A Practical Guide to

Palliative Care in Paediatrics

PalliativeCare AUSTRALIA

Paediatric Palliative Care AUSTRALIA & NEW ZEALAND

We would like to acknowledge the Traditional Custodians of the lands on which we all live and work in Australia and we recognise their continuing connection to land, waters and culture. We acknowledge that sovereignty was never ceded and that this always was and always will be Aboriginal land. We also acknowledge Elders as the holders and guardians of knowledge, lore and wisdom and pay our respects to all Elders past, present, and emerging.

We acknowledge Māori as tangata whenua (people of the land), and Treaty of Waitangi partners in Aotearoa New Zealand.

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Foreword

Australia and New Zealand are home to a wonderfully rich diversity of migrant cultures, alongside respected First Nations People of Aboriginal and Torres Strait Islander origin and Māori peoples. As a citizen of both countries and a veteran of the pioneers who first set up Paediatric Palliative Care here in the late 1990s, it is my pleasure to introduce the fourth edition of *A Practical Guide to Palliative Care in Paediatrics*.

This updated resource reflects the substantial interdisciplinary wisdom and experience of the now well-established teams who provide care to families of children with life-limiting conditions. The authors have added to the voices of the original version by including new findings and advances in our current practice, reflecting developments in care and what we have learned from families.

As it was always intended, the content seeks to be a guide for our partners in care across healthcare disciplines and in the community so that service delivery is well supported and informed. The update was prompted by the development of the *Paediatric National Action Plan* and is a joint venture of Palliative Care Australia and Paediatric Palliative Care Australia and New Zealand, representing the strength and commitment of both sectors. We thank the Australian Government Department of Health and Aged Care for funding the writing of this current edition.

If you are reading this guide while wondering how you will provide care in such challenging circumstances, I exhort you to take the courage and ‘how to’ from its pages and engage in some of the most privileged work you will ever do.

Sara Fleming, PSM

Nurse Practitioner

Paediatric Palliative Care

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Introduction

Children are not expected to die. As it becomes understood that a child has a life-limiting condition (LLC), it is natural for the child, family, their community and health professionals to have fears, concerns and questions about what will happen. The aim of this book is to bring the voices of these children and young people and their families, along with the wisdom and experience of those who have cared for them, to the interdisciplinary teams across Australia and New Zealand who become their healthcare and support community.

Background

The speciality of paediatric palliative care has a reputation and recognition for the positive outcomes that this approach to care can deliver to patients and their families.[1, 2] From its outset, paediatric palliative care has shared the same philosophy of care as the adult specialty (e.g., interdisciplinary care, maximising supports at home and collaborative practice), while also developing its own distinctive model. For example, more than half the patients supported by a paediatric palliative care service will have non-cancer LLCs that are not seen as often in adult practice. Paediatric palliative care services will typically remain consultative and collaborate closely with other healthcare teams involved in the child's care.[3]

The types of diseases encountered, the symptoms experienced and how children understand and communicate about their illnesses differ in each case. These differences must be acknowledged and inform the care provided. Throughout this guide, there are references to 'child'; this is generally inclusive of the age range served by this speciality, covering from an antenatal diagnosis (foetus/baby) to neonate, infant, child and adolescent or young adult (18 years).

It is vital that children and families receive care appropriate to their needs at the right time in the place of their choice ('right care, right place, right time'). Flexible options in care location (i.e., home, hospital or hospice) need careful exploration and consideration across the multiple dimensions of geography, diagnosis, age and the values and preferences of each family.

The geographical vastness of Australia and topography of New Zealand often means that a child who is at home may be significantly distanced from the tertiary paediatric hospital where they received their diagnosis, management or treatment. This includes First Nations and Indigenous people of Australia, Aboriginal and Torres Strait Islanders and Māori, the Indigenous people of Aotearoa (New Zealand), some of whom live in remote communities. In these situations, health professionals from the child's local community are the key providers to meet the palliative care needs of the child and family. Only a relatively small number of children die each year, which can present a challenge to the health professional by limiting the opportunities for regional and rural health professionals to develop experience in paediatric palliative care.

It is for this reason that *A Practical Guide to Palliative Care in Paediatrics* has been developed.

This guide addresses the many and varied aspects of caring for dying children and their families. This includes pain and symptom management, practical supports, psychosocial issues, bereavement support, communication and available resources. This edition has been updated with improvements and changes in practice and to better reflect the diversity of society in Australia and

New Zealand, including more information on First Nations peoples, LGBTQIA+ families, spirituality, communicating with adolescents and community development perspectives.

Due to the success of the first three editions of *A Practical Guide to Palliative Care in Paediatric Oncology* and *A Practical Guide to Palliative Care in Paediatrics*, the current edition has been produced with contributions from multiple disciplines working in Australia and New Zealand. It is hoped that this approach will benefit children and families and those caring for them, across all locations, diagnoses and ages.

Definitions

For the purpose of this book, a 'child' has been defined as a young person up to their 19th birthday. The specific upper age range of children managed by a paediatric palliative care service can vary between jurisdictions. There may be some flexibility depending on whether the child is currently being managed by a paediatric team or is still attending school.[4]

The World Health Organization defines paediatric palliative care as follows:

- Paediatric palliative care is the active total care of the child's body, mind and spirit, involving giving support to the family.
- It begins when illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, spiritual, psychological, cultural 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 tertiary care facilities, in community health centres and in children's homes.[5]

In addition to these concepts, Together for Short Lives in the UK[4] highlight the additional point that care of the family continues through into bereavement.

A key concept, and one that is not always well understood, is that palliative care can be integrated with ongoing efforts to cure or modify disease. The child and their family are supported to live as well as they can for as long as they can, within the limits imposed by the illness. In this context, palliative care is about both living and dying.

Categories of life-threatening and life-limiting conditions

Life-threatening conditions (LTCs) are those for which curative treatment may be feasible but unsuccessful (e.g., cancer). Children in long-term remission or following successful curative treatment are not included.[6]

LLCs are those for which there is no reasonable hope of cure and from which children or young people will die.[6] Some of these conditions cause progressive deterioration over months to years, rendering the child increasingly dependent on parents and carers.[6] Other conditions include non-progressive severe disabilities that can make the child more susceptible to health complications.

Both LTCs and LLCs can also be considered 'serious illness'. A 'serious illness' may be a health condition that carries a high risk of mortality and either negatively affects a person's quality of life, or excessively strains their caregivers.[7]

There are four broad groups of LTCs and LLCs (*see* Table 1). The examples used are not exhaustive or definitive. The categorisation of conditions can vary as diseases can be classified by more than one group. A child might experience more than one category of LLCs (e.g., a child with cancer who develops a severe respiratory disease).

In addition to diagnosis, the spectrum and severity of the disease, subsequent complications, and the needs of and impact on the child and family must also be considered.

Table 1 **Categories of life-threatening and life-limiting conditions**[6]

Group	Definition	Example
1	Life-threatening conditions for which curative treatment may be feasible but may not be successful	Children with cancer when curative treatment is not successful (e.g., progressive brain or solid tumours) Irreversible organ failure not amenable to transplantation or if transplantation is unsuccessful
2	Conditions where premature death is inevitable; however, there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities	Examples of this category are evolving and changing with emerging therapies (including medical, surgical and genetic therapies)
3	Progressive conditions without curative treatment options, where treatment is exclusively palliative and commonly extends over many years	Neuro-degenerative conditions Metabolic conditions (e.g., mucopolysaccharidoses and Niemann-Pick Type C disease)
4	Irreversible but non-progressive conditions causing severe disability, leading to susceptibility of health complications and likelihood of premature death. Complications that may cause death include severe recurrent pneumonias or intractable seizures	Severe cerebral palsy (disease of the nervous system) Rett Syndrome (pervasive developmental disorder) Multiple disabilities, such as following brain or spinal cord injury (e.g., hypoxic ischaemic encephalopathy)

With emerging therapies (especially genetic), treatment options for children with LLCs are evolving. Some conditions that were traditionally Category 3 may now better fit in Category 2. For example, there are now various genetic therapies for spinal muscular atrophy (SMA).[8]

Some children with trisomy 13 and 18 (previously deemed 'incompatible with life') are also living longer and may fit into Category 2. This may depend on the severity of the child's condition and the preferences of the child's parents in either undergoing medical and surgical interventions or adopting a more comfort-focused pathway of care.[9, 10] Medical and surgical interventions that can be considered for these children in the context of whole-family considerations include gastrostomy, tracheostomy and cardiac intervention.[9]

Epidemiology

In 2021, it is estimated that approximately 28,976 (43.2 per 10,000 population) children and young people aged 0–21 years were living in Australia with a condition that would limit their life expectancy.[11] This number has increased over previous years and is anticipated to continue to rise as advances in medicine and supportive care mean that some children are living longer, with a proportion transitioning to adult services. As of 2023, the actual proportion of children and young people living with a LLC in Australia is unknown due to the lack of readily available epidemiological data.

Queensland data report the prevalence of conditions to be greatest for children less than one year of age, with a large proportion represented by the neonatal population (less than one month of age).[11] Figure 1 presents the prevalence by age group.

