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What is palliative care?

What is palliative care?

The World Health Organization defines palliative care [\[Note 1\]](#) as an approach that improves the quality of life for patients and their families facing the problem(s) associated with life-limiting 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. Palliative care:

- 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 patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance 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.

The end of a human life due to a life-limiting illness is generally characterised by progressive physical change and decline, and very commonly a period of disruption to the social, psychological and spiritual aspects of life for the patient and their family. Palliative care is the active, holistic care of a person during this phase of deteriorating health, through to their death.

Good palliative care can significantly reduce both physical suffering and emotional distress, and aims to minimise the impact of the progressing illness so that patients can have the maximum function, symptom relief and comfort possible within the limits of their illness. Good palliative care is not different from good clinical practice in any field—it includes holistic patient assessment (of both the physical and psychosocial dimensions of need), pharmacological and other interventions tailored to the patient, and regular review to ensure care is adapted to the changing needs of the patient and their family as death approaches. Discussing prognosis, goals of care and advance care planning with the patient and their family are important elements of palliative care.

The principles of palliative care can be applied to the care of patients of any age with life-limiting illness, at any stage of their illness. Any general practitioner or specialist who cares for patients with life-limiting illness can adopt a palliative approach to a patient's care; in many cases it does not involve complex interventions. The decision to adopt a palliative approach reflects a recognition that the goals of care are shifting from managing disease and prolonging life towards optimising the quality of remaining life; it acknowledges that intensive efforts to prolong life are unlikely to be beneficial and may not be wanted by the patient.

Any general practitioner or specialist who cares for patients with life-limiting illness can adopt a palliative approach to a patient's care.

If a patient requires management of complex problems that are beyond the skills of their usual healthcare provider(s), referral may be made to a specialist palliative care service. These services can provide advice and support on an as-needed basis, or may assume full responsibility for the management of patients with complex and difficult problems. They can assist with management of refractory symptoms or complex

psychosocial or spiritual distress, and in situations when communication is challenging or there are difficulties with decision-making.

Direct exposure to people who are dying has become much less common in the developed world—many people are uncomfortable discussing their own death or the death of someone close, and healthcare providers may find the prospect of caring for dying patients confronting. These issues are discussed in [Communicating with the patient in palliative care](#), [Support for families and carers in palliative care](#) and [Caring for dying patients: impact on healthcare providers](#).

Specific aspects of palliative care in children are discussed in [Principles of paediatric palliative care](#).

Note 1: World Health Organization definition of palliative care [[URL](#)].

Which patients should receive a palliative approach to care?

Which patients should receive a palliative approach to care?

Apart from people who die suddenly, anyone with a life-limiting illness can benefit from a palliative approach to their care, regardless of their age, medical condition or place of care.

Patients with advanced cancer are still the most frequent recipients of specialist palliative care services. However, the burden of pain and other symptoms in patients with progressive nonmalignant conditions is often not fully appreciated, and these patients also benefit from a palliative approach to care; such care may be provided by their regular general practitioner or specialist. A palliative approach is increasingly used for patients with progressive organ failure (eg heart failure, chronic obstructive pulmonary disease, chronic kidney disease), progressive neurological conditions (including dementia), and the end stages of genetic disorders (eg cystic fibrosis).

A palliative approach to care is also applied to patients with acute severe illnesses or injuries who are not expected to recover. These patients are often treated with life-sustaining measures initially while their condition is assessed; however, once it is confirmed that life-prolonging treatment is not appropriate or desired, and after discussion with the patient and/or their family, the goal of care becomes palliation. These patients may deteriorate rapidly after withdrawal of life-sustaining measures; adopting a palliative approach or referral to a specialist palliative care service can improve symptom management for the patient and provide support for the family.

In this guideline, a ‘palliative care patient’ means any patient who is receiving a palliative approach to their care, whether provided by a specialist palliative care service, a general practitioner or specialist, or another healthcare provider.

Timely introduction of a palliative approach to care

Timely introduction of a palliative approach to care

Identifying patients at risk of deteriorating and dying

Identifying patients at risk of deteriorating and dying

As a patient's life-limiting illness progresses, it is important for clinicians to consider the patient's prognosis and regularly review the management approach. At some point it is likely that a change in approach will be needed, with a shift from disease management or life prolongation to a palliative approach that focuses on the quality of the patient's life. One way to do this is for the clinician to reflect on what can realistically be achieved for the patient. This can be the starting point for a frank discussion with the patient about their health status, with the aim of assessing their goals and wishes, and discussing the clinical outcomes that might realistically be expected; this process is known as [advance care planning](#).

It is important for clinicians to regularly review their patients with life-limiting illness, and consider whether

a shift to a palliative approach is needed.

Various tools have been developed to assist clinicians to identify patients who are at greater risk of deteriorating health and dying, and who may benefit from advance care planning and a change to a palliative approach to care. One is the 'surprise question' that the clinician might ask themselves— 'Would you be surprised if this patient were to die in the next 6 to 12 months?' If the answer is 'no', it may be timely to review the patient's situation and needs, and start planning future care.

The Supportive and Palliative Care Indicators Tool (SPICT) is a clinical prognostication tool based on general indicators of deteriorating health (eg recent unplanned hospital admissions, dependent on others for care) and indicators for specific conditions (including cancer, dementia, kidney disease) that can be used in the community or hospital setting. In those who are identified as being at risk of deteriorating and dying, the tool recommends reviewing patient needs and care planning. This includes medication review, considering referral for specialist assessment, and discussing goals and a care plan with the patient and their family; for further information see the SPICT [website](#).

Introducing a patient to a palliative approach to care

Introducing a patient to a palliative approach to care

Many people live for a long time, often years, after the diagnosis of a life-limiting illness. Some patients decline the offer of potentially life-prolonging treatment (eg chemotherapy, dialysis) and opt for palliation at the time of diagnosis. Others may not accept the inevitability of death even when all conventional therapeutic options have been exhausted. Between these extremes, there are many ways that patients incorporate the palliative approach into their care while maintaining their hopes for life prolongation or even cure.

Healthcare providers are in the best position to initiate or facilitate discussions about the introduction of a palliative approach to care. However, these discussions can be difficult and confronting for the patient and their family; skill and patience are required.

The timing of the introduction of a palliative approach is influenced by many factors, including:

- the nature of the patient's disease
- the acceptability and effectiveness of the treatment available
- the patient's beliefs and cultural values regarding illness, dying and social roles and expectations
- the patient's age and the presence or absence of intercurrent illnesses
- family and other responsibilities.

Making the decision to shift to a palliative approach to care can be stressful for a patient and their family, and healthcare providers can help with this process. Patients may have complex problems that can be challenging to manage—reassure them that they can be referred to a specialist palliative care service if necessary. Specialist palliative care services can achieve satisfactory control of symptoms for most patients and, if necessary, will continue to care for a patient until their death, and support the family afterwards.

Most patients who are dying appreciate acknowledgment and validation of the changes they are experiencing, however distressed they may become at the time. Examples of questions that a healthcare provider may use to open such a discussion are:

Can you tell me what you understand is going on with your (insert disease), and do you have any questions about it?"What changes in your condition have you noticed recently?"Many people worry about what might be happening to them. Are there any particular issues that you are worrying about or fearful of?"Are there any issues that you would like to discuss?"

Benefits of early introduction of a palliative approach to care

Benefits of early introduction of a palliative approach to care

It is often appropriate to introduce a palliative approach to care from the time it is recognised that a patient has a progressive, life-limiting illness. When a palliative approach is introduced early, supports can be put in place and symptoms can be addressed. In addition, emotional issues can be discussed, and the patient can take time to consider their life goals and preferences. Early discussions can help patients to feel more secure knowing that they will be supported whatever happens.

It is often appropriate to introduce a palliative approach to care from the time it is recognised that a patient has a progressive, life-limiting illness.

For example, many renal units introduce the palliative approach early in the management of patients with progressive chronic kidney disease. They discuss the values and goals of the patient (as part of advance care planning), and the limitations of dialysis, before considering whether to offer renal replacement therapy. Discussion includes explaining to the patient how they will be cared for if dialysis is not appropriate or when dialysis is stopped. The same principle may be applied to many life-limiting illnesses.

Evidence shows that patients with complex illnesses who engage with palliative care services that are integrated with their disease-related care can achieve better outcomes. A study of patients with newly diagnosed advanced lung cancer showed that those patients who met with a member of the palliative care team regularly (in addition to standard oncology care) had a better quality of life, lived longer and received less aggressive treatment than those who received standard oncology care [\[Note 2\]](#). In the palliative care visits, specific attention was paid to assessing physical and psychosocial symptoms, establishing goals of care, assisting with decision-making regarding treatment, and coordinating care on the basis of the individual needs of the patient. While it is not clear which of these interventions influenced the study outcomes, the results showed that patients exposed to a palliative approach to care had better outcomes.

Note 2: Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010;363(8):733–42. [\[URL\]](#)

Common illness trajectories in people approaching death

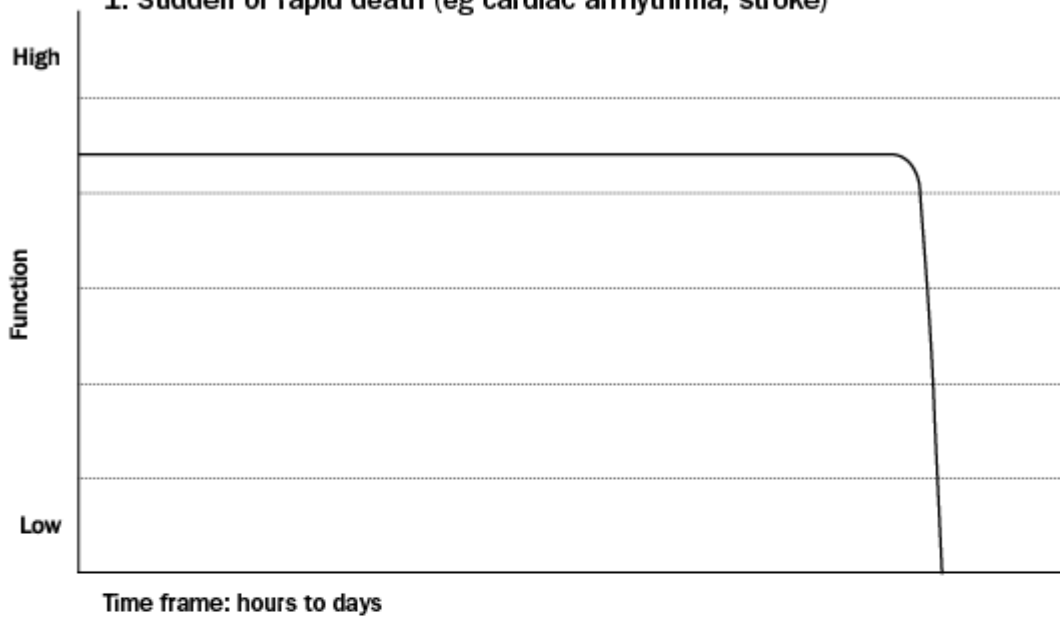
Common illness trajectories in people approaching death

A number of common patterns of decline have been recognised in patients who subsequently die; representations of these common illness trajectories are shown in [Figure 10.1](#). While every patient's trajectory will be different (and not many will look exactly like those in the figure), these concepts can help healthcare providers to guide patients and their families to a better understanding of the possible course of disease, and to plan care accordingly.

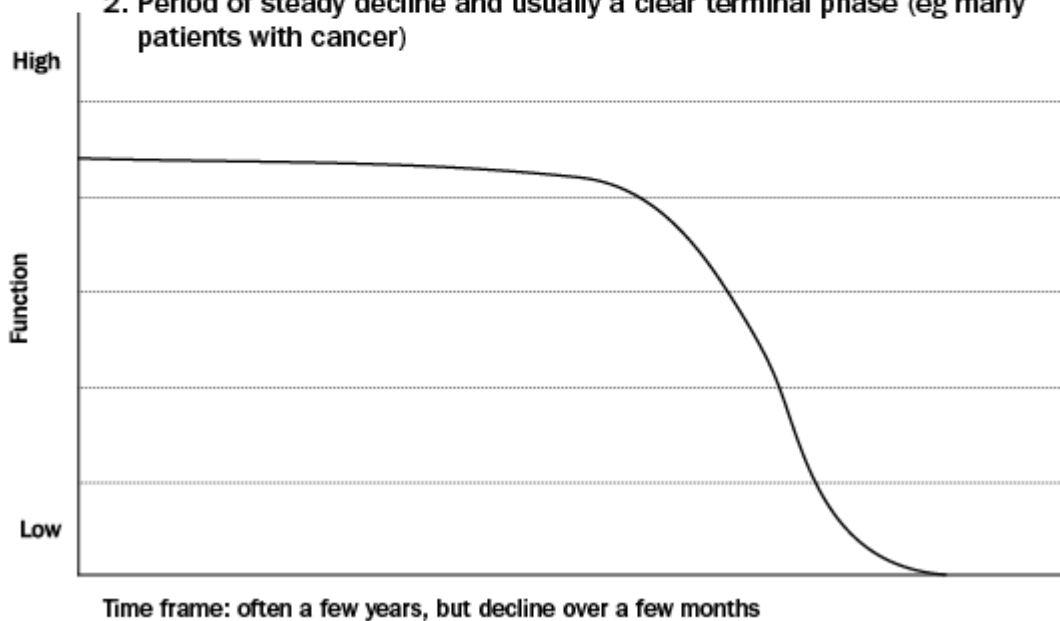
Patients with cancer and other life-limiting illnesses may become seriously ill on a number of occasions only to have their life prolonged for a significant but unpredictable period; this uncertainty can be stressful for the patient and their family. The use of drug therapy and other modern technologies to prolong life can introduce the phenomenon of prolonged dying, rather than a sustained period of life with quality. Discussion about which interventions are acceptable to a patient should be considered in [advance care planning](#), while the patient is well enough to participate in discussions and before decision-making becomes urgent.

