



Palliative Care

Essential CPE

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Palliative care
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A Department of Health Project to develop, implement and evaluate the role of the pharmacist as a member of the community palliative care multidisciplinary team was undertaken by Sandy in 2009/2010.

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Learning objectives

After reading this Essential CPE, a pharmacist should be able to:

- Define palliative care and identify when palliative care is provided and to whom
- Discuss the phases of palliative care, as well as the treatment goals and expectations for each phase
- Discuss the role of the pharmacist in a multidisciplinary palliative care team
- Explain advance care planning and its role in ensuring people's values are discussed and respected when the person can no longer voice their decisions
- Discuss the role of the caregiver in palliative care and medication management
- Summarise concepts of using medicines in people with swallowing issues
- Summarise deprescribing medicines for people receiving palliative care
- Identify the symptoms people may experience during the terminal phase of care
- Discuss the current clinical guidelines and treatment strategies for people receiving palliative care in the last days of their life
- Discuss the treatment strategies for symptom care including pharmacological and non-pharmacological interventions
- Communicate effectively with people and caregivers about palliative care and their medicines management plan
- Respect cultural and linguistic diversity of people and their families, friends and caregivers and provide culturally-appropriate communication
- Recognise people's rights to contribute to decision making about their own health
- Recognise common risk factors that are likely to lead to concerns for pharmacists' mental health when working in the palliative-care setting or interacting with people receiving palliative care and their caregivers
- Identify self-care strategies for pharmacists to help reduce psychological distress and stress-related situations in the palliative-care setting.



Accreditation number: CESS1901

This activity has been accredited for 4 hour(s) of Group 1 CPD (or 4 CPD credits) suitable for inclusion in an individual pharmacist's CPD plan, which can be converted to 4 hours of Group 2 CPD (8 CPD credits) upon successful completion of relevant assessment activities.

How to earn CPD credits

To obtain CPD credits, carefully read through the module, complete the assessment sheet, and submit your answers online to receive immediate feedback. Visit www.psa.org.au. Alternatively post your answers to PSA. Group 2 CPD credits are allocated to members who achieve 75% of questions correct.

If posting your assessment, photocopy your assessment sheet for your own records. Should you require your assessment to be returned to you, enclose a stamped, self-addressed envelope. Submission is encouraged within 8 weeks of receipt; however will be accepted up to 2 years from the date of publication.

Competency standards

Pharmacists can self-assess their abilities against the competency standards relevant to their role to determine areas in which further development is needed.

This Essential CPE addresses the following competencies (2016):

Domain 1: Professionalism and ethics

Standard 1.1: Uphold professionalism in practice

Enabling competency 1: Promote a culture of professionalism

Enabling competency 2: Uphold the professional role of a pharmacist

Enabling competency 3: Apply understanding and knowledge of medicines management and use in society

Enabling competency 5: Work with commitment, diligence and care

Standard 1.2: Observe and promote ethical standards

Enabling competency 1: Support ethical professional practice

Standard 1.3: Practise within applicable legal framework

Enabling competency 1: Comply with statute law, guidelines, codes and standards

Enabling competency 2: Respond to common law requirements

Standard 1.4: Maintain and extend professional competence

Enabling competency 1: Adopt a scope of practice consistent with competence

Standard 1.5: Apply expertise in professional practice

Enabling competency 3: Demonstrate accountability and responsibility

Standard 1.6: Contribute to continuous improvement in quality and safety

Enabling competency 1: Collaborate to improve quality and safety across the continuum of care

Domain 2: Communication and collaboration

Standard 2.1: Collaborate and work in partnership for the delivery of patient-centred, culturally responsive care

Enabling competency 1: Respect the personal characteristics, rights, preferences, values, beliefs, needs and cultural and linguistic diversity of patients and other clients, including Aboriginal and Torres Strait Islander peoples

Standard 2.2: Collaborate with professional colleagues

Enabling competency 1: Show a commitment to interprofessional practice

Enabling competency 2: Engage in teamwork and consultation

Enabling competency 3: Promote effective interprofessional practice

Standard 2.3: Communicate effectively

Enabling competency 1: Use appropriate communication skills

Enabling competency 2: Confirm the effectiveness of communication

Standard 2.4: Apply interpersonal communication skills to address problems

Enabling competency 1: Analyse the problem or issue to be addressed and the possible solutions

Domain 3: Medicines management and patient care

Standard 3.1: Develop a patient-centred, culturally responsive approach to medication management

Enabling competency 1: Obtain relevant health and medicines information

Enabling competency 2: Assess medication management practices and needs

Enabling competency 3: Collaborate to develop a medication management strategy or plan

Standard 3.2: Implement the medication management strategy or plan

Enabling competency 2: Provide primary care and promote judicious use of medicines

Enabling competency 5: Provide counselling and information for safe and effective medication management

Enabling competency 6: Facilitate continuity of care including during transitions of care

Standard 3.3: Monitor and evaluate medication management

Enabling competency 1: Undertake a clinical review

Enabling competency 2: Apply clinical review findings to improve health outcomes

Enabling competency 3: Document clinical review findings and changes in medication management

Standard 3.5: Support quality use of medicines

Enabling competency 1: Review trends in medicine use

Standard 3.6: Promote health and well-being

Enabling competency 1: Assist development of health literacy

Enabling competency 3: Support evidence-based public health programs

Domain 4: Leadership and management

Standard 4.4: Participate in organisational planning and review

Enabling competency 5: Develop and maintain supporting systems and strategies

Domain 5: Education and research

Standard 5.3: Research, synthesise and integrate evidence into practice

Enabling competency 1: Identify information needs and resource requirements

Terminology

Terms	Definitions
ACD	Advance care directive is a formal advance care plan that is recognised by common law or specific legislation
Ambulance Authorised Adult Palliative Care Plan (NSW only)	Document completed by a doctor in discussion with the person and their caregivers authorising paramedics to administer medications in accordance with instructions detailed and within their scope of practice. May also include resuscitation treatment decisions and limitations, preferred location of care, instructions for care after death and contact details for other healthcare providers involved in the person's care. Effective for a maximum period of 12 months. Further information regarding palliative care ambulance plans can be accessed at: www.coordinate.org.au/assets/...for-general-practice/GP-booklet-ACPs-2017-Final.pdf
Background opioid	Opioid given to provide continuous analgesia to manage background pain (see below). It may be a regular dose of slow-release or immediate-release opioid, or a transdermal patch or continuous subcutaneous infusion of opioid
Background pain	A pain that is always present and is consistently in the background of the person's experience. The term is used to differentiate from 'chronic pain' syndrome, which is managed in a different manner and where opioids are not generally recommended
Caregiver	A person who regularly provides care and support to a person who has a disability, mental illness or terminal illness. They could be a person's family member, friend, neighbour or paid helper. May also be known as carer.
COPD	Chronic obstructive pulmonary disease
CSCI	Continuous subcutaneous infusion
CTZ	Chemoreceptor trigger zone
GP	General practitioner
HMR	Home Medicines Review
Hospice	A dedicated palliative care unit where the person can be admitted for management of burdensome symptoms or to assist with care during the terminal phase
Life-limiting illness	An illness where it is expected that death will be a direct consequence of the specified illness (e.g. cancer, heart disease, chronic obstructive pulmonary disease, dementia, heart failure, neurodegenerative disease, chronic liver disease and renal disease)
MND	Motor neurone disease
NP	Nurse practitioner
NSAID	Non-steroidal anti-inflammatory drug
PBS	Pharmaceutical Benefits Scheme
PEPA	Program of Experience in the Palliative Approach
PRN	When necessary (latin: pro re nata)
RACF	Residential aged care facility
SPC	Specialist palliative care
Surrogate decision maker	A person nominated by the person receiving palliative care, who ensures the person's care is consistent with what is known of the person's own value and wishes

Overview of palliative care

Palliative care is holistic care provided to people who have a progressive life-limiting illness that cannot be cured and will lead to death.¹ It incorporates treatments in the physical, spiritual, psychosocial and cultural domains. Palliative care is delivered by healthcare providers and caregivers, and aims to relieve symptoms and maximise a person's quality of life. Palliative care continues after death, and includes the support of families, friends and caregivers, including bereavement support.²



The World Health Organization defines palliative care as:

'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.'³

Palliative care is guided by a number of overarching principles³:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of person care
- offers a support system to help people live as actively as possible until death
- offers a support system to help the person's caregivers cope during the person's illness and in their own bereavement
- uses a team approach to address the needs of the person, their caregivers and those close to them, including bereavement counselling, if indicated
- enhances the quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Providing palliative care

Palliative care is provided on the basis of need and is independent of a person's age or medical diagnosis. Many people who receive palliative care have advanced cancer. However, people with other conditions and illnesses may also benefit from palliative care (see Table 1).

People receiving palliative care may also experience concurrent co-morbidities and chronic illnesses. These illnesses can have an effect on their clinical condition, life-limiting disease trajectory, prognosis, symptoms and symptom management.⁴ However, the goals of palliative care remain the same regardless of the person's illness or comorbidities.⁵

Clinical prognostication tools can assist clinicians identify people who would benefit from a palliative approach.⁴ For example, the Supportive and Palliative Care Indicators Tool (SPICT) consists of general and disease-specific clinical indicators used to identify people at risk of deteriorating and dying from one or more advanced health conditions and who would benefit from holistic palliative care.⁶

As treatments become increasingly limited and burdensome, the person's general condition and physical function decreases. There is a shift from active disease management, intervention and life-prolongation to symptom management, supportive care and a priority to quality of life. Realistic expectations regarding treatment outcomes, disease trajectories, and negotiation of person-centred goals of care, are discussed and set with the person and caregivers allowing for the opportunity to focus on quality of life.⁴

For further information on palliative care in Australia, see *National Palliative Care Strategy 2018* and for information about state-based palliative care services, see the *Resources* section of this document.

Disease trajectories

Estimating when a person living with an advanced, progressive, life-limiting illness will die is very difficult. It is more useful clinically to identify people for whom increasing disability and illness may lead to their death sometime in the next year.⁷ Traditionally, people with a cancer diagnosis have a fairly predictable disease trajectory and decline at the end of life. People with chronic disease often have a longer and less predictable disease trajectory.

There are four types of disease trajectories (see Table 2). People's life expectancy may vary from these disease trajectories, as acute events can contribute to rapid decline and death.⁸

Table 1. Medical conditions and illnesses that would benefit from palliative care involvement

Condition/illness	Description	Examples
Advanced, progressive, incurable	Cancer	Breast cancer, lung cancer, prostate cancer
	Neuromuscular disorders	Multiple sclerosis (MS), motor neurone disease (MND), Parkinson's disease
	Diseases that cause end-stage organ failure	Chronic lung disease, cardiac disease, chronic kidney disease, chronic liver disease, and acquired immune deficiency syndrome (AIDS)
	General frailty and co-existing multiple medical conditions that cause gradual decline and failure of multiple body systems	Dementia
	Genetic disorders	Cystic fibrosis
Existing	Medical conditions that put a person at risk of dying from a sudden acute crisis in their condition	Coronary artery disease, valvular heart disease, Addison's disease
Life-threatening, acute	Conditions caused by sudden catastrophic events	Stroke, myocardial infarction

Table 2. Types of disease trajectories

Trajectory	Definition	Timeframe	Description
1	Sudden or rapid death (e.g. cardiac arrhythmia, stroke)	Hours-days of life	People are well and die from a sudden and unexpected death from an acute medical problem
2	Period of steady decline with a clear and relatively short terminal phase (e.g. advanced cancer)	Last years of life Steady decline in last months and weeks of life Rapid deterioration in last days of life	Reasonably predictable decline in physical health over a period of weeks, months or years People experience weight loss, reduction in performance status, and reduced ability for self-care in the last few months and weeks of their life, followed by a clear and relatively rapid decline Generally, there is time to anticipate palliative needs and plan for care during the last months and weeks of life, which informs and directs the care provided in the last days of life
3	Gradual decline with intermittent episodes of exacerbation (acute deterioration and improvement) with eventual quick death (e.g. end-stage heart failure, end-stage COPD and some people with cancer)	Last years and months of life, with rapid deterioration in last days of life when death can often seem sudden Timing of death remains uncertain	People experiencing chronic conditions usually unwell for many months or years with occasional acute, often severe, exacerbations Deterioration is generally associated with admission to hospital and acute treatment People usually do not return to their previous baseline on recovery Each exacerbation may result in death, although the person usually survives many of these episodes. A gradual deterioration in health and functional status is characteristic
4	Prolonged gradual decline and general frailty of multiple body systems (e.g. dementia)	Variable, can be many years	People without a cancer diagnosis or organ system failure are likely to die at an older age from generalised frailty of multiple body systems or dementia Characterised by progressive disability from an already low baseline of cognitive or physical functioning Slowly lose weight and functional capacity, and then acutely deteriorate from a physical event occurring in combination with declining reserves, which can lead to death (e.g. death occurs after a fall with a fractured neck of femur, a chest infection with a development of pneumonia, or from urosepsis from recurrent urinary tract infections)

Reference: Palliative Care Expert Group⁴; Palliative Care Network⁷; Murray⁸

Care planning and management plans

‘...a good death...it shouldn’t come as a surprise to everyone, that there’s actually been some time...just to recognise that, the patient’s life is ending, and so there’s a plan in place; people know what they’re doing and what they’re treating’ (Trankle (BMC Palliat Care 2014:13)

Supporting people and their families and friends to accept the inevitability of death is acknowledged as a central part of palliative care. Planning for, and discussing the changing goals of care is an important part of this process. Spiritual care is regarded as important by many at the end of life and requires discussion and consideration. Cultural differences also need to be identified and appropriately addressed.⁹

Advance care planning

Advance care planning aims to encourage people to consider, discuss, and document their future wishes for care ideally before reaching the terminal palliative care phase. The process encourages people to reflect on what is important to them, their beliefs, values, goals and preferences. In addition, how they want to be cared for if they reach a point where they are unable to communicate decisions about medical care for themselves.^{9,10}

Advance care planning, advance care plans, Advance Care Directives (ACDs) and appointment of surrogate decision makers are governed by state and territory legislation. Specific advance care planning information and resources for each state and territory can be found at the Advance Care Planning Australia and Department of Health palliative care projects websites (see *Resources*).

Advance care planning includes discussions about communication, and health system and medico-legal considerations relating to care planning processes and documentation. All healthcare providers such as occupational therapists, pharmacists, physiotherapists, social workers, may be involved with advance care planning. They may be asked to provide information and education to help inform these discussions.

In palliative care, an ACD is especially important as it assists healthcare providers understand what choices and decisions have been made, how a person would like to be cared for, and the direction of treatment plans if they are unable to speak for themselves.

A recent prevalence study identified that only 30% of Australians have a documented advance care plan or ACD.¹¹ People are advised and encouraged to share their ACD with all healthcare providers involved in their care. They can upload their ACD to their My Health Record, if they choose. Advance care planning discussions should be documented as verbal wishes may not be correctly conveyed.

Pharmacists should determine whether an ACD is in place, and work within that plan to provide appropriate care for the person with regard to medication management.

If further information regarding advance care planning is requested by the person or caregiver, the pharmacist can access state and territory relevant resources and information from Advance Care Planning Australia at: www.advancecareplanning.org.au.

Delivering palliative care

Palliative care is person-centred and delivered by a multidisciplinary team consisting of a range of generalist and specialist clinicians and other service providers. They support the person and caregivers. As a person's care needs are multifactorial and often complex, a team approach to care is essential. Palliative care needs to be flexible, especially as people move between care settings and care providers.^{4,5}

Generalist palliative care is provided by clinicians across the health and aged care system in differing practice settings such as in the community and hospitals. It is integrated into many health services, including complex and chronic care, diabetes, heart failure and COPD consultancy services, aged care services, medical and surgical care, intensive care, accident and emergency care and paediatrics.

Specialist palliative care (SPC) is provided to people with complex problems by a multidisciplinary team of SPC professionals.⁴

Caregivers

In Australia, a significant amount of care required by people receiving palliative care is provided by caregivers. Caring for a person in their home, particularly when they have been diagnosed with a life-limiting illness, can be extremely difficult physically, psychologically, socially, financially and spiritually. Caregiver roles and responsibilities vary and may include personal, domestic, nursing, and financial care.¹² Caregivers may also have other responsibilities apart from caring (e.g. paid employment, additional family commitments) that may cause them to neglect their own personal needs and health.

Caregivers can be assisted by generalist and specialist services, as well as community home-care organisations. Care support services, from both government and non-government organisations, can provide assistance with personal care for the person, housework, in home respite and shopping services. Services assess the person and caregiver to determine the support that may be required. There is often a nominal cost involved in securing these services, which is assessed individually depending on financial circumstances. Culture, family background and geographical location can significantly influence the type, amount and accessibility of caregiver support.

Financial assistance is available for caregivers from government-funding schemes. The Australian Government, Department of Human Services provides financial assistance to caregivers that qualify for support. Further information can be accessed from: www.humanservices.gov.au/individuals/subjects/caring-someone-illness-or-disability

Multidisciplinary team

Palliative care provided by a multidisciplinary team (MDT) is the optimal model to support the person receiving palliative care and their caregivers. Multidisciplinary teams include general practitioners (GP), specialist clinicians, nurses, pharmacists and a range of allied health providers (see Table 3).⁵ The composition of the team depends on location, populations serviced, and disease complexity.

Box 1. Program of Experience in the Palliative Approach (PEPA)

PEPA provides free workshops and placements (up to 2–4 days) in palliative care services for practicing healthcare providers, including pharmacists.

By undertaking a PEPA placement you will:

- demonstrate a clear understanding of the principles of palliative care
- identify the needs of people receiving palliative care
- identify the role of practitioners within your field in managing common problems faced by people with life-limiting illness and their families
- recognise your own knowledge base/ scope of practice with regard to optimal palliative care provision
- identify personal coping strategies for effective management of stress related to working in this field.

A key component of the learning will also be developing networks with local palliative care providers that may assist you in your own practice when providing care to people with life-limiting illness.

For further information, go to: <https://pepaeducation.com/>

Reference: PEPA¹⁴

Palliative care settings

Almost half of all Australians receiving palliative care die in the community setting. National statistics indicate that 14% die in their own home and almost a third in residential aged care.¹⁵ Home, surrounded by family and friends, is often quoted as where most people would prefer to die.¹⁶ One of the enablers to keep people in the community until death is good symptom management (see *Symptom care*).^{17–20}

Palliative care may be required in almost all health, social and community settings. The care setting could change as the person receiving palliative care moves between settings during their journey. Ideally, a person should be cared for and die in the place of their choice. This is essential in providing optimum palliative care. Studies show that people who received palliative care in their preferred location had more positive experiences.^{21–23} A person's preference for where they wish to be cared for, and where they wish to die, can also change over time.²³

There are many factors that influence a person and their caregivers' decisions regarding place of care and death, including^{21,23}:

- specific care needs, including management of the person's symptoms
- the availability of a caregiver
- support from trained healthcare providers
- support for the caregiver
- availability of required equipment to assist with care at home
- cultural preferences
- adequate planning, communication and coordination of all involved.