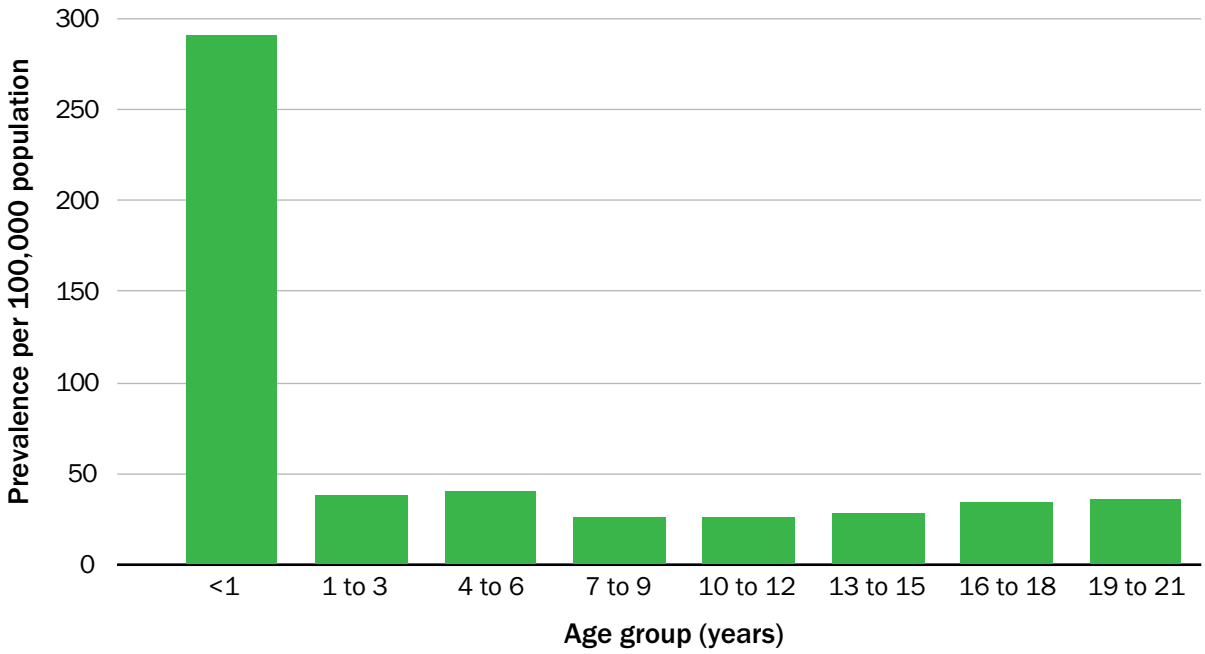

***Figure 1*. Prevalence of life-limiting and life-threatening conditions by age group for Queensland in 2016.**

Non-oncological conditions are reported to be significantly more prevalent than oncological conditions.[11, 12] For 2016, the estimated proportion of children and young people living with a non-oncological condition in Queensland was 38.4 per 10,000 population, compared to an estimated 4.9 per 10,000 population living with an oncological condition.[11] Figure 2 illustrates the prevalence of LLCs and LTCs (according to the International Statistical Classification of Diseases and Related Health Problems 10th Revision Australian Modification chapter classification).

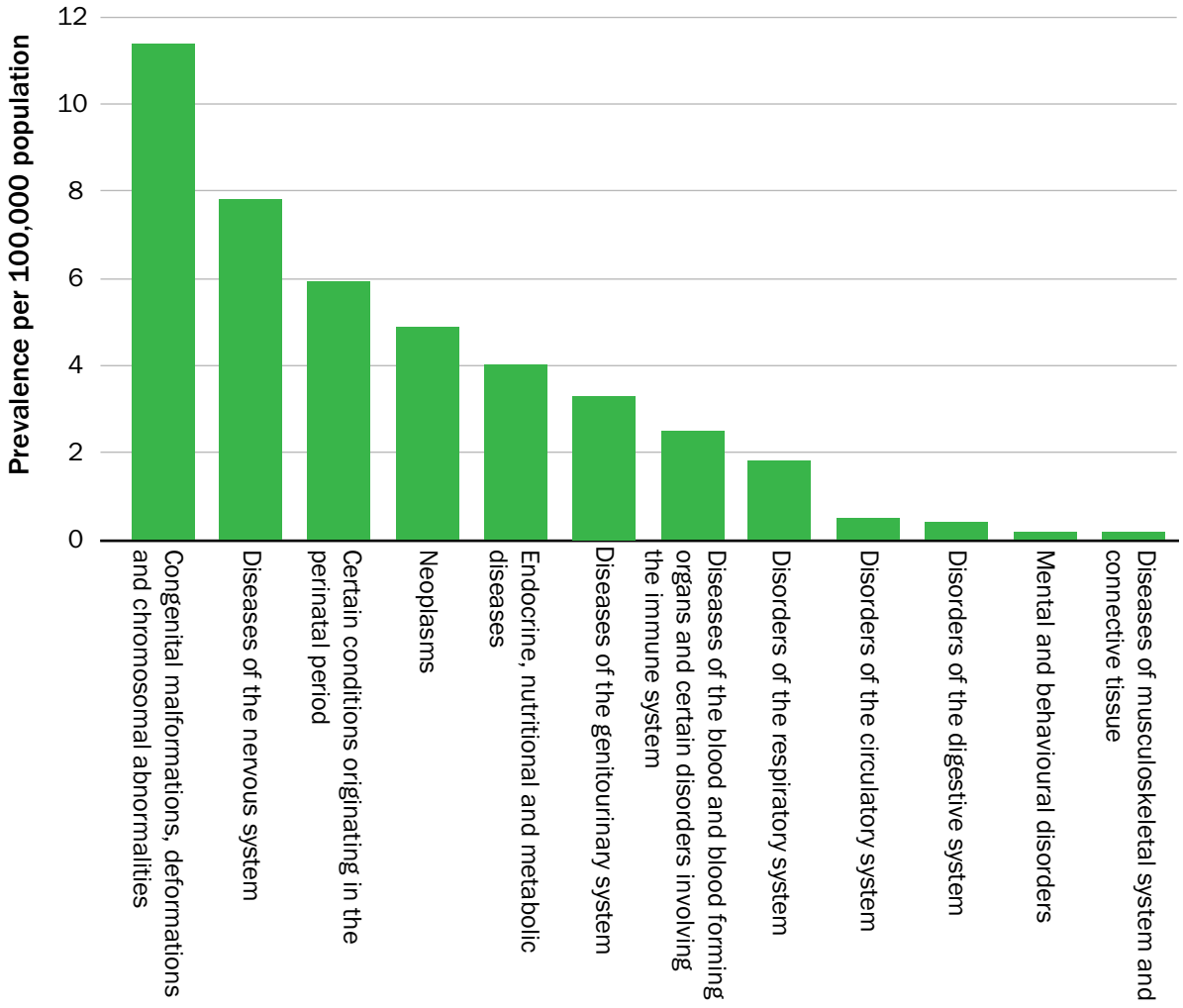

***Figure 2*. Prevalence of life-limiting and life-threatening conditions by International Statistical Classification of Diseases and Related Health Problems 10th Revision Australian Modification chapter classification.**

Note: Neoplasms represent the oncological classification; all other chapter classifications represent non-oncological conditions.

While there are thousands of children and young people with a LLC or LTC living in Australia, not all individuals require referral to a palliative care service.[11-14]

Figure 2 demonstrates that many subspecialties of paediatrics may need to refer to palliative care (e.g., oncology, neurology, metabolic, cardiac, gastrointestinal, respiratory, dermatology and renal). Many patients with multiple congenital anomalies or some genetic disorders will also benefit from referral to paediatric palliative care.

It can be difficult for treating teams to know when to refer to a specialist palliative care service. 'Would you be surprised if this patient died within the next 12 months?' is a question that can act as a useful indicator of when palliative care would be appropriate. If the answer is 'no', with the agreement of the family, a referral should be made. There is increasing acknowledgement of the benefit of early referral to palliative care for some patients. In this context, a referral could be made even if the child is expected to live for a number of years. With a focus on quality of life and

support for the entire family, palliative care can be a helpful additional support in the management of chronic and complex paediatric conditions. This can allow the specialist paediatric palliative care services to assist in meeting complex needs (e.g., symptom management or psychosocial needs). With paediatric palliative care services being consultative, the patient, their family and the primary treating team can access advice and support from the service at different times when needed.

Transition to palliative care

For many childhood LLCs, there is no definitive point at which a curative or treatment-oriented focus changes to a palliative focus. Palliative care is most effective for patients and their families when it is integrated seamlessly across the healthcare continuum. When this is achieved, the transition is often more 'fluid' in nature and is directed by the child's illness. This transition varies widely from a child who has had a long curative approach to their illness with a relatively short palliative care period to a child who, from diagnosis, is treated with a palliative focus over several months or even years.

Figure 3 illustrates the continuum of care for a child with a progressive condition. Treatment intended to modify the disease decreases as illness progresses, while palliative care increases as the child or young person reaches the end of their life. Various components of the palliative approach can be provided during this entire period by the health professionals who provide the frontline care for these children and their families. Such components include pain and symptom management, interdisciplinary care, psychosocial care, spiritual support and various practical supports (e.g., assistance with finances and equipment). The curved line illustrates that this is not a linear process. Further, highly technical invasive treatments may be used in conjunction with palliative care to prolong life and improve quality of life with each becoming dominant at different stages of the disease.

After the child dies, bereavement support for parents, siblings, grandparents and friends becomes important. Parents experience grief and loss at the time their child is diagnosed with an LLC and as the illness unfolds. Therefore, they can require bereavement support before their child dies.