Figure 10.1 Representation of common illness trajectories for people approaching death (Figure 10.1)

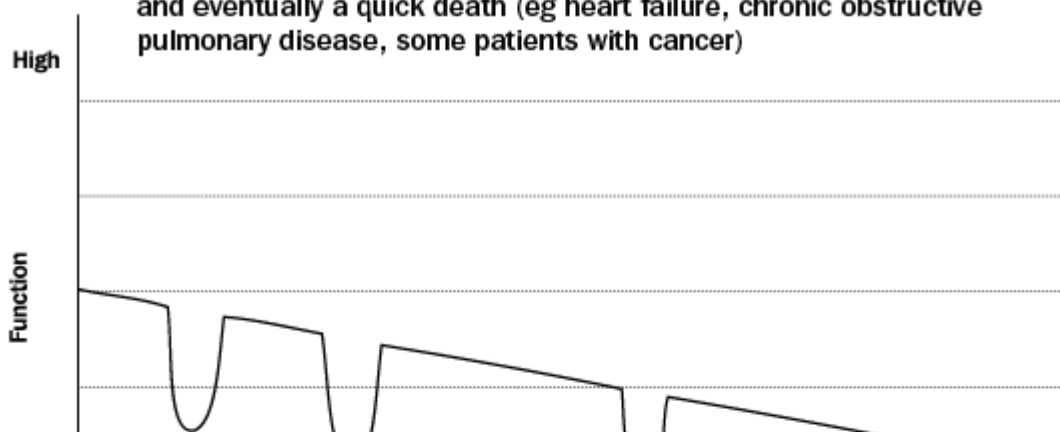
1. Sudden or rapid death (eg cardiac arrhythmia, stroke)

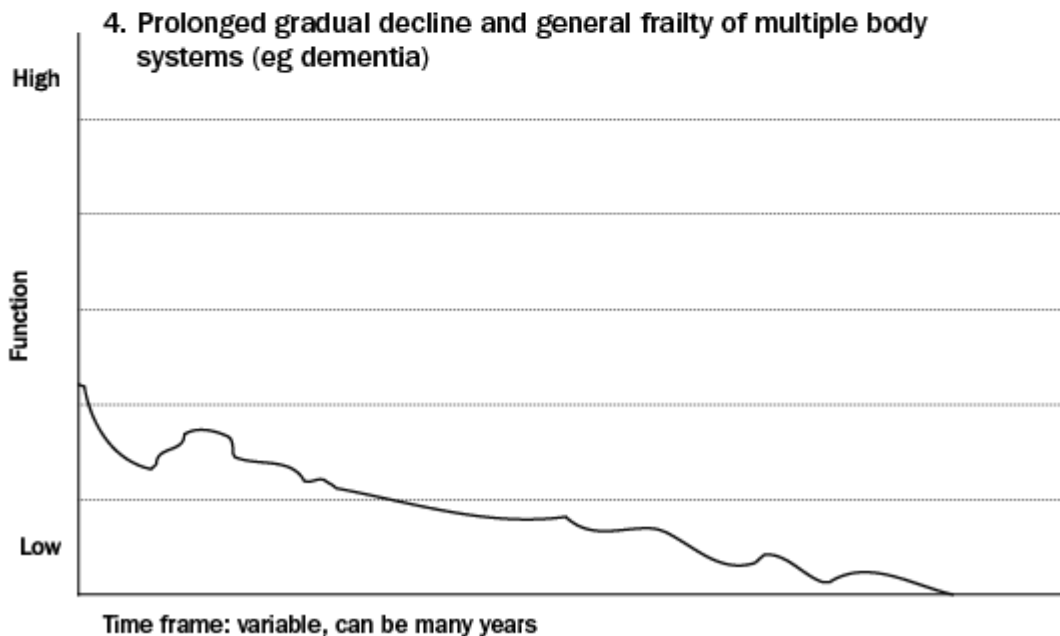
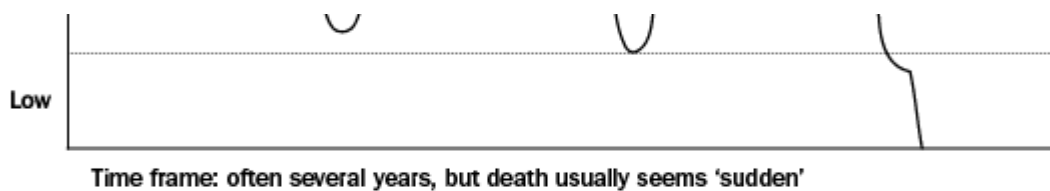


2. Period of steady decline and usually a clear terminal phase (eg many patients with cancer)



3. Gradual decline with episodes of acute deterioration and improvement, and eventually a quick death (eg heart failure, chronic obstructive pulmonary disease, some patients with cancer)





Adapted with permission from the RAND Corporation from Lynn J & Adamson DM. Figure 3. Chronic illness in the elderly typically follows three trajectories, in: Living well at the end of life: adapting health care to serious chronic illness in old age. Santa Monica, CA: RAND Corporation; 2003.

Who provides palliative care?

Who provides palliative care?

The problems that arise in the care of patients who are dying are often complex and, because no one person can provide all the services required, a team approach is necessary. As in all fields of medical practice, it is important that one person (generally a senior doctor) takes responsibility to ensure that decisions are made, care is properly coordinated, and healthcare providers are aware of their responsibilities. It may be appropriate to nominate a case manager for complex cases.

All patients who are dying can benefit from a palliative approach to care, but not all need specialist palliative care services. The palliative care of many patients can be managed in the community by general practitioners, and in hospitals by almost any specialty team; however, the care of patients with complex problems is more likely to be coordinated by a specialist palliative care team (with participation by others who know the patient). The team includes medical staff, nurses and allied health care providers who bring a broad range of skills and knowledge. Family, friends, volunteers and other ancillary workers also play a vital role in palliative care, and care of patients in the community would not be possible without their support.

All patients who are dying can benefit from a palliative approach to care, but not all need specialist palliative care services.

Patients often wish to maintain their relationship with the healthcare providers they already know; these relationships should be encouraged whenever possible, regardless of who is primarily responsible for a patient's care. The patient's usual healthcare providers may find it helpful to work in collaboration with a specialist palliative care service.

For any healthcare provider caring for a patient who is dying, there are benefits to be gained from spending time getting to know the person—their life story, family, relationships, occupation, beliefs, goals and values. This can help the provider to develop a more effective relationship with the patient based on trust and mutual respect, and enhance their understanding of how to provide care appropriate to the patient's needs and wishes.

Medical care

Medical care

Many doctors manage patients who require palliative care, including general practitioners (GPs) as well as medical specialists who manage patients with life-limiting conditions (eg chronic kidney disease). They may access the resources of a wide range of community agencies and work in conjunction with specialist palliative care (or other specialist) services. Doctors are encouraged to establish a link with their local specialist palliative care service.

The GP is often the primary medical provider and coordinator of care for patients in the community. They may be able to manage all of a patient's physical symptoms and psychosocial needs, as well as organising services required, or may refer a patient with complex problems for specialist palliative care. For more information on the role of the GP, including when to refer, see [Role of the general practitioner](#).

Palliative care medical specialists provide support for the management of complex problems faced by people who are dying (and their doctors). Increasingly, palliative care services offer consultation by video- or teleconference. A specialist palliative care service should be consulted early when problems arise.

Nursing care

Nursing care

The nursing needs of palliative care patients range from basic hands-on care to complex and specialist problem solving. Any nurse may be required to provide palliative care on occasion. Specialist palliative care nurses and nurse practitioners are vital to the successful care of patients with complex problems, and in some settings may be the key healthcare providers.

Doctors often rely on a nurse's clinical assessment of a palliative care patient for much of their decision-making, particularly when the patient is in the community or in a rural or remote area where daily review by doctors is not practical. For more information, see [Community nursing services](#).

Allied health care

Allied health care

Allied health care providers bring a range of skills that are vital to help patients to achieve the best possible function and quality of life as their disease progresses. They can be particularly effective in helping a patient to remain in the community, or facilitating discharge from hospital to home. Allied health workers who may be involved in palliative care include occupational therapists, physiotherapists, pharmacists, speech pathologists and dietitians.

Psychosocial, spiritual and other support

Psychosocial, spiritual and other support

Psychosocial support can be part of the day-to-day role of any healthcare provider caring for a patient with life-limiting illness, or it may be provided by specialised staff such as a psychiatrist, psychologist, social worker, counsellor or pastoral care provider.

Cultural liaison workers (eg Aboriginal and Torres Strait Islander Health Workers) or members of the patient's community of cultural origin can provide cultural liaison and support.

Many specialist palliative care services employ dedicated counsellors whose job includes supporting patients to address complex life issues. This may include managing conflict between a patient and their family, between family members, or between a patient, family and care providers. Counsellors also follow up bereaved families and carers after the patient has died.

Social workers help to organise a wide variety of practical supports, from arranging accommodation and social security benefits to facilitating legal matters such as making a will. Their role frequently merges into practical counselling and in many services, particularly in rural areas, they are the designated counsellors.

The role of pastoral care staff is often not religious and involves providing help to patients dealing with issues such as inner conflict, the search for meaning, and unresolved spiritual or religious issues.

Specialist palliative care services may provide access to therapists who offer services such as art therapy, music therapy, massage or aromatherapy as part of a holistic support program.

Families, carers, volunteers and community groups

Families, carers, volunteers and community groups

Family members frequently find themselves in the role of primary carer for a person who is dying. The role that a carer takes depends on their capabilities and the needs of the patient. Families and carers may be able to carry out personal care (eg hygiene, mouth care, skin care, continence care), the management of medications (which may include administration of parenteral drugs or management of syringe drivers) and complex care tasks (eg use of hoists). Many family members become highly proficient in the care of the patient, with an intimate understanding of their wishes and idiosyncrasies. Caregiving can be intense and stressful, and families and carers frequently need support; see [Support for families and carers in palliative care](#).

While volunteer services vary from one community to another, volunteers generally contribute by offering their time to complement the work of paid staff. Most specialist palliative care services select, train and supervise volunteers through structured programs, and they should be treated as professional colleagues. The involvement of volunteers enhances awareness of care at the end of life in the broader community. For more information, see [Volunteers and other community-based services](#).

A wide range of community organisations offer support to patients (both adults and children) and their families. Disease-based groups provide information, material aids and support meetings (eg Cancer Councils, National Heart Foundation, Motor Neurone Disease Australia) [\[Note 3\]](#). Numerous community groups provide support to their members and/or to disadvantaged members of the community; see [Volunteers and other community-based services](#).

Many patients have their own networks of care, advice and advocacy, including family and friends who often provide an enormous amount of assistance. On the other hand, patients can also be inundated with gratuitous advice about 'treatments' of variable quality, and while this may be well-meaning, it can be confusing and is sometimes exploitative. Healthcare providers need to take time to guide and support patients dealing with such issues.

Note 3: For a list of support groups and disease-based organisations, see CareSearch [website](#). For organisations supporting children receiving palliative care, see 'A practical guide to palliative care in paediatrics' (Queensland Health) [\[URL\]](#).

Where is palliative care provided?

Where is palliative care provided?

Palliative care can be provided to patients in any setting where health care is provided. Whenever possible, it should be provided in the place of the patient's choice, and ideally patients should be able to move seamlessly from one location to another as required. In practice, the place of care is determined by the nature of a

patient's illness and associated clinical problems, the practical suitability of their home, the personal support available from family and friends, and the resources available through the health system.

Patients living in rural and remote areas may be at a disadvantage with regard to access to specialist palliative care services; however, the ingenuity shown by families, communities and rural healthcare providers to meet patients' needs should not be underestimated. Many specialist palliative care services undertake outreach clinics in smaller communities, and may offer video- or teleconferencing to support clinicians in the care of individual patients, and for teaching. Patients from rural areas might wish to consult with specialist palliative care services when they visit larger centres for disease-centred treatment.

Specialist palliative care services may operate from a variety of settings, including hospitals, palliative care units and community-based services. Members of the specialist palliative care team should help other healthcare providers to understand how specialist services operate locally, and ensure members of the specialist team can be contacted easily.

Places of care

Places of care

The patient's home—Most palliative care occurs where a patient lives, for example in their home or a residential aged care facility. Even if a patient dies in a hospital or palliative care unit, they will usually have spent most of their time during their illness at home. Specialist palliative care services, supplemented by community-based providers and the contribution of family and friends, are often able to create an environment that delivers care in the home that is equivalent to inpatient palliative care. Many people express a wish to die at home; however, there are a variety of reasons why this may not be possible or may not be their final preference. See [Providing palliative care in the community](#) for more information.

Hospitals—Hospitals deliver care at the end of life in different ways. General medical services, geriatric services and subspecialty teams care for many of their patients who are dying without referral to specialist palliative care services. In hospitals where specialist palliative care services are available, they may provide consultation and advice only, or they may manage patients either in a general ward or a dedicated palliative care unit. Most specialist palliative care services have clearly defined admission policies, and some form of triage is often undertaken before admitting a patient to the service.

Small rural hospitals may manage with a single palliative care room and services that are activated only when a patient is in need ('pop-up' palliative care). Care in small hospitals may be supported by formal links to specialist palliative care services in larger centres.

Palliative care units—Palliative care units (or hospices) provide a place where people who are dying may spend their last days or weeks of life when they cannot be managed at home. Patients may also be admitted during their illness for assessment and symptom management, or a period of respite, before returning to their home. Even when co-located on the campus of a large hospital, these units are usually designed to create a home-like environment while providing high quality medical and nursing care.

Phases of palliative care

Phases of palliative care

The course of life-limiting illness has been defined in five phases that provide a common language to enhance communication between healthcare providers looking after palliative care patients. The Palliative Care Outcomes Collaborative (PCOC) uses these phases (and other standardised clinical assessment tools) to measure and benchmark patient outcomes in palliative care; many specialist palliative care services across Australia participate in the Collaborative. The five phases are described below (summarised and adapted from the PCOC clinical manual; for the full definitions see the [PCOC clinical manual](#)).

The palliative care phases are not sequential—a patient can move back and forth between phases.

A patient is in the **stable phase** when their problems and symptoms are adequately controlled, further interventions to maintain symptom control and quality of life have been planned, and the family/carer situation is relatively stable. Many patients with life-limiting illness experience periods when their symptoms remain unchanged, sometimes for a significant length of time. In the stable phase a patient may be quite comfortable and no action is necessary, apart from watchful waiting. Sometimes the patient and their family can be surprised when things start to deteriorate, particularly if they have become lulled into a state where it seems that there is no disease progression.

A patient enters an **unstable phase** when they develop a new problem, there is a rapid increase in severity of a current problem, or the circumstances of the family/carer change suddenly and impact on patient care. These factors necessitate an urgent change in the plan of care, or emergency treatment.

In the **deteriorating phase** a patient's overall functional status is declining and they have progressively worsening problems, a new problem, or the family/carer's distress is worsening and is impacting on patient care; the care plan requires periodic review during this phase. For more information about the deteriorating phase, see Terminal care: care in the last days of life.

In the **terminal phase** a patient's death is likely within days. This phase may develop very quickly and unexpectedly, but more often is preceded by days or weeks of decline. For more information about the terminal phase, see Terminal care: care in the last days of life.

The **bereavement phase** occurs when a patient has died and bereavement support is provided to the patient's family and carers. For information about bereavement care, see Loss, grief and bereavement.

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What is advance care planning?

What is advance care planning?

Advance care planning is the process by which a person considers their values, hopes and goals in relation to their health, and informs their healthcare provider(s) and people close to them about their preferences for health care in the event they are unable to make or communicate decisions.

Many patients will lose the capacity to make or communicate decisions at the end of their life, and research has shown that patients often receive nonbeneficial or inappropriate interventions at the end of life. Advance care planning provides the opportunity for a patient to consider and plan for their end-of-life care while they are able to. It can help them to maintain a sense of control and achieve greater peace of mind, knowing they will be more likely to receive the care they want. It can also relieve family members and carers of the stress associated with unguided decision-making. However, there can be challenges in creating advance care plans, and in using them (see [Challenges in using advance care plans](#)).

While advance care planning is relevant for everyone, it becomes increasingly important as the likelihood of dying increases, for example in people who are older or who have life-limiting illness. For palliative care patients, healthcare providers should ascertain whether advance care planning has been considered; if not, patients who have decision-making capacity should be encouraged to undertake the process as a matter of priority.

A patient can record their preferences in an advance care plan (see [Advance care planning documentation](#)) and appoint a [substitute decision-maker](#) to convey their preferences and participate in decision-making on their behalf if required. Information that may be included in an advance care plan is shown in [Figure 10.2](#). This documentation helps to guide clinical practice at the end of life and assists healthcare providers and family members to make decisions that are consistent with the patient's wishes. An advance care plan should be prepared early, but it only comes into effect when a patient is not able to make or communicate their own decisions (see [Patient capacity to make decisions about their health care](#)).

An advance care plan should be prepared early, but it only comes into effect when a patient is not able to make or communicate their own decisions. [Figure 10.2](#) Information that may be included in an advance care plan

- a patient's values, goals and wishes; what 'living well' means to them
- the patient's preferences in relation to:
 - treatment to maintain quality of life (ie palliative or comfort care)
 - receiving life-prolonging treatments (eg cardiopulmonary resuscitation, ventilation, intravenous antibiotics)
 - transfer to hospital in the event of deterioration
 - place of death (eg home, residential aged care facility, hospital)
 - after-death care (eg funeral director, preference for cremation or burial, cultural practices)
- requests for organ, tissue or body donation
- names and contact details of substitute decision-maker(s)
- other issues that are important to the patient (eg religious or spiritual requirements, care of pet).