Table 3. Palliative care multidisciplinary team practitioners and their roles

Team member	Role within the multidisciplinary team
Specialist palliative care physician	<ul style="list-style-type: none"> • Provides home visits, phone consultation, and out-patient review • Works in partnership with the person's GP, Nurse practitioner (NP), SPC team and wider nursing and support services • Refers a person to hospital if specialist in-patient care is needed
General practitioner	<ul style="list-style-type: none"> • Coordinates care within the community • Cares for the person's ongoing medical needs • May complete medical certificate for cause of death in the community setting, and provides ongoing bereavement support for the person's caregivers and those close to person
Specialist palliative care nurse	<ul style="list-style-type: none"> • Has an expanded scope of practice with specialised knowledge and experience in palliative care • Assesses, supports and coordinates palliative care to people in both the community (home) and residential aged care facility • Delivers care independently or in conjunction with other services within the healthcare system or in collaboration with non-government organisations • Provides equipment and coordinates the provision of other community-based support and provides a liaison role with hospital services • Provides education and mentoring for clinicians providing generalist palliative care
Nurse practitioner	<ul style="list-style-type: none"> • Same as the SPC nurse including: <ul style="list-style-type: none"> • Coordinates care in some residential aged care and in many SPC settings • Assesses people with complex needs • Prescribes a range of predetermined medicines within their specialty area • Orders blood tests and other tests • Refers people to other services including specialists such as renal etc.
Generalist community nurse	<ul style="list-style-type: none"> • Provides home nursing care and support for people and families • Assists and support families in accessing information, equipment and additional community services, and provide a liaison role between hospital and community to facilitate ease of transfer and delivery of care in the community • Delivers palliative care in the home with SPC nurses • Coordinates care and liaises with members of the wider palliative care team as necessary depending on local models of care
Specialist palliative care pharmacist	<ul style="list-style-type: none"> • Responsible for the medicine needs of the person receiving palliative care within the specialist unit or dedicated beds within the hospital • Reviews a person's medicines on admission and at discharge, making recommendations as appropriate • Provides advice on appropriate drug doses, alternative routes of administration of medicines when people are unable to tolerate oral medicines • Monitors for and provides advice on the management of adverse effects • Assists in deprescribing of medicines • Counsel people and caregivers regarding medication-related issues whilst an inpatient and on discharge • Provides pharmaceutical advice for people receiving palliative care with complex medicine regimens (particularly useful in care settings and locations where generalist clinicians provide the majority of palliative care services) • Note: Palliative care hospital pharmacists have undergone specialist training and have an extended scope of practice • Liaises with pharmacists in other practice settings to organise ongoing supply of a person's medicines and provide them with appropriate transfer of information related to the person's medicines regimen • Assists in accessing medicine that is not readily available in the community, such as non-PBS and Special Access Scheme (SAS) medicines
Pharmacist (e.g. community pharmacist, GP pharmacist, Aboriginal and Torres Strait Islander Health Services pharmacist)	<ul style="list-style-type: none"> • Assists in the delivery of community-based palliative care, particularly medication management and deprescribing • Supports people receiving palliative care at home along with their caregivers • Provides MedsCheck services to review current medicines and develop a medication plan considering the person's palliative care journey and goals of care • Reduces the risk of medication misadventure • Provides Home Medicines Reviews to rationalise medicines, and provide support and education for both the person and caregiver • Ensures the pharmacy is prepared to supply injectable medicines that may be required during the terminal phase
Aboriginal and/or Torres Strait Islander health worker	<ul style="list-style-type: none"> • Assists healthcare providers to develop respectful relationships with Aboriginal and Torres Strait Islander people and their families • Identifies key family members, spokesperson and decision makers, and guide culturally appropriate communication regarding palliative care, death and dying • Provides appropriate support. Healthcare providers need to be mindful that Aboriginal health workers are usually part of the person's cultural community and the person may be a member of their close or extended family. Appropriate support may need to be provided to the workers themselves • Further resources have been developed by Program of Excellence in the Palliative Approach (PEPA) to assist provision of palliative care for Aboriginal and Torres Strait Islander people (see Box 1), at: https://pepaeducation.com/support-and-education/palliative-approach-to-care-for-aboriginal-and-torres-strait-islander-health-workers/
Bereavement counsellor	<ul style="list-style-type: none"> • Provides support to the person's caregivers and those close to the person prior to and after death • Provides one-on-one, group and support session counselling • Refers people to specialist practitioners in cases of complicated grief

Team member (continued)	Role within the multidisciplinary team
Counsellor and psychologist	<ul style="list-style-type: none"> Provides specialist psychological interventions to people with complex needs and pre-existing mental health Supports the person and their caregivers and people close to the person to address complex life issues Provides therapeutic psychological intervention and manages mental health diagnoses Provides support for healthcare providers working in palliative care
Dietitian	<ul style="list-style-type: none"> Assists optimal nutritional intake and develops a nutritional plan that focuses on the person's needs and wishes Considers current disease context, treatment plans and overall quality of life to set realistic nutritional goals
Music, art, diversional and complementary therapist	<ul style="list-style-type: none"> Provides holistic palliative care Improves quality of life through a variety of diversional, music and complementary therapies
Extended care paramedic	<ul style="list-style-type: none"> Ambulance support for people receiving palliative care varies across states/territories within Australia according to their ACD or Ambulance Authorised Care/Management Plan and local legislation Paramedics who have completed additional training in palliative care amongst training Work collaboratively with palliative care providers to manage and treat people in their usual residence. Particularly those who wish to be cared for and die at home or in their residential aged care facility (RACF)
Paramedic	<ul style="list-style-type: none"> Assist in the management, transfer and care of people receiving palliative care at home, particularly for those in the final days of their life Transfer and support of the person and caregiver throughout their journey from the hospital to place of care and vice versa Manage symptoms to support home care in line with the wishes of the person and caregivers They may also have a role in the after death care. The person may die expectedly at home or in a RACF. This role may include verifying expected deaths in areas where a GP, SPC service or community nursing service is unavailable
Pastoral care worker and chaplain	<ul style="list-style-type: none"> Assists people in identifying existential distress Addresses concerns associated with dying such as a search for meaning, inner conflict and unresolved personal issues Provide pastoral and spiritual care for all people and their families and friends, irrespective of what religion or world view held Provides support for healthcare providers working in palliative care <p>Note: A chaplain is usually formally qualified, whilst a pastoral care worker will have worked in another healthcare field such as nursing, teaching or social work, before retraining in pastoral care</p>
Physiotherapist and occupational therapist	<ul style="list-style-type: none"> Assists people to maintain and improve function Supports patients to achieve greater quality of life and fulfil their goals of care Provides equipment and home modification Provides education and support regarding fatigue, breathlessness and anxiety management, breathing techniques and exercise
Social worker	<ul style="list-style-type: none"> Assists access to social care and financial support Provides counselling and support for the person and their caregivers including discussions with children and how to support them through the death and bereavement of a family member Organises and facilitates 'family meetings' to discuss the person's wishes Assists in navigating advance care planning documents, including power of attorney, enduring guardian, wills and funeral planning Provides pre-bereavement and grief support and counselling for bereaved relatives
Speech pathologist	<ul style="list-style-type: none"> Identifies priorities and preferences in maintaining communication and managing swallowing difficulties Develops strategies that minimise the impact of symptoms on comfort and quality of life
Volunteer	<ul style="list-style-type: none"> Provides a support service for the person and their caregivers including spending time with the person at home, in hospital or the hospice environment Builds supportive relationships with people and their caregivers Provides diversion therapy, e.g. having a cup of tea or reading a book with the person, taking the person to appointments, assisting with shopping Some SPC services provide specific training and accreditation e.g. writing a person's biography or making a memory box Further information: Palliative care biographies at: www.pallcarevic.asn.au/library-media/volunteers-record-biographies-part-1/

References: Palliative Care Expert Group⁴; Caresearch⁵; Gutsell³; PEPA¹⁴

Studies show that hospitals are not the preferred place of death for the majority of Australians.¹⁶ However, over half of Australians die in hospital.²⁴ A person receiving palliative care may experience exacerbations of their disease or difficulty in managing disease progression resulting in unplanned hospitalisations. Depending on where the person lives and availability, they may be admitted to a standalone hospice, a dedicated palliative care unit, or a bed in public and private hospitals. This admission may be planned and coordinated from the person's home or direct transfer from an emergency department or hospital ward. Therefore, acute care facilities have an important role in the delivery of palliative care. National Safety

and Quality Health Service standards provide guidance to best practice for palliative care in the healthcare system.^{25,26}

Many studies have shown that most people would prefer to be cared for and die in their own home.²⁷ What a person considers as their 'home' can vary – they may live alone, with friends or family or in a residential aged care facility (RACF).²³ A person with a life-limiting illness remaining in their home can be achieved through community support, teamwork and adequate planning. Community support can be obtained from GPs, community palliative care services, community nursing services and other service providers.²⁷

Caregivers can become overwhelmed and require planned respite. The person receiving palliative care may be admitted to supportive care environments, such as aged care facilities, hospice or dedicated palliative care units. Caregivers need to be aware and reassured, that decisions regarding care setting can change as required to improve support for the person and caregiver.

It is important for healthcare providers to be aware that different cultures have distinct perceptions of comfort, quality of life and the role of the family. It is important to respect and address the fundamental cultural beliefs held by people and caregivers, and involve the appropriate support personal to ensure needs are met.

Anticipatory and advance care planning has an influence on ensuring the person's wishes are met, including arrangements for their desired place of care and death.²⁷ For more information on advanced care planning, see *Care planning and management plans*.

Palliative care phases

There are five palliative care phases – stable, unstable, deteriorating, terminal and bereavement.⁴ The Palliative Care

Outcomes Collaboration defines a phase as 'the distinct stage in the person's journey. Phases are classified according to the clinical need of the patient and their family and carers. Phases may not be sequential and a person may move back and forth between phases. The phase then provides a good indication of the type of care required for the person.'²⁸

The person receiving palliative care is regularly assessed by the SPC team to determine which phase they are in. Determining the phase assists the team to provide the most appropriate care. Pharmacists have a role in recognising how a person's ability to perform activities of daily living (or functional capacity) and manage medicines may be affected in each phase. For example, if the person is bed bound, consider which subcutaneous medicines are likely to be required; if the person is unable to swallow, consider how this may impact their oral medicines, and if the person is having difficulty walking, discuss the need for walking aids and home delivery services.

Pharmacists have a role in each phase of palliative care (see Table 4). For further information about the pharmacist's role, see *Medication management*.

Table 4: Classification of the phases of palliative care and the role of the pharmacist

	Definition	Clinical management	Pharmacist's role
Stable	Disease, which could be advanced and extensive, is adequately controlled. Established plan of care remains unchanged. Phase can be very short or can last for weeks to months.	Symptoms and distress is being managed. Caregiver is managing adequately. A care plan is meeting the needs of the person and their caregiver.	Continue to review the person's medication plan and provide medication management advice. Review the person's ability to perform activities of daily living and provide assistance, if required.
Unstable	Person and/or caregiver do not have adequate control of symptoms and/or are in distress. Care plan may no longer be meeting their needs and an immediate change is needed.	Urgent medical review by GP, SPC team, emergency treatment or hospitalisation to gain rapid control and stability over distressing symptoms. Immediate change to the care plan required. Review within 24 hours.	Be responsive to the changing needs of the person and their caregiver - provide medication advice and review the person's functional capacity and provide assistance (e.g. ambulatory devices, delivery services), if required. Rapid changes to the medication plan are likely and often overviewed by a SPC team.
Deteriorating	Person is experiencing the gradual and expected worsening of the condition and function.	Change in plan of care required to address increasing needs. Increase in care and support services is usually required to assist the person and their caregivers. Referral to medical or allied health may be required. Caregiver support may increase.	Provide advice about deprescribing, and alternative routes of medication administration if needed. Consider pre-empting medication needs in terminal phase. Review the person's functional capacity and provide assistance (e.g. ambulatory devices, delivery services), if required.
Terminal	Death is likely within hours or days. Person is displaying rapid, irreversible day-to-day deterioration. Person may experience symptoms such as increased weakness, reduced or loss of consciousness, reduced or failing ability to swallow, increasing fatigue, reduced ability to ambulate, becoming bed bound and incontinence.	Rapidly address any symptoms as well as pre-empting symptoms if possible. Medicine availability and access is a priority. Commence end of life care (adjust plan of care if required). Discuss change in condition with caregivers and those close to the person.	Medicine availability and access is a priority. Provide explanation about the change of route of the medicines (e.g. oral to subcutaneous). Person and caregivers require intense support and increased communication about what is happening. (See <i>Terminal care and Medication management</i>)
Bereavement	Person has died. Caregivers and people close to the person may be experiencing symptoms of grief.	Bereavement-related practical and emotional support should be provided for grieving caregivers and people close to the person, including healthcare providers.	Support the person's caregivers experiencing normal grief and if necessary, refer them to local bereavement services. Identify those at risk of experiencing complicated grief and refer to specialist bereavement support. (See <i>Bereavement care and Bereavement resources</i>)

References: Palliative Care Expert Group⁴; Caresearch⁵; PCOC²⁸

Goals and expectations of care

Setting goals with the person receiving palliative care, and discussing expectations of treatment, is usually the responsibility of the treating specialist clinician, the SPC team and/or the GP or NP. People and their caregivers often ask questions and convey their opinions regarding goals of care to trusted healthcare providers, including their pharmacist.

Goals may range from the person wishing to maintain and improve functional levels, improve their appetite, return to work, or be more involved with family and friends. Establishing a preferred place of care at the end of life may also be a goal.

Goals may change depending on the person's palliative care phase, physical and cognitive ability, and changing wishes. Healthcare providers should change and adapt with the changing goals. People need to be supported to feel safe to discuss and achieve their goals in the context of their fluctuating

or deteriorating ability and their decreasing independence. Healthcare providers can assist people achieve realistic goals through a process of shared decision making and clear communication.²⁹

Discussing goals of care is important, yet challenging, for people and their caregivers. Time must be allowed to discuss the disease and its treatment, understand the likely natural history of the illness and its prognosis, and to answer their questions. Clinicians and healthcare providers should be open, honest and consistent in their message, and deliver this information empathetically.⁵

Pharmacists are not expected to be able to answer all of a person's, and caregivers' questions. Often, people simply wish to be heard and listened to. For questions that cannot be answered easily, pharmacists should direct them to someone who can, such as their GP, NP or another member of the SPC team.

Symptom care



Most people with advanced disease experience symptoms. A comparison study identified that people with advanced non-malignant illnesses where death is expected due to a specific illness such as advanced AIDS, heart disease, COPD, and renal disease had a similar prevalence of symptoms to those with advanced cancer. Pain, breathlessness and fatigue were found to be the most common and were present in greater than 50% of all groups.³⁰

Management of symptoms requires thorough assessment and investigation to determine the underlying cause. Treatment should be individualised with a management plan that includes reversal of the cause if possible and should utilise both non-pharmacological and pharmacological approaches. The person's prognosis, disease progression, ability to perform activities of daily living, and goals of care, together with benefit versus burden of treatment and quality of life, must be considered.³¹

Pain

Pain is subjective and multifactorial. The term 'total pain' is attributed to Dame Cicely Saunders, founder of the modern hospice movement, who suggested that pain has physical, psychosocial, social, emotional and spiritual components (see Figure 1).³²

Pain is associated with most advanced diseases. People frequently experience more than one type of pain in more than one area. Each pain may have a different cause and will need individual attention (see Table 5). Not all people with advanced disease will experience pain. Pain only occurs in 25–70% of people with advanced cancer.^{4,33} Also, the person may have had pain prior to their diagnosis, or develop pain from pre-existing conditions, such as osteoarthritis.

Figure 1. Total pain

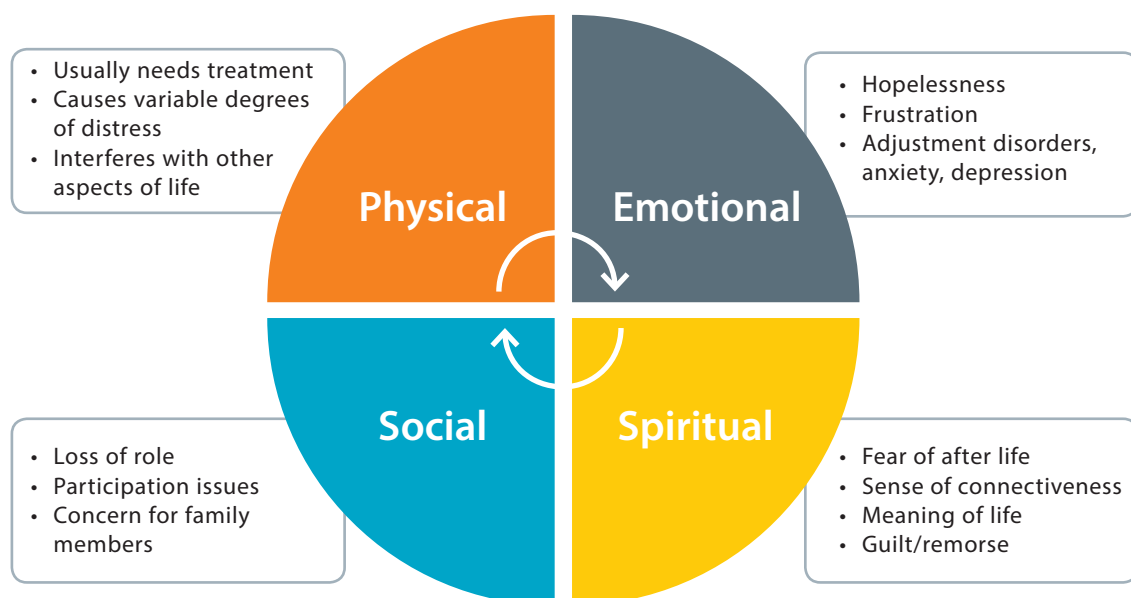


Table 5. Examples of causes of pain in different diseases

Disease	Possible causes of pain
Advanced cancer	Malignant diseases e.g. primary tumour, bone, liver or brain metastases
	Treatments e.g. surgery, chemotherapy or radiotherapy
Advanced heart failure	Ischemia/angina
	Oedema e.g. leg swelling, ascites
	Non-angina chest pain (dull pressing pain)
Motor neurone disease	Musculoskeletal e.g. weakness, immobility and stiffness

References: Palliative Care Expert Group⁴; Goodlin³⁴; MND³⁵

Assessment

Effective management of a person's pain involves conducting an accurate and detailed pain assessment. To comprehensively assess a person's pain, obtain a detailed pain history at each site of pain including⁴:

- an understanding of the underlying disease(s) that are causing the pain, likely prognosis and palliative care phase
- description of the pain including the severity and intensity (see Table 6)
- physical and functional impact
- social impact
- psychosocial factors related to the pain
- review of medicines and treatments.