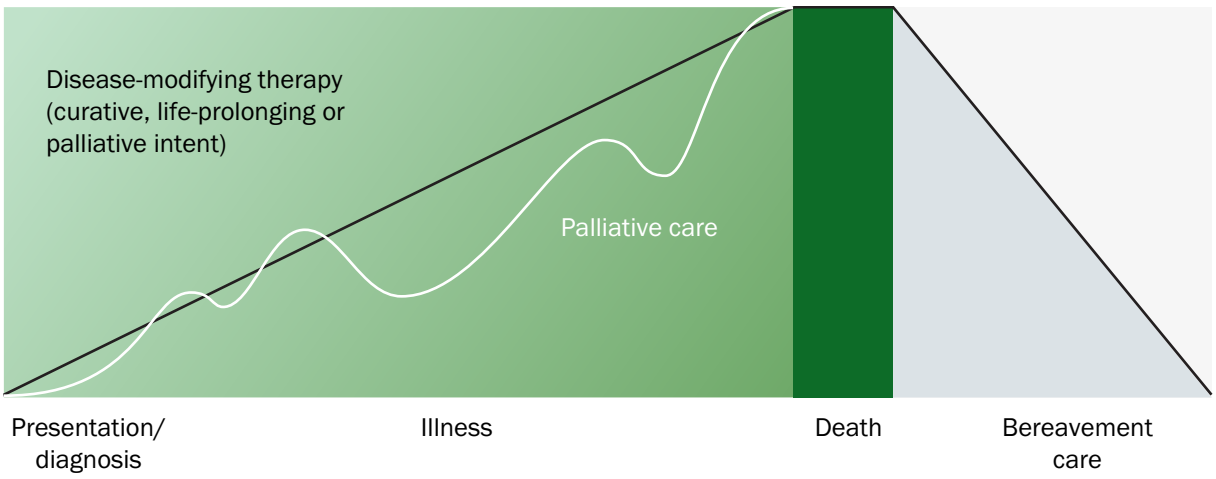

***Figure 3*. Continuum of care associated with disease-modifying therapy and palliative care for a child with a progressive condition.**[15-17]

Transition to palliative care

The care of a dying child often requires the combined effort of the primary treating team, a palliative care service and health professionals in the child's local area. Early referral, good communication and meticulous care planning enables health professionals to adopt the palliative approach with more confidence and competence.[18] Effective communication includes gaining an understanding of the uniqueness of each family (*see* section Respect for the uniqueness of each family). It also means that those who will be providing care to the child at home have a chance to develop a trusting relationship with the child and family. Joint home visits and telemedicine are extremely valuable in facilitating the sharing of knowledge and expertise.[19-21]

While integration of the principles of palliative care with disease-modifying therapies is the best approach for much of a child's illness, there typically comes a time when palliative care becomes the dominant mode of care. Through gentle guidance, compassionate discussion and often after several days of contemplation, a formal transition from a curative to a palliative focus begins. The child's medical team discusses the facts with the family and the child, if appropriate. This would typically include discussing what palliative care means for that particular child and family. This is generally a shared decision and occurs when all realistic curative avenues have been exhausted or if symptom burden is high.

Every child's situation will be different. For some, a rapid transition to exclusively palliative goals will occur (e.g., transfer from an intensive care unit [ICU] to home for end-of-life care). For others, decisions regarding such interventions will be made in a stepwise fashion (e.g., initial withdrawal of invasive ventilation, progressing to withdrawal of non-invasive ventilation [NIV] and other measures such as intravenous antibiotics).

A parallel planning approach of 'hoping for the best, while preparing for the rest' can be helpful. At this time, the family's sense of hope may begin to evolve. The hope for a cure evolves into a hope for a pain-free and dignified death. In the perinatal context, parents can modify their hopes from having a healthy infant to other hopes, such as having time with and holding their infant after delivery.[22] However, this evolution is not necessarily linear. Parents can hold seemingly contradictory hopes simultaneously: hope for a cure and hope for the best quality of life *with* awareness of their child's guarded prognosis and likely death.[23] It is important to be aware that while the child and family may appear to intellectually comprehend that death is now inevitable, they may have greater difficulty in emotionally accepting this knowledge.[20] Parents may experience feelings of shock and disbelief when their child dies, even when this has been anticipated for some time.

The move from a curative focus to palliative care is disease-directed and also dependent on the preferences and values of the family. Each family will respond to this difficult transition in their own way. Some families are accepting of a palliative focus; for others, the desire for a cure remains dominant, and all therapeutic options are explored and insisted upon. In many cases, there is a combination of acceptance with hope for a 'miracle'. Each individual family's approach must be respected by staff caring for the child and family. Specialists in palliative care bring considerable experience and skill to talking to families about these difficult decisions. Health professionals who have known the child for some time, such as their general practitioner (GP), also have an important role to play as trusted family confidantes. Many GPs will have experience in palliative care, which can be of benefit to the child and family.

Transition to palliative care

Some children can survive against all odds, and patients do sometimes ‘graduate’ from the palliative care service. This model of care can allow children to receive the supportive benefits of palliative care when prognostic uncertainty exists. Evolving technologies, coupled with the excellent care parents provide, mean that a number of adolescents with LLCs are now transitioning to adult care services.

Quality of life

Understanding 'quality of life' involves making some kind of judgement about the satisfaction that people feel about their lives. This sense of satisfaction generally includes many dimensions, such as quality of relationships, access to necessary resources (e.g., housing), physical health and comfort. Access to activities that are intellectually, emotionally and physically fulfilling and the pursuit of important life goals, including cultural and spiritual rituals, are also important. When thinking about children and young people aged between newborn and 18 years, we must also consider play, school, development, comfort and security.[24]

When quality of life is discussed in the context of palliative care, it must be approached within the limitations imposed by the disease or condition and its trajectory. However, even this is a relative concept. It is important to identify with the child and their family the goals of care, especially as the disease progresses. Discussions about quality of life should occur throughout the entire illness and take into consideration the wishes of the carers and the child and, where appropriate, the siblings and extended family. This often allows the family and child to get on with living in the present and to be reassured that there are plans in place for future care. It is also suggested to encourage families to document life along the way in their own unique ways (e.g., photographing, scrapbooking, digital recording and stories).

It is important for a health professional to create and recognise such opportunities. It is also important to recognise that the goals of care for individuals within a family can be very different, and individuals within a family may protect each other from discussions that involve considering the possibility of the death of the child.[25]

Therefore, enabling quality of life is a goal that a health professional should consider, but that the child and family should define for themselves. It is important not to superficially confuse quality of life with the concept of being busy or achieving a particular activity. Quality of life is often more deeply connected to the quality of relationships and of time spent together, which brings joy, comfort and connectedness to their people and culture, than it is with activity or outward achievement. However, the challenge is to enable families to achieve their sense of quality of life and to be able to do this within the changing circumstances of progressive disease. In these circumstances, it is quite normal for the defining issues for families to change over time; therefore, it can be very helpful to assist with modifying these goals so they may still be achievable in some sense.

At first, pursuing quality of life may focus on doing things the family thought they would have had more years to achieve (e.g., having special holidays, going to the beach or visiting theme parks). Later, it may focus on achieving physical comfort and peaceful time together, away from the interruptions of visitors, such as recording story times or listening to familiar music.

Whatever the case, the role of a health professional is to assist families to identify what quality of life means for them and to assist them to overcome blocks to achieving it. Importantly, as the disease progresses and the limitations on quality of life are increasingly imposed, there will be elements of grief that the health professional can help the family to address. There are lots of books available now to help children, siblings and young people understand death and dying, grief and loss (*see* section 'Resources').

Place of care

In the early stage of an LLC, children can feel quite well and may have very few symptoms. They are likely to be at home with their parents, attending school and participating in family activities, and most children express the wish to have fewer trips to hospital. As the child's disease progresses and symptoms develop, closer follow-up will be necessary. Depending on where the family lives, this may be via telephone review, telehealth consultation, home visits or hospital visits. At times, the child may require admission to a hospital (or hospice if available) for assessment and management of difficult symptoms and for respite care.

During this period of increased interaction with trusted health professionals, there may be an opportunity to initiate conversations with the family and, if appropriate, the child regarding where they would prefer to receive care towards the end of the child's life, including their preference for place of death. Some families presume their child will have to die in hospital and may not be aware of the alternative options available to them and their child.

Engaging in these conversations early in the end-of-life phase allows families time to consider their options for place of care. There is time to ask questions about what care would look like in either a hospital, home or a children's hospice (if available) and to visit these facilities and explore the services available. When supporting Aboriginal and Torres Strait Islander families, it is important to involve community and hospital Aboriginal Health Workers where possible to allow sufficient time for the family to consult with extended family and Elders when necessary (*see* section 'Indigenous and First Nations populations in Australia and New Zealand'). Giving families the opportunity to plan for the location of care is considered a valid measure of high-quality palliative care, including the flexibility to change and adapt their choice at any time.[26]

End-of-life care at home

Some families will choose to provide care towards the end of their child's life in the privacy of their home with the support of specialist paediatric and adult palliative care services, local paediatric teams and community nursing services. Reasons for choosing home as the location of care include:

- siblings and extended family feeling more involved in the child's care
- respecting the child's wishes to be at home
- parents having more control over the home situation
- the child being nursed in a familiar environment surrounded by the possessions, people and pets they love.
- spiritual and cultural needs being easier to address at home.

There are challenges to providing end-of-life care in the home, including:

- the physical and emotional burden of care (i.e., parents may be freer to be parents when they are in a hospital or hospice)
- some symptoms being difficult (though not impossible) to manage at home (e.g., airway obstruction, severe haemorrhage)
- health professionals not always being immediately available to attend
- feelings of abandonment and loss of connection from treating teams
- painful memories if the child dies at home.

For families who choose to care for their child at home, it is essential that health professionals acknowledge the additional complexities of providing end-of-life care at home. It is essential to plan ahead, anticipate potential symptoms and have medications ready in the home for when required. Access to 24-hour phone support, written symptom management plans, equipment, home visits and flexibility for admission to hospital or hospice at short notice all contribute to scaffolding supportive home-based care.

It can be very reassuring for families to know that there is always a hospital bed available if, for any reason, they feel hospital care is more appropriate. When developing a plan of care, it is important to ensure the family has access to appropriate contact details should they wish to move place of care urgently, or after hours. For example, some families may decide to return to the hospital in the last few days or hours of life. Some families may be fearful of having 'bad' memories if their child dies at home. However, experience demonstrates that this fear often decreases over time, and families often ultimately choose to be at home despite their earlier concerns.

Parents may have made a very strong commitment to support the child dying at home and may struggle with this commitment if home care demands become too difficult, either physically or emotionally. This possibility can be anticipated and discussed openly with the family to ensure that such a transition of care can occur, without inducing a sense of failure or guilt in the parents or health professionals.

Prior research into parents' experiences of providing end-of-life care at home has identified that parents can experience a sense of fear and abandonment.[27] Retaining connections with the primary treating teams through phone calls, telehealth consultations or joint home visits with community palliative care teams are ways of continuing these relationships that are important to families.

