneficial. It is a key component of palliative care. For current medicines prescribed for long-term effects, assess risks, short-term benefits and potential withdrawal effects, including:

- medicines for cardiovascular disease (ie hypertension, angina, dyslipidaemia), diabetes, cancer, epilepsy, neurological diseases, psychiatric illness
- anticoagulants and antiplatelet medications, thyroid replacement, antivirals (human immunodeficiency virus [HIV], hepatitis), corticosteroids.

Changes should occur gradually unless the patient is close to death, has minimal oral intake and is unable to take their usual medicines.

## Prescribing

Medications used in palliative care are available as no script ('over the counter'), private script, Pharmaceutical Benefits Scheme (PBS) script, PBS Authority script and PBS Authority (Palliative Care). Medicines listed in the PBS Palliative Care Schedule are 'authority required'; larger quantities can be prescribed, reducing burden in terms of costs and need for repeat prescriptions.

'Off-label' medications are often prescribed as private scripts for palliative care patients for a different indication or route than the one for which they are approved by the Therapeutic Goods Administration (TGA). Palliative care services can provide advice to GPs based on considerable clinical experience with common off-label uses of medications in palliative care, such as:

- antipsychotics or antihistamines for nausea
- antidepressants or anticonvulsants for neuropathic pain
- administration of intravenous (IV) preparations by the subcutaneous route.

Anticipatory prescribing is prescribing medicines in advance for anticipated symptoms or problems, or to avoid crisis or urgent hospital transfer. GPs can promote effective symptom management in the community by anticipatory prescribing for common end-of-life symptoms and involving carers in symptom management.

Table 2 is a consensus-based list of eight palliative care medicines suitable for managing terminal symptoms in the community. It has been endorsed by the Australian and New Zealand Society of Palliative Medicine (ANZSPM).

**Table 2. Consensus-based list of eight palliative care medicines suitable for managing terminal symptoms in the community**

Medication	Ampoule strength	Stock
Clonazepam drops (PBS-listed for seizures only)	2.5 mg/mL	1 bottle (10 mL)
Fentanyl citrate injection (not listed on PBS)	100 mcg / 2 mL	10 ampoules
Haloperidol injection	5 mg/mL	10 ampoules
Hydromorphone injection	2 mg/mL	5 ampoules
Hyoscine butylbromide injection	20 mg/mL	5 ampoules
Metoclopramide injection	10 mg/ 2 mL	10 ampoules
Midazolam injection (not listed on PBS)	5 mg/mL	10 ampoules
Morphine sulphate injection	10 mg/mL	5 ampoules

Details on prescribing these medicines with doses for patients' symptoms are available in the Resources section.

## Bereavement support

### Support for carers and family

Most bereaved people do not require counselling or specialist support. Simple reassurance, acknowledgment of their loss and access to information may be all that is required. Reactions commonly seen as part of normal grief include:<sup>50</sup>

- physical – hollowness in stomach, tightness in the throat or chest, oversensitivity to noise, sense of depersonalisation, breathlessness, dry mouth, muscle weakness, lack of energy
- behavioural – crying, sighing, sleep disturbance, restlessness and overactivity, appetite disturbances, absentmindedness, social withdrawal, dreams of the deceased, avoiding reminders, searching and calling out, visiting places associated with the deceased, carrying reminders
- mental – disbelief, confusion, preoccupation
- emotional – anxiety, fear, sadness, anger, guilt, inadequacy, hurt, relief, loneliness.

Bereavement has a significant effect on the health of surviving family members. Grief can cause poorer health outcomes, depression, and alcohol and drug dependency in some people. Mortality of the surviving spouse doubles in the 12 months after the death. Issues to consider in bereaved people include:<sup>50</sup>

- sleep problems and fatigue, worsening memory
- clinically significant depression – this may occur in 10–20% of bereaved people (refer to Part A. Mental health)
- changed social circumstances – this can affect the bereaved person’s physical activity levels, nutritional status, and self-management of chronic health problems
- social isolation and changes in other important relationships.

Strategies to actively follow up recently bereaved people in general practice may include:<sup>50</sup>

- offering an appointment to talk about what happened with a GP; this may be appreciated, particularly if the GP cared for both deceased and bereaved
- flagging bereaved patients for the practice nurse to contact by condolence letter or a phone call with an offer of a check-up
- offering to review the bereaved person’s overall health status and medical conditions when they attend the clinic
- identifying bereaved persons who need specialist support.

## Support for healthcare professionals

GP self-care and support of colleagues is important to prevent stress and burnout from accumulated losses and grief associated with providing palliative care, especially in a solo practice or rural setting. Measures for self-care include:<sup>18</sup>

- education, training, and skills development for palliative care, including communication skills
- self-awareness and realistic expectations
- workload and work–life balance
- expressing grief and sharing experiences of loss (eg of long-term or close patients)
- peer and professional support with colleagues, mentors, professional supervision
- debriefing with colleagues, multidisciplinary case conferences.