A physical examination is usually conducted by a GP, NP or physiotherapist to further assess a person's pain. This examination may identify the clinical need for appropriate clinical investigations that will be initiated by the person's GP, SPC doctor or NP.

Validated tools should be used in the assessment of the person's pain. Common examples include the Numeric Rating Scale (0–10 scale) and the Verbal Descriptor Scale (mild, moderate, and severe).⁴ The Abbey Pain Scale and PAINAD are useful pain assessment tools for people with cognitive impairment.^{4,36} It can also be valuable to ask the person to score their worst pain experienced in the last 24 hours,³⁷ their average pain over the last 24 hours and their current pain severity.⁴

Management

Comprehensive pain management requires input from a multidisciplinary team and multiple methods of care. For pain to be effectively managed, there must be:

- accurate and detailed assessment
- knowledge of the types of pain (e.g. somatic, visceral, neuropathic)
- likely cause
- treatment with non-pharmacological and pharmacological approaches as part of a coordinated care plan
- knowledge of analgesics
- ongoing reassessment.

Pain is managed using both pharmacological and non-pharmacological measures. Healthcare providers including physiotherapists, occupational therapists, and psychologists can assist the person and their caregiver by exploring non-pharmacological treatment approaches. Some of these include transcutaneous electrical nerve stimulation (TENS), acupuncture, massage, music and art therapy and mind-body therapies (e.g. cognitive behavioural therapy, relaxation/meditation, acceptance and commitment therapy).^{4,13}

Table 6. How to describe pain

Element	Examples of questions	Reason for element
Location	Where is/are the pain/s located?	Determine site(s) of pain
Quality of pain	What does the pain feel like?	Words such as sharp, dull, cramping may help determine the cause and type of pain Words such as discomfort, unbearable, annoying can indicate how the person reacts to their pain
Radiation	Does the pain move (or radiate) from one site across an area of the body?	May be an indication of neuropathic pain and require referral
Severity	How strong is the pain (on a scale of 0–10)?	Helps prioritise the urgency of response and appropriate treatments
Timing	What time of the day is the pain at its worst? What makes the pain worse?	Helps to determine the time of onset of pain If there are fluctuations in pain during the day or movement of pain
Understanding	What do you think is causing your pain?	Knowing what the person understands and feels about their pain will assist in conversations about treatments and prognosis
Treatment experience	What makes the pain better or worse? What medicines have you tried for your pain? How useful were these?	Assists determining the cause of pain (e.g. pain on breathing helps diagnose a rib fracture) Gives indication of what the person has tried and the outcome (e.g. heat packs being beneficial for movement pain)

Reference: Palliative Care Expert Group⁴

Other treatments may be used instead of, or in addition to, analgesic medicines including surgery, chemotherapy, radiotherapy and interventional analgesic techniques, such as a coeliac plexus nerve block for pain caused by pancreatic cancer.

Analgesics

The foundation of effective analgesic use in palliative care includes choosing the most appropriate analgesic for the person's pain, delivered by the most practical route. Consideration of adverse effects, the safe use of opioids, and the use of adjuvants for pain management is also important. For more information about pain, see essential CPEs, *Overview of pain and pain management Part 1 and 2*.

Non-opioids

Paracetamol

Paracetamol is used to manage mild-to-moderate pain. It has been demonstrated to significantly decrease the dose of opioids required in managing severe post-surgical pain.³⁸ This knowledge has been used in other pain settings resulting in continued regular dosing of paracetamol when opioids are added to the regimen. However, a Cochrane review found no high-quality evidence for the use of paracetamol with opioids in cancer pain.³⁹

Consider the most appropriate formulation of paracetamol for each person. Tablets are large and often difficult to swallow, so a dissolvable preparation may be preferred. Using a controlled-release preparation may decrease tablet burden, but consider the total dose of paracetamol when changing from one preparation to another. Ensure the person, and their caregiver, understands the different dosing regimens.

Non-steroidal anti-inflammatory drugs

Non-steroidal anti-inflammatory drugs (NSAIDs) can be used with, or instead of, paracetamol for mild-to-moderate pain, where there is an inflammatory component to pain and tissue damage, metastatic bone pain, malignancy-related fever or postoperative pain. In general, the choice of NSAID will be determined by the person's co-morbidities.⁴ Celecoxib has been shown to cause less mucosal harm throughout the gastrointestinal tract than other NSAIDs.³⁹

Corticosteroids

Corticosteroids are used to alleviate acute inflammatory pain in cancer, peritumour oedema such as liver capsule distension and cerebral metastases, and neuropathic pain. Dexamethasone is the steroid of choice in palliative care due to its minimal mineralocorticoid effect. The lowest effective dose should be used for the shortest amount of time possible, with careful monitoring for adverse effects. Refer to specialist guidelines for indications and use of steroids in palliative care, withdrawing therapy and adverse effects.⁴

Opioids

Opioids are commonly used for pain relief in palliative care. However, not all pain is opioid responsive. The choice of opioid is determined by several factors including⁴:

- prescriber familiarity with the analgesic
- person's prior experience with opioids
- person's ability to swallow
- person's renal and hepatic function
- other medicines the person is taking
- cost of the formulation.

Opioids are also available in varied dosage forms. Transdermal patches are useful in people with swallowing difficulties and adherence issues, but should be used with caution in people with cognitive impairment. Transdermal patches are used only in people with stable pain. Sublingual tablets are potent, have delayed time-to-effect and extended duration of effect and should be used with caution in the elderly. Oral mucosal tablets and lozenges are useful when fast onset is required, but duration of action is very short. Use is recommended only under the guidance of a SPC clinician.^{4,40}

Pharmacists should be aware of the general principles for prescribing opioids (see Box 2) and the different opioids used in palliative care and the associated practice points (see Table 7).

Box 2. General principles for the prescribing of opioids

1. Prescribe one opioid at a time. If additional pain relief is required, the dose of the opioid can be increased first before choosing to add another opioid.
2. Prescribe opioids conservatively in older people, people with renal impairment, and people who are opioid naïve due to increased susceptibility to adverse effects.
3. Prescribe opioids regularly for background pain, along with an immediate-release opioid on a PRN basis.
4. Use PRN dosing for:
 - a) breakthrough pain that occurs between regular background doses of opioids
 - b) incident pain that may be associated with activity and can be anticipated e.g. showering, wound dressing.
5. Use the same opioid for background and breakthrough pain, where possible. For example: Morphine (*MS Contin*) use twice daily with *Ordine* PRN; Oxycodone (*OxyContin; Targin*) use twice daily with *OxyNorm* or *Endone* PRN.
6. Calculate a PRN dose for breakthrough or incident pain as generally 1/6th–1/12th of the prescribed 24-hour background dose. When the background opioid dose is increased due to increasing symptom burden, ensure that the PRN dose is increased proportionally.
7. When a background opioid dose is increased: It is recommended that the total background dose be increased by a maximum of 50% at any one time⁴
 Note: PRN doses used for incident pain are generally not considered when calculating a new background opioid dose.
8. When changing from one opioid to a different opioid (due to poor opioid response or adverse effects are unacceptable): Allow for incomplete opioid cross tolerance and reduce the equianalgesic dose by 25–50%^{4,39}
 Note:
 - If the person is frail or elderly, consider a dose reduction closer to 50%.
 - Use opioid conversion calculators and tables to assist with converting between opioid formulations, regardless of route (see *Resources*). Calculators can vary, so it important to become familiar with one and use that consistently.
 - Due to the differing pharmacokinetics of opioids, refer to specialist guidelines for advice regarding timing when changing between different opioids and formulations.⁴
9. Seek SPC advice when the person requires 100 mg/day or more of oral morphine or equivalent.^{4,34,39}

Table 7. Practice points for opioids commonly used in palliative care

Opioid	Practice points
Buprenorphine	<ul style="list-style-type: none"> • No active renally-excreted metabolites, therefore one of the opioids of choice in renal impairment • Use with caution in cirrhosis and severe hepatic impairment
Fentanyl	<ul style="list-style-type: none"> • No active renally-excreted metabolites, therefore one of the opioids of choice in renal impairment • Use with caution in cirrhosis and severe hepatic impairment
Hydromorphone	<ul style="list-style-type: none"> • More potent than morphine and oxycodone • Care needed to ensure correct medication and dose given (similar name to morphine), to avoid overdose • Use is recommended under guidance of SPC clinician only • Slow-release formulation is prescribed once daily • Caution in mild-to-moderate renal impairment, avoid in severe renal impairment • Avoid in cirrhosis and severe hepatic impairment
Methadone	<ul style="list-style-type: none"> • SPC clinician use recommended due to complex pharmacokinetics • Can be used in severe renal impairment
Morphine	<ul style="list-style-type: none"> • First-choice opioid for people receiving palliative care • Adjust dose in mild-to-moderate renal impairment, avoid in severe renal impairment • Caution in cirrhosis and severe hepatic impairment
Oxycodone	<ul style="list-style-type: none"> • Adjust dose in mild-to-moderate renal impairment, avoid in severe renal impairment • Avoid in cirrhosis and severe hepatic impairment • Refer to text (below) for oxycodone with naloxone

References: *Palliative Care Expert Group*⁴; *Wood*³⁹; *Rossi*⁴⁰; *Twycross*⁴¹;

Opioids not commonly used in palliative care

Opioids, such as tapentadol, tramadol and codeine, may not be routinely used in palliative care. For example, codeine has a dose-ceiling effect limiting its use in palliative care. It is also ineffective in people who are poor metabolisers and unable to convert codeine to its active metabolites. However, these medicines may be considered if a person is already taking these medicines and their pain is well-controlled. These medicines may also be used to treat certain types of pain when other opioid options have been exhausted. For example, tapentadol also inhibits noradrenaline uptake and may benefit people with neuropathic pain.⁴

Oxycodone/naloxone modified-release combination

Oxycodone/naloxone fixed-dose combinations should be avoided in people with hepatic impairment.⁴ It may cause reduced analgesic effects by increasing the availability of naloxone, precipitating opioid withdrawal syndrome.⁴² Converting to another opioid or using an oxycodone only formulation is recommended in people with decreasing hepatic function. Careful consideration and monitoring must be undertaken as a direct conversion calculation may result in opioid overdosing. Seek SPC advice or refer to the SPC guidelines for recommendations.⁴

Adverse effects of opioids

The adverse effects of opioids differ slightly. Hallucinations, myoclonus and confusion are reportedly higher with morphine than oxycodone, fentanyl and buprenorphine. Buprenorphine and fentanyl are less constipating than other opioids.³⁹ Management strategies to alleviate the adverse effects are discussed in the *Palliative Care Therapeutic Guidelines*.

Opioid-induced hyperalgesia

Opioid-induced hyperalgesia is a phenomenon where pain is experienced with increasing doses of opioids, usually on the background of rapidly increasing or high doses of opioids. Specialist advice should be sought if people experience this phenomena.

Safe use of opioids

Pharmacists need to be aware of issues regarding the safe use of opioids. All opioids have potential for abuse and/or misuse and they should consider:

- that a person's risk for opioid therapy or their potential for abuse and/or misuse cannot be determined
- regularly following up with the person and monitoring their use of opioids
- providing regular education about adverse effects of opioids, achieving ongoing pain management, and dose and regimen adherence for the person and caregivers
- determining if opioids are securely stored in the home and appropriately disposed of
- establishing if a treatment agreement exists between the person, the prescriber and the pharmacy
- encouraging a single opioid prescriber and nominating a dispensing pharmacy.

Adjuvant analgesics

The combined use of different classes of analgesics can improve the effectiveness of pain relief. Pain in a person receiving palliative care is likely to be due to a number of different mechanisms, such as nociceptive and neuropathic. It can also reduce the dose of each analgesic medicine with a reduction in the intensity of any adverse effects.⁴

Adjuvant analgesics can be used alone or in addition to an opioid. Adjuvant analgesics are used in the treatment of a variety of pain types, including neuropathic pain (although in palliative care rarely introduced as a sole therapy for neuropathic pain without an opioid),⁴ bone pain and muscle spasm, which may only be partially responsive to opioids (See Table 8).

Table 8. Examples of adjuvant analgesics used in different pain types

Pain type	Examples	Practice point
Neuropathic pain	<ul style="list-style-type: none">• Tricyclic antidepressants (TCAs) e.g. amitriptyline• Serotonin noradrenaline reuptake inhibitors (SNRIs) e.g. duloxetine• Anticonvulsants e.g. gabapentin, pregabalin• Lignocaine transdermal patches	<ul style="list-style-type: none">• TCAs and SNRIs may be effective at doses lower than those required for use in depression or other mood disorders. Therefore, they should be initiated at a low dose and titrated according to response.• Gabapentin also require response-dependent dose titration• Lignocaine transdermal patches may provide localised benefit in the management of difficult neuropathic pain
Bone pain	<ul style="list-style-type: none">• Non-opioid analgesics e.g. paracetamol, NSAIDs• Bisphosphonates e.g. intravenous pamidronate, intravenous zoledronic acid	<ul style="list-style-type: none">• Paracetamol and NSAIDs are used to treat mild-to-moderate pain• Use paracetamol with caution in people with impaired liver function, and nutritional status• Use NSAIDs with caution in older people and those with kidney impairment, history of peptic ulcer disease, hypertension or heart failure• Bisphosphonates can reduce the incidence and severity of metastatic bone pain, and with regular dosing, improve quality of life, typically suppressing pain after 2 weeks⁴¹
Muscle spasm	<ul style="list-style-type: none">• Benzodiazepines and baclofen for skeletal muscle spasm• Anticholinergics and calcium channel blockers for smooth muscle spasm	<ul style="list-style-type: none">• For skeletal muscle spasm, medicines with antispasmodic activity are more effective than conventional analgesics• Increased risk of respiratory depression if a benzodiazepine is prescribed in combination with an opioid

References: *Palliative Care Expert Group*⁴; *Twycross*⁴¹

Pharmacists should seek advice from the Medicines Information Centres or SPC services when a person receiving palliative care:

- is taking a morphine equivalent daily dose of oral morphine ≥ 100 mg/day
- has renal and/or hepatic impairment
- is switching opioids
- has acute severe pain, unstable or new pain, or refractory pain
- is experiencing hyperalgesia
- has alcohol and/or drug problems
- is needing pain management in the last days of life where pain has been previously controlled with a transdermal opioid analgesic patch.

Pharmacist's role in pain management

Pharmacists can help people receiving palliative care and their caregiver manage pain by encouraging discussion about some of the difficulties they may be experiencing.

By discussing the use of analgesics, such as complicated dosing regimens, risk of tolerance, and possible adverse effects, pharmacists can improve the person's and their caregiver's understanding of their pain and how to manage it. In addition, pharmacists should alleviate any concerns or misconceptions about pain and pain medicines that the person and their caregiver may have (see Box 3). The pharmacist can provide the person with written information about palliative care medicines, such as '*Facts about morphine and other medicines in palliative care*' available from Palliative Care Australia.⁴³

Box 3. Examples of misconceptions by people and caregivers about opioids and dying

- Dying is always painful.
- Enduring pain and suffering can enhance one's character.
- Pain medicines always cause heavy sedation.
- Opioids are addictive.
- People become tolerant to opioids and they will stop working.
- There is a limit to the dose of painkillers that can be prescribed.
- Strong pain relievers should be 'saved' until close to the end.
- Once they start giving you morphine, the end is near.
- Opioids will shorten life.
- People have to be in a hospital to receive effective pain management with morphine.

Reference: *Palliative Care Australia*⁴³

Pharmacists may also explore the person's other symptoms such as anxiety, depression and delirium. These symptoms may be barriers to effective pain management. The pharmacist, with the person's permission, may contact the person's prescriber for further discussion.⁴

Gastrointestinal symptoms

Nausea and vomiting

Nausea and vomiting are often referred to as a single and/or overlapping symptoms. However, they should be considered as separate symptoms that require independent assessment and management based on their definitions.⁴⁴

- Nausea is the sensation of the need to vomit.
- Vomiting is the oral expulsion of gastric contents.
- Retching is the physical effort of vomiting without the oral expulsion of gastric stomach contents.

In people receiving palliative care, nausea can be intermittent or persistent, and either with or without vomiting. Nausea and vomiting can arise from all parts of the gastrointestinal tract and/or be centrally mediated. Nausea and vomiting can also be associated with anxiety or it may be a learned response (e.g. the anticipatory nausea associated with chemotherapy).⁴

General principles of management for nausea and/or vomiting include⁴:

- assess likely cause
- treat any reversible causes
- use non-pharmacological measures such as avoid foods with strong tastes and smells, eat small and frequent meals and use distraction techniques
- prescribe a regular and PRN antiemetic depending on the likely aetiology, remembering that cause(s) may be multifactorial (see Table 9)
- review symptoms if necessary and make adjustments such as up titration of dose, changing the route of administration, and adding a second antiemetic.