The laws and processes related to advance care planning differ between Australian states and territories; healthcare providers should be familiar with the legislation and required documentation in their jurisdiction (see state health department websites or the [Advance Care Planning Australia website](#)).

Laws and processes related to advance care planning differ between the states and territories; healthcare

providers should be familiar with local requirements.

Legal arrangements for the administration of other personal matters (eg arranging finances, writing a will, power of attorney), may also be considered around the time of advance care planning.

For specific considerations related to advance care planning for children, see [Paediatric palliative care: advance care planning](#).

General care planning

General care planning

General care planning is the development of an individual management or care plan to address a patient's current health problems, and those that the clinician expects to arise at some point in the future as the patient's illness progresses. For example, planning should be undertaken for patients with heart failure so that they have medications available and know who to call for help if they wake up at night with acute shortness of breath. The problems that commonly arise are often predictable, but their timing is not, especially for patients with nonmalignant conditions.

Communicating a management or care plan to relevant healthcare providers and the patient, family and carers can help them to be prepared and know what to expect as the situation changes.

General care planning can be done alongside the process of advance care planning; it is frequently overlooked or put off, and advance care planning provides a good opportunity for the clinician to prepare a management or care plan at the same time.

For information on the principles of symptom management in palliative care, see [Principles of symptom management in palliative care](#).

Advance care planning in practice

Advance care planning in practice

Advance care planning conversations

Advance care planning conversations

Advance care planning usually takes place over a period of time rather than in a single session, and may include members of a patient's family or others who the patient would like to be involved. It may take place in different settings; for example, with a general practitioner or in a residential aged care facility or hospital (see [Advance care planning in different settings](#)).

Ideally, discussion about advance care planning for a patient with life-limiting illness is undertaken in the context of a trusted relationship between the patient and their healthcare provider. Many patients expect their doctor to raise the subject of advance care planning.

Many patients expect their doctor to raise the subject of advance care planning.

Talking about end-of-life care can be difficult and emotional for the patient, even those who are not imminently dying. Healthcare providers can find it difficult to initiate these discussions; sensitivity and empathy are required. If possible, the subject of advance care planning should be raised with the patient early in the course of their illness rather than when they are acutely ill or distressed. For guidance, see [Figure 10.3](#).

Figure 10.3 Guidance for advance care planning discussion and follow-up

These points are provided as guidance; however, conversations will vary and may not follow the steps outlined below. Before commencing, check whether a patient already has an advance care plan.

Preparation

Assess the patient's willingness to discuss advance care planning.

Find out if they would like to have others involved in the conversation (be aware of cultural issues related to decision-making; see [Cultural issues in palliative care](#)).

Allow enough time; these are sensitive discussions that should not be rushed.

Conversation

Explain the potential benefits of advance care planning, and that a written plan only comes into effect if a person loses decision-making capacity.

Find out what the patient already knows about their health status and prognosis.

Provide specific information on the patient's medical condition(s) and what may happen in future, including the expected impact of the condition(s), prognosis, dilemmas that may arise, and possible treatment options. Offer realistic hope and use positive language; avoid medical jargon.

Acknowledge the patient's emotions; watch for signs of discomfort and stop the conversation if necessary. Check their understanding along the way.

Explore the patient's beliefs, values, fears and concerns, and the type of health care they want in future. Assist them to clarify their goals of care.

After this general framework is established, discuss their preferences for specific interventions such as cardiopulmonary resuscitation, ventilation, feeding, hospitalisation and place of death (as applicable).

Encourage the patient to identify a [substitute decision-maker](#).

Completing the conversation and follow-up

Make a follow-up appointment to continue the discussion if needed.

Document the conversation and encourage or assist the patient to record their advance care plan (see [Advance care planning documentation](#)).

Reassure the patient that they can change or revoke their plan while they have the capacity to do so.

Encourage the patient to make their wishes known to those close to them, and to distribute their plan to relevant parties.

Assist the patient to communicate the information to relevant healthcare providers, with permission.

Review the plan periodically or when there is a change in the patient's condition.

Substitute decision-makers

Substitute decision-makers

A patient may nominate a substitute decision-maker to represent them when they no longer have decision-making capacity [\[Note 1\]](#). If more than one substitute decision-maker is nominated, the means of decision-making between them should be made clear (eg any one of them, a majority, or all of them are required to make a decision).

If a substitute decision-maker is not nominated by a patient, they may be identified by law. Do not assume the patient's next of kin will automatically become the substitute decision-maker. State-based legislation specifies the hierarchy of persons who can fulfil this role (eg spouse, de facto partner, carer, close friend, relative), and they should be contacted in the order specified in that jurisdiction.

Substitute decision-makers only have a role when a patient is not able to make or communicate their own decisions (see [Patient capacity to make decisions about their health care](#)). The substitute decision-maker can convey the patient's preferences to the healthcare team, and may participate in decision-making on a range of issues. When participating in decision-making, substitute decision-makers must act in the best interests of the patient, and take into account the patient's wishes as well as advice from the treating clinicians about the value (or futility) of the proposed action. Prior expressions of the patient's wishes should always be taken into consideration, whether they were made in an official document or not.

Substitute decision-makers only have a role when a patient is not able to make or communicate their own decisions.

When a substitute decision-maker is not available, or when there is disagreement between substitute decision-makers, an independent statutory body known as a guardianship board or tribunal may be called upon to make a decision or provide consent if required (similar legislation, albeit with significant variations, exists in all states and territories).

Note 1: The legal term for a substitute decision-maker varies between jurisdictions, for example they may be known as a 'Person responsible', 'Medical Power of Attorney' or 'Enduring Guardian'; see the Advance Care Planning Australia [website](#) for details.

Advance care planning documentation

Advance care planning documentation

Australian states and territories have developed documents and resources to assist people to record their advance care plan (see state health department websites or the Advance Care Planning Australia [website](#)). The plan may be known as an advance care plan, advance care directive, living will or statement of choices; there may be separate documents to appoint a substitute decision-maker or for refusal of treatment. Other expressions of advance care planning are also acceptable and are enforceable under common law; for example, a letter to the general practitioner (GP) or a witnessed verbal statement (written down at the time, signed, dated and witnessed). Some health services have developed electronic tools (eg online forms) to assist patients to record and share their plans.

Information that may be included in an advance care plan is shown in [Figure 10.2](#).

A patient's GP or other doctor may assist them to record an advance care plan, or, in some health services, a specialist nurse or other trained staff may assist. The patient's decision-making capacity should be considered when undertaking this process—adults are presumed to have capacity unless it is established that they do not have capacity (see [Patient capacity to make decisions about their health care](#)).

Patients' goals and preferences may change over time and advance care plans should be reviewed on a regular basis; for example, annually or when a patient is hospitalised or their condition changes. If changes are made, the old version should be updated or replaced and relevant people notified.

Communication of an advance care plan

Communication of an advance care plan

When a patient has completed their advance care plan, they should keep the original document in a prominent place so that they remember it and carers can easily find it. Valid copies should be provided (as applicable) to the next of kin, substitute decision-maker(s), general practitioner, local hospital and other healthcare providers who may be involved in medical decision-making. It may also be stored in the patient's eHealth record.

While distribution of the plan is the patient's responsibility, healthcare providers should encourage patients to distribute their plan to relevant parties, and can assist them to do so (eg the GP may send a copy to the local hospital). Distribution of advance care plans will vary depending on the systems that local health services

have in place to manage such documentation; it can be challenging to ensure all relevant parties have access to the information when they need it.

Healthcare providers should encourage patients to distribute their advance care plan to relevant parties, and can assist them to do so.

For patients at the end of life who are likely to deteriorate at home or in a residential aged care facility, it is essential that there is a written plan available at the place of care. This plan should include instructions about resuscitation and transfer to hospital. If an ambulance is called, the paramedics usually do not know the patient and they must follow ambulance service protocols, including initiation of cardiopulmonary resuscitation and transportation to the nearest emergency department in certain circumstances. These actions may be inappropriate and/or contrary to the patient's wishes, but will ensue unless paramedics see an advance care plan that states these actions should not be undertaken, or they have access to information about appropriate care for that patient, provided in advance by the patient's doctor [\[Note 2\]](#).

Note 2: Some states have systems that allow doctors to authorise care for a patient that varies from normal ambulance practice; this information is logged with the ambulance service and is available to paramedics if they are called to the patient's place of residence.

Challenges in using advance care plans

Challenges in using advance care plans

When a patient has lost capacity to make health-related decisions and an advance care plan is available, healthcare providers must consider whether it is valid (eg Does it meet jurisdictional requirements? Does it reflect the patient's current wishes?) and applicable to a particular situation [\[Note 3\]](#). In the case that an advance care plan does not cover a particular situation, the clinician should seek the counsel of the patient's substitute decision-maker. The general intent of the patient, if known, may help to inform the situation.

In some cases, an advance care plan will direct a healthcare provider to carry out treatment which is clearly nonbeneficial or where harm outweighs benefits. Statutory law protects healthcare providers who do not comply with an advance care plan in these circumstances. The situation should be discussed carefully with the patient's substitute decision-maker or a guardianship board (or equivalent) before such decisions are made.

Note 3: For information on the law and advance care planning, see the [Advance Care Planning Australia website](#).

Advance care planning in different settings

Advance care planning in different settings

Primary care

Primary care

General practitioners are well placed to have conversations about advance care planning as they often have trusted relationships with their patients, and can introduce the subject of advance care planning in the nonacute phase of a patient's illness, when it is easier to talk about these matters.

It can be difficult to know the right time to initiate discussions about advance care planning. Potential triggers include routine health checks in older people (eg Age >75 years health assessment), a change in a patient's clinical status, or recent hospitalisation. There are tools available to help identify patients who are at greater risk of deteriorating and dying and who may benefit from advance care planning.

Residential aged care facilities

Residential aged care facilities

People living in residential aged care facilities often have multiple medical conditions and limited life expectancy. Increasingly, they also have dementia, with limited capacity to make decisions for themselves. Advance care planning in the early stages of a person's disease is particularly important in this setting to ensure staff and family know about the person's wishes for care and treatment. Admission to a residential aged care facility is a useful trigger to initiate the process of advance care planning; some aged care facilities require residents to complete an advance care plan on admission.

It is helpful to provide staff of residential aged care facilities with instructions on how to manage likely health complications in a resident if they arise. In particular, clear instructions on what to do out of hours can prevent inappropriate resuscitation measures or transfer of residents to hospital by ambulance; see [Communication of an advance care plan](#).

Hospitals

Hospitals

An advance care plan can guide management when a patient is admitted to hospital for acute care. Without clear direction, staff in the emergency department may feel obliged to actively treat a patient when it may not be appropriate; for example, a person with advanced life-limiting illness or dementia.

Hospitals generally have systems in place to ascertain whether a patient has an existing advance care plan, or to initiate advance care planning if they do not (if appropriate). They also have processes to record information about appropriate resuscitation measures for a patient, and may require staff to discuss a patient's goals of care at the time of admission.

Without documentation about the goals of care and appropriate interventions for a patient, clinical decisions about care at the end of life may result in the provision of life-sustaining treatment that is not appropriate or is not wanted by the patient. It is important to be clear about which clinician is ultimately responsible for decision-making for a patient. If decision-making responsibility is not clear, patients with multiple comorbidities who are receiving treatment from more than one clinical unit may receive inappropriate interventions.

If advance care planning is initiated in a hospital, it should be followed up after discharge in the hospital outpatient clinic or by the patient's general practitioner.

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Introduction to ethical issues in palliative care

Introduction to ethical issues in palliative care

Most ethical issues in palliative care relate to how decisions are made and the extent of medical investigation and treatment, including withholding or withdrawing treatment. Ethical dilemmas arise because of concerns or differing views about what kind of care is best for a patient, especially when the patient is unable to communicate their wishes or make decisions themselves. This can cause conflict between healthcare providers, patients and families.

Specific ethical considerations in paediatric palliative care are discussed in [Paediatric palliative care: ethical issues and decision-making](#).

Decision-making in palliative care

Decision-making in palliative care

Making decisions about care at the end of life is often not straightforward, even when a patient has decision-making capacity. Decisions can be clinically complex and emotionally distressing, especially those related to withholding or withdrawing treatment. Some decisions may involve uncertainties and ethical or religious dilemmas that further complicate the decision-making process.

Decision-making in palliative care is a collaborative process that should involve the patient (or their substitute decision-maker), their family and carers (with the patient's permission), and members of the healthcare team. Some cultural groups place great importance on involving family and community members in decision-making; it is important to try and find out what is most appropriate for each person, and to respect their preferences (see [Cultural issues in palliative care](#)). 'Family' should be interpreted in the broadest manner—it includes whoever the patient says is important to them. When there are ethical dilemmas involved in decision-making it can take time to agree on how to proceed; healthcare providers may need to answer questions and explain issues to the patient and family on multiple occasions.

The key principles of palliative care should be borne in mind in the decision-making process: a patient-centred approach to care, careful attention to symptom control, and clear and open communication about what (if any) choices there are as the patient approaches the end of their life. It is also important to remember that while the unit of care in palliative care is described as being 'patient and family', the patient's right to confidentiality remains (see [Privacy and confidentiality in palliative care](#)).

Ethical principles and other factors to consider

Ethical principles and other factors to consider

While there may not be a 'right' answer to an ethical dilemma, considering the issues in an ethical framework using the following principles can be helpful in making decisions. The four key ethical principles in health care are described below.

- **Autonomy** means 'self law or self rule'. An autonomous person acts intentionally, with understanding, and without controlling influences. In a clinical setting, this means respecting a person's decision to refuse or accept treatment, and creating the conditions necessary to help them make decisions.
- **Beneficence** is an action for the benefit of others. In a clinical setting, this means that healthcare providers should act in the best interests of their patients.

- **Non-maleficence** means to do no harm. In many clinical situations there is a balance between beneficence and non-maleficence, ie a need to weigh up the benefits and harms.
- **Justice** means that healthcare providers should be as fair as possible when offering treatments to patients and allocating limited medical resources. Equality and equity are two elements of the principle of justice.

These four principles provide an essential framework for medical decision-making; however, they may not be sufficient to guide decisions in practice, or they may be conflicting. Other factors to consider when making decisions for patients with life-limiting illness may include:

- What are the patient's goals, hopes, fears and expectations?
- How much information does the patient want about their disease and prognosis?
- What are the treatment options, and what are the benefits and burdens of each?
- Does the patient have decision-making capacity, and if not, have they previously expressed their preferences (eg in an advance care plan) or appointed a substitute decision-maker?
- What are the family dynamics and how do these influence decision-making?
- Are there religious or cultural factors to be considered?
- Are there legal aspects relevant to the issue?

Patient capacity to make decisions about their health care

Patient capacity to make decisions about their health care

‘Competence’ is the legal term that relates to a patient having capacity to make decisions. A person with decision-making capacity should be able to understand the possible options, the likely outcomes of a decision, and should be able to provide a rationale for decisions they make. Healthcare providers should assume that an adult has capacity to make decisions about their health care unless there is evidence to indicate otherwise.

A patient's capacity to make decisions can vary depending on the issue at hand. Assessment of capacity to make health-related decisions (ie to give informed consent) may be made by a mental state examination (eg Mini Mental State Examination) combined with physical examination and appropriate laboratory evaluation. Document whether the patient understands the proposed treatment options and the likely outcomes, can express their preferred option, and explain the reason for their choice. This information may be used later to decide whether the patient was competent (from a legal perspective) to make a particular decision at the time of the assessment. Assessment of capacity should take place as close as possible to the time at which the decision is required.

Decision-making capacity may become impaired as a patient's condition deteriorates, and may be lost as death approaches. A substitute decision-maker can make healthcare decisions on behalf of a patient who has lost decision-making capacity; this person is usually appointed as part of the advance care planning process. Healthcare providers should encourage all patients with life-limiting illness to consider advance care planning early and not delay it.

Healthcare providers should encourage patients with life-limiting illness to consider advance care planning early and not delay it.