End-of-life care in hospital

If care is to be provided in hospital, it is vital that, where possible, the child is nursed in a single room and can personalise this space by bringing in their own doona or quilt, pillows, favourite toys, photos and other special items from home. The hospital option may include the hospital closest to the child's home, allowing extended family and friends to visit more easily. Transfer of clinical information and thorough handover of care is crucial when care is transferred from a tertiary children's hospital to a local hospital.

Some families prefer to be in a tertiary children's hospital with access to their specialists and in a ward environment where the child has received most of their care and where the family trusts the care provided by the staff.[28]

End-of-life care in a paediatric intensive care unit

For some children, the 'right place' to die will be the paediatric intensive care unit (PICU) or neonatal intensive care unit (NICU). In some jurisdictions, these units can also be called 'critical care units'. This requirement can be due to varying factors, such as the acute onset of illness or deterioration (e.g., sepsis or seizures), ongoing disease-modifying therapies or the use of ventilatory support. There may also be prognostic uncertainty and a very gradual realisation by parents or health professionals that a child is not responding to intensive care interventions. Excellent symptom management, care coordination, multidisciplinary support and bereavement care can, and should, be provided within the intensive care environment.[29]

Within the ICU, there may be a need for compassionate extubation.[15, 30] This involves the discontinuation of mechanical ventilatory (and other critical care) support for a child with a poor prognosis. Where possible, and after consultation with PICU staff, families should be offered a choice regarding where they would like their child extubated. Options could include the ICU (including verandas), the home ward, quiet suite, hospital garden, hospice or home. Some families will opt for these settings of care if the appropriate support systems can be put into place. It is important to acknowledge that some patients may be too unstable to move from the ICU setting despite their family's hope for them to die in an alternative setting. Alternatively, the required supports for such transition of care setting may not be available. For many patients, especially those receiving ventilatory support, transfer to a hospice, home or to a hospital closer to home for end-of-life care will require the assistance of a neonatal or paediatric retrieval service and complex logistical planning. In some regions and on some occasions, the required supports for transition of care setting may not be available.

Effective symptom management and parallel planning are required at the time of extubation. While most patients will die shortly after extubation and cessation of ventilation, a small number of patients may breathe spontaneously and live for a longer period. It is vital that families are aware of this possibility, and that the treating team ensure ongoing optimal symptom management.

It is important to recognise that when the goals of care transition from curative to palliative, many LLCs and LTCs can be managed outside the intensive care environment at a hospital closer to home, in a children's hospice or at home.[31, 32] Many families will opt for these settings of care if the appropriate support systems are put in place.

End-of-life care in a hospice

Children's hospices exist in some Australian states. Hospices offer an additional choice for place of care beyond the home or acute hospital setting. These facilities can be a source of practical support, providing a home-like environment with the backup of health professionals on site. They also offer psychosocial support for all members of the family. Examples of this type of facility are Bear Cottage (New South Wales), Very Special Kids House (Victoria) and Hummingbird House (Queensland).

There is now a hospice dedicated to adolescents and young adults (AYAs) in New South Wales that supports young people aged 15–24 with LLCs. There is also commitment to building a children's hospice in Western Australia.

Place of care

Planning for the place of the child's end-of-life care requires clear and honest communication between healthcare professionals, parents and the child, including information about the support available in the home, hospital or hospice.

Regardless of the location of end-of-life care, parents need access to 24-hour advice and support from health professionals from a variety of disciplines with experience in paediatric palliative care. Hospital-based and community-based health professionals work in collaboration to assist the family care for their dying child.

Online resources:

Transferring a Child Requiring Palliative Care At Home For Health Professionals - Paediatric Palliative Care

- https://paediatricpalliativecare.org.au/resource/transferring-a-child-requiring-palliative-care-home/

An Overview to Family Meetings and Difficult Conversations - Paediatric Palliative Care

- https://paediatricpalliativecare.org.au/resource/an-overview-to-family-meetings-and-difficult-conversations/

Coordination of care

Professional staff who may be involved in delivering paediatric palliative care include doctors, nurses, social workers, psychologists, occupational therapists, child life and music and art therapists, physiotherapists, teachers and pastoral carers (*see* Figure 4).[33] It is important to acknowledge that no one individual or health discipline can meet all the family's needs. However, by working together and sharing skills and expertise, a coordinated approach to care can be achieved.

To ensure that the family is not overwhelmed with services, a member of the team must take on the role of coordinator. The coordinator must be someone who will have ongoing involvement with the family during the palliative care phase. A specialist liaison nurse often takes on this role. However, in regional and rural areas, it may be more appropriate for a local member of the team (e.g., the GP, paediatrician, ward nurse or community nurse) to assume this role. For families moving between care settings, it may be helpful to have a coordinator in each setting to ensure continuity of care and information transfer. This should also include a plan for sharing information and communication between visits.

The coordinator must be easily accessible to the family as a first point of contact when new problems or concerns arise. A key role of the coordinator is to empower parents with the skills and knowledge needed to care for their dying child. The importance of this is discussed further in the following section. The coordinator requires excellent communication skills, compassion and the ability to listen to the child, family and other health professionals caring for the child. Knowledge of the child and family's support networks is important as parents may ask for advice on how to involve their community, such as the school.

It is important that all members of the team are kept informed of the child's progress. Hospital paediatric ward and emergency department staff must be kept up to date about the child's symptoms and know when a child may be admitted for acute symptom relief or end-of-life care. A palliative care folder may be a useful communication tool for this purpose. The coordinator can document the child's current symptoms and management in the folder, which should be made accessible to nursing staff working all shifts (*see* Appendix 1). Community nurses and the child's GP must know in advance when the child is returning home and the type of care and support the family may require. They also need a primary contact identified for further advice or peer support. It is helpful to have a clear plan worked out with community teams for after the child dies. This includes who is responsible for paperwork (e.g., life extinct forms or death certificates) both during and after hours. This coordinated, flexible approach ensures that the child and family are well supported to receive care in any environment.

Figure 4. Model of family-centred paediatric palliative care.

Note: Modified with permission from Thompson A et al.[33]

Psychosocial foundations of palliative care

The aim of this section is to provide some clear and manageable guidelines for health professionals that will enable the provision of psychosocial support. There are certain underlying principles that are essential to psychosocial support and form the foundation upon which all other aspects of palliative care are built. It is essential that this foundation is established from the beginning of involvement with a family.

These foundations foster an environment in which families can feel safe to address the strong and often unfamiliar emotions and issues that they are likely to experience in relation to palliative care.

The essential aspects of this foundation are:

- respect for, and understanding of, the uniqueness of each family (or whomever has caring or parental responsibilities), including Aboriginal and Torres Strait Islander families, LGBTQIA+ families and culturally and linguistically diverse (CALD) families
- empowerment
- excellent communication, including developing a relationship that is open and honest and fosters trust
- community perspectives
- emotional safety.

The strain experienced by a family or carers in caring for one (or more) children in the palliative phase of an illness is certain to challenge their coping capacity enormously.

The diagnosis of an LTC and the transition to palliative care causes fundamental changes and challenges to family life. It disrupts routines; increases the demands on practical, financial, emotional and spiritual resources; and affects everyone in the family—as well as extended family, friendship or collegial networks.

It is essential that health professionals openly acknowledge this, and appropriate support is provided in all these areas. All members of the team will influence the psychosocial wellbeing of the family. Consequently, the best psychosocial support is facilitated if all team members are equipped to work with families in ways that intentionally provide support and enhance the family's wellbeing and autonomy.

Respect for the uniqueness of each family

Every individual and family have unique life experiences, perceptions, strengths and challenges. Failure to respect this makes it impossible to provide the best possible individualised care. In exploring the uniqueness of a family, it is useful to understand some key issues. These fall into six main areas:

1. social (e.g., the degree of social dislocation they have experienced, the responsiveness of their support network, their financial situation)
2. cultural (e.g., being mindful of the history of intergenerational trauma and loss for Aboriginal and Torres Strait Islander families, the experiences of migration for CALD and refugee families)
3. family (e.g., the make-up of their family, their communication patterns, roles and relationships, stress management style, problem-solving skills, the specific challenges faced by LBGTQIA+ families navigating the health system)
4. individual (e.g., personality, developmental stage, past experiences of illness and grief, level of exhaustion, personal methods or means of managing experiences)
5. disease (e.g., duration, physiological impact, disease course, disfigurement, distressing symptoms)
6. grief history (e.g., exposure to death, dying, trauma, previous losses and coping strategies).

Empowerment

The death of a child is beyond a parent's control; however, how care is provided is something they can control. Parents know their child best—it is important to always respect this principle.

An empowering culture is one in which the family is enabled to have maximum control over the resources, information, decision-making and relationships that affect them. An empowering culture seeks to understand the uniqueness of each family within their social, spiritual and cultural context and demonstrates curiosity and humility in learning about the values and beliefs that are important to the family. Such a culture respects the reality that each family has their own strengths, resources and information and is capable of making decisions and maintaining and contributing to relationships (including their relationships with palliative care providers). Within this culture of empowerment, families are trusted to manage their own lives. They are not perceived as passive recipients of professional services but as competent and leading partners in their child's palliative care (*see* section 'Respect for the uniqueness of each family').

It is well documented that families facing an LLC or LTC feel an enormous loss of power and control in their lives. The psychosocial value of supporting them to regain or increase their sense of power and control whenever possible cannot be overemphasised. For First Nations families, this may mean allowing more time for decision-making, which can involve the extended family, and considering alternative ways to manage symptoms, depending on the location of end-of-life care (*see* chapter 'Symptom management'). For LGBTQIA+ families, this means recognising partners and families of choice, which may or may not include biological family members (*see* section 'LGBTQIA+ people and families').