Selection of the most appropriate medicine for the management of nausea and/or vomiting is generally based on the proposed mechanism. However, there is little evidence available to support aetiology-based targeted antiemetic therapy over empirical management.⁴⁵⁻⁴⁷ Many potential transmitters or receptors have been identified in the neural pathways involved in nausea and/or vomiting. For example, central causes of nausea including biochemical abnormalities and medicines involve dopamine neurotransmission in the chemoreceptor trigger zone. For a summary of the antiemetic receptor site affinities, refer to *Twycross Palliative Care Formulary*.⁴¹

Table 9. Practice points for antiemetics

Medicine	Practice points
Cyclizine	<ul style="list-style-type: none"> • Histamine antagonist • Less sedative, and anticholinergic properties may enhance antiemetic effects over promethazine • Negates prokinetic effect of metoclopramide and domperidone
Dexamethasone	<ul style="list-style-type: none"> • Corticosteroid anti-inflammatory; mechanism of action unknown • Nausea and/or vomiting due to raised intracranial pressure and other causes of peritumour oedema (such as squashed stomach syndrome from liver metastases) • Delayed nausea and vomiting in chemotherapy • Lowest effective dose used due to adverse effects
Domperidone	<ul style="list-style-type: none"> • Dopamine antagonist and prokinetic (stimulates motility of the oesophageal and gastrointestinal muscles) • Useful in symptoms mediated through gastrointestinal tract (reduced gastric motility e.g. widespread cancer) and chemoreceptor trigger zone (CTZ) (e.g. medicines and metabolic dysfunction) • Does not cross the blood brain barrier, therefore minimal adverse effects and useful in people with Parkinson's disease • Only an oral formulation is available; not useful if person is vomiting or in terminal palliative care phase • Avoid in bowel obstruction as may aggravate colic
Haloperidol	<ul style="list-style-type: none"> • Dopamine antagonist • Useful in nausea and/or vomiting mediated through the CTZ including opioids, and in metabolic dysfunction, such as hypercalcaemia • Useful if needed for delirium management • Adverse effects include sedation, postural hypotension, akathisia and extrapyramidal effects • Avoid in Parkinson's disease and Parkinsonism as it crosses the blood-brain barrier
Hyoscine butylbromide	<ul style="list-style-type: none"> • Blocks acetylcholine/muscarinic antagonist • May be useful in symptoms mediated through the vomiting centre • Reduces peristalsis and inhibits exocrine secretions in gut, therefore useful in bowel obstruction
Lorazepam	<ul style="list-style-type: none"> • Oral tablet only, can be administered sublingually • Useful for nausea associated with brain processing (e.g. odours) • Useful if anxiety component to nausea and vomiting • Sedation and confusion are common adverse effects
Metoclopramide	<ul style="list-style-type: none"> • Dopamine antagonist and prokinetic • Useful in symptoms mediated through gastrointestinal tract (reduced gastric motility e.g. widespread cancer) and CTZ (e.g. medications and metabolic dysfunction) • Adverse effects include sedation, postural hypotension, akathisia and extrapyramidal effects • Avoid in Parkinson's disease and Parkinsonism due to ability to cross the blood-brain barrier • Avoid in bowel obstruction as may aggravate colic
Olanzapine	<ul style="list-style-type: none"> • Antagonistic at multiple receptors, including dopamine receptor sites • Fewer drug-induced movement disorders than haloperidol • Nausea and vomiting is an off-label indication
Ondansetron	<ul style="list-style-type: none"> • Serotonin antagonist, specific to 5-HT₃ • Ineffective for opioid-induced nausea and vomiting • Receptor blockade in vomiting centre, CTZ and terminals of afferents in gut, therefore, useful in symptoms associated with chemotherapy, radiotherapy, surgery and bowel obstruction • Constipation and headache are common adverse effects • Off-label when prescribed for indications other than chemotherapy and radiotherapy
Prochlorperazine	<ul style="list-style-type: none"> • Dopamine and histamine antagonist • Useful for movement-induced nausea and vomiting • Uncommon in palliative care
Promethazine	<ul style="list-style-type: none"> • Histamine antagonist • Sedative and anticholinergic properties may enhance antiemetic effects • Sedative effects may limit use • Negates prokinetic effects of metoclopramide and domperidone

Reference: Palliative Care Expert Group¹; Rossi¹⁰

Constipation

People with a life-limiting illness commonly suffer constipation. Constipation is often defined as organic (having an identifiable cause) or functional (no identifiable cause). There are various factors that contribute to constipation (see Table 10).

Table 10. Factors contributing to constipation

Types of constipation	Factors contributing to constipation
Organic	Medicines e.g. opioids, anticholinergics Metabolic e.g. hypokalaemia, dehydration Neuromuscular disorders e.g. myopathy Structural e.g. pelvic mass, anorexia-cachexia syndrome Pain e.g. cancer pain, anorectal pain
Functional	Diet e.g. inadequate fluid and food intake Environment e.g. lack of privacy, positioning to assist gravity Other e.g. age, frailty, inactivity

Reference: Larkin⁴⁸

Non-pharmacological measures to manage constipation are important and should be encouraged. Self-care practices that help to avoid constipation include adequate fluid intake, regular toileting, consideration of privacy, positioning to assist gravity and encouragement of activity.⁴⁸

Opioids commonly cause constipation, and therefore, a laxative should be considered. Opioid-induced constipation is more common in females, and in people using morphine and oxycodone.⁴⁹ Fentanyl and buprenorphine are reported to cause less constipation.⁴⁹

Stimulant agents with softeners (e.g. docusate and senna), or iso-osmotic agents (e.g. macrogol) are generally used first line, and may be used in combination if needed. Oral osmotic laxatives (e.g. lactulose) and bulk-forming laxatives (e.g. isphagula husk) are not recommended in people who are not eating or drinking as they are less effective and can worsen constipation. In addition, lactulose may cause bloating.

The oxycodone-naloxone combination has been shown to cause less constipation compared with placebo in people taking opioids for chronic pain.⁴⁹ However, studies conducted in people receiving palliative care have not been conducted, limiting the application of these findings as often their constipation is multifactorial, not only opioid-induced. Methylnaltrexone is approved in Australia for opioid-induced constipation that is refractory⁴ to other laxatives in people receiving palliative care.

If constipation continues for several days, a comprehensive assessment will be required, possibly including a rectal examination and an abdominal X-ray, and therefore referral to their GP is recommended.

Diarrhoea

The causes of diarrhoea are varied, and may be due to treatment modalities, tumour, or unrelated (see Table 11).⁵⁰

Table 11. Causes of diarrhoea

Cause	Example
Treatment	Chemotherapy Targeted therapies Immunotherapy Hormone therapy
Tumour	Colon cancer
Other	Infection, including <i>Clostridium difficile</i> Enteral feeding Medicine e.g. antibiotics Overflow diarrhoea due to constipation

Loperamide is the drug of choice to slow peristalsis in uncomplicated diarrhoea, with attention to oral hydration and diet modification. Diarrhoea in people receiving palliative care can be complex and requires thorough assessment and physical examination prior to treatment.⁴⁸

Respiratory symptoms

Dyspnoea (breathlessness)

Breathlessness is a subjective experience where the person has difficulty breathing. It may be associated with advanced disease such as heart failure, COPD, MND and cancer. Physiological, physical, social and environmental factors may contribute to feelings of breathlessness and associated anxiety. Breathlessness can be frightening for the person to experience and their caregivers to observe.

Acute breathlessness should be thoroughly assessed and consideration made to treat potentially reversible causes. Potential causes include infection, pulmonary embolism, pleural effusion, superior vena cava obstruction and airway obstruction. Pharmacological management is based on treating the cause of breathlessness. For example, if as a result of an infection, antibiotics may be used. Symptomatic management includes non-pharmacological measures, such as increasing airflow by opening a window or using a fan and sitting the person up.

Low-dose opioids have been demonstrated to improve symptoms of breathlessness in people receiving palliative care without a detrimental effect on respiratory function.^{51,52} In addition, no cases of respiratory depression were reported in people with severe COPD when using low-dose sustained-release opioids (≤ 30 mg morphine per day).⁴⁹

Benzodiazepines, such as sublingual lorazepam and subcutaneous midazolam, are considered in addition to opioids when anxiety is a contributing factor.⁵²

The Thoracic Society of Australia and New Zealand suggest that oxygen therapy may provide relief for breathlessness and significant hypoxia, as well as symptom relief in non-hypoxic people receiving palliative care.⁵³

Cough

Causes of cough in people receiving palliative care include infection, aspiration and concurrent disease such as COPD.⁴

- Acute cough: consider treating the underlying cause. Potential causes of acute cough include concurrent illnesses (e.g. asthma, COPD and heart failure), respiratory infection, aspiration or recurrent laryngeal nerve palsy, superior vena cava obstruction.⁴
- Moist cough: treat by shifting secretions rather than attempting to dry them. Consider treating the underlying cause. Positioning, steam inhalation, saline nebulisers and mucolytics agents may be helpful.
- Dry cough: treat with cough suppressants, such as simple linctus, dextromethorphan, diphenhydramine, codeine linctus or low-dose morphine.⁵⁴
- Refractory cough: treat the underlying cause, if possible. Potential causes include non-acid reflux (with prokinetic agents such as metoclopramide and domperidone), acid reflux (with a proton pump inhibitor), or a muscle relaxant, such as baclofen, which works on the lower oesophageal sphincter.⁵⁴

Non-pharmacological measures, including repositioning the person to a more upright position and speech therapy, have also been found to be helpful.⁵⁴

Neurological symptoms

Headache

Headache is a common symptom in the general population and may be unrelated to the person's life-limiting illness. The pain should be managed while assessment as to the cause is undertaken, if appropriate to do so. Paracetamol and NSAIDs are reasonable analgesics to recommend, with the addition of an opioid if the pain is uncontrolled with simple analgesia.

Causes of headache in a person with advanced disease can include infection, intracranial bleed or embolic intracranial event, metabolic disorders, adverse effects from medicines, opioid withdrawal, dehydration, and stress or tension.⁴

A common cancer-related cause of headache can include metastases to the brain raising intracranial pressure causing headache. Dexamethasone is the medicine of choice for raised intracranial pressure in this setting. Caution is recommended in using NSAIDs for a person prescribed dexamethasone due to the increased risk of gastrointestinal bleeding. Concurrent prescription of gastric protection (e.g. a proton pump inhibitor) is recommended with steroids.⁴¹

Seizures

Seizures can arise due to pre-existing epilepsy, or be related to the person's life-limiting disease (e.g. brain tumour, infection, or metabolic disturbance). Seizures can also be medication related (e.g. benzodiazepine withdrawal or drug interactions).

Routine use of prophylactic antiepileptics in a person at risk of seizures is not recommended due to their adverse effects and significant drug interactions. A range of oral and parenteral antiepileptics are used for seizure control in people receiving

palliative care. Those particularly useful in palliative care include clonazepam, midazolam, levetiracetam and phenobarbitone as they can be administered subcutaneously. Pre-emptive prescription of such medicine should occur when people transition into the terminal palliative care phase and can no longer take oral antiepileptic medication.⁴

Psychological symptoms

Depression

Depression is common in palliative care. While sadness is expected, depression is not a normal part of dying.⁴

Depression should be managed in a person receiving palliative care and antidepressants are used. There is no evidence that one antidepressant is more effective than another. Selection will depend on the adverse effect profile and possible drug interactions and on the other symptoms the person may be experiencing. For example, the choice of an antidepressant as an adjuvant analgesic to better manage neuropathic pain.

Delirium

Delirium is frequently underdiagnosed in people receiving palliative care, and can be distressing for the person and their caregivers. Delirium can present as hyperactivity, hypoactivity or a combination of both. Screening for delirium should be carried out if the person exhibits a new psychological symptom or behavioural change. A mnemonic can be useful in looking for a cause of delirium (Table 12).⁴

Table 12. A delirium mnemonic

D	Drugs (e.g. opioids, benzodiazepines, anticholinergics); dehydration
E	Electrolytes, environmental stimulus
L	Lungs (e.g. hypoxia), liver, lack of sleep
I	Infection (e.g. pneumonia), infarction (e.g. cardiac, cerebral)
R	Renal failure
I	Intoxication
U	Urinary tract infections, unfamiliar environment
M	Metabolic abnormalities (e.g. hypercalcaemia, hypoglycaemia), metastasis (e.g. brain)

Reference: Ger-EM⁵⁵

Reversible causes of delirium, such as hypercalcaemia or infection, should be treated if appropriate. A medication review should be undertaken and the dose of medications potentially contributing to delirium reduced or ceased, if possible.

Non-pharmacological management of delirium may involve ensuring that the person is in a familiar environment, familiar people including caregivers are present, darkness and bright lights are avoided but there is noticeable night and day lighting, and music.⁴

Antipsychotic drugs are used to manage delirium, although there is no high-quality evidence for this use. Clinically, haloperidol is used for symptom control. Risperidone, olanzapine and quetiapine are used as alternatives for a person with Parkinson's

disease or if they are unable to tolerate haloperidol. A trial showed that antipsychotics have been linked with poorer delirium symptom scores and longer duration of symptoms compared to when individualised support care strategies are implemented.⁵⁶ However, people in the terminal phase were excluded from this trial, and consensus expert opinion continues to recommend the use of haloperidol for symptomatic management of people who are agitated in the last days of life.⁴ For further information about emergency presentations in palliative care, see *Therapeutic Guidelines*.

Anxiety

Similarly, anxiety is a common symptom in palliative care and may co-exist with depression. Poor symptom control, underlying panic disorders, fear, distress and personal concerns, as well as drug-induced causes, can contribute to anxiety. Withdrawal from alcohol and long-term benzodiazepine use may also be contributing factors.

Non-pharmacological interventions are important, including psychosocial support. Advising the person and their caregiver on methods to manage anxiety with breathing techniques, relaxation and distraction will be helpful. Referral to a counsellor or psychologist may be necessary.

Antidepressants can be used in severe anxiety, with selection dependent on similar factors for the management of depression. Short-term use of benzodiazepines can be useful, and longer term therapy may be required in some people. Preference is to use shorter-acting drugs, such as oxazepam and lorazepam, to decrease the possible adverse effects of sedation and concentration problems.⁴

Palliative care emergencies

Emergencies can develop in palliative care that require urgent identification, assessment and management. When a palliative care emergency occurs, the treating palliative care team in consultation with the person and their caregivers should consider a number of factors. These include the reversibility of the emergency, adverse effects of any required treatment, degree of underlying disease, current function and performance of the person, and current palliative care phase. Most importantly, the person's goals of care and wishes in undertaking any treatment concerning their quality of life.

Some palliative care emergencies are unexpected whereas some can be predicted from the nature and location of the person's disease. For example:

- spinal cord compression can occur in people with vertebral metastases
- bowel obstruction can occur in people with peritoneal disease
- massive haemorrhage can occur in people with tumours invading large vessels or who have bone marrow failure.

Pharmacists have a role in talking with people receiving palliative care and caregivers about planning ahead for potential problems. This includes educating and preparing them about signs and symptoms that require escalation and urgent management, if they occur.

Pharmacists can also educate people and their caregivers about emergency medicines, known as a 'crisis pack'. These medicines should be left in the person's home with written medical orders, or given as a crisis order. Caregivers, in some areas of Australia, may have been trained to administer subcutaneous medicines. Pharmacists can support these caregivers, give them further education and ensure they have a phone contact for clinical support. As with all palliative emergency management, this strategy in particular requires excellent communication skills to discuss and advise the caregiver.

To manage a palliative emergency, ensure that the person has a documented advance care and resuscitation plan. This plan must be easily accessed by all healthcare providers involved in the person's care. In some states, an Ambulance Authorised Palliative Care Plan can be developed to assist paramedics, who may be called to attend an emergency. Local SPC services have considerable experience in dealing with such emergencies, and are available to provide advice. Many SPC teams provide a 24-hour on-call service.⁵

For further information about the main palliative care emergencies, symptoms and treatment strategies, see *Therapeutic Guidelines, General Principles: Emergency care in palliative care*.

Terminal care



During this phase, major organs fail leading to changes within the body as it progressively shuts down. Typically, the terminal phase involves a sequence of progressive and irreversible physical changes. The person will be bedbound, have reduced oral intake of fluid and food, drift between levels of semi-consciousness and unconsciousness. They will experience altered breathing patterns as death approaches.⁴

While this process is anticipated, it may present suddenly and escalate rapidly. Anticipation of symptoms that may arise is essential. Symptoms commonly seen in the terminal phase include pain, breathlessness, anxiety, terminal restlessness, nausea and/or vomiting, and excessive respiratory secretions (see Figure 2). These occur with varying intensity.⁵⁷

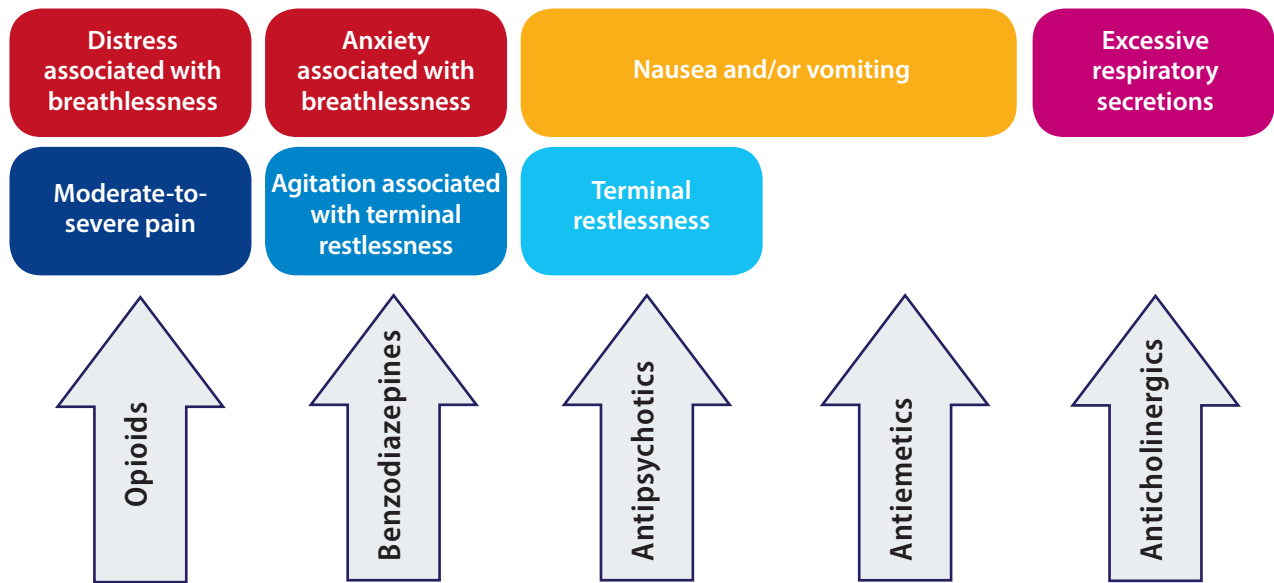
Non-pharmacological interventions can provide significant benefit in managing some symptoms. Medicines are also used for symptom management throughout the terminal phase. While

understanding common symptoms expected in this phase is important, these should be managed in the context of a review of the person's usual medicines. Dysphagia is inherent during the terminal phase; oral medicines are often unsuitable at this time and the subcutaneous route is often used.⁴ The range of medicines likely to be prescribed can be anticipated.

The aim of therapy throughout the terminal phase is to relieve symptoms. Medications should be carefully titrated against symptoms to minimise adverse effects, including sedation. Reduced consciousness in the terminal phase is associated with the physiological deterioration of the dying person. Caregivers often require reassurance that this is the case rather than being due to use of medicines.

Useful information leaflets for a person receiving palliative care, and their caregivers are available, some are listed under *Resources*.

Figure 2. Common symptoms and medicines used to treat in the terminal phase



Pain

Opioids continue to be first line in managing pain in the terminal phase. While subcutaneous morphine is a preferred option, alternative opioids may need to be used in some clinical situations including where the person has a genuine morphine allergy or renal impairment. Subcutaneous hydromorphone and fentanyl are suitable alternatives in a person with end-stage kidney disease. Hydromorphone is used by some specialists for people with renal impairment, despite the risk of accumulation of toxic metabolites.^{4,58} Due to its potency, and deaths associated with its use, specialist initiation and oversight is recommended. Formulations of injectable morphine and hydromorphone are available through the PBS, making them favoured over fentanyl by some prescribers, particularly in the community setting.