While decision-making for a patient who lacks capacity can be complicated, common sense prevails in most situations provided there is good communication and appropriate consultation before decisions are made. Exceptions occasionally occur when there is family conflict, disagreement between healthcare providers and the family, or when the substitute decision-maker appears to be acting in a way that does not support the patient's best interests. The professional and legal duty of healthcare providers is to act solely in the best interests of the patient who lacks decision-making capacity. For advice on conflict resolution, see Differences in opinion and approach to conflict resolution.

Limits to patient autonomy and choice

Limits to patient autonomy and choice

A patient's needs and preferences are central to the provision of health care—especially at the end of life—but there are limits to patient autonomy. For a range of reasons, there will be times when a patient's wishes cannot be met. Patients depend on healthcare providers, family and carers, and they may need to be reminded of the impact of their wishes and decisions on others. For example, a patient may wish to be cared for at home, but family members may be unable or unwilling to provide such care.

Healthcare providers should be honest and clear with patients in discussing limitations to treatment and care, and explain the choices available, even though these are often limited. It is not helpful to offer choice when none really exists. It is important to support the patient, and their family and carers, through times when the patient's wishes cannot be met.

Differences in opinion and approach to conflict resolution

Differences in opinion and approach to conflict resolution

Good communication is key to both preventing and resolving conflict about care at the end of life. There may be fundamental differences in beliefs between a patient (or their substitute decision-maker), family, carers and healthcare providers, but it is usually possible to agree on core values and what constitutes good and compassionate care at the end of life, eg relief of suffering and maintenance of dignity as goals of care. Each person may need to compromise a little to get to an agreed common direction.

When there are differences in opinion it may be helpful to hold a family meeting and use a generic approach to conflict resolution, as follows:

- clarify the issues without prejudice or any attempt to solve the problem(s)
- identify people's different positions and then attempt to lay them aside
- identify the patient's interests and try to get agreement about them
- explore solutions that further these interests
- adopt workable solution(s) through a process of consensus.

Occasionally it is prudent to obtain a second opinion from an independent or expert source before any action is taken in a conflict situation. This is particularly important when a patient does not have decision-making capacity, or when a patient has capacity but the proposed treatment options are in conflict with their beliefs or values. If the patient is an inpatient, hospitals may have a patient advocate or risk manager to assist in conflict resolution. States and territories have public officers or bodies such as a public advocate or guardianship board (or similar) if further advice is needed.

Advance care planning can help to prevent conflict.

Requests to withhold information from a patient

Requests to withhold information from a patient

It is not uncommon for family members to ask that a patient not be told of their diagnosis or prognosis. It is helpful during these discussions to:

- acknowledge the family's concerns
- enquire about the reason for the request to withhold information from the patient
- consider the social and cultural factors affecting the situation. In some cultures it is common to keep distressing news from patients
- discuss the benefits of honest and open communication. Explain that patients often already know they are dying, and talking about it allows them to discuss their concerns and receive appropriate support
- offer to ask the patient open questions in the presence of family members (and interpreter when appropriate), and be prepared to 'back off' if the patient does not wish to know any more
- advise the family that direct questions from the patient will be answered truthfully and sensitively if and when they arise.

The healthcare provider should decide whether to raise issues such as diagnosis and prognosis if there is no request from a patient. Research suggests that patients expect their doctor to raise these issues. At the start of these conversations, it is prudent to find out what the patient understands about the situation and what they would like to know. For more information about communication with the patient, including breaking bad news and discussing prognosis, see [Communicating with the patient in palliative care](#).

Withdrawing or withholding treatment in palliative care

Withdrawing or withholding treatment in palliative care

The goals of palliative care are to relieve a patient's symptoms and suffering, not to intentionally hasten or postpone death. As a patient's condition deteriorates, the relative benefits and harms or burdens of treatment will shift, and decisions about withdrawing or withholding treatment may need to be considered.

These decisions can be difficult and emotional for everyone involved. It is important to negotiate the goals of care and discuss the potential benefits and burdens of treatment with the patient (or their substitute decision-maker) and the family before making a decision. Patient preferences related to withdrawing and withholding treatment are usually discussed as part of the advance care planning process; ideally this should happen early in the course of a patient's illness.

Doctors have a duty to recognise when efforts to prolong life may not benefit the patient, and to know when not to initiate and when to cease attempts at prolonging life; they are not obliged to try to prolong life at all costs.

When there is disagreement between clinicians and a patient or family about whether a treatment should be continued (or a new treatment started), it may be appropriate to undertake a 'time-limited trial' to assess whether the treatment is beneficial and to help reach consensus. In a time-limited trial, the parties involved agree to a trial of treatment over a specified period, with agreed outcome measures, while the patient is monitored. At the end of this period, treatment is usually continued if the patient has improved, or is withdrawn if the patient has not benefitted or has deteriorated. Examples are a trial of reduction in opioid analgesia to ascertain whether sedation is mainly due to opioids or the dying process itself (ie is the patient more alert and is analgesia adequate with a lower dose of opioid), or a trial of subcutaneous fluids to find out if this improves patient comfort.

Withdrawing or withholding treatment may apply to a wide range of medical interventions. Medically assisted nutrition and hydration and resuscitation are discussed below. Withdrawal of drug therapy is discussed in [Managing comorbidities and deprescribing in palliative care](#). Withdrawal of ventilatory support and renal dialysis, and deactivation of implantable cardiac devices, is discussed in [Palliative care for life-limiting illnesses other than cancer](#).

Medically assisted nutrition and hydration

Medically assisted nutrition and hydration

Conflict may arise when decisions need to be made about starting or stopping medically assisted nutrition and hydration such as parenteral fluids, total parenteral nutrition or enteral feeding via a tube. From an ethical and legal perspective, medically assisted nutrition and hydration are considered to be medical treatments; there is no medical, ethical or legal requirement for these to be administered to a patient who is dying unless they actually provide relief of symptoms.

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There is little evidence that medically assisted nutrition or hydration are beneficial in the last days of life; however, the emotional, cultural and social factors related to providing nourishment are important, and many families (and some healthcare providers) find it distressing to withhold or withdraw such treatment.

A family may ask for medically assisted nutrition or hydration to be started for a patient who is dying and can no longer eat or drink. Alternatively, they may be reluctant to withdraw such treatment even when the healthcare provider believes it is no longer beneficial. It is important to explain to the family that medically assisted nutrition or hydration is unlikely to be beneficial when the patient is dying, and may cause problems that can make the patient uncomfortable and prolong their suffering (for details, see [Nutrition and fluids](#) in the Terminal care topic). If family members and carers feel they are neglecting their role and duty to provide nourishment, suggest other ways for them to contribute to care. Some cultural and religious groups have strong beliefs on this issue, and advice and support from someone of the same culture or faith (eg pastoral care worker, spiritual leader) may be helpful.

Occasionally, a time-limited trial may be appropriate when there is ongoing disagreement about withholding or withdrawing medically assisted nutrition or hydration; for information on time-limited trials, see [Withdrawing or withholding treatment in palliative care](#).

Resuscitation planning

Resuscitation planning

For a patient in the early stage of their disease, active interventions such as admission to an intensive care unit, ventilatory support or cardiopulmonary resuscitation (CPR) may be appropriate in the event of a rapid deterioration in their condition. However, as the patient approaches the end of their life, these measures are unlikely to be beneficial, and the outcome of CPR in particular is universally poor.

It is important to try to discuss with patients the realistic options for healthcare interventions that might be possible for them, including resuscitation measures. For some patients and in some cultures it may be more appropriate to discuss these issues with someone other than the patient—generally an open enquiry about who is the best person to speak to will clarify the situation. Some patients do not wish to discuss these issues at all. In this situation, there needs to be a balance between respecting a patient's choice and considering the impact on healthcare providers if the goals of care are uncertain, as well as difficulties that may arise for the family if these matters are left unattended.

Conversations about resuscitation and related issues can be difficult for healthcare providers and patients and their families, and need to be managed sensitively; however, this is not a valid reason to avoid them (for guidance, see [Advance care planning conversations](#)). These discussions are particularly important when patients are admitted to hospital. Healthcare providers should be aware of cultural sensitivities when raising the subject of resuscitation, for example Aboriginal and Torres Strait Islander patients may not wish to discuss resuscitation, or may wish to discuss it only once and not be asked about it each time they are admitted to a hospital.

Some questions that may be used to raise these issues are: 'It is important for me to understand what you are hoping to achieve from this period in hospital. Have you ever discussed which interventions and medical treatments you would like to have, and which you would not like to have? Is it alright for me to ask you about these things? Is there anyone else you would like me to talk to about these things?' or 'Have you ever discussed the extent of treatment that might be appropriate and acceptable for you with your local doctor, or your family? I'm talking about things like taking over your breathing if it failed, and trying to restart your heart if it was not working properly, ie cardiopulmonary resuscitation (CPR). Some people would like to be considered for any possible medical intervention, whereas others decide that they no longer want interventions such as CPR, or going to an intensive care unit, having surgery or receiving intravenous antibiotics. How do you feel about these things?'

After these discussions, document the agreed goals of care and specific resuscitation measures that will and will not be provided for a patient when they deteriorate; this information should be recorded in medical case notes, notes kept in the patient's home, and as part of an advance care plan. In the case that an ambulance is called, it is particularly important that paramedics have access to such documentation to ensure that CPR or other resuscitation measures are not initiated inappropriately (see [Communication of an advance care plan](#)). Families and carers should also be aware of the patient's wishes in relation to resuscitation measures.

Jurisdictions and healthcare services often have standard processes to ascertain and document whether acute resuscitation is appropriate for patients who are in hospital; for information about advance care planning in the hospital setting, see [Hospitals](#).

Sedation for refractory distress in palliative care

Sedation for refractory distress in palliative care

Sedation for refractory distress, or palliative sedation, is the use of sedation for a patient with life-limiting illness to relieve severe symptoms that are resistant to all other treatments, usually until death occurs. The intention of palliative sedation is to relieve intolerable symptoms, not to hasten death. It is considered a measure of last resort and is suitable for only a small group of patients. (Note that many patients who are dying need some degree of mild or intermittent sedation to relieve agitation or other symptoms as death approaches; this is not considered to be palliative sedation.)

A decision to prescribe palliative sedation should not be taken lightly, and should be discussed in depth with all of the healthcare providers involved in direct care of the patient. There are many factors to consider when making this decision, including the patient's wishes, their prognosis, and the goals of care. If a patient's symptoms are difficult to control and palliative sedation is being considered, seek specialist palliative care support.

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Situations where palliative sedation is used generally cause some distress or disquiet for both family members and healthcare providers. Careful explanation and reassurance is important for the family, and members of the healthcare team may need extra support.

Healthcare providers have no reason to fear legal sanction when they provide adequate relief of pain and other distressing symptoms if the prevailing standards of palliative care are adhered to, and the decision is documented; they should be comfortable giving medication doses that are sufficient to achieve effective relief of the patient's symptoms. See also [Last days of life: sedation for refractory distress](#).

Requests for assistance to die

Requests for assistance to die

It is not uncommon for palliative care patients to have a fluctuating will to live, and to say things like 'I wish it was all over' or 'I wish I wasn't here'. Family members may voice similar sentiments, or ask a healthcare provider 'to just hurry it up'. These sorts of statements are often a way of expressing how difficult the situation is for a patient and their family, and may be a cry for support and the need to talk about their distress, rather than actually wanting to hasten death. For information about providing psychosocial support for patients who are distressed, see [Distress in palliative care](#) and for information about supporting families and carers, see [Support for families and carers in palliative care](#).

In contrast, a small number of patients have a persistent desire to hasten their death. They talk and think about dying regularly over a prolonged period, and may ask their healthcare provider for assistance to die. These emotions are perfectly understandable when a patient is facing death, and healthcare providers should not be alarmed when faced with such requests. Clarify who is making the request and explore the reasoning behind it (eg it may be that the family is suffering, and the patient is making the request to try and protect the family).

Many patients fear being in a situation where they have little or no control, or face loss of dignity. They often have strong concerns about uncontrolled symptoms (particularly pain) and suffering without adequate support. It is important to manage the symptoms that are causing concern, and to reassure the patient that ongoing support will be provided. Alleviating suffering and ensuring the patient is able to maintain their dignity and some sense of control as their life comes to an end is the essence of good palliative care.

Alleviating suffering and ensuring a patient is able to maintain their dignity and some sense of control as their life comes to an end is the essence of good palliative care.

It is also important to assess a person's mental health and look for conditions that may be treatable, such as depression. It can be difficult to distinguish between sadness that is realistic when facing the end of life, a situational or reactive depression, and a severe depressive illness; seek specialist palliative care advice if necessary. For further information, see [Depression in palliative care](#) and [Suicidal ideation in palliative care](#).

In some cases, a sensitive and open conversation about a person's particular fears, how the future may unfold, and the realistic supports available, may be sufficient to reassure the patient and their family. These conversations can be challenging and require good communication skills.

In other cases, the most appropriate course of action may be to withdraw life-prolonging treatment and allow nature to take its course. Doctors have a duty to understand the limits of medicine to prolong life, and that at times withdrawal of life-prolonging treatment may be in the best interests of the patient; this is not euthanasia (see [Withdrawing or withholding treatment in palliative care](#)).

Some patients—even those with good control of physical symptoms—would rather die and cannot understand why they should not have the right to make this choice, ie access to voluntary euthanasia or physician-assisted suicide. Healthcare providers will generally find that it is helpful in this situation to make a nonjudgmental and open offer of continuing palliative care support (including emotional support), to reiterate the benefits of palliative care, and to reassure the patient that they will continue to be cared for until they die; this may be sufficient to address the patient's concerns.

Euthanasia is a complex issue and there are diverse views on it in society. Some healthcare professional associations and peak bodies have position statements on euthanasia and related issues; healthcare providers should be aware of the views of their own professional association(s).

Privacy and confidentiality in palliative care

Privacy and confidentiality in palliative care

Although the WHO definition of palliative care considers a patient and their family to be a unit of care, it is important not to breach the confidentiality that exists between a healthcare provider and a patient. Healthcare providers looking after patients at the end of life are often given access to sensitive personal information about patients and their families, including their social situation. While confidentiality in health care is well established and understood, multidisciplinary teamwork sometimes includes discussion of personal matters related to a patient and/or their family, and occasionally this may cause offence or difficulty with the parties involved.

Before divulging sensitive information, individual team members may need to check with the patient or family members whether such information can be shared. They should also consider whether it is in the patient's interest to reveal such information, and whether disclosure is necessary for effective clinical work or for the safety of the patient, family, carer or healthcare provider. If there is any doubt, it can be helpful to discuss the matter confidentially with a trusted senior colleague or supervisor.

Participation in research for palliative care patients

Participation in research for palliative care patients

There is a large and increasing body of knowledge about patient management in palliative care as a result of recent research, and there are increasing opportunities for patients to participate in clinical trials. There may be benefits for a patient and their family in taking part in a trial (eg access to newer treatments, improved symptom control), but even when they are unlikely to benefit, some patients wish to participate in research for altruistic reasons. Similarly, parents of children with life-limiting illnesses and adolescents may also wish to be involved in research. Clinicians should be careful not to create unnecessary barriers to participation in research if the patient or parents of a child wish to participate.

Researchers should be aware that palliative care patients may be vulnerable and have limited time; they must ensure they do not waste the time that is offered freely by patients. Studies should be well designed and structured to answer the research question, and the results published to disseminate this valuable information as widely as possible.

Researchers need to be thoughtful about how they approach patients and their families to participate in research—they need to strike a balance between providing adequate information to ensure a patient understands the study, while trying to avoid lengthy and burdensome consent forms. Particularly in the inpatient setting, researchers should be mindful of the burden of participation and limit the number of trials in which any patient is asked to participate.

Patients who do not wish to be involved in clinical trials may fear being abandoned by their treating team; they should be reassured that this will not happen.