Empowerment can be facilitated by the healthcare team listening to the family's needs, recognising their strengths, offering encouragement and advice, being advocates for them and their child and ensuring they have access to skilled health professionals and practical assistance, including home care equipment. It is also essential to use interpreters when English is not the family's first language, including Indigenous interpreters for families in remote Aboriginal communities.

Communication

Communication is the exchange of meaningful information from one person to another. However, communication is a complex and multi-levelled process. The physical environment, availability and attentiveness of participants, their emotional responsiveness and cultural biases are all part of communication, as are numerous other verbal and non-verbal components.

In palliative care, the goals of communication are to:

- establish a positive working relationship between the family and health professionals involved
- develop an accurate understanding of the family and the messages they are attempting to communicate
- consider the uniqueness of each family and any specific considerations (e.g., the needs and strengths of Aboriginal and Torres Strait Islander, Māori, LGBTQIA+, CALD and refugee families)
- enable the family to understand the information communicated by the health professionals
- use interpreters where indicated and follow good practice guidelines
- understand the communication styles and processes that occur naturally within the family and use these to facilitate manageable communication for the child, family and all involved
- account for the developmental stage of the child or young person and their siblings when communicating with families
- actively explore with the family any other sources of information they may be accessing through the internet and social media
- make use of telehealth and other forms of telecommunications to assist in communication with families in rural, regional and remote settings, especially when extended family are involved in decision-making.

Listening

Conversations with families often commence with professionals telling families what can be done for them or what their opinion is about the situation. It is always important to listen to families and give them the opportunity to share their perspectives or ask questions. This involves recognition of both verbal and non-verbal cues.

Health professionals should listen to the family's perception of a situation, especially their views on the problems, needs, solutions and resources inherent in it. Consider what understanding the child or young person has and how their views and wishes can be elicited and included. It is important to not only listen to the obvious content of what families are saying but also notice and recognise the emotion(s) expressed and other less obvious content—including assessing what is not said overtly. By doing this, health professionals join alongside the family rather than telling them what they should do. This ensures that the family feels respected and empowered and concerns, skills and resources are identified from their perspective. From this foundation, health professionals are well positioned to offer their expertise to the family in the most needed and useful ways.

Effective listening is a dynamic process requiring active participation from the listener. Health professionals must demonstrate that they are listening to and valuing what families are communicating by showing recognition, clarifying what the family is expressing and then exploring this.

For example, in the context of discussing palliative care issues with families, it is not uncommon for a parent to say something like 'I can't cope with this'. Often, health professionals respond via providing a superficial reassurance that while the situation is very hard, 'you will cope' or 'everyone feels that way'. Such statements may be accurate, but their immediate effect can block the opportunity to hear:

- how the individual is really feeling
- what their perceptions are
- what other influences are affecting their perception of the situation.

Additionally, such comments do not communicate an acceptance of what the individual is feeling or a sense of partnership.

A better response would seek clearer understanding of what the parent was actually meaning and invite further information from them. This could be achieved through giving careful attention to the parent by using open questions and reflective feedback, such as 'as I understand it, what you are saying is …'. This is more likely to lead to an understanding of what it really means for this person to say, 'I can't cope with this'.

In this example, it may have been assumed that the parent was expressing fears about caring for the child at home; however, they may have been expressing a more acute physical stress reaction at that very moment, such as the need to get some fresh air or to be physically sick.

Alternatively, the parent may have helped care for a dying grandmother in their own childhood and have stressful memories that need to be processed. In the case of Aboriginal and Torres Strait Islander families, they may have experienced the death of many family and community members in the recent past and, therefore, need additional support in the current situation.

Giving information

The giving of open and honest information is of paramount importance in palliative care. This requires intentional effort because, in dealing with issues of strong emotional pain, there is a cultural propensity (based in the desire to protect people from pain) to communicate in ways that minimise or avoid the issues.

For example, take a situation where there is the possibility that a child may experience seizures. If this risk is not discussed with the family, or if superficial statements are made about seizures being controllable and the child experiences a seizure that is difficult to control, the family will have been ill prepared for the situation. The culture of trust may also be damaged.

In giving information, being aware of both sides of the communication equation is vital. It can often be helpful to discuss with families how they want important information to be given to them; for example, some families like to have all the information ahead of time, while others prefer to have information provided in real time. Choosing a mutually acceptable time and place that is without

distractions is important when holding a discussion with a family. When information is being given to the family, health professionals must check that the family understands the information. This can be as simple as asking a family (in non-patronising language) what they understand has been said: for example, 'does this make sense to you? Are there parts of this I need to explain better or differently?' Simply asking if they understand is not enough because this can lead to a simple 'yes' answer, which does not provide the opportunity to listen to what the family understood. This checking process will help to identify misconceptions and enable further clarification. Extra care must be taken with CALD families. For example, some languages do not have a word for 'palliative care'. Other considerations must include the literacy and cognitive skills of the caregivers involved.

It is through open and honest communication about all issues, especially the most difficult issues, that the health professional can assist families to prepare for the challenges of palliative care and establish and maintain trusting relationships with families.

Communicating with children

For many health professionals, being involved with children receiving palliative care is as difficult an issue to deal with as death and grief itself. Among other reasons, this is often due to their uncertainty about the correct thing(s) to say or do with children.

Although the fact the children require palliative care and that their families face bereavement is undeniably sad, competent and caring adults can be of enormous assistance to these children.

The most significant issue raised by most people regarding children in palliative care is 'what do we tell the children?' This question reveals one key problem—**adults are more inclined to tell children things than to listen to children.**

The starting point with children is to listen to them. By listening, we:

- show that we respect and regard them as important in their own and unique right
- gain an understanding of their world (i.e., their understandings and perceptions about their lives and the life of their family)
- build the kind of trusting relationship that children must have with an adult to receive support from them.

Children with diverse communication and sensory requirements

Specific consideration must be given to communication with children who have developmental or sensory needs, meaning that they require different ways of communicating, such as the use of social stories, sign language or play. Where possible, it is beneficial to involve colleagues from child life therapy, child art or music therapy, occupational therapy and social work who have additional skills, resources and a range of communication tools.

Effects of illness on children

Children with serious illness and their families experience major disruptions in all areas of family life. Consequently, these children may have lost, to a greater or lesser degree, the relatively safe and predictable routine of the life they had before diagnosis.

Sick children will have had experiences of illness, painful and distressing treatments; geographical relocation; and loss or reduction of contact with key family members, peers and friends. They may also have experienced disability and loss of function or changes in their personal appearancerespect fornce.

Siblings will also have experienced the loss of parental availability. This may have been due to the parents' physical absence while at treatment centres, their involvement in increased care for the sick sibling and the strong likelihood of the parents being, to some degree, emotionally unavailable. They will have experienced multiple disruptions to their lives, significant changes in their relationship with their sibling, loss of routine, concern for their sibling and displacement from their usual role and position in their family. They will also have witnessed treatments and the physical effects of treatment and disease. To a greater or lesser degree, all these experiences are inevitable. They may have also become a carer for their sibling.

For some families, there is an additional burden of more than one child being affected with the same condition, such as neuromuscular or inherited metabolic diseases. In these circumstances, the often younger and less debilitated child witnesses the worsening condition of their sibling and possibly death, while considering their own illness and future. Due to these factors, the family-centred model of care ensures consideration of all within the family network.

On a positive note, many siblings and extended family will experience a greater bond or connection with the sick child and other family members due to this experience. Some children, if well supported, will exhibit extraordinary tolerance, resilience and wisdom. Most bereaved children will not need counselling or intervention in the long term; however, counselling should always be considered if the child is struggling emotionally and socially or learning or development is not progressing as expected.

Children's perceptions of illness

Children strive to make sense of their world, gain a sense of mastery over it and understand how they fit into it. They gather information to do this from multiple sources—direct verbal communication is only one small part thereof.

There can be no doubt that from their experiences and observations of both subtle and unsubtle clues, children in palliative care situations will recognise that something serious is happening in their family (e.g., parents crying after a meeting but being told 'nothing is wrong', overhearing mobile phone conversations). Due to this recognition, they will have anxieties or concerns, attempt to make sense of the situation and work out where they fit into it. Often, their imagination creates more fear and anxiety than if the facts are delivered in a compassionate, truthful and developmentally appropriate manner.

Useful strategies for parents and practitioners might include using a range of activities (e.g., reading, drawing, play or writing) to help families communicate with their child or children. This is equally important for the ill child and any siblings or close friends or relatives.

Adults instinctively want to protect children from the distress of any situation and may convince themselves that children do not understand what is going on or can be protected by giving them as little information as possible or by keeping it secret. This is understandable, especially considering the stress under which the children's parents are living.

Children may also engage in a similar strategy of protecting their parents. They may do this by not discussing topics that they recognise as being stressful for their parents. This mutual 'protection' can lead to both children and parents having similar concerns yet being isolated from one another's support.

Failing to assist children to develop an accurate understanding of what is going on and where they fit into the situation can leave them ill informed, unprepared and at the mercy of their limited life experience, imagination and fears. Two examples of this are common conclusions that children may reach: that they are in some sense to blame for what is going on or that they are no longer loved by the family. Crucially, these feelings of exclusion from the family can arise at the very time when children most need to feel the security of inclusion and trust.

The absence of communication with children leaves them with no trusted source of information about what is happening. As health professionals, it is vital to create opportunities to assist families with these challenging situations while also respecting the parents' own expectations of communication with their child. This can be challenging when a parent does not wish to inform their child of the situation at all and does not wish to have a child involved in their own decision-making or planning for end-of-life care.

Ideally, children need a sense of safety, nurturing relationships with their caregivers, assistance to make sense of their world and their feelings and a sense of self-worth.