In the terminal phase, opioids are usually initiated as PRN doses for people who are opioid naïve. When three or more doses have been administered in a 24-hour period, it is best practice to commence either regular bolus doses or a continuous subcutaneous infusion (CSCI). This provides continuous, background analgesia. The dose of medicine given by regular bolus doses or in the CSCI should be titrated upwards in accordance with the person's ongoing analgesic requirements.⁴

For those already established on oral opioids, refer to Box 2 General principles for prescribing opioids and see section: Healthcare provider resources (*e.g. Australian Medicines Handbook and Palliative Care Therapeutic Guidelines*) for opioid conversion information.

It is inappropriate to commence opioid patches in the terminal phase. For people already established on an opioid patch prior to entering the terminal phase, it is recommended practice to keep this in place, using additional opioids by CSCI if needed, taking into account total background analgesia. If the decision

is to remove the patch, be aware that the skin is likely to carry reserves of the opioid. In these circumstances, a safer approach is to prescribe bolus doses of an opioid for the first 24 hours and then commence the CSCI. Breakthrough doses should also be prescribed and SPC advice should be sought.⁴

As several other medicines may be co-prescribed with opioids for the patient, checking compatibility before commencing the CSCI is important. Pharmacists should contact their local Medicines Information Centre or SPC for advice.

Anxiety

In the terminal phase, anxiety can be related to the person's breathlessness or be a separate symptom. In the management of breathlessness, the evidence supports the use of morphine. Lower doses are used in comparison to those used for pain, as discussed in general symptoms.⁵² Commonly prescribed benzodiazepines include clonazepam and midazolam.⁵⁹

Clonazepam has a long half-life and can provide extended symptom relief by regular doses without the need to use a CSCI. Clonazepam oral drops, are coloured blue and can be unsightly if they stain drooling saliva. However, they offer a practical option for caregivers to administer in the community setting. Importantly, caregivers should be advised to place the required number of drops onto a teaspoon before administering, rather than administering directly from the bottle into the person's mouth. The caregiver can discard the dose if too many drops have spilled and start again to measure the dose.

Midazolam has a short-half life and, therefore, is best administered by CSCI rather than regular bolus dosing.⁴

Terminal restlessness

Terminal restlessness (also referred to as agitation, confusion or delirium) is common in people in the terminal phase. The person may continuously try to find a more comfortable position to lie or speak non-sensically. Terminal restlessness may be due to metabolic changes, uncontrolled symptoms (e.g. pain), physical problems (e.g. urinary retention) or acute withdrawal of substances (e.g. nicotine, illicit drugs) or medicines. The person should be assessed and the underlying cause of terminal restlessness treated, if known.

Management of terminal restlessness could include identifying and addressing potential underlying causes, if possible, and using other non-pharmacological approaches (e.g. reducing distractions from bright lights and noise, surrounding the person with familiar people).

Addressing underlying causes may include treating pain with analgesia, relieving urinary retention with catheterisation, and constipation with rectal laxatives and managing acute substance withdrawal (e.g. using nicotine replacement patches for a person who has continued to smoke until the terminal palliative care phase). Australian guidelines suggest using subcutaneous benzodiazepines (midazolam or clonazepam) and/or haloperidol on a PRN basis, and in a CSCI.⁴

Terminal restlessness is very distressing for caregivers and staff to observe.⁶⁰ Caregivers report high levels of anguish from observing the behaviours associated with delirium and are 10 times more likely to experience generalised anxiety than caregivers of a person without delirium.^{57,61} Pharmacists can support caregivers experiencing high levels of distress and may need to refer for further support.

Nausea and/or vomiting

Nausea, with or without vomiting, can occur intermittently or continuously, in the terminal phase. It may be challenging to identify the underlying cause and an extensive investigation is inappropriate. The most probable causes are medicine, electrolyte disturbances or gastric stasis. Therefore, antiemetics, which act on dopamine centrally or as a prokinetic in the gastrointestinal tract, are prescribed first line. This includes haloperidol and metoclopramide. Haloperidol may be the preferred agent where the person has concomitant terminal restlessness.⁴

Subcutaneous dexamethasone may be continued in circumstances where a person has a cerebral tumour causing raised intracranial pressure, which is likely to be contributing to the nausea.

Excessive respiratory secretions

Excessive respiratory secretions are common in the terminal phase. People in this phase are unable to clear secretions from the upper respiratory tract due to weakness. This causes fluid to collect in the hypopharynx and cause an audible noise as the person breathes. It is referred to as 'noisy breathing', 'death rattle', 'retained secretions', or 'gurgly breathing'. It appears exclusively in the terminal phase. Caregivers use emotive language when describing the distressing memory of this symptom. Terms such as 'my father choked on his saliva' and 'my wife drowned' are commonly used. Pro-active conversations with caregivers ease their distress, highlighting that the person is not in pain or distressed by the secretions, despite the noise.

Non-pharmacological options are important, including positioning of the person. The person can be placed with their back slightly elevated, which encourages drainage of secretions down the oesophagus. Oropharyngeal suction is usually unnecessary.⁴

Anticholinergics are prescribed to reduce the production of secretions. Although there is significant debate regarding their routine use as this symptom does not appear to distress the person.⁴ Additionally, they are only effective in half of the people.⁶² As anticholinergics only alter the release of secretions, research suggests that they should be prescribed as soon as the symptom begins.⁶³ There is no demonstrated difference in effectiveness between any of the anticholinergic medicines.⁶⁴ Neither glycopyrronium nor hyoscine butylbromide cross the blood brain barrier and would be preferred. Hyoscine butylbromide is listed on the PBS and may be more affordable for people being managed in the community.

For further resources and clinical guidelines for symptom management in the last days of life, refer to: *Palliative Care Therapeutic Guidelines* and *palliAGED* (see *Resources*).

Medication management



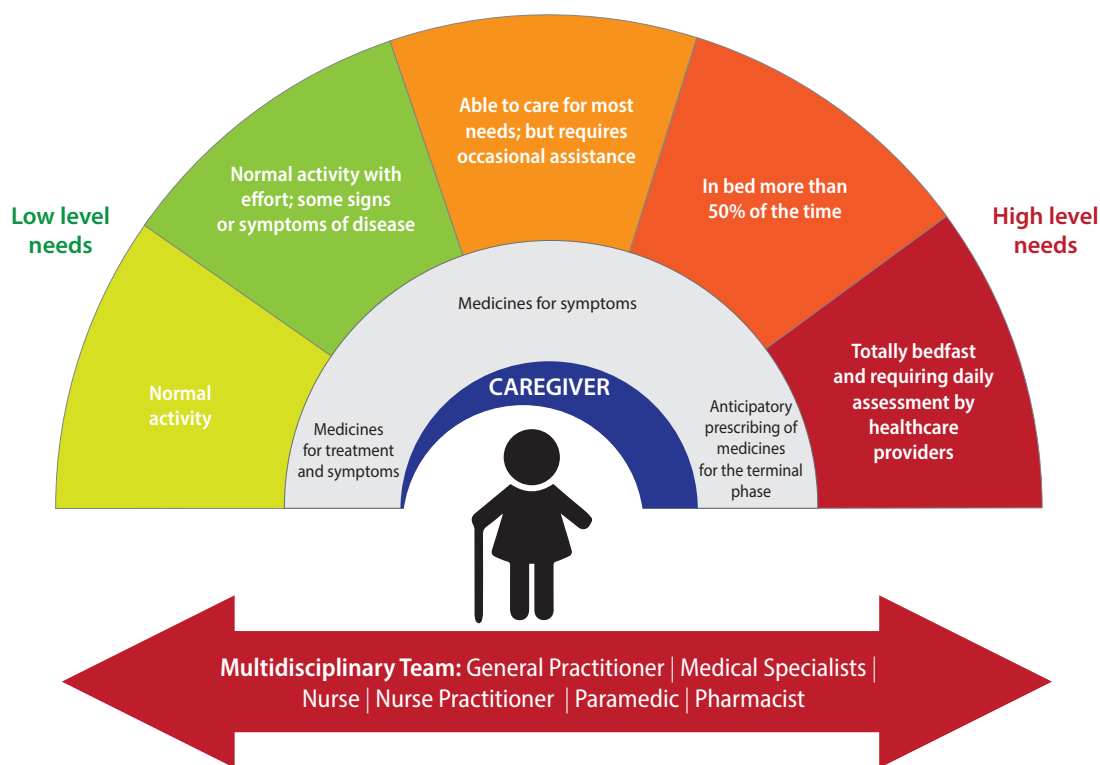
The aim of medicine use in palliative care is to manage symptoms, relieve distress and improve quality of life. A palliative approach to care may start early in a person's disease trajectory. When their disease is stable, they will require little medication change. As their disease progresses, they may need more frequent assessment and modification of their medicines (see Figure 3). The balance between benefit and harm of medicines will change and fluctuate as the disease progresses. The person's choices and priorities will also change over time. It is vital for healthcare providers, and in particular pharmacists, to frequently discuss the person's medicines and their effect on their well-being and quality of life.⁶⁵ Pharmacists are able to embed services and provide information to support the optimal use of medicines.

Providing information and support

There are many challenges in managing the medicines of people receiving palliative care. A person may have been living independently in their home as their health and function decreases. Their medicines regimens are often complex, and are adjusted repeatedly and rapidly to manage their fluctuating symptoms. An admission to hospital may result in multiple changes to their existing medicine regimen. Long-term medicines may need to be rationalised as they no longer offer advantages to the person's health and well-being.

To live and die at home, both the person and the caregiver will need a clear understanding of all medicines. This includes all medicines prescribed pre-emptively and taken PRN, and they need to feel confident to administer them. However, the

Figure 3. Medication management for people receiving palliative care



person and caregiver frequently struggle to manage the many medicines prescribed for multiple symptoms and administered by different routes.⁶⁶

Pharmacists are well placed to empower the person receiving palliative care and their caregivers to manage their medicines safely and effectively. Pharmacists should provide regular assistance to the person and their caregiver to meet their changing situation. Issues that pharmacists can discuss regularly with a person receiving palliative care and their caregiver are listed in Box 4.⁶³

Box 4. Issues to discuss regularly with people receiving palliative care

- Different routes of medication administration
- Difference between short-acting/immediate-release and long-acting/extended-release medicines
- Time-to-peak medication effect (especially in relation to PRN medicines)
- Adverse effects of medicines
- Balance between controlling symptoms and giving too much medicine
- Pre-emptive prescribing
- Safe storage and disposal of medicines

Pharmacists should conduct a MedsCheck with the person and their caregiver. This will allow them to ask questions about their medicines. The pharmacist can provide them with an up-to-date medicines list that can be shown to each of their other healthcare

providers. After a discussion with the person and their caregiver, it may be appropriate to refer them for a Home Medicines Review (see Box 5).

Box 5. Reasons for a Home Medicines Review

- Multiple medicines and complex medicine regimens
- Recent admission to hospital
- Multiple prescribers
- Swallowing difficulties
- Difficulty managing their medicines
- Caregiver expressing desire/need to become more involved in medication management
- Significant changes to their medicine regimen
- Health deteriorating and person’s disease progressing towards end of life

Reference: Hussainy⁶⁷

Pharmacists may recommend the use of a dose administration aid (e.g. *Webster Pack, Dosette* box) to help manage medicine use. However, people receiving palliative care frequently take oral liquids and PRN medicines, and use transdermal patches. It may be confusing for the person and their caregiver to have only some of the medicines packed. Also, medication changes can occur frequently and often need to be commenced quickly. Therefore, the use of dose administration aids should be discussed with the person and their caregiver, and fully considered before commencing to pack the medicines.⁶⁸

Impaired swallowing

People receiving palliative care may have swallowing or oral absorption issues, or are vomiting. Swallowing issues are common in people with advanced disease due to:

- dry mouth (caused by disease, treatments or medicines)
- disease process (e.g. MND, Parkinson's disease, cancers of oropharynx)
- breathlessness (e.g. advanced COPD)
- cognitive impairment
- weakness and fatigue as disease progresses.

The person's ability to swallow should be assessed and treated, if possible. If the cause is irreversible, then other methods to assist medication administration are needed. For example, if the person has a dry mouth, a buccal or sublingual preparation will have unreliable absorption. If this route of administration is considered the most appropriate choice, then advise the person about moistening their mouth before dosing. It is common for the person or their caregiver to crush tablets or open capsules and place the powder in soft food to enable swallowing. While this is a suitable method in some situations, it is necessary to firstly consider⁶⁹:

- if the medicine is essential
- availability of an alternative formulation (e.g. oral liquids)
- suitability of an alternative medicine administered by a different route (e.g. sublingual, transdermal)
- if guidelines, references (e.g. *Australian Don't Rush to Crush Handbook*) or the product information recommends this practice.

For some people who are completely unable to swallow, it may be necessary to insert an enteral tube for feeding (e.g. nasogastric or a percutaneous endoscopic gastrostomy). Consider each medicine before recommending it can be given via a tube. This will include can it be crushed or dispersed in water, whether it will interact with the enteral nutrition (feed), if the medicine will adhere to the tubing, and if it will be absorbed via this route. For further information, see *Australian Don't Rush to Crush Handbook*.

Non-oral routes of administration

Non-oral routes of medicine are frequently used in palliative care to assist administration and adherence. Routes including transdermal and subcutaneous administration, may be suitable. Changing between routes of administration requires careful consideration of the pharmacokinetics and practical implications of each medicine for the individual.

Transdermal administration

Transdermal patches are useful in people with swallowing difficulties. Transdermal patches need regular monitoring to ensure the entire patch is attached firmly to the skin. Peeling or slipping off is common, particularly for people living in hot or humid climates or those experiencing excessive sweating, which will affect the rates of delivery. Dressings applied over the patch make it difficult (even through a clear dressing) to check if the patch is sticking to the skin and should be avoided. People and caregivers should be advised to write the date the patch was changed on the outside of the patch as this can assist with adherence. Where adherence is an issue, referral to a community nurse to assist with medication management, may be necessary. Also, if pain is fluctuating or rapidly increasing, transdermal patches containing opioids are inappropriate as they have a delayed time-to-peak effect.

Occasionally, a continuous epidural or intrathecal infusion may be needed to provide pain management. These are highly specialised interventions. If the person is living at home, nurses will visit regularly to monitor and maintain the infusions. The person will be in contact with the SPC service and the pharmacy at the local hospital for prescribing and manufacture of the sterile infusion bags of medicines. The use of the intramuscular route is generally avoided in people receiving palliative care.

Subcutaneous administration

Subcutaneous administration is frequently used in the terminal phase. It is also useful when oral administration is challenging, such as uncontrolled vomiting or decreased absorption of oral medicines.⁴

Subcutaneous medicines can be given on a PRN basis to manage intermittent symptoms, or regularly for ongoing problems. The most common method of providing background symptom management is by CSCI. Prescribing PRN medicines will still be required for flares in symptoms, such as breakthrough or incident pain. A range of medicines are administered by this route including analgesics (e.g. opioids), antiemetics, antipsychotics, antisecretory medicines and benzodiazepines.

The prescribing, access to and administration of subcutaneous medicines in the terminal phase presents several unique challenges. If the person is being cared for in the community, these challenges are magnified.

When using a CSCI, the medicine is drawn up into a syringe that fits into a pump (commonly called a 'syringe driver') and delivered over 24 hours. The syringe driver is a small battery-operated pump

Table 13. Common compatible subcutaneous infusion medication combinations

Medicine 1	Medicine 2	Diluent
Morphine sulphate	Clonazepam	Sodium chloride 0.9% or Water for Injection
Morphine sulphate	Haloperidol	Sodium chloride 0.9% or water for Injection
Morphine sulphate	Hyoscine butylbromide	Sodium chloride 0.9% or water for Injection
Morphine sulphate	Metoclopramide	Sodium chloride 0.9% or water for Injection
Morphine sulphate	Midazolam	Sodium chloride 0.9% or water for Injection

References: Dickman⁷⁰; Eastern Metropolitan Region Palliative Care Consortium⁷¹

that is easy to manage in the home setting. Nurses visit daily to assess the person's symptoms and refill the syringe.

It is possible to combine more than one medicine in the same syringe to manage several symptoms. However, some medicines may interact when in combination. Increasing the number of medicines being concurrently delivered in a syringe driver increases the risk of incompatibilities. Some local protocols may specify a maximum number of medicines. Several resources are available to check that the medicines prescribed are compatible (see *Resources*). SPC teams and Medication Information Centres can also provide information. Common compatible medication combinations are listed in Table 13.

When PRN injections are required, they should be administered through a separate subcutaneous cannula. This will avoid disruption to the CSCI and reduce the risk of medication incompatibilities.

While compatibility guides are evidence based, it is important to visually inspect the syringe at regular intervals for visual signs of incompatibility (e.g. cloudiness or precipitate in the syringe or line; CSCI volume not infusing as quickly as expected). If the preferred medicines for symptom management are incompatible in a syringe, then other options will need to be considered (see Table 14).

Table 14. Strategies when medicines in a syringe are incompatible

Response	Discussion
Administer the medicine separately to the CSCI as a regular bolus medicine	Possible for a medicine with a long half-life (e.g. clonazepam, haloperidol) or with a long duration of action (e.g. dexamethasone)
Switch to a different medicine	Use a different medicine with the same action (e.g. replace fentanyl with morphine)
Use more than one syringe driver	Volume of the medicine is too large Non-compatibility of medicines

Off-label medicine use

Off-label prescribing refers to the use of a medicine outside the registered indication, route, dose or person groups for that medicine. This is different to an unregistered product, which has not been evaluated or approved for any use by the Therapeutic Goods Administration. Off-label prescribing is legal and is acceptable in some clinical situations after due consideration of the clinical, safety and ethical issues has been given.⁷²

Although off-label prescribing is common in palliative care, the harms-and-benefits ratio for the individual person in that situation still needs to be considered.⁷³ The risk of adverse effects has been found to increase 44% with off-label use compared with on-label use.⁷²

It is considered acceptable to prescribe off-label if there is sufficient evidence of efficacy and safety, or in exceptional cases when the clinical situation justifies the risk and the patient is informed and agrees.⁷² Well conducted studies may have found new indications or ways of administering the medicine since its registration on the Australian Register of Therapeutic Goods. Some of these medicines are identified in the *Australian*

Table 15. Examples of off-label prescribing commonly used in palliative care

Off-label reason	Example	Evidence to support practice	Reference
Unapproved indication	Morphine for dyspnoea	Clinical evidence	75
	Dexamethasone for cancer pain	Clinical evidence	76
Unapproved route	Subcutaneous metoclopramide	Pharmacokinetics	77
	Subcutaneous midazolam	Pharmacokinetics	78

Medicines Handbook with 'accepted indication'.⁴⁰ Generally, a majority of these medicines are used for the accepted indication, if other medicines approved for the indication are ineffective or not tolerated by the person. In some instances medicines are regarded as first-line therapy for a condition although not registered for that indication.⁷⁴ Table 15 lists some medicines commonly prescribed off-label.