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[\[X\] Close](#)

Overview of loss, grief and bereavement

Overview of loss, grief and bereavement

Loss is a universal part of the experience of life-limiting illness, as patients and their families, carers and friends adapt to the many changes in their lives. Just as a patient may face a great burden of change and loss, so too can family and friends—their loss may include that of parent, partner, confidante or best friend. These close relationships involve strong bonds of affection, and the loss or threatened loss of these generates grief and mourning.

‘Bereavement’ refers to the state of loss due to death, while ‘grief’ refers to the feelings or reactions experienced in response to loss, and ‘mourning’ is the process of adaptation to loss. ‘Anticipatory grief’ is often used to describe the distress, anxiety and related behaviours experienced in response to threatened loss and awareness of impending death; it may begin when a patient is diagnosed with a life-limiting illness.

Healthcare providers can play an important role by recognising the needs of bereaved family members and carers, and providing support to them. Good quality bereavement care includes communicating with the family and providing support to them when the patient is dying; this can impact positively on bereavement after the patient has died. Formal bereavement support programs are a key component of most specialist palliative care services.

For information about supporting families and carers looking after a person with life-limiting illness, see [Support for families and carers in palliative care](#).

Features of grief

Features of grief

Normal grief

Normal grief

People may express grief in many ways, but it is often characterised by:

- separation distress—preoccupation with thoughts or images of the deceased, especially yearning for the deceased
- intense sadness, tearfulness
- loss of usual levels of activity and capacity to undertake normal tasks
- withdrawal from others
- physical symptoms, including fatigue and loss of appetite
- sleep disturbance
- fleeting images and hallucinations involving the deceased
- anxiety about the future.

Symptoms of grief usually fluctuate, and gradually decline over weeks to months as a person progressively becomes involved in their usual interests and responsibilities; however, symptoms may recur at times such as anniversary dates. The time frame of ‘normal grief’ is debated, and can reflect cultural and social factors; in general, symptoms have started to improve by 6 months following the death.

Parents of a child who has died often experience grief for much longer, often measured in years. Many parents will never stop their grieving, but rather will integrate the loss and memory of their child into their

lives, and maintain a helpful connection with their child through writing, establishing memorials, rituals and prayer.

Complicated grief

Complicated grief

Complicated grief produces severe and persistent symptoms of emotional distress that impact on day-to-day functioning for a prolonged period. Be alert to the following features in a bereaved person, which indicate the possibility of complicated grief:

- intense yearning for the deceased
- feelings of purposelessness and futility
- numbness, detachment, or absence of emotional response to other aspects of life
- distressing intrusive images or memories about the death, often related to the circumstance of death (indicative of a posttraumatic stress response)
- excessive guilt, remorse and self-reproach, especially relating to events surrounding the death or the deceased
- sense of life being empty or meaningless without the deceased
- excessive irritability, bitterness or anger.

A common form of complicated grief is chronic grief, which does not ease with the passage of time.

When severe symptoms of grief are evident more than a few months after the death, assess the person for the possibility of bereavement-related depression, anxiety or other psychiatric condition (see [Depression and other complications](#)). Consider referral for specialist bereavement counselling.

Risk factors for complicated grief

Personal factors that are associated with an increased risk of complicated grief, and potentially the need for clinical intervention, include:

- limited social support (including practical and emotional support for grief)
- previous difficulties coping with loss, or past traumatic loss
- multiple losses over time
- a history of psychiatric illness, alcohol and other drug problems, or significant physical illness.

Complicated grief is more likely when:

- the patient had a traumatic death (eg severe uncontrolled symptoms, distress) or illness (eg disfiguring disease or treatment)
- the death was unexpected or sudden (even in the context of advanced illness), or untimely in the life cycle (eg death of a child)
- the death was from a stigmatised condition (eg HIV infection) or suicide, which can erode social support and isolate the bereaved; or when the death is not readily acknowledged by others in the person's social network
- the death followed an extended illness, with associated burdens and adverse personal impacts (eg as might occur in dementia or chronic disability)
- there are concurrent losses and other significant stresses
- the relationship with the deceased was ambivalent, conflicted or overly interdependent
- the family is unsupportive or in conflict.

In a bereaved person with developmental disability or significant disability from chronic psychiatric illness, pay particular attention to monitoring for the risk of complicated grief. It may be expressed in behavioural changes or, in the case of chronic psychiatric illness, relapse of the pre-existing condition.

Depression and other complications

Depression, anxiety, and alcohol and other drug problems are common in the first 12 months following bereavement. Bereavement may trigger the first occurrence of such a condition, or a recurrence of previous psychiatric illness.

It can be difficult to differentiate grief from depression, and consequently depression may go unrecognised. Healthcare providers should be alert to the presence of a depressive disorder in a bereaved person. Features include a persistent marked loss of interest and an unchanging mood of depression for an extended period, with difficulty in experiencing any pleasure or temporary relief from this mood (anhedonia). Recollections of the deceased are usually predominantly sad, distressing or coloured by a sense of personal failure or worthlessness, with a loss of hope for one's own future. The person may feel excessive guilt and self-remorse, often focusing on perceived failings in the relationship with the deceased, or in the care provided, and the presence of suicidal thoughts. Antidepressant therapy is sometimes warranted in patients experiencing these symptoms.

Suicidal thoughts accompanied by a desire to be reunited with the deceased, and a belief that one will be reunited with the deceased by dying oneself, suggest a high risk of suicide that warrants urgent assessment and clinical intervention—seek specialist psychiatric advice. For information about assessing suicide risk, see [Therapeutic Guidelines: Psychotropic](#).

Healthcare providers should also be alert to persistent behavioural signs of a depressive disorder: marked withdrawal from others, poor self-care, limited range of emotional expression, or profound sadness, agitation, anxiety or irritability. Persistent unexplained physical symptoms (eg unexplained or vague pains, weight loss, appetite disturbance) can also indicate a depressive disorder.

A bereavement-related depression or anxiety disorder should be considered if symptoms have a significant effect on a person's functioning, and continue beyond a few months after the death. For further information, see [Depression in adults](#) and [Anxiety and associated disorders](#) in the Psychotropic guidelines.

Bereavement support for adults

Bereavement support for adults

Bereavement-related care before a patient's death

Bereavement-related care before a patient's death

All members of the healthcare team have a role in providing practical and emotional support for grieving family members and carers before a patient has died. Supporting them to cope with and adapt to the impending loss can improve bereavement outcomes. Good communication is essential—keep families and carers informed about what is happening and what to expect as the patient's illness progresses, and involve them in key decisions when appropriate.

Explain to families and carers that they are likely to experience intense emotions after the patient has died, and while this will be difficult, reassure them that this is a normal response to the death of someone close. Inform them about support available, and where they can get information about grief, coping and practical issues. Consider referring those at increased risk of complicated grief for additional support, preferably to someone who can continue to provide support after the patient's death.

Disagreement in the family about how care should be provided, and difficulties in making decisions about withdrawal of treatment, can impact negatively on family members after patient death. The clinician can support families in these situations by addressing their concerns, and providing information and clear recommendations. Family members and carers should be involved in decision-making when appropriate; however, they should not be burdened by the feeling that they need to make medical decisions. They should be given adequate information, and their views and needs should be considered, but the final responsibility for medical decisions rests with the clinician.

During the dying process, support family members and carers to participate in the care of the patient as appropriate and if they wish to do so; providing care in this way can be beneficial and help them feel

involved.

If possible, letting the family know when the patient's death is imminent allows them to prepare psychologically and to make practical arrangements. An awareness of the cultural beliefs of the patient and family is important at this time (see [Cultural issues in palliative care](#)). Many families wish to be present at the time of death—tell them that this can be difficult to predict and that despite their efforts to be present it may not always occur. This is especially so in hospitals, when families try to balance rest and respite with the need to be present at the bedside.

For further information about explaining to families what is happening and helping them prepare for the patient's death, see [Terminal care: care in the last days of life](#).

Bereavement care after a patient's death

Bereavement care after a patient's death

After a patient's death, bereavement follow-up may include expressing condolences, enquiring about coping following the death, offering and providing support to the family and carer if needed, and liaising with relevant cultural or religious supports. Specialist palliative care services sometimes conduct memorial services. It may also be appropriate to send a card to the family at significant dates (eg anniversary of the death).

There may be occasions when a clinician considers it appropriate to attend a patient's funeral; for example, when they have had a longstanding connection with the patient, family or community. Attendance at a patient's funeral should not be considered essential practice, but should be guided by what is in the best interests of the bereaved family.

While there is limited evidence about best practice in bereavement care, some form of follow-up of the main carer may be of value, particularly in those at risk of [complicated grief](#). Opinion is divided about whether this should be done in a structured way, or as opportunities arise (eg as part of a general consultation). A review at 3 to 6 weeks after the death, and a follow-up assessment 6 months after the death is recommended, but the circumstances around each death should be considered and managed individually.

Family members and carers may be followed up by a general practitioner, a bereavement counsellor or a member of the healthcare team most closely connected with the family; a community nurse, volunteer or other support person may assist. Some bereaved people appreciate ongoing support from a member of the healthcare team who was involved in the care of the patient who died, while others prefer to receive support from someone who has not previously been involved.

Follow-up provides an opportunity to review medical care and to consider the coping responses and support needs of the bereaved person. Risk factors for complicated grief can be reviewed and the need for closer follow-up or intervention considered. For advice on counselling bereaved family members and carers, see [Figure 10.11](#).

People with developmental disability or significant disability from chronic psychiatric illness often have unmet bereavement support needs. It is important to tailor communication with them appropriately, and to coordinate support with other health services or community agencies, according to need.

Figure 10.11 Counselling bereaved family members and carers

When counselling bereaved family members and carers it may be helpful to:

- acknowledge their loss and related emotions
- review the circumstances of the death and history of the relationship with the deceased
- explore current symptoms of grief and coping (including asking about alcohol or drug use), and past responses to loss
- provide information and reassurance about [normal grief](#)
- ask about other current stressors (eg other losses, caregiving responsibilities, financial strain)
- ask about dominant concerns for themselves or others (eg children)

- offer further contact to review progress over time.

Role of the general practitioner in bereavement care

Role of the general practitioner in bereavement care

It is common for the bereaved to seek help from their general practitioner (GP), who can provide a critically important source of support and clinical assistance through periodic review. GPs should be aware that a bereaved person may present with physical symptoms (or other presentations), rather than obvious symptoms of grief; they should therefore enquire about symptoms of grief and be alert for symptoms of complicated grief (see [Features of grief](#)). Community-based palliative care services often have counselling and volunteer staff who can assist the GP with bereavement care if necessary.

Further information on how the GP can assist the bereaved, including tools and resources, is available on the [CareSearch website](#).

Referral for additional bereavement support

Referral for additional bereavement support

There are a number of options for referral for people with complicated grief, including:

- specialist bereavement counsellors
- specialist palliative care services usually offer bereavement follow-up, often based on a risk assessment; they may accept referrals from other sources
- other mental health professionals.

Consider seeking specialist advice when there is concern about complicated grief, depression, or persistent difficulties despite supportive counselling. Psychiatric consultation should be sought for a person experiencing suicidal ideation; see [Depression and other complications](#).

Bereavement support for children

Bereavement support for children

Talking about death and dying with children

Talking about death and dying with children

Children need open and natural communication about illness, death and dying. Concepts should be presented in an age-appropriate manner, recognising that children's understanding of what death means develops mostly between ages 6 and 8 years (see [Table 10.1](#)). There is wide variation in children's understanding, so it is essential to assess the child's level of comprehension before providing information to them. Ask the child what they already know, and make them feel comfortable to ask questions. Start by giving less information, and provide information as clearly as possible, as appropriate for that child. For children with developmental delay, disability or autism spectrum disorder, adapt the information if needed.

Encourage the family to use simple language to explain honestly to the child what is happening. Suggest they consider including children in visits to the dying person and attendance at the funeral and anniversary rituals —this normalises the experience of death and promotes the family as the continuing supportive environment. They should prepare the child for what they might see, hear and feel during visits or at the funeral, and later for the distress they may feel at significant times such as anniversaries. See also [Advice for families about children visiting a person who is dying](#).

Advice for families about children visiting a person who is dying

Advice for families about children visiting a person who is dying

The following information may be helpful to families when considering children visiting a person who is dying, particularly in a hospital or palliative care unit. Advice may vary for different age groups.

- Suggest to the parents that it would help the child to see the person who is dying, particularly if the child requests it; what they imagine may be more traumatic than the reality. Adolescents in particular may be trying to process what is happening to their parent, grandparent, sibling etc.
- Parents should follow the child's lead—if the child wants to visit, this should be honoured if possible (keep in mind that the dying person might not want the child to visit). If the child does not want to visit, this too should be honoured. It may be helpful to explore the reasons why they do not want to visit.
- It can be helpful to provide information to the child just before the visit; for example, warn them that the person may be very sleepy or have other symptoms (eg pain, shortness of breath), or their appearance may have changed. Answering questions or concerns is important.
- Parents may wish to consider having another family member (eg grandparent, aunt, uncle) or good friend present to support the child (friends of the family can be helpful because they may be less emotionally involved).
- Explain to parents how children might behave when visiting someone in hospital or a palliative care unit. Young children may want to engage in physical play and only be able to spend a short period in a confined room; this is normal. They may need to bring something into the room to allow them to disengage from the emotional intensity (eg colouring-in for young children, electronic devices for older children).
- If the child does not visit the dying person, it is important to involve them in other aspects of the family's grieving (eg providing updates on how the patient is going, attending the funeral). The child may feel more comfortable using recording devices or video chat (eg Skype) to connect with the dying person. They might feel guilty about not visiting, and giving them an alternative, less traumatic way to be part of the process can reduce their guilt.
- Let parents know that support from staff may be available when children are visiting a hospital or palliative care unit (eg from a social worker, psychologist, nurse). Prior arrangements may need to be made.

Children's responses to death

Children's responses to death

Children can display a range of bereavement responses including sadness, fear, guilt, insecurity and behavioural problems. Responses may be based on a child's limited understanding of death (see [Table 10.1](#)). Children's grieving can also be influenced by family dynamics, the support available, the nature of the illness and death, and reactions of those around them. Some children experience delayed bereavement reactions that manifest at other important times in their life, for example when changing schools or starting high school.

Reactions of preschoolers to someone close to them dying may include rapidly alternating between crying and playing happily, or they may hardly seem to react at all. They may experience separation anxiety, irritability, withdrawal or developmental regression (eg bed wetting, sleeping difficulties). Young children may be bewildered and physically search for the deceased, and incorporate death and grief into play activities (eg re-enacting the person's death, playing 'funerals').

School-age children may react with denial, sadness, withdrawal, guilt, anger or aggressive or oppositional behaviour, or there may be no apparent reaction. They can experience disturbed sleep or appetite, deterioration in school performance, or may refuse to go to school. Older children may be concerned about what their peers think, and be anxious about being seen as different. Some children may wish to die to be reunited with the dead person.

Adolescents are able to reason and conceptualise abstract ideas, and they express their grief in similar ways to adults. However, notions of omnipotence and immortality during this phase of development make death hard to accept. Adolescents may become oppositional and impulsive, and engage in risk-taking behaviour.

Questions are more likely to focus on spiritual issues. They often seek support from peers rather than family members; peer support groups may help.

Some children have a **greater risk of developing complicated grief or depression** following the death of someone close. In addition to the risk factors for complicated grief for adults, risk factors in children are:

- death of a parent or close relative
- bereavement when younger than 5 years of age
- bereavement in adolescence
- exclusion from seeing the dying person or attending the funeral
- lack of access to truthful information
- unstable home environment
- psychiatric illness in a surviving parent
- belief that the deceased sibling was the parents' favoured child.