Children's understanding of death

It is difficult to divide children's understandings of death into clear developmental stages. However, there is general agreement that from the age of seven onwards, a child who is cognitively intact will have a reasonably full understanding of death. They understand that it is universal, irreversible, has several causes and relates to non-functionality.[34]

Life experience (e.g., life-threatening illness, the death of a grandparent or pet, other exposure to death or information about death) has a significant influence upon children's understanding and can lead individual children to have a greater or lesser understanding of death than their peers. Often, children with LLC who are familiar with hospitals will have had a greater level of contact with illness and may be aware of the death of other children; therefore, they may have a greater understanding and awareness of these issues. Generalisations about children's understanding of death are never as important as individualised knowledge about a specific child.

Professionals who work in the area of communication with children about grief, death and palliative care have indicated that many young children (in our experience, as young as five years) have well-developed understandings of death. This understanding will not be the same as an 'adult' understanding; for example, the issue of permanence may not be fully developed. However, within their understanding, these children can process issues associated with death to a greater degree than many adults give them credit.[35]

What should we communicate to children?

It is important to realise that it is impossible not to communicate to children. Every contact with them communicates something, and every exclusion from contact communicates something. In light of this, appropriate communication with children begins with the establishment of a relationship in which the child is included, respected and actively listened to.

From that basis, ongoing communication should take place in a supportive atmosphere in which children are invited to explore and express their feelings, their needs and their understanding of what is happening. Children should be invited to ask questions; in response to their feelings, perceptions and questions, they should be given honest information in language that is accurate and appropriate to their age.

There are some very practical strategies to guide communication with children:

- Do not take over a parent's role. Parents are generally the most important people in their children's lives, and a safe open relationship with them is invaluable for the long-term wellbeing of the child. The role of the health professional is to help parents talk with their children and spend quality time with them. In doing this, the relationship between parent and child is reinforced rather than undermined.
- Answer the questions they ask but do not overwhelm them with extra details.
- Observe their play and behaviour and other non-verbal signs for cues regarding what may be issues for them and explore these.
- Be willing to use media with which they are comfortable (e.g., books, iPads, art, toys and storytelling).
- Give information gradually rather than in one large session. This is especially important with progressive disease. It is better to keep the child informed of gradual developments than to give them information late in the process when the situation is more serious.
- Keep language as simple as possible. Language must also be accurate and compassionate.
- Be prepared to give information repeatedly. Children generally need repeated explanations.
- Involve children in decision-making as much as possible.
- Beware of issues surrounding blame and guilt.
- Reassure children that the situation is not their fault.
- Do not be afraid to show feelings to children; this can provide an important model for them.

When children ask their own questions, explore with them the meaning of the question. Often, as health professionals and adults, we assume the expected answer. For many children, their 'real' question is not what is asked. For example, if a child asks, 'am I going to die?', they may not want a yes or no answer but rather to understand what will happen to Mum or Dad, a sibling or the pets.

It is important that children are supported in these conversations by a trusted person and in an age-appropriate manner. On occasion, the parents may seek the support of a health professional, and on rare occasions may find it to too difficult to be involved in such conversations.

The style of communication outlined above gives children the clear message that they will continue to be informed of what is going on and reassures them that they are a valued part of the family and will continue to be cared for. With this support, children are able to manage the major emotional challenges of palliative care and grief.

Developing a trusting working relationship with families will help identify how parents would like you to communicate with their child. This may include the approaches below, which can be revisited when/if families want and need:

- For young children, consider discussing first with the parents before the child or where that is the preference of the young person themselves.
- Be available when needed to help the parent/s talk with their child or children.
- Always aim to answer the child's questions honestly, and in an age-appropriate manner.

Answering the child's question honestly is especially important when parents do not want their child fully informed of the current situation. This may create tension between the health professionals who want to provide honest answers, and the parents who may want to protect their children from difficult discussions - and are also the expert in how they communicate with their children.

Some strategies to deal with the latter situation might include:

- Validating the child's question and asking further questions such as:
  - 'This is a very important question. What do you think?'
  - 'Why do you ask'?
  - 'Should we discuss this with your parents?'
- 'Should we ask your doctor?'
- Explain to parent/s the reasons for providing honest answers delivered in a sensitive and age-appropriate way (e.g., from research or experience) without being overly prescriptive about this.
- Listen to the parents about their concerns in sharing the truth with their child and supporting their responses to find what level of information they can agree to share with the child.

Communicating with adolescents

Adolescence is a time of many changing emotional needs, where peer relationships are very significant and where the relationship with parents is changing as the young person moves between dependence and independence. The adolescent with palliative care needs may be dealing with feelings of frustration, loss of physical independence and isolation from normal social interaction with peers. They may be more perceptive about the impact of their illness on their family than younger children. It is vital to establish patterns of communication that recognise their unique needs, particularly respect for their privacy and honest, open discussion regarding decisions about their care. At times, a young person may wish to hear information independent of their parents or have significant non-family members (e.g., boyfriend, girlfriend) included in discussions. These arrangements will need to be discussed with both the young person and the parents.

It is important that AYAs living with an LTC have the opportunity to inform their care; they want to be able to choose and record the kind of medical treatment they want and do not want, how they would like to be cared for, information for their family and friends to know, and how their life is remembered.[36] It is also important that adolescents are involved in communication that is appropriate for their age and occurs directly with them—that health professionals do not simply communicate with the family unit as a whole or speak with the parents on the adolescent's behalf.

This is because adolescents' understanding of death, its meaning and what comes after may also be different from that of their parents. Additionally, longitudinal research has highlighted that adolescents and their parents often have quite discrepant perspectives on what the young person wants in terms of their end-of-life care and communication. One study in a sample of adolescents with cancer showed that while 86% of adolescents expressed that they would prefer early timing of palliative care communication (i.e., before getting sick, while healthy, when first diagnosed, when first sick from a life-threatening illness, or all of the above), only 39% of their families knew this.[37] Put simply, family members had poor understandings of the best times to bring up end-of-life decisions with their adolescent child.

Communication considerations

Adolescents will likely want to contribute to discussions about their pain and symptom management, resuscitation planning, organ donation and funeral planning. Providing opportunities for them to express their views, hopes and fears is important. Timely, earlier introduction of these conversations (prior to the cessation of active or curative treatment) is vital to ensure that young people and families have the benefit of time in which they can make decisions and have the flexibility of real choices, such as around their quality of life or how they would like to spend their time.

Creative forms of communication such as art, music, poetry, writing and peer support groups may all be helpful in supporting the expression of young people's experiences and wishes. Health professionals should commence and facilitate end-of-life conversations with young people using processes designed to privilege the young person's voice and comfort during the process.[38, 39] For example, rather than being specific to any one particular discipline or health professional, end-of-life conversations may be best facilitated by whichever member of the healthcare team has the strongest rapport with the young person and is most comfortable broaching potentially complex or confronting emotional concerns within the context of that professional relationship.[40] Table 2 details further clinical considerations for how the process of end-of-life communication can be supported in age-appropriate ways for AYAs.

Table 2

Key practice recommendations for end-of-life communication with adolescents and young adults[38]

When	**Introduce palliative care team members earlier during treatment to facilitate opening conversations to end-of-life concepts before disease- or symptom-related 'crises' or the cessation of active (curative) treatment**
	Raise the possibility of palliative care at various time points in the treatment journey, including key transition points during care or where symptom burden may have increased Introduce the palliative care team early during treatment (e.g., for symptom management) to provide a 'bridge' if it becomes evident that treatment may not be successful Readdress end-of-life concerns at the time of relapse and also at key treatment junctures (e.g., at the introduction of stem cell transplantation) so families can become better prepared for the possibility of death
Who	**Ensure the wider multidisciplinary team is confident and adequately skilled to support end-of-life conversations with adolescents and young adults (AYAs)**
	Flag the need to have conversations about treatment goals and the future with the AYA patient and check whom they want involved in that conversation Check understanding of end-of-life and current treatment goals with both the parent and AYA while simultaneously focusing on their current life, quality of life, goals and activities
What	**Tailor the content of end-of-life conversations to the individual patient and the unique context of the particular time point at which the conversation is being introduced**
	Provide honest and complete information regarding disease progression Discuss AYAs' priorities regarding their current lifestyle, including key aspects of their routine and social activities Keep AYAs informed about their diagnosis, treatment and prognosis even if treatment is ineffective or prognosis is poor If available, offer AYAs hospice services so that they can make an informed decision

How	**Use structured advance care planning tools to scaffold conversations and as a mechanism to facilitate communication between AYA patients, their families and members of the multidisciplinary care team**
	Address AYA and family willingness and comfort with opening end-of-life conversations by acknowledging their concerns while also gently outlining the ways such conversations may be helpful Empower the AYA/family to determine how much they wish to delve into these topics at each given conversation opportunity Be aware of and help the AYA to clarify how they would like to spend their remaining time, as well as concerns they may have around involving/including family and loved ones (e.g., concerns about burdening family) and how the treating team can support them Support the AYA by maintaining their quality of life, continuing and pursuing current activities, spending time in the environments they want to as much as possible and exploring/identifying place of death preferences, as well as preferences for how they may be remembered and/or their family/loved ones supported after their eventual death Recognise each patient as an individual who may have different personal preferences that change throughout care Be aware of the language used to initiate end-of-life discussions and the potential to misinterpret meaning; for example, comments such as 'there is nothing more we can do' may be perceived as abandonment

Advance care planning

Advance care planning (ACP) is an intervention that developed in healthcare to capture the adult patient's voice, values and preferences in anticipation of loss of their decision-making capacity as underlying illnesses advance. It aims to enshrine and respect the patient's autonomy in complex decisions, such as those related to the patient's end-of-life. Paediatric ACP differs because most children with LLCs do not have decision-making capacity. Clinicians and families are making decisions *for* them rather than *with* them,[41] and these decision-makers are typically present at the time of acute deterioration. When approaching end-of-life decision-making, clinicians try to balance respect for parental autonomy (which differs from patient autonomy) and promotion of best interests and protection from harm for the child.[42]