Pharmacists should inform the person and their caregiver that the medicine is being used off-label. They should discuss the reason for choosing this medicine explaining the safety, risks and implications. When using medicines off-label, PBS subsidy will be unavailable increasing the cost. The indication for use will also be omitted from the consumer medicines information (CMI), which may raise concerns for the person and their caregiver that the medicine has been prescribed incorrectly. Regular monitoring of efficacy and adverse effects is essential for all off-label medicines.

Funding of medicines

In 2004, a palliative care section was added to the PBS. This facilitated access to a broader range, and larger quantities, of medicines for people living with a life-limiting illness.⁷⁹ Pharmacists can support prescribers by increasing awareness to these PBS medicines. Prescribing medicines listed in this section is in agreement with the requirements for general PBS unless otherwise described in the listing for the item. Most listings within the palliative care section are presented as Authority Required (Streamlined) or Restricted Benefits, simplifying access to medicines for these people.

Medication rationalisation and deprescribing

Deprescribing for people receiving palliative care should be part of a holistic approach to care and correlate with their goals of care and quality of life wishes. Deprescribing should be done in discussion with the person and their caregiver. It is important to understand and address beliefs and concerns regarding medicines and the implications of ceasing them. While many people are keen to decrease their number of medicines, others find it emotionally distressing to stop medicines they were told to take for the rest of their lives.

Deprescribing should be staged with the aim of ceasing all unnecessary medicines (those not for symptom management) prior to the person being unable to swallow medicines or reaching the terminal phase of their disease.

The priority of deprescribing should be ceasing medicines where:

1. time-to-benefit exceeds prognosis (e.g. statins)
2. risks outweigh the benefits (e.g. paracetamol in deteriorating liver function)
3. outcome conflicts with the person's goals of care (e.g. chemotherapy, anticoagulation)
4. therapy becomes burdensome.

With good pre-emptive planning, deprescribing will involve several discussions, ceasing one medicine at a time and weaning medicines likely to precipitate withdrawal symptoms. There is more urgency as the person's life expectancy decreases. Although not ideal, it may be necessary to employ a quicker approach to deprescribing if the person's health is deteriorating rapidly.

The rapid changes associated with the onset of the terminal palliative care phase mean that a systematic and progressive deprescribing approach (as described earlier) is inappropriate. It should be determined which medicines need to be continued. A useful method to determine this is to consider:

- medicines that are providing symptom control (comfort medicines)
- medicines that are likely to contribute to a withdrawal reaction if discontinued immediately.

All other medicines can be safely stopped.

Medication challenges unique to the terminal phase

Care in the terminal phase is multidisciplinary involving GPs, NPs, community nurses, pharmacists, and SPC services. Each clinician and organisation will have their own way of managing care of people who are dying at home. This diversity increases the risk of medication error, especially if care is not co-ordinated between the different disciplines.

Providing optimal care to the person receiving palliative care can be challenging. The need for care increases in the terminal phase. There is the possibility of an increased number of ambulance call outs and unplanned hospital admissions, which may not be in line with the person's wishes and goals of care. People close to the person dying often wish to participate in care at home, particularly in the terminal phase. Providing care in this way can be beneficial and help them feel involved. However, the situation might not go as expected due to a lack of planning and misguided assumptions. The caregiver may be left feeling overwhelmed, guilty, angry, or burdened by a perception of failing their loved one, leading to a more complex experience of grief.

When the person is unable to swallow their usual medicines, symptom management is challenging. Either onset of withdrawal reactions or exacerbation of uncomfortable symptoms can follow. The inability of the person to safely swallow their usual tablets can trigger the caregiver to urgently seek help.

Comfort medicines

Comfort medicines require immediate conversion to the subcutaneous route. This will either involve:

- switching from an oral to a subcutaneous formulation (e.g. dexamethasone) and considering the bioavailability when calculating the dose
- switching to an alternative medicine with the same effect, when a subcutaneous form does not exist (e.g. pregabalin) or when the medicine is expensive (e.g. parenteral oxycodone).

Preventing and responding to withdrawal reactions

Medicines that are likely to cause a withdrawal reaction when stopped suddenly should be replaced with an alternative subcutaneous medicine to prevent the expected withdrawal. For example, a person taking oral antiepileptics may require a change to a subcutaneous benzodiazepine to prevent seizures.⁸⁰

It may also be necessary to provide medicines to manage withdrawal symptoms. For example, a benzodiazepine to manage agitation from sudden cessation of a selective serotonin reuptake inhibitor.

Anticipatory prescribing

Timely access to subcutaneous medicine is critical to enable people to stay at home in the terminal phase. This proactive approach to care involves anticipating the person's needs, and ensuring subcutaneous medicines and equipment are in place to manage symptoms in the terminal phase, when they occur.^{55,81} This is termed anticipatory prescribing. It involves the prescriber ordering subcutaneous medicines in anticipation of the terminal phase. It is best practice as it allows a smooth transition from the oral to subcutaneous route at a vulnerable point in care ensuring ongoing symptom management and avoiding unnecessary hospital admissions. Anticipatory prescribing is particularly important for people living in rural and remote areas, where access to medicines maybe limited.

Prescribers are guided by comprehensive national and state-based terminal phase guidelines (see *Resources*). While these guidelines offer an extensive range of medication options, the literature reveals most community pharmacies are unable to stock all subcutaneous formulations.²³ Also, pharmacists may choose to wait for a prescription before ordering medicines, contributing to delays in symptom management. Neither of these situations is ideal.

To address this, standardised medicines lists that detail commonly prescribed medicines in the terminal phase have been developed. Many of these lists arose from prescriber surveys. Community pharmacies or aged care facilities can ensure that these prescribed medicines are stocked.⁸²⁻⁸⁶ However, this approach ignores practical aspects such as PBS availability, cost to the caregiver and sustainable stock turnover.

In 2012, an Australian multidisciplinary group developed a standardised medicines list, known as a core medicines list (see Box 6).⁶⁴ This resulted from assessing the:

- evidence for the management of common terminal phase symptoms
- cost of each medicine including the availability of the medicine on the PBS
- availability through the PBS emergency drug supply (doctor's bag) list.

Box 6. Examples of medicines that may be included in a core medicines list for managing terminal phase symptoms

- Clonazepam 1 mg/mL injection
- Haloperidol 5 mg/mL injection
- Hyoscine butylbromide 20 mg/mL injection
- Metoclopramide 10 mg/2mL injection
- Morphine 10 mg/mL injection

Importantly, the PBS emergency doctor's bag lists a number of medicines that can be given subcutaneously in the terminal phase.⁸⁷ While this is an impractical way to supply medicines to all people in the terminal phase, it does provide a useful safety net, when the person deteriorates after hours. Prescribers can have them available when visiting someone at home. The PBS emergency doctor's bag also contains useful medicines that are unlisted on the general PBS, such as parenteral midazolam.

Accessing subcutaneous medicines

In Australia, access to core palliative care parenteral medicines to manage symptoms expected in the terminal phase through community pharmacies is often poor.²⁷ This is observed across large and small pharmacies and there are little differences between pharmacies across metropolitan or rural settings. Poor

access is likely because pharmacists are unable to anticipate which medicines to stock. Regardless of the cause, the importance of ease of access to medicines (at a time of high stress and rapid change) should never be underestimated.

People can enter the terminal phase rapidly and unexpectedly. Pharmacists may receive an urgent request for a subcutaneous medicine but this may be the first notice they have that the person is dying. The way pharmacists respond to this request has serious consequences on the ability of the person to remain at home. Not being able to supply the caregiver or nurse with a medicine may result in unnecessary escalation of care because of uncontrolled symptoms. There are strategies that can be used in pharmacies that focus on anticipation or advocacy (see Table 16).

Caregiver's role

Medicines used in the terminal phase are usually administered by nurses through home visiting programmes, SPC services across different jurisdictions. In some areas of Australia, nurses educate the caregiver about how to give PRN subcutaneous injections. A caregiver can be trained to confidently administer PRN doses of medicines to the person in the absence of a nurse. This is considered a privileged role for many caregivers and is particularly useful in rural and remote settings.⁸⁸

The nurse inserts a line attached to a bung under the person's skin (cannula). The caregiver uses this line to deliver the medicine, when symptoms are exacerbated. The caring@home program, an Australia-wide initiative, has been funded to develop and provide a standardised resource kit to support nurses in the caregiver training role (see *Resources*).

When caregivers are trained to administer PRN medicines, it is useful to ask them to keep a record of which medicine they gave, how much, the symptom they were responding to, and its effect. Many SPC services have their own version of a medicines diary for caregivers, and is a resource available from the caring@home program.

Table 16. Pharmacist response to requests for subcutaneous medicines in the terminal phase

Timing	Strategy	Advantages	Disadvantages
Anticipation	Stock a standard list of subcutaneous medicines	<ul style="list-style-type: none"> • Recommended medication lists that guides practice (see <i>Anticipatory prescribing</i>) • Builds relationships with local palliative care team • Offers an opportunity to market the pharmacy to the prescribers in the region 	<ul style="list-style-type: none"> • Expiry of medicines
Advocacy	Contact the prescriber to discuss alternative medicines or formulations	<ul style="list-style-type: none"> • Develops a supply plan with the prescriber • Offers greater understanding and improved collaboration between prescriber and pharmacist (i.e. prescriber informed of deadline for requests to have medicine delivered the following day) • Builds relationships with prescribers 	<ul style="list-style-type: none"> • Relies on the pharmacy having alternative options available
	Contact other pharmacies in the region to either borrow stock or forward the prescription	<ul style="list-style-type: none"> • Reduces stress for the caregivers and emphasises pharmacist empathy • Builds relationships with other healthcare providers 	<ul style="list-style-type: none"> • Assumes other nearby pharmacies have medicines • Delays access to symptom control medicines
	Rural pharmacies may borrow stock from the local hospital	<ul style="list-style-type: none"> • Reduces stress for the caregivers and emphasises pharmacist empathy • Builds relationships with local organisations 	
	Order medicines from the distributor		<ul style="list-style-type: none"> • Delays access to medicine: particularly over a weekend or public holiday

Communication



Effective communication is a vital part of quality care. It develops the relationship between the healthcare provider, the person and their caregiver. The person must feel comfortable to communicate their beliefs, experiences and values as these shape who they are as individuals and will influence their wishes and goals of care. For strategies to effectively communicate with people receiving palliative care and their caregivers, see Box 7.⁸⁹

Box 7. Effective communication strategies

- Consider the setting: right place, adequate time, no distractions/interruptions, and privacy
- Mutual respect: active listening, demonstrate empathy, acknowledge feelings, maintain appropriate eye contact
- Use language the person understands, avoid medical or technical jargon
- Use open-focused questions to allow people to talk
- Use repetition to assist people to understand.
- Be comfortable with silence as this can allow people to gather their thoughts

Adapted from: Zeppetella⁸⁹

There are a number of barriers that could contribute to ineffective communication. These are summarised in Table 17.

Table 17. Communication barriers

	Communication barriers
Person	Language barriers Fear of getting upset/emotional Tiredness/illness Feeling like a burden/taking up too much time Considers the staff too busy or not interested
Caregiver	Language barriers Not knowing what to say Fear of saying something wrong Fear of dealing with strong emotions
Healthcare provider	Language barriers Not knowing what to say Fear of dealing with strong emotions Time constraints Not knowing enough

Adapted from: Zeppetella⁸⁹

Professional boundaries

Professional relationships are built and strengthened over time as relationships develop with a person and their caregivers. The role of caring for people receiving palliative care can be rewarding but also very challenging. It can be extremely difficult to see people experience deterioration due to a life-limiting illness. Sometimes the line between professional and personal relationships can become blurred, particular in small regional, rural and remote communities.⁹⁰

Maintaining professional boundaries can be difficult, particularly if you feel invested in the situation and outcomes. It is important to remember the influence and trust healthcare providers have in the lives of the person and their caregiver. Similarly, it is important to remember that you are part of a team and that together you share the care of the person. Talk to colleagues if you feel that you may be over-involved with a person's care.

If you feel your professional boundaries may be compromised, ask yourself the following questions⁵:

- Is my relationship with the person and their caregivers adversely influencing my professional judgement?
- Whose needs are being met through the relationship? (The person's/the caregiver's/mine?)
- Would I feel comfortable or uncomfortable about colleagues observing my behaviour?
- Does the type of relationship I have with this person or their caregiver changed my professional treatment or management?

If you say 'yes' to any of the above questions, seek assistance, guidance and support from your manager, a colleague or a member of your local SPC team.

Responding to strong emotions

Palliative care can be challenging as people and their caregivers find themselves in new and different circumstances. They may experience a range of mixed emotions over time, some of which may be easier to face or to talk about than others. The person can express their emotions in different ways, including frustration and anger; it is important not to take the expression of these strong emotions personally.

Pharmacists can participate in PEPA. They can work alongside experienced practitioners, learning strategies on how to respond to the strong emotions of a person and their families and how to look after themselves (see Table 18).

When a person dies

The death of a person can leave you with feelings of loss. It is important to acknowledge this and find a way that helps you manage your feelings. Respecting professional boundaries and being aware of your own feelings is important. There may be an opportunity to attend the funeral of a person, but this is not always possible or appropriate. It can be helpful to develop your own strategies to say goodbye to people who have died.

Pharmacists may experience feelings of grief, sadness and loss when they see the person's caregivers in the pharmacy. This is a normal reaction. Connecting with another trusted staff member may be a way to talk about feelings. Providing support to colleagues is also important, as they will have cared for the person as a team, and may notice that they are having similar feelings following the death of a person. Informal support can be obtained by debriefing with peers and colleagues and is often found to be most helpful.

Some clinicians benefit from support from outside of their immediate workplace. A member in the local palliative care team can also provide informal support.

Bereavement care

The support for caregivers and people close to the person that continues after death is known as bereavement care. This is provided by a GP, member of the palliative care multidisciplinary team or a counsellor, depending on the local services available. Grief counselling can occur either with individuals or in a group session.⁹¹

The pharmacist is in an ideal position to monitor and determine how the caregiver is coping with bereavement. Everyone reacts differently when someone dies. There is no right or wrong way to grieve. The usual pattern for the bereaved person is for comfort and support in the early bereavement period to be provided by family, friends, neighbours and others in the community. There are usually set periods of contact depending on cultural and spiritual beliefs such as visitation, funeral and other ritualistic formalities. Over time, gentle encouragement is provided to re-engage in life, even when the bereaved person is not motivated to do this. Studies have shown for most bereaved person, normal social supports will be adequate and the health and emotional consequences will resolve over a few months.⁵

The loss of a loved one can be associated with worsening health, including weight loss, increased rates of illness and functional impairment. Bereavement also appears to increase the risk of mortality in the grieving person in the early period after the death. In particular, mortality rates appear to primarily be attributed to suicide, accidents, heart disease and cancer.⁵

Occasionally, bereaved people may experience complicated grief or persistent complex bereavement disorder. This can lead to serious complications if not recognised. Experienced grief counsellors and/or mental health services usually provide assistance. Studies have shown an association with worsening bereavement outcomes in people with a past history of depression, in women, and in those where less education and income were also associated. Symptoms include:

- prolonged acute grief (grief experienced shortly after the death of the person), such as frequent intense yearning
- intense sorrow and emotional pain
- preoccupation with the deceased and/or circumstances of the death
- excessive avoidance of reminders of the loss
- difficulty accepting the death
- feeling alone and empty
- feeling that life has no purpose or meaning without the deceased person.

If a bereaved person is exhibiting signs of complicated grief, referral to their GP or the SPC team involved, as specialist bereavement support is required.^{4,5} For further bereavement resources, see *Resources*.

Self-care strategies for pharmacists and pharmacy staff



Pharmacists and pharmacy staff should develop personalised self-care strategies both in and out of work to support their wellbeing as professionals and to sustain long-term, positive self-care.⁹² Strategies for holistic self-care are included in Table 18.

Pharmacists and pharmacy staff may experience grief at all stages of a person's disease progression. The person's death can be extremely upsetting for all pharmacy staff. While dealing with their own grief, pharmacists need to support the other staff members and potentially provide professional direction for the caregivers of the person. If not recognised and addressed, these pressures can lead to burnout. Dunkley discusses factors and strategies for pharmacists to assist in dealing with the emotional impact of death, including^{4,94}:

- reduce stress and burnout by addressing self-care, peer and professional support and team building within the organisation
- access education and training to maintain professional boundaries, develop relationships with others to debrief and maintain work-life balance with attention to exercise and other past-times
- establish informal peer support with colleagues.

Professional support can be accessed through organisations, such as the *Pharmacist's Support Service*.^{94,95}

Supporting people and their caregivers through a life-limiting illness can be extremely satisfying. There are inherent stresses with providing this care as well. This may be more so when managing palliative needs is an infrequent element of care delivery and the healthcare team is geographically separated, making communication challenging.

Table 18. Strategies for holistic self-care

Type of self-care	Self-care activities
<p>Workplace and professional</p> <p>Activities that help you work consistently at your expected professional level</p>	<ul style="list-style-type: none"> • Engage in regular supervision • Consult with a more experienced colleague • Set up a peer-support group • Be strict with professional boundaries • Read professional journals • Attend professional development programs
<p>Physical</p> <p>Activities that help you to stay fit and healthy, allowing enough energy to achieve your work and personal commitments</p>	<ul style="list-style-type: none"> • Develop a regular sleep routine • Aim for a healthy diet • Take lunch breaks • Go for a walk at lunchtime • Take your dog for a walk after work • Use your sick/personal leave • Get some exercise regularly before/after work
<p>Psychological</p> <p>Activities that help you to feel clear-headed and able to intellectually engage with the challenges of your work and personal life</p>	<ul style="list-style-type: none"> • Keep a reflective journal • Seek and engage in external supervision or regularly consult with a more experienced colleague • Engage with a non-work hobby • Turn off your email and work phone outside of work hours • Make time for relaxation • Make time to engage with positive friends and family
<p>Emotional</p> <p>Activities that allow you to safely experience your full range of emotions</p>	<ul style="list-style-type: none"> • Develop friendships that are supportive • Write three good things that you did each day • Play a sport and enjoy some time together with your team after training • Go to the movies or do something else you enjoy • Keep meeting with your social group • Talk with friends about how you are coping with work and life demands
<p>Spiritual</p> <p>Activities that help you obtain a sense of perspective beyond day-to-day of life</p>	<ul style="list-style-type: none"> • Engage in reflective practices like meditation or mindfulness • Go on bush walks • Go to church/mosque/temple • Do yoga • Reflect with a close friend for support
<p>Relationship</p> <p>Activities that help you maintain healthy, supportive and diverse relationships, so that you are not only connected to work colleagues</p>	<ul style="list-style-type: none"> • Prioritise close relationships in your life e.g. with partners, family, friends and children • Attend the special events of your family and friends • Arrive to work and leave on time every day • Create your own self-care plan

Adapted from: ReachOut⁹³

Case scenarios



Case scenario 1

Maureen comes to your pharmacy regularly. She lives at home with her husband, Joe. She has a history of hypertension, hyperlipidaemia, congestive cardiac failure and type 2 diabetes. She experienced a myocardial infarction about six months ago.