Table 10.1 Children's understanding of the concepts of death

Concept and average age it is understood	Consequences of incomplete understanding of the concept
separation —the deceased are located separately to the living (age 5)	
causality —death is caused by illness, age, trauma (age 6)	child may believe they have caused death through bad behaviour or thoughts, and feel excessive guilt
irreversibility —the dead do not physically return (age 6)	child expects deceased to return as if from a trip; they may not detach personal ties to deceased
cessation of bodily functions —the dead cannot move, breathe (age 6)	child may be preoccupied with physical suffering of deceased, eg worries about buried person being cold, hungry or in pain
universality —all living things ultimately die (age 7)	child may see self and significant others as immortal; death may be viewed as punishment or the result of bad behaviour or thoughts
insensitivity —the dead cannot feel pain, fear (age 8)	child may be preoccupied with psychological experience of the deceased, eg worries that they may be suffering or feeling sad

Support for bereaved children

Support for bereaved children

After a person has died, providing children with an understanding of the death minimises the potential for them to blame themselves. Use the word 'dead', rather than 'lost' or a 'long sleep', to avoid confusion and anxiety. Parents should address any concerns related to an incomplete understanding of death (eg 'Is it my fault?', 'Will it happen to me?', 'Who will take care of me?'), and reassure the child that their life will go on. Explaining that the doctors and nurses did their best to try and make the person better, but weren't able to, helps to maintain the child's confidence in the health system if someone else gets sick. Continue with normal routines and discipline as much as possible; children in distress need the reassurance of structure and limits.

Allow children to search for the dead person if they wish to—physically searching in places previously frequented by the person is a way of testing and affirming reality. Parents (and significant carers) should express sadness openly with children, and may want to share age-appropriate books about grief and loss with them. They should allocate special time for the child each day (this does not necessarily need to be for talking), and allow time for the child to play with peers, affirming that it is acceptable to have fun. Some children may express their feelings through play, music or art, and may benefit from play-based, music or art therapy. It may be helpful to recruit family, friends or teachers to help, and to inform the child's school or kindergarten about the death.

Parents (or significant carers) can help children create memories of the deceased, eg stories, photos, drawings. Adjusting to the death does not necessarily require letting go, and bereaved children (and adults) often maintain a connection with the dead person by constructing a new relationship that is maintained by reminiscing, treasuring belongings, and writing to or talking with the deceased. This process is referred to as 'continuing bonds'.

Parents who feel unable to adequately attend to their child while they are grieving may delegate this responsibility to another trusted adult (eg it may be that one of the child's parents has died, or occasionally both parents).

Most children adjust to the death of someone close without the need for counselling. Features that may require intervention are outlined in [Figure 10.12](#). If these are present, consider referring the child to a specialist centre for counselling. As with adults, there are a number of options:

- specialist children's bereavement counsellors
- specialist paediatric palliative care services or hospices usually offer bereavement follow-up, often based on a risk assessment; they may accept referrals from other sources
- community-based organisations offering group programs
- child and youth mental health professionals.

For specific information on supporting a child whose sibling has died, see [Siblings](#).

Figure 10.12 Features requiring intervention in bereaved children

Consider obtaining advice about further intervention for bereaved children who display the following features:

- persistent aggression, oppositional behaviour or conduct disorder
- persistent failure to acknowledge the death
- obvious and persistent deterioration in school performance
- feelings of worthlessness
- anhedonia—withdrawal from and lack of interest in friends and activities previously enjoyed
- disturbed sleep or frequent nightmares
- persistent unexplained physical symptoms (eg abdominal pain, headache, limb weakness)
- anorexia and weight loss; often this improves with time but requires close follow-up
- prolonged negative thinking about the future
- suicidal or self-harming ideation or behaviour (requires immediate attention).

Bereavement support for families whose child has died

Bereavement support for families whose child has died

Bereavement support for the parents and families of a child who has died is an integral part of paediatric palliative care. The general principles of bereavement support apply (see [Bereavement support for adults](#), [Bereavement support for children](#)); additional considerations are discussed below.

A continuum of care can be helpful to families, when the healthcare provider or team who provided support to the family while the child was ill continues to do so after the child's death. Feedback from parents suggests that the most comforting and responsive bereavement care is built on the relationships with healthcare providers prior to a child's death. However, services that only provide bereavement support after a child's death also play a role—some people find it beneficial to speak to a bereavement counsellor who is new to the situation. Families who have had conflict or other challenges with their healthcare team may also prefer to see a new counsellor. Families whose child died suddenly (eg from trauma or infection) may not be linked to a healthcare team as the death was not expected.

Many children's hospitals and hospices have bereavement support programs that offer ongoing contact with the family. Bereavement support may be coordinated through one of these programs, or by the family's general practitioner, a community nurse, a social worker or a pastoral care or faith-based worker. All families are different and a flexible approach is required to support those who need or request help. Education about the 'normal' range of grief reactions after the death of a child can be reassuring to the family.

It is important for healthcare providers to make contact with the family after a child has died (eg by telephone or visiting), and offer ongoing support that can be realistically maintained. Healthcare providers (and other people) often feel apprehensive about the level of distress they may encounter when first making contact with

a grieving family after the death of a child, and don't know what to say or how to help. They may be reassured to know that most families appreciate a phone call from a healthcare provider.

When making a phone call to a grieving family, the following may be helpful:

- Before contacting them, identify the names of the family members, including children (to help to identify who has answered the phone).
- Acknowledge the grief the family is experiencing, and that you are calling at a difficult time.
- Listen actively, answer questions and follow up on any specific requests.
- Some people will not say very much; asking how other family members (by name) are coping can facilitate further conversation.
- Recalling memories or positive experiences with the patient and family can be helpful.
- Offer support if needed, but seek consent from family members before involving them in a formal bereavement program.
- If unable to make contact during the day, consider calling in the evening, if feasible. Alternatively, leave a message on an answering machine, or send a card or letter.

Many parents find support within their own community, but not everyone has a good support network. Some families appreciate practical support such as assistance with transport, childminding or meals. Support groups can be very helpful—the shared experience of the death of a child builds trust and understanding, and creates bonds that can cut across differences in age, social status, education and religion. It can be helpful to hear others expressing similar thoughts and feelings, and to know they face similar difficulties. Groups may provide support for fathers, mothers, siblings or grandparents.

While the bereavement period is extremely difficult for families, with adequate support many families get through this period without specialist intervention or medications. However, if family members have previously been connected with mental health services, it can be helpful to ensure such support continues.

Siblings

Siblings

The general advice on bereavement support for children applies to siblings, see [Support for bereaved children](#). Additional considerations for children whose sister or brother has died are discussed below.

The best way to support siblings is through their parents. If parents are able to include their children in their experience of loss (eg keeping them involved and informed), and maintain a sense of safety and security in the family, then siblings are likely to cope better. Parents are best placed to answer their children's questions and provide reassurance; in particular it is important to reassure surviving siblings that the parent loves and cares for them equally.

Some parents managing their own grief may find it hard to attend to the needs of their surviving children. If parents are not able to take care of their children for a period, or they are emotionally incapable of giving this kind of attention, a relative may fulfil some of this role.

Most children benefit from meeting with other bereaved siblings. Sibling support groups and activities (eg sibling days, sibling camps) can be helpful. If necessary, general practitioners can refer siblings for age-appropriate counselling and support. Some community organisations specialise in supporting children who have experienced particular forms of grief and loss.

For information about the experience of siblings and how to support them while their sister or brother is alive, see [Support for siblings](#).

Resources for bereaved people

Resources for bereaved people

Australian Centre for Grief and Bereavement—Grief information sheets for adults and children [[URL](#)].

Calvary Health Care—Bereavement support across cultures [\[URL\]](#).

CareSearch—Bereavement, loss and grief [\[URL\]](#).

National Association for Loss and Grief—Brochures about grief [\[URL\]](#).

Palliative Care Australia—Information about grief and links to telephone counselling [\[URL\]](#).

Solace Australia—Group support programs for people whose partner has died [\[URL\]](#).

For children, and families whose child has died

For children, and families whose child has died

Some children's hospitals and hospices offer bereavement services; hospital-based social work departments or paediatric palliative care services can provide advice about services available in each state.

The National Centre for Childhood Grief [\[URL\]](#).

CanTeen and Redkite offer services for bereaved adolescents whose sibling has died from cancer, including phone support (from a social worker).

Books on grief and loss

After the loss of a child: a resource for parents of children in palliative care. Melbourne, VIC: Australian Centre for Grief and Bereavement; 2015. [\[URL\]](#).

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Introduction to palliative care for children

Introduction to palliative care for children

Paediatric palliative care is a holistic approach to caring for children with life-limiting illness, which aims to enhance the quality of life for the child and provide support to the child's family. Paediatric palliative care is often provided alongside curative or disease-modifying treatment.

The following definition of palliative care appropriate for children and their families has been adapted from the World Health Organization definition [\[Note 1\]](#):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when a life-limiting illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Healthcare providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources. It can be successfully implemented even if resources are limited.
- It can be provided in hospitals, community-based health services or in the child's home.

Many of the principles and the philosophy of adult palliative care also apply to children. Issues specific to paediatric palliative care are considered in this section.

Bereavement support for families whose child has died is a key component of paediatric palliative care.

The principles of supporting healthcare providers working in paediatric palliative care are similar to those for healthcare providers who care for adults; see [Caring for dying patients: impact on healthcare providers](#).

Note 1: World Health Organization definition of palliative care [\[URL\]](#).

Which children benefit from palliative care?

Which children benefit from palliative care?

All children with a life-limiting illness will benefit from a palliative approach to their care. In some situations, the child's general practitioner or paediatrician may be able to sufficiently support the child and family; however, access to a specialist paediatric palliative care service should be available to all children in Australia.

There are over 400 life-limiting conditions of childhood, affecting neonates through to adolescents and young adults. Any organ system can be affected, and most paediatric subspecialties have a cohort of patients requiring palliative care. Some conditions are associated with a gradual deterioration in function that occurs over a number of years, with those affected becoming increasingly dependent on their parents and carers.

More than half of the diagnoses in children with life-limiting illnesses are of nonmalignant conditions.

There are four categories of life-limiting illness in paediatric palliative care:

- Conditions for which curative treatment may be feasible, but can fail (eg some metastatic or relapsed cancers, end-stage organ failure when transplantation is not an option).

- Conditions that are progressive and not curable, but can be managed with disease-modifying therapies (eg cystic fibrosis, Duchenne muscular dystrophy).
- Conditions for which only supportive treatment options are available, and management is palliative from either birth or the time of diagnosis (eg trisomy 18, Batten disease, mucopolysaccharidoses).
- Nonprogressive conditions and disabilities (eg severe cerebral palsy). Children in this category are at risk of death from complications such as intractable seizures or respiratory problems.

Caring for a child with a life-limiting illness: impact on the family

Caring for a child with a life-limiting illness: impact on the family

Caring for a child with a life-limiting illness is associated with immense grief and suffering, and is one of the most difficult situations families can face. Parents may feel a sense of failure at not being able to protect their child from illness, suffering and death. Those caring for a child who is debilitated for a long period may experience chronic sorrow and an increasing burden of care. Even when parents have a thorough understanding of their child's condition and prognosis, and have been preparing for the death of their child for a long time, they can still feel numbness, shock and disbelief when the child dies.

Grandparents may be a significant support, but they can also be greatly affected as they experience sadness and grief for both their child and grandchild, and other family members.

Parents of children with a genetic condition often experience anger and guilt, and feel anxious about the risk to their other children. Genetic conditions can also have a significant emotional impact on younger siblings—not only do they face their sister or brother's illness and deterioration, but they may face the illness themselves in future.

It can be difficult for parents to share their thoughts and feelings with those around them, or when they do, others may not fully understand or validate their experience. They may feel reassured to know other families have experienced similar difficulties.

Families often have fears and concerns about what will happen as their child's condition deteriorates and death approaches. While healthcare providers may feel a sense of failure when a child's illness is no longer curable, they can help to alleviate the child and family's suffering, and reassure them that support is available.

Healthcare providers can help families to maintain hope. Even parents who appear to 'accept' that their child is dying may privately hold on to the hope that a miracle will occur or that the doctors have 'got it wrong'. Despite expectations of a poor outcome, there can be considerable prognostic uncertainty and some children live for longer than expected. It is important to respect and facilitate the family's hopes by using a 'hope for the best, prepare for the worst' approach. As the child's condition deteriorates, parents' hopes may change; for example, hope for a cure evolves into hope for a pain-free and dignified death. In the perinatal setting, parents may modify their hopes from having a healthy baby, to having time to spend with the baby or holding a live baby.

Despite the sadness and challenges associated with childhood life-limiting illness, many children and parents strive to live life fully; for example, by attending school, going on holidays together and engaging in hobbies and other activities. There is often a great sense of love and meaning when family life is focused on the care of the affected child and their siblings, and this can provide some counterbalance to witnessing the decline and death of the child.

Paediatric palliative care: introducing a palliative approach to care

Paediatric palliative care: introducing a palliative approach to care

Factors that influence the introduction of a palliative approach to care in a child include the nature of the underlying condition and its expected disease trajectory, the clinical assessment made by the child's primary paediatrician, the parents' preferences, and the views of the child (if appropriate).

The child's paediatrician is often in the best position to discuss the prognosis and goals of care with the family, including the possible introduction of a palliative approach to care. This can be very difficult, but it is important to start these conversations as early as possible. In perinatal palliative care, these discussions may take place in the maternal–foetal medicine unit before a child is born.

The ‘surprise question’ can be a useful way to consider whether a palliative approach to care is appropriate for a child—‘Would you be surprised if this child were to die in the next 6 to 12 months?’. If the answer is ‘no’, consider referral to a specialist paediatric palliative care service for additional support. Other factors that may trigger referral to a specialist service are a high symptom burden (eg uncontrolled pain, intractable seizures) or complex psychosocial factors. Early referral can be associated with a number of benefits; see [Benefits of early introduction of a palliative approach to care](#).

The nature of a child's condition and the expected disease trajectory may influence the timing of transition to a palliative approach. Many neurodegenerative and metabolic conditions do not have any curative treatment options, and palliative care is provided from diagnosis. For children with malignancies, transition to palliative care may occur when the cancer progresses despite treatment, or there is a relapse; however, this can evolve and change because many children's cancers can be cured even if the disease has relapsed or is widespread. For children with heart failure, transition to a palliative approach may occur when they no longer respond to medical management (eg diuretic therapy) and further surgery or transplantation is not possible. Alternatively, some children may be managed using a palliative approach while they are awaiting heart transplantation.

In many children the process of transition to palliative care is gradual rather than occurring at a specific point in time. The principles of palliative care (eg pain and symptom management, practical and emotional support, spiritual care) can be incorporated into a child's care while treatment is directed towards cure. When curative options no longer exist, disease-modifying therapies may enhance the child's quality of life (eg antibiotics and chest physiotherapy for children with cystic fibrosis). As the child's condition progresses, there is increased emphasis on treatment with palliative intent, while treatment directed towards cure recedes. In the terminal phase of the illness, management is usually directed towards palliation only.

In some cases, referral or transition to palliative care is made despite prognostic uncertainty; a child may benefit from palliative care support (eg pain management, respite) and then subsequently improve and ‘graduate’ from palliative care.

For further information about the introduction of a palliative approach to care, see [Timely introduction of a palliative approach to care](#).

Care during the transition from adolescence to adulthood

Care during the transition from adolescence to adulthood

Increasingly, there are children with life-limiting illnesses who would have died before the age of 18 years in the past, but who are now living to adulthood (eg children with cystic fibrosis or Duchenne muscular dystrophy). This is due to the meticulous care that parents provide, as well as improvements in health care and new technologies. When an adolescent reaches an age at which they need to transition to adult services (often around the age of 16 to 18 years), both healthcare services and community support agencies may change. Adolescents may be referred to an adult specialist palliative care service (if they meet admission criteria) or to another care provider if more appropriate (eg respiratory or other medical specialist, rehabilitation service). Ideally, the young person has an established relationship with their general practitioner, who can play a key role in assisting with the referral and transition to adult services.