Paediatric ACP is a process of conversations where clinicians, families and, if possible, the child with a LLC share their concerns about a child's medical susceptibility. The child and family's values are elicited to help think in advance about decision-making before the child approaches the end of their life. This process may result in documented treatment decisions, such as 'do not resuscitate' (DNR) or 'not for resuscitation' (NFR) orders; however, it does not necessarily need to. However, clinicians often focus on and emphasise these documented 'orders'.[43-45] This can be perceived negatively by children and their families because the focus is on what should *not* be done rather than what *can* be done. ACP may not be appropriate for all families of children with LLCs. Some

families may be unable to engage in discussions of the child's future and would rather remain in the moment. However, this does not mean that they will be unable to participate in decision-making when their child deteriorates acutely. Other families prefer discussions related to concerns about the child's prognosis and health status to occur in advance but decision-making to happen in real time rather than in the hypothetical.[46] These families want the information upfront but decisions to be deferred, recognising that at times of advancing illness, they will be present to engage in this decision-making in real time. Further, some clinicians find it difficult to consider treatment decisions in the hypothetical or at times of prognostic uncertainty.[43, 47, 48]

Clinicians and families value a process of preparatory conversations for end-of-life decision-making irrespective of whether this results in documented treatment decisions.[49, 50] There are many communication tools and frameworks to help facilitate this discussion, such as 'Thinking Ahead' and 'Voicing My CHOiCES™'. Developed in Australia, the 'Thinking Ahead' framework provides a four-step approach to conversations; it includes discussion prompts to help guide clinicians in facilitating this process, paced appropriately with the child's health journey.[51] These discussion prompts recognise that even a young child can provide invaluable insights into their experiences of life and medical treatments and their hopes and fears, which can inform their goals of care. Recognition of the need to empower and include young people in these discussions is formalised further in 'Voicing My CHOiCES™', which similarly provides a guide for discussion as an adolescent with developmental decision-making capacity approaches the end of their life. Voicing My CHOiCES™, an ACP communication guide developed initially in the USA and designed by and for AYAs living with serious, life-limiting and life-threatening illnesses.[52] This tool is designed to be completed collaboratively together with a trusted health professional and includes sections to support young people to voice their end-of-life preferences around topics including preferences for their medical care, supportive and psychosocial care when sick, and legacy considerations. This tool has since been translated into other languages (e.g., Spanish) and has undergone cultural adaptations, including in Brazil and Australia.[53, 54] Guidance on introducing the tool has been published previously.[55] This might involve letting a young person know that the guide is designed to help them share particular things they want—or do not want—for their medical care and current life outside of it.

Culture and Diversity

People are social beings—they have most of their needs met through their families and communities. Therefore, it should be remembered that families do not make decisions in isolation; health professionals should identify the 'significant' people involved in the decision-making process. These people may need to be part of the discussion when decisions are being made, such as religious, spiritual or cultural leaders or extended family members. This is particularly essential when working with Aboriginal and Torres Strait Islander families.

Communities include formal organisations such as schools, churches, charitable organisations, hospitals, First Nations health services and other health services, employers and government agencies. They also include informal support networks such as family, friends, neighbours and hobby or sporting groups.

These community relationships can play an important role in supporting a family in the palliative phase of their child's illness. Consequently, it is essential to understand the role they play for an individual family and that they *could* play if they were appropriately informed, resourced and linked to the family. For some families, it may be helpful to have a 'family/friendship network meeting', which can provide an opportunity to inform the network of the current situation and how they can best assist—especially if a family is struggling to articulate their needs and wishes. This can be organised by the social worker or other key worker and should include First Nations/cultural health workers where appropriate. Facilitating this active support is an important role played by health professionals.

A vital consideration in using these networks is the issue of empowerment for the family. Families can experience challenges to their sense of power and control when a child is dying. Before engaging in work with any part of a family's social network, it is essential to consult with and gain permission from the family. This respects their right to be in control of information about themselves and protects their relationship with those social supports and their role in the decision-making process. Ideally, families' direct involvement with their communities should be maximised. The health professional's role should be to facilitate this process rather than represent the family.

Spiritual and cultural perspectives

There is a broad spectrum of belief systems and cultures within our community.[56, 57] Death, dying and loss often highlight spiritual and cultural differences and may give rise to new spiritual awareness as people search for meaning in response to life-changing events. Personal and team preparation is vital to ensure that our own self-awareness, concerns, biases and beliefs can be addressed safely and willingness to understand and accept those of others is secured. These needs and experiences may be very individual and fall outside formal cultural or religious expressions. They may also be unique for each member of the family, and the spiritual experience of children may be quite different to that of adults.[57-59] It is important to provide opportunities for everyone to explore and express their spiritual and cultural needs and experiences and to be mindful of the need for meaningful rituals for many at this time.

An example of the importance of being aware of spiritual and cultural needs would be when health professionals encourage families to take time in planning and holding the funeral after a child has died. In some cultures, such as the Muslim community, the body must be buried within 24

hours. In this situation, encouraging the family to 'take their time' would demonstrate a lack of understanding of their needs. Another example is the importance of understanding the significance of dying on Country or away from Country for Aboriginal and Torres Strait Islander families and the specific support they may need in either situation. Spiritual assessment tools can be useful, such as the FICA (see Figure 5).[59, 60]

Table 1. The FICA method of taking a spiritual history

F	*Faith and belief.* Ask: Are there spiritual beliefs that help you cope with stress or difficult times? What gives your life meaning?
I	*Importance and influence.* Ask: Is spirituality important in your life? What influence does it have on how you take care of yourself? Are there any particular decisions regarding your health that might be affected by these beliefs?
C	*Community.* Ask: Are you part of a spiritual or religious community?
A	*Address/action.* Think about what you as the health care provider need to do with the information the patient shared—e.g., refer to a chaplain, meditation or yoga classes, or another spiritual resource. It helps to talk with the chaplain in your hospital to familiarize yourself with available resources.

***Figure 5*. The FICA method of taking a spiritual history.**

Effective communication is the key to gaining a better understanding of spiritual and cultural needs. This communication can occur directly with the family or as directed by them with representatives from the same cultural or religious group. Being able to use a professional interpreter service has benefits, including translation of complex medical information and protection of privacy. In all cases, the communication principles discussed in this guide should be followed. Additionally, there are available to most families and teams pastoral care, spiritual care or chaplaincy services—they can provide sensitive support and connections to appropriate resources.

Cultural sensitivities may exist regarding providing the best care to a patient and their family. This could be related to communication styles, language, a lack of specific support or resources or other concerns or fears the family may have.[61] It is important to discuss these worries respectfully and with humility, where possible. Open statements, such as 'help me understand how we can best support your family', help to show a willingness to respect and support these needs.

Indigenous and First Nations populations in Australia and New Zealand

Aboriginal and Torres Strait Islander peoples

Aboriginal and Torres Strait Islander peoples are the First Peoples of Australia; for more than 65,000 years, they have been the custodians and traditional owners of this land. While the diversity of culture, language and customs is as broad as the country we live in, the connection to family and to Country is at the heart of all Aboriginal and Torres Strait Islander cultures.[62]

'Country' is the term often used by Aboriginal and Torres Strait Islander peoples to describe the lands, waterways and seas to which they are connected. The term covers complex ideas about law, lore, place, custom, language, spiritual belief, cultural practice, material sustenance, family and identity. Aboriginal and Torres Strait Islanders may also hold Christian beliefs and practices and could be supported by pastoral care practitioners. Early on, it is essential to establish a family's wishes and priorities based on their individual belief systems.

First Nations peoples live in urban, regional and remote areas around Australia and are present in all communities, not necessarily on their traditional lands or islands. Each person has their own specific clans, mobs, communities, islands or nations with which they identify and connect. It is always best to ask people what they prefer regarding identification and connection. Some people may choose to identify with their language groups and traditional Country. For example, Gunditjamara people are the traditional custodians of western Victoria, the Gadigal people of the Eora nation are from Sydney, and the Yawuru people are the traditional custodians of Broome in Western Australia. Others may prefer to reference their regional identity, such as Koori, Murri, Nunga or others. These regional identities do not necessarily adhere to Australia's state or territory boundaries. Torres Strait Islanders generally define themselves as being from specific islands, tribes, family groups or sea country. In the Torres Strait, you may live in one community but have historical ties across multiple different islands.[63]

Aboriginal and Torres Strait Islander peoples generally have a holistic understanding of health, which encompasses the physical, psychological, social, emotional, spiritual and cultural wellbeing of the individual and the community (*see* Figure 6).[64, 65] We must be open to learning about how the connectedness of culture and spirituality can sustain and energise the child and their family in mind, body and spirit during the experience of living with serious illness.