Today, you notice a marked difference in her health since her last visit to the pharmacy. She needs to sit to restore her breath. She tells you she has just been discharged from a three-week stay in hospital, due to increasing difficulty with breathlessness, cough and leg oedema. During her admission, she had a pacemaker inserted. She is now taking multiple new medicines. The doses of some of her existing medicines have been

increased and some medicines have been ceased. She is struggling with the changes to her medicines regimen and remembering them all.

What can you do?

Maureen and Joe would benefit from a MedsCheck. You discuss this with them saying it will give them both an opportunity to discuss Maureen's medicines and the recent changes. You can also develop a plan if her health deteriorates further. You can educate Joe about his wife's medicines and together decide if a dose administration aid may be helpful. They both agree to a MedsCheck.

Three months later Joe comes into the pharmacy for Maureen's medicines. Joe says Maureen has been in hospital again for a few weeks with similar symptoms to last time. She is now on continuous

oxygen and spends most of her day in a chair. She is still experiencing breathlessness and has a cough. In hospital, Maureen was given morphine mixture and lorazepam for her breathlessness. Now at home, Joe is nervous about measuring the right dose of morphine. He doesn't know when she is meant to have the lorazepam. Maureen is very fatigued, and Joe needs to assist her with showering and does all the cooking, although she eats very little. She is having difficulty swallowing all her medicines and is finding constipation distressing.

Pharmacist's role

Joe is taking on a huge responsibility as a caregiver and needs practical help, psychological support and education. The pharmacist is well placed to assist with medication management and providing education. You explain to Joe about the use of opioids and benzodiazepines in breathlessness and provide a hands-on demonstration on how to measure oral liquids using an oral-dosing syringe. You also talk about the reasons for Maureen's constipation and provide a suitable laxative including information about how to take it (crushing or dissolving in water).

You take the opportunity to talk with Joe about having a HMR. As Maureen is taking a lot of medicine, a HMR would help Joe understand and manage these better. It will also allow you to determine which medicines are essential and recommend how Maureen could take them as her swallowing deteriorates. Although Joe is seeing Maureen's health deteriorate, he may not appreciate that many of the medicines she is currently taking may provide more harm than benefit. A conversation about this may prepare him for future discussions about medicines and ongoing care needs.

Joe may need to contract some community services (e.g. cleaning, cooking and respite) to continue to care for Maureen in their home. You could suggest that he discusses their need for these services with their GP. Joe should also be advised to ask about referral to home care services and the local community SPC service.

Key messages

- People with progressive chronic diseases are frequently taking multiple medicines. These may change with each exacerbation and can make ongoing understanding of their regimen difficult.
- Caregivers often take on the role of managing medicines and are frequently unprepared for this role. They require ongoing education about the medicines.
- People are frequently unable to swallow medicines as their disease progresses and advice about crushing medicines or using alternative preparations is important.
- Conversations about a person's deteriorating health can be difficult. It is usually beneficial to discuss concepts one at a time, giving the person time to understand each concept before the next issue is discussed.
- MedsChecks and HMRs are a valuable intervention for the person and their caregiver especially as a person receiving palliative care may have many medication changes.



Case scenario 2

Ayesha is 34 years old and lives with her husband and their four-year-old son. She migrated to Australia from Lebanon five years ago. She has regularly come to your pharmacy, although recently you have not seen her. Today, she comes to the pharmacy looking pale and withdrawn, and has lost a significant amount of weight. She hands you a prescription for opioids and other medicines.

You invite Ayesha into the counselling area to discuss how she is feeling and to review the medicines she has been prescribed. She hands you a hospital discharge summary. Her ability to communicate in English is limited, but she says she has been in hospital with 'a sore on her left breast that was getting worse'. Through tears, Ayesha tells you she has been diagnosed with breast cancer and that the sore on her breast has opened. She is taking some medicine to help with the pain, but doesn't recall the name. She looks scared and says she is not ready to die and leave her young son. You are shocked and saddened. You sit with Ayesha and let her have the time she needs. You leave the interview room to prepare her medicines and take a deep breath.

Discharge Summary

Medical history

Small lesion found on left breast 3 months ago and treated herself hoping it would heal. Lower back pain commenced six weeks ago. Investigations revealed late diagnosis of stage 4 metastatic breast cancer with lumbar spine metastases.

Left fungating lesion approximately 3x4 cm in diameter left breast with ongoing small-to-moderate bleeding at dressing changes.

Malodorous wound, requiring topical preparations, as per specialist palliative care consultant.

Five fractions of palliative radiotherapy completed for spinal metastases for pain management; completed whilst inpatient with some symptom improvement noted.

Social History

Ayesha is a stay-at-home mother. She is a Muslim women of strong faith. Her community supports her. Ayesha's husband works shift work as a taxi driver. She has no other immediate family in Australia, as her elderly mother and sister live in Lebanon.

Discharge Management Plan

For specialist palliative care home medical review, social work consult and community nurse involvement with a female Arabic interpreter.

Monitor for large bleed to fungating breast, requires discussion and potential crisis pack set up by palliative care team.

Monitor for symptoms of spinal cord compression.

Daily/PRN dressings to fungating wound on left breast as per direction of palliative care team.

Medication Management Plan

Medicines on discharge

Morphine sulfate modified-release tablets, 60 mg twice daily

Morphine hydrochloride 10 mg/1 mL mixture, 3 mL every four hours PRN and prior to dressing changes

Dexamethasone tablets 4 mg each morning, reducing dose of 0.5 mg weekly then cease.

Amitriptyline hydrochloride tablets 25 mg at night

Metoclopramide hydrochloride tablets 10 mg four times daily before meals

Flucloxacillin tablets 250 mg three times daily

Paracetamol tablets 1,000 mg four times daily

Metronidazole 0.75% gel apply to affected area 1–2 times a day when dressing is changed

Kaltostat wound dressing to areas of bleeding

Allergies: nil known

Seven weeks later, the palliative care nurse brings Emneh, Ayesha's sister, to the pharmacy. Emneh has come to Australia to care for her sister. The nurse tells you that Ayesha developed severe and excruciating pain in her left hip and was readmitted to the SPC unit for pain management. It was discovered she had further metastatic disease in her hip bone. She was given two additional fractions of radiotherapy to her hip and her pain management was titrated. Ayesha then returned home but was unable to mobilise and was weakening generally.

Ayesha has had difficulty swallowing over the past week and is sleeping the majority of the time now. Emneh is crying as the nurse says that Ayesha is in the terminal phase of her life.

Ayesha is deteriorating quickly. She wants to die at home. The nurse hands you a prescription from the local doctor and note from the SPC team.

Dear Community pharmacist,

Please provide the following to Ayesha's sister, Emneh:

Morphine sulphate 30 mg/mL amps, 60 mg over 24 hrs subcutaneously via syringe driver

Midazolam solution for injection 5 mg/mL amps

Haloperidol 5 mg injection 5 mg amps

Hyoscine butylbromide solution for injection 20 mg

You supply these medicines to Emneh. Ayesha dies at home the following day. After the funeral, Emneh comes to the pharmacy with left over oral and injectable medicines. Ayesha's family require much support and bereavement care post death.

Considerations for the community pharmacist

Support and advice for a person with a fungating wound

Malodorous fungating breast wound management is extremely difficult for the person and caregivers. These wounds often have a malodour due to the breakdown of cells within the tumour and the presence of infection. They will not heal and each wound is managed with specialist dressing techniques and topical preparations by SPC nurses. Research is not consistent in the best way of managing these wounds, so an individual approach is used for each person.

Ayesha is prescribed metronidazole gel to apply topically to the wound at dressing changes. She requires specialist dressings with a calcium alginate preparation (e.g. *Kaltostat*) to minimise bleeding. Wound dressing products, such as charcoal-based products to contain and manage the odour and exudate from her wound, are also used. These products are generally supplied by community nursing or SPC services.

Ayesha's disease trajectory

It is likely that Ayesha has had breast cancer for some time. She may have denied symptoms or, due to her lack of knowledge about the disease and her limited English, has not appreciated the need for review by her doctor.

Ayesha's disease trajectory followed a typical cancer disease trajectory with a slow-to-medium progression of disease, then a relatively quick decline to death. Due to her reluctance to seek medical assistance, and the resultant delayed diagnosis, Ayesha was unable to access treatment early in her disease. Her trajectory was probably faster than what would normally have occurred.

Communicating with people who don't have English as their first language

Communication is very important when caring for a person from non-English speaking backgrounds. Though Ayesha's English is adequate to communicate verbally, she is unable to read English. The Translation and Interpreting Service (TIS) can assist in explaining to people and educating them about their medicines (see Box 8).

Box 8. Translation and Interpreting Service

The Translation and Interpreting Service (TIS) is a national interpreting service provided by the Department of Home Affairs. This service is available for people who do not speak English and for service providers who need to communicate with them. TIS is available 24 hours a day, 7 days per week for any person or organisation in Australia requiring interpreting services. TIS can provide immediate telephone interpreting services as well as prebooked telephone and onsite interpreting.

For more information, go to: www.tisnational.gov.au

Immediate phone interpreting: 131 450

Free telephone interpreting access is available to registered pharmacies around Australia

Manufacturers of prescribed medicines could be contacted for access to a consumer medicines information (CMI) in Arabic. The Victorian Government, Health Translations site, www.healthtranslations.vic.gov.au provides a directory of accurate, and up-to-date health and wellbeing information in many languages.

Self-care strategies for a pharmacist providing care to a person receiving palliative care

As Ayesha has been coming to your pharmacy for over five years, you have developed a professional relationship with her and her immediate family. Seeing Ayesha so unwell and deteriorating is very difficult for you.

Self-care strategies are important in managing your feelings and emotions. Acknowledge that this is difficult, and determine which strategies you would feel comfortable pursuing. You will need to be active in ensuring self-care and may need to pursue several strategies to find the best fit and most supportive for you.

Developing skills and knowledge in palliative care may improve your confidence in supporting people receiving palliative care. Also, establishing stronger links with colleagues in your local palliative care team will assist you to give advice in line with the person's goals of care and consistent with other care being provided. The Department of Health's, PEPA is part of the Palliative Care Education and Training Collaborative and offers training courses for healthcare providers (see Box 1).

Palliative care emergencies

In Ayesha's case, she is at risk of a number of palliative care emergencies, including spinal cord compression and a major bleed/haemorrhage from her fungating breast tumour. The SPC service will be monitoring for these symptoms and providing advice and management strategies.

Unused medicines

Pharmacists have an important role in educating the person and their caregivers about the most appropriate and safest way to discard unwanted medicines. This is known as the Return Unwanted Medicines Initiative. For further information, go to: www.returnmed.com.au/pharmacists/

Role of a pharmacist in grief and bereavement care

You monitor Emneh when she comes to the pharmacy to return unwanted medicines. She is crying when she greets you but is so thankful for your support and guidance. She has extended her visa to stay in the country to look after Ayesha's son. The Muslim Women's Association is great support.

Eight weeks later, Emneh returns with a prescription for antibiotics for Ayesha's son. She looks withdrawn, tired and has minimal eye contact. You ask Emneh if she would like to talk in the consultation room and she agrees. Emneh says she is not managing and is worried she is going to catch the cancer and die as well. She doesn't go out very much. She is managing to make sure the house is clean and tidy and food is cooked for her nephew and brother-in-law.

The pharmacist can support Emneh find appropriate services to address her ongoing social and psychological needs. Generally, the community palliative care service will follow-up and provide referrals to appropriate services. The pharmacist could ask if they have been in contact with her and, if not, Emneh could contact them. The pharmacist could also recommend an appointment with her GP as they will generally co-ordinate counselling and support. Emneh may feel more comfortable reaching out to someone in the Muslim community, which could be facilitated by the Muslim Women's Association.

Case scenario 3

Bill and his wife Joan have regularly come to your pharmacy for more than 20 years. They are in their mid-80s and lived independently until about one year ago when they started getting cleaning services each fortnight and help from their children in the garden. Bill was diagnosed with prostate cancer 8 years ago. He had surgery and hormone therapy and was well until he was diagnosed with bone and liver metastases one year ago. Since that time, his health has been fluctuating with episodes of pain, constipation, vomiting and fatigue. His analgesic needs have been increasing over the past couple of months.

Joan comes into the pharmacy and tells you Bill is in a lot of pain and is unable to get out of bed. She presents prescriptions for:

Oxycodone/naloxone modified-release 40/20 mg twice daily
Pregabalin 150 mg twice daily
Amitriptyline 25 mg at night
Oxycodone immediate-release (IR) 10 mg four times daily PRN
Docusate with senna 2 tablets at night

Role of the pharmacist

To assess Bill's pain, you ask Joan:

- How long has Bill been in severe pain?
- Where is his pain?
- Has he been taking all his regular medicines?
- How frequently is he taking each of his PRN medicine?
- Do his PRN analgesics relieve pain when he takes them?

Joan says that Bill's pain has been rapidly increasing over the past couple of days. In the last 24 hours, it's been terrible. He didn't get any sleep last night. It started about the same time as he started vomiting. The pain is his usual pain, in his back and pelvis. He has been taking his regular pain medicines but sometimes vomits after taking them. Bill has been taking about six oxycodone IR and three buprenorphine tablets every day. The extra tablets usually relieve his pain but haven't seemed to work for the last day. Joan is very distressed and starts crying.

You provide advice and support for Bill and Joan. You take Joan to a private area, offer her a cup of tea and sit with her. Encourage her to talk about what has been happening at home. It is tempting to offer solutions to all her difficulties, but giving her time to talk, listening and showing that you care is usually what is needed most.

It is probable that Bill is not absorbing his oral medicines because he is vomiting and so his pain is worsening. Also, Bill has liver metastases and therefore, even if absorbed, the naloxone may be accumulating and preventing the analgesic effect of the opioids.

Bill is going to need a non-oral formulation of analgesia. Also his vomiting will need managing. You recommend that he visits his GP, or if this is not possible, call an ambulance to take him to the local hospital's emergency department. You may like to suggest that Joan asks a family member or friend to stay with her and assist her to get a medical assessment for Bill.

A week later Joan returns to the pharmacy with her son. Bill stayed in hospital for 3 days and the doctors told them that he only had a few days or weeks to live. He wanted to die at home and his family wanted to provide that care for him. They have nurses from the community/SPC service visiting him every day. Joan says she doesn't understand about the medicines and gives you prescriptions for:

Morphine 30 mg/mL ampoules - give 30 mg by subcutaneous infusion over 24 hours

Haloperidol 5 mg/mL ampoules - give 2 mg by subcutaneous infusion over 24 hours and 0.5 mg PRN

Morphine 10 mg/mL ampoules – give 5–10 mg by subcutaneous injection hourly PRN

Clonazepam oral liquid 2.5 mg/mL – give 0.5 mg (5 drops) sublingually PRN

Hyoscine butylbromide 20 mg/2 mL – give 20 mg PRN

Providing support

Explaining the purpose of each medicine to Joan and her son will be useful and providing a medicines list, including their purpose, will also be a useful reference. The medicines on the prescription are pre-emptive medicines for pain, breathlessness, nausea, anxiety, excessive secretions and terminal restlessness. Explain to Joan and her son that the medicines will only be given if Bill displays those symptoms and the visiting nurse will assess and administer medicines as needed. Explain how to administer clonazepam drops by dropping the solution onto a teaspoon before giving to Bill under his tongue. It will be used if Joan and his family are unable to settle his restlessness by providing reassurance and talking calmly to him.

Caregivers often blame the medicine for the person being unconscious. However, it is the disease process which is largely responsible. Medicines given in appropriate doses and titrated appropriately will not contribute to drowsiness. Withholding

them will not reverse the dying process but will rather result in the person being in pain and having other symptoms. You may feel comfortable explaining this to Joan. You check the dose using an opioid conversion chart, and reassure Joan that the dose of morphine is about the same as the regular dose of oxycodone/naloxone Bill was taking before he went to hospital.

You can supply most of the medicines immediately.

Unfortunately, you have no morphine 30 mg/mL ampoules or hyoscine butylbromide 20 mg/mL in stock and offer to contact the three nearby pharmacies to borrow stock and deliver these to Joan's house. You are aware the SPC nurse is coming in at 3 pm to set up the syringe driver for Bill.

You check remaining stock holdings of all medicines, in case further supplies are required. You make a note to confirm with the prescribers in your area the subcutaneous medicines they regularly prescribe so you can anticipate which ones to keep.

It would be appropriate to offer to deliver any further medication requirements.

Key messages

- A person with a life-limiting illness can deteriorate very rapidly and expectantly and their medication needs will change.
- It is common for non-oral routes of administration to be needed.
- Having a stock of the most commonly required medicines for terminal phase symptoms will allow for rapid symptom management and be of great comfort to the caregiver.
- Discussions and explanations of the purpose of medicines with the caregiver is important in the terminal phase.
- Pharmacists can provide support to caregivers as they can become very stressed and need support; particularly if there is a longstanding relationship with the person and caregiver.