Planning for the transition to adult services as early as possible allows time for the young person to establish relationships with their new care providers. Even when receiving adult healthcare services, many patients wish to maintain contact with their paediatrician.

For information about caring for adolescent patients, see [Adolescents](#).

Paediatric palliative care: advance care planning

Paediatric palliative care: advance care planning

Many of the principles of advance care planning for adults are applicable in children (see [Advance care planning](#)); however, there are some notable differences that relate to decision-making and the relevance of legislation. In the paediatric setting, the parent is usually the decision-maker for the child, until the child is competent to make their own decisions (see [Decision-making and the child's autonomy](#)); this includes decisions made about advance care planning. State-based legislation relating to advance care planning usually does not apply to people younger than 18 years, and while advance care planning can still be undertaken for a child, a written plan is not a legally binding document, as it usually is in adults—that is, it is not an ‘advance care directive’ (or similar document known by different names in different jurisdictions).

Advance care planning in paediatric palliative care gives a family time to consider and discuss their child's condition and prognosis, and to explore options, before an acute deterioration in the child's condition. Many families find that it provides peace of mind.

Advance care planning can be a helpful clinical decision-making tool. It usually includes consideration of the goals of care at the end of life (including resuscitation plans), as well as preferences for the location of care, spiritual issues and organ and tissue donation. Nonmedical domains of a child and family's life may also be included, for example schooling, going on a family holiday or reaching an important milestone such as a birthday.

Discussion about advance care planning should focus on a child and family's quality of life, and what is in their best interests. It is helpful to highlight the interventions that are likely to be beneficial (eg supportive care, pain and symptom management), rather than those that will not be provided (eg resuscitation measures). Talking about ‘allowing a natural death’ can help to focus on the activities and interventions that might lead to ‘[dying well](#)’.

Decision-making should include the wishes of the child and the knowledge and expertise of their family and the healthcare team. Younger children may have a view on treatments offered, and their wishes should be taken into consideration even if they are not directly involved in the conversations. Many older children and adolescents have the ability and willingness to be involved in such discussions and should be part of the process. Research has shown that adolescents find it helpful to discuss and document their wishes for care at the end of life; in particular, they value being able to make arrangements for their death and leave messages for their loved ones.

Ideally advance care planning should be undertaken well ahead of time and written into a plan for the family. However, some families are unable to make these difficult decisions; it is important to take a flexible and patient-centred approach on this matter.

Paediatric palliative care: ethical issues and decision-making

Paediatric palliative care: ethical issues and decision-making

Many of the ethical issues in palliative care for adults are also relevant in the paediatric setting (see [Decision-making and ethical challenges in palliative care](#)). However, there are some important additional considerations when the patient is a child, including recognising the best interests of the child, and considering the child's autonomy in relation to decision-making. The ‘[zone of parental discretion](#)’ is a tool that can be helpful when there is disagreement between parents and healthcare providers. Decisions in paediatric palliative care are made in the context of the child's family, including siblings.

Decision-making in paediatric palliative care

Decision-making in paediatric palliative care

Decisions about health care for a child should be made in the child's best interests. Determining the best interests of the child involves weighing the benefits, burdens and risks of treatment, and taking into account the child's prognosis, while trying to achieve the best possible outcomes for the child and their family. The

goals of care may prioritise the child's quality of life over their survival. It can be helpful to consider questions such as 'What is life like for this child?' and 'How does this child feel?'.

Parents and healthcare providers should make these decisions together; the parent bringing a detailed understanding of the child's hopes, wishes, personality and preferences, and the healthcare team sharing experience and knowledge of the available clinical evidence. Whenever possible, the child should be consulted.

Involvement of both parents is important as they may have different perspectives or be separated. Sometimes a parenting order issued by a family court will determine that one parent is the decision-maker, although it remains important to consider the views of the other parent in this situation. In some cases, parents may be unwilling or unable to contribute to the decision-making process, or it may not be appropriate for them to do so. In these cases, a person (or agency) with parental authority based on appointment as a guardian will become the child's decision-maker.

In some circumstances, parents feel they must pursue every possible avenue to prolong their child's life, even when it is clear that the burden will outweigh the benefit. This can lead to conflict with the healthcare team. In such circumstances, it is important to acknowledge the parents' grief and their need to 'do everything', and allow them time to understand the situation and focus attention on the child's best interests.

'What we are trying to do is to help parents see that sometimes, being the very, very best parent—which is what every parent wants to be—does not mean fighting to cure, but fighting to do the best you can for your child's quality of life at this point. It is as though we give people permission to still be a good parent by making a very difficult choice'. (Goldman)

When disagreement between parents and healthcare providers cannot be resolved, the 'zone of parental discretion' can be a useful ethical tool to consider whether the parents' wishes should be accepted. Seeking a second opinion or consulting with a clinical ethics service may also be helpful. Legal intervention is rarely required if these steps are followed.

Zone of parental discretion

Zone of parental discretion

When parents and healthcare providers disagree about a particular treatment for a child and what constitutes the child's best interests, the 'zone of parental discretion' can be a useful ethical tool to consider whether the parents' wishes should be accepted [\[Note 2\]](#) . Parents may refuse medically recommended treatment, or may request (or demand) treatment that is not recommended. The 'zone of parental discretion' focuses on whether the child would be harmed if the parents' wishes were carried out.

If a treatment is expected to produce a very favourable outcome and the parents refuse the recommended treatment, it is likely that a court would mandate that the treatment be given; for example, providing a blood transfusion to a child who is bleeding and the family are Jehovah's Witnesses.

On the other hand, clinicians are not required to offer a treatment that is unlikely to be beneficial, particularly if it is also burdensome or the likelihood of adverse effects is high; for example, if parents ask for mechanical ventilation to be started in a child with a progressive end-stage metabolic or neurological condition. If a court was asked to make a decision on this, they would likely support the clinician's view that this treatment should not be provided.

Between these two scenarios lies the 'zone of parental discretion', where decisions about a child's best interests are uncertain or open to interpretation; for example, treatment to manage symptoms or the use of complementary and alternative therapies at the end of life. The boundary of this zone occurs at the point where significant harm is being done to the child, rather than a treatment being unhelpful or not optimal. When a decision is considered to fall into the 'zone of parental discretion' and the treatment (or nontreatment) requested by the parents is not likely to harm the child, healthcare providers must respect the parents' decision, unless doing so constitutes abuse, neglect or violates the child's rights.

Note 2: Gillam L. The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child. Clinical Ethics 2016;11(1):1–8. [\[URL\]](#)

Decision-making and the child's autonomy

Decision-making and the child's autonomy

Decision-making in paediatric palliative care can be complicated by considerations related to the autonomy of a child.

The capacity to act autonomously evolves as a child grows and develops, and in this way children represent a continuum from the nonverbal infant to the adolescent striving to live independently. Although a young child may not be able to make decisions about major health issues, they can make decisions about certain aspects of their medical care (eg pain control, venipuncture sites), and empowering them to do so can help give them a sense of control. The child's preferences and insights should be actively sought, and used to guide decision-making by others.

Adolescents become more autonomous with an increased ability to make their own decisions as they grow older. While some states have legislation relating to the age at which a minor can consent to medical treatment, in practice there is no fixed age at which a young person is automatically capable of consenting to medical treatment. In common law, the assessment of competence is based upon the young person's ability to demonstrate sufficient maturity and intelligence to fully understand the nature and implications of a proposed treatment; this is known as 'Gillick competence' [\[Note 3\]](#). As a young person's ability to make decisions increases, the parents' right to consent decreases, although there will be a period of overlap.

Note 3: Bird S. Consent to medical treatment: the mature minor. Aust Fam Physician 2011;40(3):159–60. [\[URL\]](#)

Paediatric palliative care: coordination of care

Paediatric palliative care: coordination of care

The coordination of palliative care for a child should take a family-centred approach and empower the family to care for their child. Decisions about care should be made in collaboration with the family and should be consistent with their wishes.

Continuity of care is very important to families.

Continuity of care is very important to families who have a child who is receiving palliative care, including consistency in the approach to care taken by the different healthcare providers involved. This is particularly important when there are changes in the place of care; for example, moving a child from a neonatal unit or hospital to home, or from a tertiary hospital to a metropolitan or regional hospital.

Families often find it helpful to have one point of contact for enquiries during office hours. This person may be known as the care coordinator or key worker, and may be a nurse, social worker, paediatrician or general practitioner. The coordinator liaises with other healthcare providers to address any patient or family concerns, and may adjust the management plan if required. It is helpful to provide the family with a written plan that includes information about any anticipated problems or symptoms, and particularly how to obtain advice or assistance after hours.

For general information about coordination of care and providing palliative care in the community, see [Providing palliative care in the community](#).

Role of the paediatrician and the specialist paediatric palliative care service

Role of the paediatrician and the specialist paediatric palliative care service

A child's general paediatrician (or paediatric subspecialist) is usually the lead clinician in the care of children with life-limiting illnesses. The paediatrician has often known the child and their family since diagnosis and has a good understanding of the child's underlying condition. Paediatricians usually wish to remain closely involved in the care of their patients even as they transition to palliative care; the importance of this continuity of care cannot be overstated.

Specialist paediatric palliative care services generally act in a consultative manner, to support the paediatrician and other members of the healthcare team. They can provide assistance in a range of areas including pain and symptom management, practical supports (eg arranging equipment or respite), emotional and spiritual support, and support when making difficult clinical decisions that impact on a child's quality of life.

Team-based approach

Team-based approach

Caring for a child receiving palliative care often requires input from a cohesive multidisciplinary team, including medical, nursing, allied health and pastoral care providers, and volunteers. Allied health care providers play a particularly important role in paediatric palliative care, providing services such as social work, psychology, physiotherapy, occupational therapy, pharmacy, nutrition, speech pathology and music, art or play therapy. They can improve the child's quality of life by assisting with symptom management and developmental support, and help to normalise the child's experience as much as possible.

Some children will require more than one service or agency to be involved in their care. Multi-agency support can be complicated, and requires clear definition of roles and good communication and collaboration between teams. For example, in regional and rural areas, there may be a team of healthcare providers based in close geographic proximity to the family, in addition to a team at a tertiary children's hospital located in a capital city or major centre (which is usually specialty based). Coordination and collaboration can be maintained by good clinical handover, often using telemedicine.

For more information about the people involved in providing palliative care, see [Who provides palliative care?](#).

Community-based services

Community-based services

Healthcare providers in the community (eg nurses, allied health providers, general practitioners) can provide excellent support for parents who are committed to caring for their child at home. Most parents of young children will not have had any experience caring for a dying person; in addition to providing practical support and care, healthcare providers with palliative care experience can be a comforting and knowledgeable presence through a frightening experience.

Community-based providers may need to liaise with paediatric staff at their local hospital for assistance with issues related to caring for a child (eg developmental issues, obtaining child-sized equipment). Many paediatric wards and children's hospitals have 'hospital in the home' nurses who can provide excellent paediatric care in the home. While some of these nurses have palliative care experience, they often benefit from collaboration with hospital-based palliative care nurses, or community nurses who have palliative care but not necessarily paediatric experience. A flexible approach is required to ensure the child and family's needs are met.

Role of the general practitioner

Role of the general practitioner

General practitioners (GPs) can provide essential medical, practical and emotional support at a local level to a child and their family, both before and after the child's death. GPs may have paediatric patients with complex nonmalignant conditions (eg severe cerebral palsy) who require palliative care support, and occasionally look after children with cancer who require palliative care. In rural and remote communities in particular, the GP is likely to be the main medical support for the child and family.

GPs can help to avoid unplanned visits to hospital for the child by reviewing intercurrent illnesses, providing prescriptions for medications, and providing medical review at home when the child finds it difficult to attend the hospital or clinic, or is receiving care at the end of life.

The GP's role can be enhanced by frequent communication with the paediatric team. Specialist paediatric palliative care services can provide the GP with advice and support as required. In general, a shared approach to care with the paediatric palliative care team is optimal. Case-planning meetings (sometimes using telemedicine) may be useful to define roles and responsibilities.

In addition to providing care for the child, GPs may also understand the healthcare needs of other members of the family, including siblings; this can be particularly helpful when parents and siblings require bereavement support.

For more information about the role of the GP in palliative care, see [Role of the general practitioner](#).

Paediatric palliative care: place of care

Paediatric palliative care: place of care

It is important to support children and parents to be in their preferred place of care whenever possible. Most children have capable and willing parents who are able to care for them throughout their illness. If the parents wish, and with the right supports in place, they can often look after the child at home. However, the situation can be complicated for parents who are separated or divorced, for children in foster care, or when children have complex medical and nursing needs (eg a child with a tracheostomy).

Parents value being able to choose their child's place of care, and they should be aware that they can change their mind at any time. Research shows that when parents are given the option of where to care for their child and plan for the place they will die, they are more likely to feel prepared for the child's end of life and have fewer regrets in the bereavement phase.

For general information about the location of care for palliative care patients, see [Where is palliative care provided?](#).

Home

Home

Advantages of providing palliative care in the home include privacy and the opportunity for siblings and extended family to feel more involved. The child can be nursed in a familiar environment and be surrounded by the possessions and pets they love. Parents will have control over their home and may feel less judged by others. Spiritual and cultural needs can be more easily addressed at home.

Even in children, most symptoms (including severe pain, seizures and respiratory distress) can be adequately managed in the home environment with appropriate planning, expertise and support.

Parents generally assume the role of principal carers and although they often view this as a positive experience, the burden of providing 24-hour care at home can be great (for information about the caregiving role, see [Supporting the principal carer in palliative care](#)). [Respite care](#) can be important in this context.

For further information about home-based palliative care, see [Providing palliative care in the community](#).

Hospital

Hospital

There are a number of situations when a child receiving palliative care may be cared for in hospital. Difficulty in managing symptoms at home may trigger a hospital admission, but once the child is stable the parents will often continue care at home. Sometimes parents prefer hospital care for a longer period because they appreciate the constant nursing care available, and feel they are better able to 'just be the parent'. Hospital care may also be preferred when there is an uncertain prognosis, or to provide disease-modifying treatment or care at the end of life. Parents who are separated or divorced may find that the hospital is neutral ground.

Many children's hospitals and paediatric wards have large single rooms with bathrooms, which give the family privacy and are suitable for palliative care. This space can be personalised with the child's bedding, toys, photos and other special items from home.

The hospital may be the one closest to the child's home, or a tertiary hospital where the child has received much of their care and where the family has established relationships with staff.

Paediatric hospice

Paediatric hospice

There are paediatric hospices in some states in Australia. These facilities have inpatient palliative care beds and provide respite care for children with complex diagnoses and care needs. They also provide an alternative option to families as the place where they would like their child to die. The family may have become familiar with the environment and staff of the hospice during respite admissions, and it may feel like a second home. At other times families may prefer the hospice environment to a hospital because a similar level of health care is available, but with more home-like surroundings. Paediatric hospices may also offer other services such as sibling and family support, and bereavement care.

Respite care

Respite care

Respite care (also known as 'short breaks') plays a particularly important role in paediatric palliative care, providing children and families with additional support at times of need. It complements the care provided by families at home, and may be provided in the home or out of the home.

Respite breaks may include the whole family, providing an opportunity for them to be together while receiving support to care for their child, or they may offer care for the child only. The providers of respite breaks usually offer both medical care and activities and entertainment for children.

Paediatric palliative care: communication and support

Paediatric palliative care: communication and support

Communicating with a child with life-limiting illness

Communicating with a child with life-limiting illness

Children's understanding of illness and death evolves as they grow. The concepts that need to be understood before a child is said to have a complete understanding of death include separation, causality, irreversibility, cessation of bodily functions, universality and insensitivity; for a description of these concepts, and the average age at which they are understood, see [Table 10.1](#).