# Resources

## Professional development

GPs are encouraged to develop palliative care skills and experience early in their career. This can be built on and enhanced by:

- using tools and resources (listed below) to supplement palliative care practice
- shared care with local team-based support services, including community home-based and RACF services; informal care networks, service groups and Compassionate Community organisations; specialist palliative care services and hospice care
- peer support and training, including
  - GP palliative care interest groups (eg primary health networks [PHNs], The Royal Australian College of General Practitioners [RACGP])
  - membership of the [ANZSPM](#), which provides professional development to support and educate Australian and New Zealand medical practitioners with an interest in palliative medicine
  - the [Program of Experience in the Palliative Approach \(PEPA\)](#), which is a clinical attachment and e-learning program
  - web-based and group training programs in advance care planning, communications skills, advanced chronic disease, palliative care

- [Advance Project](#), which is a toolkit and training package to help GPs and practice nurses initiate advance care planning, assess likely end-of-life care needs, and provide team-based palliative care in everyday clinical practice
- [CareSearch](#)
- [end-of-life law for clinicians](#).

## Clinical applications

- [SPICT app](#)
- [palliAGEDgp](#) – this is available as an app or online for GPs to support care of older palliative patients living at home or in RACFs. An offline capacity makes it practical for use in remote and rural settings. It provides free, accessible, evidence-based information to help clinical decision making for each phase of palliative care:
  - [Advance care planning](#)
  - [Case conferencing](#)
  - [Terminal care management](#)
  - [Prescribing guidance](#)
- [palliMEDs](#) – this app is useful for anticipatory prescribing at end of life. It was developed by NPS MedicineWise for [caring@home](#) as a guide to prescribing eight palliative care medicines, was endorsed by the ANZSPM for management of terminal symptoms, and covers off-label prescribing and medico-legal issues
- [Opioid Calculator](#) – this tool simplifies the calculation of equianalgesia expressed as total oral morphine equivalent daily dose (oMEDD), and was developed by the Faculty of Pain Medicine, Australian and New Zealand College of Anaesthetists.

## Clinical tools

- [SPICT](#)
- NAT-C or NAT-CC [Caregiver needs assessment](#) – these are needs-assessment tools for carers of people dying with cancer and non-cancer. They are available as self-completed checklists for carers, which allows them to identify their own major concerns. These are available online and can be discussed in a GP consultation
- [Palliative Care Outcomes Collaboration \(PCOC\)](#) – PCOC uses five clinical assessment tools to help identify and manage common symptoms, evaluate effectiveness of treatments, and help patients, carers and families to communicate their experiences and preferences. Specific useful tools for GPs are:
  - [SAS](#) (clinical assessment tools to help identify and manage common symptoms, available in 15 languages)
  - [Australia-modified Karnofsky Performance Status \(AKPS\)](#) (score of physical abilities across activity, work and self-care).

## Guidelines and resources

- [Localised palliative care and advance care planning pathways](#) are divided by area in Australia and available from local PHNs. The pathways are designed and written for use during the consultation and provide clear concise guidance for patient assessment, management, and referral to local health services. Included are pathways that contain information specific to Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse communities.
- [Therapeutic Guidelines: Palliative care](#) provides practical detailed clinical guidelines, including palliative care and symptom management, decision making and ethical challenges, communication, support for carers and families, medications and prescribing, terminal care, and bereavement support.
- [CareSearch](#) – the GP section provides easy-to-navigate guidance at all points along the patient's pathway of care, including patient assessment, planning care, symptom assessment and management, clinical decisions, the dying patient, bereavement, use of the PBS and MBS, and professional practice (ongoing education and self-care). It also provides advice on prescribing and symptom-management advice, psychosocial complexity and



refractory symptoms, clinical decision making for the deteriorating patient, emergencies, and planning for a home death. Refer to the following links for specific information.

- [Communication](#)
- [Clinical care issues](#)
- [Residential Aged Care Palliative Approach Toolkit](#)
- [Caregiver needs assessment](#)
- [Bereavement](#)
- [Advance Care Planning Australia](#) – this website provides extensive resources on advance care planning.
- [Palliative Care Australia](#) provides resources for palliative care and advance care planning tailored for use for people from culturally and linguistically diverse backgrounds. Important patient resources for GPs include:
  - [multilingual brochures about palliative care](#)
  - [ACPTalk](#).
- [Caring@home](#) provides resources to support GPs in promoting effective symptom management by anticipatory prescribing for common end-of-life symptoms, and involving carers in symptom management, including preparing and giving subcutaneous medicines for breakthrough symptoms. The resource includes the palliMEDS app.
- [End of Life Law in Australia](#) informs clinicians of the law, their rights and duties; helps navigate challenging legal issues that can arise with end-of-life decision making in each Australian state and territory; and provides GP training modules. Legal issues covered include palliative medicine, euthanasia and assisted dying, capacity and consent to medical treatment, advance care directives, stopping treatment, and organ donation.

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