Resources

The community setting is an important place of care for many in the last days of life. The Australian Government is investing in innovative models to support a person to remain at home in the last days of life.^{5,96,97}

Care plans and management

Title	Hyperlink
Department of Health Palliative Care - Advance Care Planning	www.health.gov.au/internet/main/publishing.nsf/content/acp
Advance Care Planning Australia	www.advancecareplanning.org.au
NSW Ambulance Authorised Palliative Care Plans – Respecting patient wishes	www.slhd.nsw.gov.au/btf/pdfs/Amb/GP_Booklet.pdf

Healthcare provider resources

Resource	Description	Web link
Australian Medicines Handbook	General medicines resource Contains an opioid equivalence table	www.amh.net.au
Australian and New Zealand Society for Palliative Medicine (ANZSPM)	An article from Australian and New Zealand Society for Palliative Medicine (ANZSPM) describing how the essential medicines list was developed, 'What is essential medications in palliative care? – a survey of Australian palliative care doctors.'	www.ncbi.nlm.nih.gov/pubmed/16642246
Cancer Council Australia Cancer Pain Management Guidelines	A guideline providing recommendations for screening, assessment and management of cancer-related pain in adults	https://wiki.cancer.org.au/australia/Guidelines:Cancer_pain_management#_ga=2.193152361.574507399.1550628901-894210341.1549922548
CareSearch	Information about palliative care for the person, caregivers and families as well as for healthcare providers providing care	www.caresearch.com.au
Caring@home	Resources to support people to be cared for and to die at home, if that is their choice Resources are applicable Australia-wide for community service providers, healthcare providers and caregivers to support caregivers to help manage breakthrough symptoms safely using subcutaneous medicines	www.caringathomeproject.com.au
Eastern Metropolitan Region Palliative Care Consortium	Clinical guidance documents pertaining to care of people receiving palliative care including: 1. Guidelines for using the BD Saf-T-Intima System in Aged Care 2. Management of Respiratory Secretions in the Terminal Phase 3. Syringe Driver Drug Compatibilities 4. Opioid Conversions	www.emrpcc.org.au/health-professionals/resources-2/
End of Life Directions for Aged Care (ELDAC)	Information, guidance, and resources for healthcare providers and aged care workers to support palliative care and advance care planning to improve the care of older Australians	www.eldac.com.au
eviQ	Online opioid equivalence table. Prints results as a PDF, which could be useful for documenting	www.eviq.org.au
GP Pain Help smartphone app	Targeted at GPs for managing cancer pain. Has a useful opioid equivalence converter and a treatment decision tree	www.gppainhelp.com/Title.html

Resource	Description	Web link
Guidelines for the handling of palliative care medicines in community services	Developed by NPS MedicineWise and can be used by community service providers to inform the development of detailed protocols and procedures tailored to the requirements of individual services	www.caringathomeproject.com.au/Portals/13/Documents/NPS-Palliative-Care-Guidelines-v16-jg-171018-ACC.PDF
Opioid Calculator smartphone app	Opioid equivalence calculator developed by Developed by the Faculty of Pain Medicine, Australian and New Zealand College of Anaesthetists (ANZCA)	www.opioidcalculator.com.au
Pain in Residential Aged Care Facilities: Management Strategies. 2nd ed. The Australian Pain Society 2018	Information and resources for the RACF workforce It is relevant for a multidisciplinary audience to identify, assess and manage pain by addressing various pain management strategies	www.apsoc.org.au/publications
palliAGED	Palliative care evidence and practice resources in aged care for an Australian Healthcare audience	www.palliaged.com.au
palliAGEDgp smartphone app	The app makes use of a framework of care which starts with a GP considering if they would be surprised if this person died in the next 6–12 months. Useful prescribing guidance for the terminal phase	www.palliaged.com.au/tabid/4351/Default.aspx
Palliative Care Outcome Collaboration	National routine point-of-care data collection for quality improvement measuring outcomes for people receiving palliative care. Standardised assessments tools and benchmarking	ahsri.uow.edu.au/pcoc/index.html
palliMEDS smartphone app	Prescribing guidance for management of terminal symptoms	www.caringathomeproject.com.au/tabid/5159/Default.aspx
Program of Experience in the Palliative Approach (PEPA)	Education and online learning about the palliative approach to enhance the quality of palliative care delivery	pepaeducation.com
Residential Aged Care – Palliative Approach Toolkit	Comprehensive guide to implementing a palliative approach in RACF	www.caresearch.com.au/caresearch/tabid/3629/Default.aspx
Tasmanian Adult Palliative Care formulary	Resource for healthcare providers who provide care for the person receiving palliative care	www.dhhs.tas.gov.au/palliativecare/health_professionals/Tasmanian_Adult_Palliative_Care_Formulary
The Palliative Care Bridge	Resources and videos from palliative care practitioners (videos include the person and caregiver perspectives)	www.palliativecarebridge.com.au
Therapeutic Guidelines (Palliative Care)	Australian palliative care text for all healthcare providers, particularly those working in primary care Expert consensus on a range of practical issues, including symptom management, communication guidance and support for deprescribing	www.tg.org.au
State-based resources		
NSW Health Clinical Excellence Commission – Last Days of Life Toolkit	A resource for healthcare providers and consumers on managing care in the last days of life.	www.cec.health.nsw.gov.au/quality-improvement/people-and-culture/last-days-of-life
NSW Health End of Life and Palliative Care Framework 2019–2024	The Framework describes how people and services can work together to provide accessible, high quality end of life and palliative care. It reflects wide engagement with stakeholders, health providers and community members.	www.health.nsw.gov.au/palliativecare/Pages/eol-pc-framework.aspx
Department of Health, Government of WA - WA Cancer and Palliative Care Network	A group of professionals and organisations committed to improving a person receiving palliative care experience and access to palliative care services. Includes an <i>Essential palliative care medications list for community pharmacists and general practitioners</i>	https://ww2.health.wa.gov.au/Articles/U_Z/WA-Cancer-and-Palliative-Care-Network https://ww2.health.wa.gov.au/~/_media/Files/Corporate/general%20documents/Health%20Networks/WA%20Cancer%20and%20Palliative%20Care/Palliative%20care/Essential-Palliative-Care-Medication-Lists-for-Community-Pharmacists-and-General-Practitioners.pdf
Department of Health and Human Services, Tasmanian Government – Specialist Palliative Care service	Provides information on managing issues from life-limiting illness. Includes an adult palliative care formulary of medicines with specialised palliative care indications, known as Tasmanian Adult Palliative Care formulary	www.dhhs.tas.gov.au/palliativecare www.dhhs.tas.gov.au/palliativecare/health_professionals/Tasmanian_Adult_Palliative_Care_Formulary

Resource	Description	Web link
SA Health, Government of South Australia Pharmacological management of symptoms for adults in the last days of life	Information and resources for medication management for the last days of life in adults.	www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/clinical+resources/clinical+topics/medicines+and+drugs/pharmacological+management+of+symptoms+for+adults+in+the+last+days+of+life www.racgp.org.au/afp/2014/januaryfebruary/core-palliative-medicines/
Brisbane South Palliative Care Collaborative - Guide to the Pharmacological Management of End of Life (Terminal) Symptoms in Residential Aged Care Residents	A resource for healthcare providers on the caring for persons at the end of life in the community. It includes a consensus-based list, endorsed by the ANZSPM	www.caresearch.com.au/caresearch/tabid/3589/Default.aspx

Bereavement resources

Title	Hyperlink
Alzheimer's Australia - Coping after the death of someone with dementia	fightdementia.org.au/support-and-services/families-and-friends/taking-care-of-yourself/coping-after-the-death-of-someone-with-dementia
Australian Centre for Grief and Bereavement - Grief information leaflets for adults and children	www.grief.org.au/ACGB/Publications/Resources_Bereaved/Grief_Information_Sheets/ACGB/ACGB_Publications/Resources_for_the_Bereaved/Grief_Information_Sheets.aspx?hkey=19bfe37f-d79f-4e70-85e7-82b94bca248b
Calvary Health Care - Bereavement support across cultures	www.caresearch.com.au/caresearch/Portals/0/Documents/PROFESSIONAL-GROUPS/Calvary_A5_real.pdf
Care Search - Bereavement, loss and grief	www.caresearch.com.au/caresearch/tabid/1074/Default.aspx
Bereavement Care Centre - Coping with grief	www.bereavementcare.com.au/resources/books.htm
National Association for Loss and Grief - Brochures about grief	www.nalag.org.au/Pages/brochures.htm
NSW Health Clinical Excellence Commission – Last Days of Life Toolkit – Information for patients, families and carers	www.cec.health.nsw.gov.au/quality-improvement/people-and-culture/last-days-of-life/information-for-patients
Palliative Care Australia - Information about grief and links to telephone counselling	palliativecare.org.au/understanding-grief
Solace Australia - Group support programs for people whose partner has died	www.solace.org.au

Self-care strategies for pharmacist resources

Title	Hyperlink
ReachOut Australia – Developing a self-care plan	schools.au.reachout.com/articles/developing-a-self-care-plan
Pharmacists' Support Services – Australian pharmacists peer support and telephone counselling	Ph. 1300 244 910 www.supportforpharmacists.org.au

Other resources

Resource	Description	Web link
Palliative Care Australia <i>Facts about morphine and other medicines in palliative care factsheet</i>	Consumer information	palliativecare.org.au/resources/facts-about-morphine-and-other-opioid-medicines-in-palliative-care
Palliative Care Australia (PCA) <i>Palliative Care Service Development Guidelines</i>	Government and healthcare provider information regarding PCA's expectation of providing palliative care services to Australians	palliativecare.org.au/quality
National Palliative Care Strategy 2018	Overarching vision for palliative care in Australia	www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BDB047E2FCA257BF000206168/\$File/12291_PC-Strategy.pdf

Multiple choice questions

Each question has only one correct answer.

- 1. Fred is receiving palliative care at home and Marie is his full-time caregiver. They have come to the pharmacy to ask some questions about what medicines and equipment they might need towards the end of Fred's life. To effectively communicate with Marie and Fred, you should:**
 - a) Provide an appropriate area (e.g. a private counselling room) to allow privacy to discuss and address any of their questions.
 - b) Actively listen to the person and acknowledge their feelings and beliefs.
 - c) Identify language barriers and use a translation and interpreting service to provide medicines information in a language the person and their caregiver understand.
 - d) All of the above.
- 2. Advance care planning encourages people to consider, discuss, and document their future wishes for care before reaching the terminal palliative care phase. What is the pharmacist's role in advance care planning?**
 - a) Discuss advance care planning with the person and complete a plan as soon as possible.
 - b) Sensitive discuss the person's wishes and goals of care in respect to medication management in a private area of the pharmacy after establishing that an Advance Care Directive has been developed.
 - c) Document the person's past care history and communication issues in the advance care plan.
 - d) Encourage the person to establish an ambulance plan as soon as possible to avoid hospitalisation.
- 3. There are five phases of palliative care - stable, unstable, deteriorating, terminal and bereavement. Which of the following statements about the phases of palliative care is correct?**
 - a) Palliative care phases occur sequentially as a person moves towards death.
 - b) Palliative care phases are classified based on the clinical needs of the person receiving palliative care.
 - c) Palliative care phases are all experienced during the life time of the person.
 - d) Palliative care phases provide pharmacists direction on the appropriate care needed to support the person and their caregiver.
- 4. From the following statements about the role of caregivers and medicines, which of the following is NOT correct?**
 - a) Caregivers in some areas of Australia can administer subcutaneous medicines to the person they are caring for if appropriately trained to do so.
 - b) Caregivers should be discouraged from participating in medication management reviews as these are confidential between the person and the pharmacist.
 - c) Caregivers frequently struggle to manage the medicines of someone dying at home.
 - d) Caregivers can use a medicine diary to keep record of the PRN medicines they administer, including the dose and frequency, and symptom they responded to.
- 5. Which of the following statements is NOT a reason for recommending a Home Medicines Review (HMR)?**
 - a) The person requires to start receiving PRN medicines administered by their caregiver.
 - b) The person has recently been discharged from hospital.
 - c) The person is entering the terminal phase of palliative care.
 - d) The person is experiencing swallowing difficulties.
- 6. In the terminal palliative care phase, benzodiazepines may be needed for people experiencing anxiety associated with breathlessness. Which of the following statements is NOT correct?**
 - a) Lorazepam and oxazepam are regularly prescribed to patients experiencing distressing breathlessness in the terminal phase.
 - b) Clonazepam can be given both orally and subcutaneously.
 - c) Clonazepam has a long half-life and may negate the need for a continuous subcutaneous infusion.
 - d) Benzodiazepines can be given with opioids to treat breathlessness.

7. 'Noisy breathing' in the terminal phase is due to build-up of fluid in the hypopharynx that the person is unable to clear. Which of the following statements about managing this symptom is correct?
- Repositioning people may help shift the pooled secretions, reduce the noise and encourage drainage of the secretions.
 - Anticholinergics, are commonly used to reduce the pooling of secretions, and are effective in all patients.
 - Oropharyngeal suction is commonly used.
 - Glycopyrronium and hyoscine butylbromide cross the blood brain barrier so are rarely used to reduce the production of respiratory secretions.
8. Opioids are commonly used for pain relief in palliative care. However, choosing an opioid and an appropriate route of delivery is complex and based on many patient factors. Which ONE of the following statements about using opioids for pain relief in a person receiving palliative care is NOT correct?
- Morphine is considered first line for cancer pain.
 - Fentanyl can be used in severe renal impairment.
 - Oxycodone/naloxone can be used in severe liver impairment.
 - Methadone should only be initiated in the SPC setting as its pharmacokinetics are complex.
9. A person receiving palliative care who is experiencing severe pain will generally be prescribed opioids. Which of the following statements is NOT correct?
- An opioid is given at regular intervals for background pain with a PRN dose given for breakthrough and incident pain.
 - The PRN dose prescribed is generally 1/6th–1/12th of the total daily background opioid dose.
 - If one opioid isn't effective in controlling pain, firstly add a second opioid.
 - If possible, use the same opioid for regular and PRN dosing.
10. People receiving palliative care may experience intermittent or persistent nausea, with or without vomiting. Medicine selection for nausea and vomiting is generally based on the likely cause. Which of the following statements is correct?
- Metoclopramide and domperidone are prokinetic drugs and can assist in the vomiting associated with bowel obstruction.
 - Cyclizine is useful to prescribe as a second-line agent with prokinetic antiemetics.
 - Olanzapine is used off-label when prescribed for nausea and vomiting in radiation treatment for malignancy.
 - Domperidone does not cross the blood brain barrier and therefore extrapyramidal adverse effects are less likely.
11. Peter has been prescribed a background dose of morphine sulphate controlled release (CR) 30 mg twice daily with 10 mg oral morphine solution PRN for breakthrough pain. In the last week, he has consistently required 6 breakthrough doses per day plus an extra 2 doses prior to showering and wound dressing changes. To better control Peter's pain, an option is to increase his opioid dose. What is the new dose that would you recommend?
- Morphine sulphate CR 45 mg twice daily plus 10 mg oral morphine solution PRN.
 - Morphine sulphate CR 45 mg twice daily plus 15 mg oral morphine solution PRN.
 - Morphine sulphate CR 60 mg twice daily plus 10 mg oral morphine solution PRN.
 - Morphine sulphate CR 60 mg twice daily plus 15 mg oral morphine solution PRN.
12. Constipation is commonly experienced by people receiving palliative care. Which of the following is NOT a contributing factor for constipation?
- Increased levels of serum potassium.
 - Age and frailty.
 - Presence of a pelvic mass.
 - Anorectal pain.
13. Delirium can be distressing for caregivers to observe in the person receiving palliative care. Which of the following statements is NOT correct?
- Hypercalcaemia and urinary tract infections should be treated if appropriate.
 - Antipsychotics have been found to improve a person's delirium score more than non-pharmacological support strategies.
 - A medicines review is essential to screen for drugs contributing to delirium.
 - Haloperidol is commonly used in Parkinson's disease to control symptoms of delirium in people receiving palliative care.
14. Swallowing difficulties occur regularly in people receiving palliative care. Which of the following statements about impaired swallowing is NOT correct?
- Due to muscle weakness, many people with motor neurone disease experience difficulty swallowing.
 - While many medicines can be crushed, each one should be assessed to determine if crushing is appropriate.
 - All people receiving palliative care with impaired swallowing require a nasogastric tube.
 - Caregivers should consider the formulation of all medicines before they crush or dissolve it.

15. Doris has entered the last days of life (terminal phase). She is correctly prescribed fentanyl 75 micrograms/hour via transdermal patch. Currently, her pain is controlled. Which of the following statements is an appropriate response?
- As Doris is now in the terminal phase, increase the dose of fentanyl to 100 microgram/hour.
 - Keep the fentanyl patch in place and prescribe additional opioid if needed via continuous subcutaneous injection (CSCI) as well as giving appropriate breakthrough doses for pain.
 - Remove the fentanyl patch and replace immediately with CSCI containing 10 mg morphine administered over 24 hours.
 - Remove the fentanyl patch and wait until the person exhibits symptoms before adding an additional medicine for breakthrough pain
16. A community nurse presents prescriptions for morphine sulfate, hyoscine butylbromide, dexamethasone and clonazepam injections with instructions to 'give subcutaneously by CSCI as directed'. He asks for your advice about putting them in a syringe driver together. Which of the following is the most appropriate action and advice?
- Add them all to a syringe, start the infusion and wait to see if any precipitation occurs.
 - Give them each via a separate infusion.
 - Contact your local Medicine Information Centre or SPC service and ask for advice.
 - Wait until the person has symptoms and then administer the appropriate medication(s) PRN.
17. Palliative care aims to provide holistic care to people with a life-limiting illness. Which of the following statements is correct?
- Palliative care improves quality of life only in people with advanced cancer.
 - Palliative care is mainly delivered at home or in residential aged care with over half of Australians dying at home.
 - Palliative care may be initiated early in the course of a person's life-limiting illness optimally by a multidisciplinary team.
 - Palliative care has five phases that incorporates physical treatment as a preferential method in all phases for the patient.
18. People receiving palliative care may be taking multiple medicines. Deprescribing should be part of a holistic approach to care and can improve medication management. Which of the following statements about deprescribing for people receiving palliative care is correct?
- Discussing a planned, staged approach to deprescribing with the person and their caregiver can help to alleviate any potential emotional distress to stopping medicines.
 - A systematic, planned approach to deprescribing is always appropriate in all palliative care phases.
 - When a person enters terminal palliative care phase, immediate cessation of comfort medicines is appropriate as they are not required.
 - All unnecessary medicines should be ceased when a person begins to receive palliative care despite any conflict with their advance care plan.
19. Which of the following statements relating to anticipatory prescribing is NOT correct? Anticipatory prescribing:
- Can assist in timely and appropriate access to medicines and equipment enabling symptom management during the terminal phase of a person in their home.
 - Anticipates the chance of specific symptoms developing in the person during the terminal phase.
 - Is a proactive approach to care.
 - Is only appropriate once the person is in the terminal phase.
20. Josephine comes to the pharmacy to return a bag of unused medicines. Celia, her partner, had multiple sclerosis and has recently passed. What is the LEAST appropriate action for a pharmacist to demonstrate in this situation?
- Comfort Josephine, allow her to reflect and express her sadness and offer to connect her to bereavement groups to assist her dealing with her grief.
 - Have an informal team meeting with the pharmacy staff who knew Celia to gauge how they are coping and if they need further counselling services.
 - Encourage Josephine to engage in strategies to promote self-wellbeing such as regular exercise, keeping a reflective journal or practice yoga.
 - Compartmentalise your own feelings of grief and do not talk to anyone about them as your priority is to care for other patients that need prescriptions dispensed.

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