Three-year-olds are aware of death but think of it as a temporary, reversible state. Most 8- to 9-year-old children have a mature understanding of death. Most 12-year-olds have some understanding of what a dead person looks like. However, there is considerable variation, particularly in younger children, and children may regress at times of extreme stress such as illness and bereavement. It is essential to assess the child's level of understanding and tailor communication accordingly.

It is essential to assess the child's level of understanding and tailor communication accordingly.

The experience of life-limiting illness can also impact on a child's understanding and behaviour. Children from diverse cultures are able to distinguish between a potentially life-threatening illness and an acute or chronic illness from which they will recover. A chronically ill 6-year-old child may know more about illness and death than a healthy 9-year-old. Children who are aware they have a life-limiting illness may show the following behaviours:

- preoccupation with death in conversation and play
- displaying anger especially in relation to procedures and medications
- reluctance to discuss events in the future
- social withdrawal.

Healthcare providers and parents often worry about what to tell dying children. Even when children are nursed in isolation and 'protected' from information, they rapidly find out about their disease, their prognosis and the fate of other patients. It can be more helpful to focus on how best to support the child and respond to their questions.

Children are extremely sensitive to nonverbal communication. They know when parents and healthcare providers are avoiding their questions or answering them dishonestly. They also know when their parents are upset or anxious. Effective communication can minimise anxiety and feelings of isolation in the child. Key points for communicating with children are outlined in [Figure 10.13](#).

It is important to find out what a child's real concerns are. The subject of death may concern adults, but children do not necessarily share this anxiety. They may be more worried about whether they will be in pain, who will be there for them, what their friends will think, and changes in their appearance and physical ability. Children may also fear the loss of attachment and bonds they have with their family after they die.

Play is important to allow children to express their concerns and wishes. Both parents and healthcare providers can use age-appropriate activities for children to express themselves (eg play, art, music, story books). Parents may find some of the subject matter disconcerting; reassure them that 'playing funerals' and drawing graves and dead people can be appropriate in the context of a life-limiting illness.

Figure 10.13 Key points for healthcare providers communicating with a child with life-limiting illness

Respect the parents' views and expertise on how best to communicate with their child.

Listen carefully to learn what a child already understands, what their concerns are and what they want to know.

Take the child's hopes and desires seriously.

Be honest and provide information in simple, age-appropriate language.

Repeat information and check comprehension.

Be alert to misunderstandings that may arise from immature concepts of death (eg the child views illness as punishment for misbehaving).

Validate the child's questions (eg 'That is an important question to ask').

Be curious about what the child says (eg 'Why do you ask that?').

Be honest if you do not know the answer to a question (eg 'Can I think about that?').

Express your own emotions to help the child do so.

Adolescents

Adolescents

Adolescence is a time of transition from dependence to relative independence, characterised by rapid physical growth and cognitive and psychological maturation. Life-limiting illness may impact significantly on the 'work' of adolescence by its effect on body image, mobility, decision-making, sexuality and peer interactions.

Adolescents benefit from the support of their parents, yet continue to need contact with and support from their peers, where the challenge is to appear normal. The developmental changes of adolescence continue despite life-limiting illness, and it is important to maximise independence (where possible), autonomy, social contact and daily functioning. The heightened awareness of body image and concerns around physical attractiveness may make physical differences such as scars and hair loss particularly devastating for adolescents. For practical tips that may be useful when working with adolescent patients, see [Figure 10.14](#).

Adolescents often prefer to be cared for at home and this should be accommodated whenever possible. When they require inpatient care, some adolescents prefer to be in a paediatric hospital or hospice, where they have established relationships with staff, while older or more mature adolescents may prefer to be in an adult hospital or palliative care unit because it better meets their needs.

Adolescents may have been ill since childhood, and the illness may accompany them into adult life. The transition to adult health services is discussed in [Care during the transition from adolescence to adulthood](#).

Figure 10.14 Practical tips for working with adolescent patients in palliative care

Work on building rapport with the patient and finding out what they like to talk about (this can be a prerequisite before they are willing to talk about their symptoms or how they are feeling)

Respect patient confidentiality and inform the adolescent of their right to confidentiality.

Dedicate a portion of the consultation to seeing the adolescent alone.

Respect their need for physical privacy.

Seek the adolescent's perspectives about their illness and goals of care.

Provide honest responses to questions.

Modify treatment regimens to facilitate mobility and independence whenever possible.

Consider the impact of possible treatment on physical appearance.

Allow options and choices when possible.

Encourage school participation and socialising with peers (eg camps, parties).

Enlist peer support groups where possible (eg CanTeen).

School

School

Attending school helps a child maintain a sense of normality and routine, and allows them to socialise with their peers. Later, as their illness progresses, brief attendance at school each day may still be possible. When they can no longer attend school, contact with peers can be maintained through letters, email, social media and visits.

A meeting between teachers, parents and the community nurse or general practitioner may be useful to discuss the needs of the child and family, and what the school can offer. Schools may need advice on how to support staff and students, and to identify those at risk of severe reactions to the illness or death of the child. The child and their parents should be consulted before staff discuss the child's illness with other parents and students.

Detailed information on how schools can support children and families is available in 'A practical guide to palliative care in paediatrics' (Queensland Health) [[URL](#)].

Communicating with families

Communicating with families

Building rapport with a family in the early stages of care is crucial for effective ongoing support; part of this process is to understand and acknowledge the unique needs of each family.

Building rapport with a family in the early stages of care is crucial for effective ongoing support.

Early involvement of a specialist palliative care team can be helpful to assist with communication; they can provide guidance to parents on how to talk to their child about death and dying, prepare them for the medical aspects surrounding death, and facilitate sibling support.

Guidance for communicating with families in paediatric palliative care is provided in [Figure 10.15](#). See also [Family meetings](#) and [Discussing bad news and prognosis](#).

Figure 10.15 Communication tips for a paediatric palliative care meeting or consultation

The following tips may be helpful when communicating with a family in a meeting or consultation in paediatric palliative care:

Preparation

- Obtain permission from the parents (or adolescent) to have the meeting and to share their personal information.
- When possible, have more than one healthcare provider present, preferably from different disciplines (eg doctor, nurse, social worker). One healthcare provider usually communicates information, while the other can observe nonverbal cues and emotions.
- Ensure that family members are not outnumbered by healthcare providers, and that they have a support person if they would like one.
- Healthcare providers who are trusted by and well known to the family should conduct difficult conversations, if possible.
- Ensure the setting is private and comfortable for everyone.
- Adolescent patients may choose to be part of family meetings, but younger children are generally not involved. Ensure children and siblings who are not participating can be cared for away from the discussion. Offer the opportunity for older siblings to be involved in discussions if appropriate.

Discussion

- Give the family time to raise their concerns and questions, preferably as early as possible in the meeting. When possible allow silence to occur, so family members can ask their own questions.
- Obtain permission from the family before broaching a difficult subject.
- Family members may have strong emotional reactions. It is helpful to acknowledge and validate these (eg 'I can see this is really upsetting you', 'Any family receiving this news would be devastated').
- If necessary, discuss with the parents how best to communicate information about prognosis and treatment to their child.
- At the end of the meeting, formulate a plan for next steps.

After the consultation or meeting

- Ongoing contact is important so that the family can clarify issues and does not feel abandoned.
- It can be helpful for healthcare providers to debrief with a colleague after a difficult meeting.

A family-centred approach means that healthcare providers should empower each family to provide the best care and support for their sick child, and should endeavour to facilitate communication between parents and their children.

It is important to acknowledge that parents are the experts on how best to communicate with their children. They should be encouraged to give honest, age-appropriate information to their child, but ultimately it is the parents' choice to decide what to discuss with their children, and when to have these discussions. This can become more difficult as the child develops increasing understanding and independence from their parents.

When parents do not want their child to have access to information, several options are available. Explain to parents that children nearly always have an understanding of their illness, and are sensitive to nonverbal cues that suggest healthcare providers and parents are distressed or concealing information. A child may feel anxious and lonely if the truth is withheld from them. It is also helpful to explain that families who have adopted a truthful, compassionate and age-appropriate way of communicating with their child about illness and dying often have fewer regrets about this after their child has died.

For parents who find open communication too difficult, or when the opportunity for a conversation with the child has not arisen, another helpful approach is to focus on how parents might respond if the child asks a question about their illness. Reassure parents that they will often intuitively know the right thing to say. Strategies for parents to respond to questions include:

Validate the question. For example: 'That is a very important question to ask.' Find out what the child already knows or understands. For example: 'What do you think?' or 'Why did you ask that question?'

For some families, it can be helpful to identify a trusted relative or carer who can talk openly about difficult issues with the child, while allowing the family to maintain patterns of communication they are able to cope with. Some children, especially adolescents, choose to discuss these issues with a friend or healthcare provider as they do not want to cause distress to their parents.

Regardless of how parents decide to communicate with their children, it is important that this issue does not become a source of disagreement and conflict between the family and the healthcare team. With time and support, many parents will communicate honestly and sensitively with their child as the child's condition progresses.

Support for siblings

Support for siblings

Siblings of children who are dying almost universally experience distress, but many do not share their thoughts and feelings. This may be because their parents are distracted or physically unavailable, or because they do not want to add to their parents' difficulties. Siblings who are unable to express themselves adequately can develop behavioural problems such as attention seeking, school failure, developmental regression or physical symptoms resembling those of the sick child.

Siblings often have unique bonds with each other, and the illness or death of a brother or sister may represent the loss of a friend with whom they have shared many life experiences. Siblings can feel isolated and rejected; they may resent the sick child for the extra attention they receive, and then feel guilty for harbouring such thoughts. Young children may fear for their own health or may be concerned that they caused the illness through bad behaviour or thoughts. Siblings who are bone marrow or organ donors are at particular risk because they often feel responsible if the outcome is bad.

Interventions to support the siblings of a child with life-limiting illness are shown in [Figure 10.16](#).

Figure 10.16 Interventions to support the siblings of a child with life-limiting illness

Helpful interventions and activities to support the siblings of a child with life-limiting illness include:

- participating in care of the sick child and visits to hospital
- spending time with their sister or brother
- provision of accurate, up-to-date information by parents and healthcare providers
- allocation of special time for parents to be with them
- reassurance that the illness is not their fault
- reassurance that they are very unlikely to develop the same condition (if that is true)
- appointing a trusted adult as 'special person' for the child, someone who they can talk to openly
- liaison with the school
- maintaining routine and structure in their life where possible
- participation in activities for siblings provided by a hospital, hospice or community organisation
- counselling and age-appropriate therapies (eg art, music and play therapy)
- age-appropriate books
- support groups.

Paediatric palliative care: principles of symptom management

Paediatric palliative care: principles of symptom management

Principles of assessment and management of symptoms in children receiving palliative care are outlined below. For detailed information on symptom management, including pain management, see 'A practical guide to palliative care in paediatrics' (Queensland Health) [[URL](#)], other [resources for healthcare providers](#) or consult a specialist paediatric palliative care service.

Assessment of symptoms

Assessment of symptoms

Comprehensive and ongoing assessment of symptoms is essential in children receiving palliative care. It is important to tailor assessment to a child's age and developmental level, and to consider their general health, previous pain experience, family support and cultural values. Take into account the impact of their symptoms on school attendance, hobbies, sport, sleep and mood.

Assessment of pain in children (including pain assessment tools) is described in the [Pain and analgesia guidelines](#). Whenever possible, give the child the opportunity to report their own pain levels using a validated pain assessment tool. For children who are unable to describe their pain, assessment tools based on observer estimates are available. Parents are also reliable proxies to report pain and other symptoms in young nonverbal children, or those with significant disability (eg children with severe cerebral palsy, progressive brain tumours or neurological disorders).

At the time of writing, validated tools for assessment of other symptoms in children are not available. However, it may be useful to ask an older child (or parent) to rate the severity of symptoms such as nausea on a scale of zero to ten.

Symptom management in paediatric palliative care

Symptom management in paediatric palliative care

Many drugs used to manage symptoms in adult palliative care are also used in children; off-label drug use is common. Prescribing information for children, including drug doses, is available from:

- AMH Children's Dosing Companion [[URL](#)]
- A practical guide to palliative care in paediatrics (Queensland Health) [[URL](#)]
- the [Pain and analgesia guidelines](#)—the approach to managing pain in children generally also applies in paediatric palliative care.

The general principles of opioid use in palliative care for adults also apply in children; for example, the opioids used in palliative care, using different routes of administration, and adverse opioid effects—see [Pain](#):

opioid therapy in palliative care.

For prescribing information not adequately covered in these resources, contact a specialist paediatric palliative care service or a Medicines Information Service.

Medicines should be administered by the simplest, most effective and least painful route. Analgesics are usually given orally as tablets or specially formulated liquids; if appropriate, ask parents which formulation is preferred for their child. Many children receiving palliative care, particularly those with progressive neurological disorders, have a nasogastric or gastrostomy tube in place that can be used to administer medicines. A variety of formulations may be administered this way, including some modified-release products (eg MS Contin controlled-release suspension can be dispersed in water and administered via an enteral feeding tube without affecting the modified-release properties) [\[Note 4\]](#) . When oral administration is not possible or not effective, subcutaneous, transdermal or intravenous administration may be appropriate. If subcutaneous cannula insertion is necessary, consider using a topical local anaesthetic preparation; wait for it to become fully effective before inserting the cannula. For information about subcutaneous drug administration in palliative care, see [Subcutaneous drug administration in palliative care \(Appendix 10.1\)](#).

Occasionally other routes of administration are used for children, including sublingual, buccal and intranasal administration. In general, intramuscular injections should not be used unless absolutely necessary. Rectal administration is unpleasant for many children, but is preferable to intramuscular injection.

Nonpharmacological strategies can also be used for symptom management in paediatric palliative care—they are widely used to manage pain. See ‘[A practical guide to palliative care in paediatrics](#)’ (Queensland Health) and [Nonpharmacological management of acute pain](#) in the Analgesic guidelines. Many nonpharmacological strategies for pain are based on distraction and playing. Children often enjoy these activities and gain from them a sense of empowerment and control. They also allow the family to work out new ways of interacting with each other and involving siblings.

Note 4: For information on drug administration via an enteral feeding tube, check the product information, the Australian Don’t Rush to Crush Handbook (available for purchase from The Society of Hospital Pharmacists of Australia <www.shpa.org.au>), or consult a pharmacist or Medicines Information Service.

Paediatric palliative care: resources

Paediatric palliative care: resources

Selected paediatric palliative care resources are provided below.

The publication ‘A practical guide to palliative care in paediatrics’ (Queensland Health) [\[URL\]](#) includes an extensive list of resources for healthcare providers, parents, children and others.

For a list of state-based paediatric palliative care services, see the CareSearch [website](#).

For resources on grief and bereavement, see [Resources for bereaved people](#).

Resources for healthcare providers

Resources for healthcare providers

A practical guide to palliative care in paediatrics (Queensland Health) [\[URL\]](#).

National Paediatric Palliative Care Clinical Guidelines (Starship Children's Health, New Zealand) [\[URL\]](#).

International Children's Palliative Care Network [\[URL\]](#). This website has an e-learning program for healthcare providers.

Together for Short Lives (UK) [\[URL\]](#). This website has resources for both healthcare providers and families.

Resources for families and children

Resources for families and children

Books for young children

Karst P, [illustrated by] Stevenson G. The invisible string. Camarillo, CA: DeVorss Publications; 2000.

Mellonie B, Ingpen R. Beginnings and endings with lifetimes in between. Melbourne, VIC: Puffin Books; 2005.

Books for older children and adolescents

Vercoe E, Abramowski K. The grief book: strategies for young people. Melbourne, VIC: Black Dog Books; 2004.

Zagdanski D. Something I've never felt before: how teenagers cope with grief. Melbourne, VIC: Hill of Content; 1990.

Resources for parents

Palliative Care Australia. Journeys: palliative care for children and teenagers.

Palliative care for children with cancer: a guide for parents [[URL](#)].

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