Quality of life

The following 'Wheel of Wellness' shows the various aspects of life that Aboriginal and Torres Strait Islander peoples consider important:

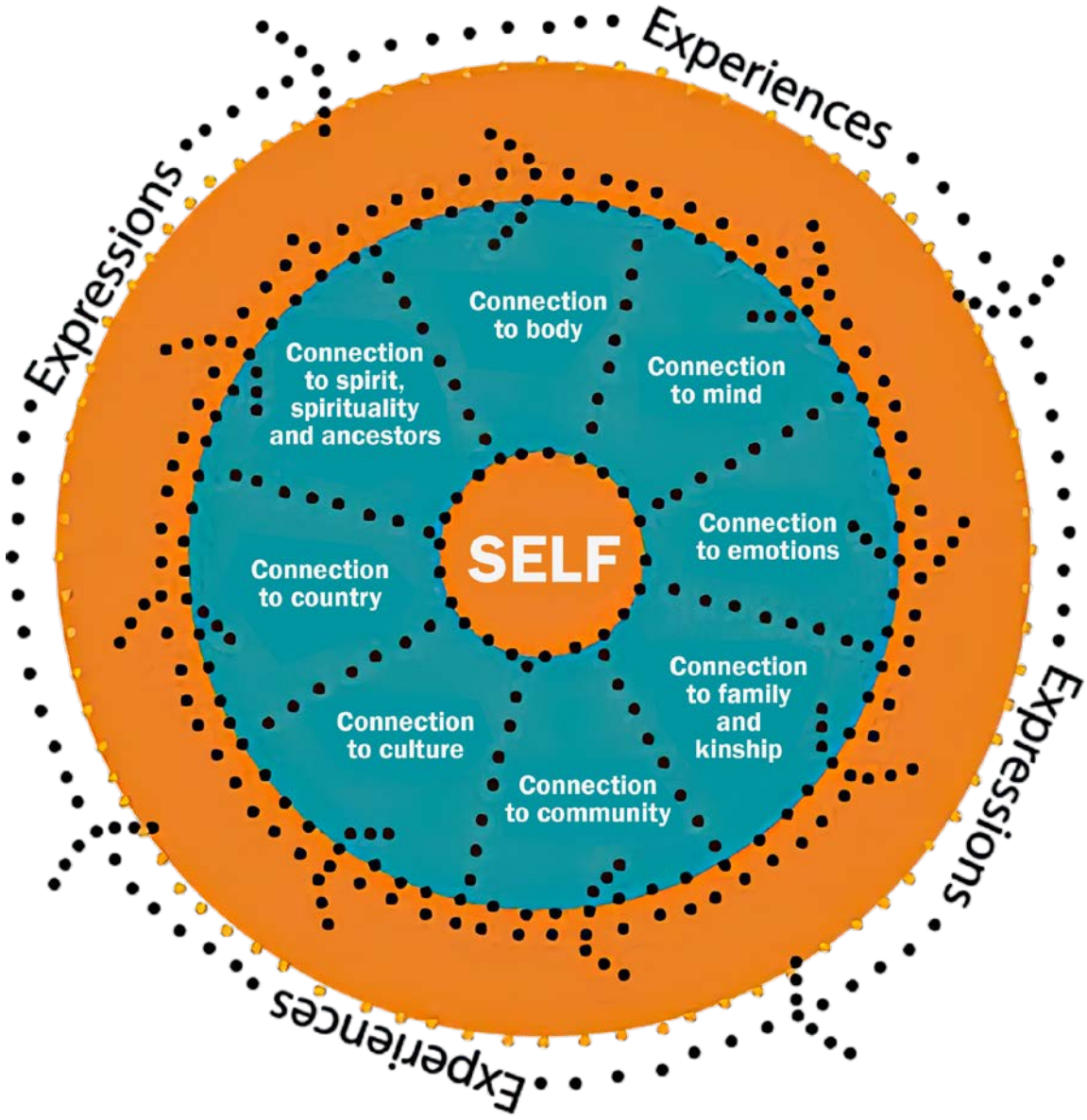

***Figure 6*. The wheel of wellness. Diagram sourced from: Gee, Dudgeon, Schultz, Hart & Kelly, 2014, Aboriginal and Torres Strait Islander Social and Emotional Wellbeing**

First Nations peoples are proud of the strengths within their culture and spirituality, which have enabled them to survive and resist colonisation. At the same time, real harm has been done to families and communities, which has resulted in significant intergenerational loss and trauma. This may affect how families cope when their child is diagnosed with an LLC. Cultural sensitivity and humility, respect and a trauma-informed approach to care are essential when caring for Aboriginal and Torres Strait Islander children and their extended family and community.

It is essential for us to work on building trust and connection with the family as the starting point for the more difficult discussions and decisions ahead. This will also help avoid causing unintentional

harm and develop an understanding of the family's strengths and the cultural beliefs and values that are important to them and will influence their thinking about illness and pain. Be mindful of the hospital environment, including our body language and shared patient areas. Allow sufficient time and privacy for the family and their nominated support persons to receive and make sense of information about treatment options and medication. Be open to culturally significant healing practices and traditions that are practised before and after death and, where possible, validate and incorporate these into the child's treatment.

We must work closely with our Aboriginal health colleagues in hospitals[66] and the community. They can assist and mentor us in learning about the cultural needs of, and building trust with, families so that we increase the sense of cultural safety for the family (*see* Figure 7).

Cultural beliefs and requirements will differ depending on whether the child and family are from a remote Aboriginal community or live in an urban or regional setting. For example, in remote communities, several Indigenous languages may be spoken; for these families, it is essential to engage Indigenous interpreters and Aboriginal Health Workers where possible.

It is important to understand who in the family network has responsibilities for the care of the child and, where possible, ensure they are included in family meetings. Consider how and when the family wishes information to be presented, including the use of written and visual information. Decision-making may need more time to allow some families to have discussions with extended family and community Elders, who may not be physically present in the hospital. Offering information for consideration and having follow-up conversations without rushing can be extremely important and worthwhile.

The use of telehealth through community clinics closer to the family's home and community can be an invaluable tool in assisting communication between families in tertiary hospitals and their extended family. Try to develop an understanding of what the family imagines will be the best quality of life for their child, despite their serious illness.

In remote communities, families may face challenges with medication, including access, storage and administration; however, we should do our best to adapt our support and allow the family the best chance of being supported to have end-of-life care at home. The caring@home project provides specific resources for Aboriginal and Torres Strait Islander families, health professionals and clinical services to support palliative care provision at home and on Country.

Home

https://www.caringathomeproject.com.au/

Being culturally respectful also extends to developing an understanding of the Aboriginal and Torres Strait Islander family's spiritual and cultural beliefs about death and dying and the customs and rituals they may wish to observe. With some families, it will be important to use the term 'Sorry Business' or 'finishing up' instead of 'death' and 'dying'. Families from remote communities may also follow stricter protocols around using the names and images of the deceased person and the rituals that must be followed after death. However, families living in urban areas may be more comfortable saying their child's name and sharing photos. The key principle is that we do not make assumptions but rather strive to build rapport and respectfully explore each family's wishes, thereby moving closer towards culturally safe care.

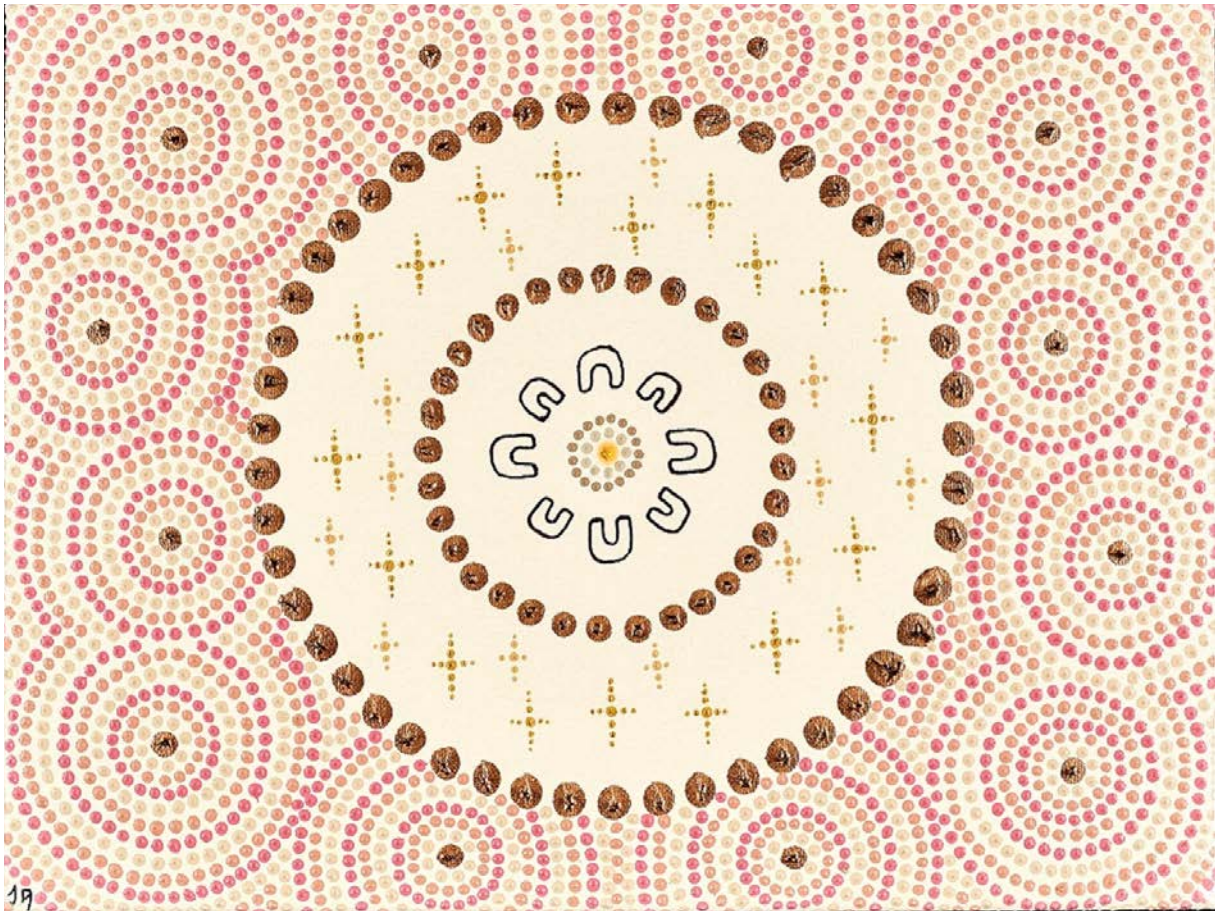

Figure 7. **A palliative pathway to the Dreamtime ...**

The outside circles represent all our paediatric patients and their families being supported by palliative care teams.

The middle circle represents all our paediatric patients who have gone to Spirit and others who are on the next part of their journey.

The inner circle shows everyone coming together in a yarning circle to work as a team to support all of our paediatric patients and their families.

Artwork by Proud Gamilaraay woman Tanya Quinn (Antaw)

Māori peoples

Māori are tangata whenua, the Indigenous people of Aotearoa (New Zealand). There are over 100 iwi (tribes) across Aotearoa that all have their own pūrākau (stories) that influence their tikanga (cultural customs and practices). As with other Indigenous peoples, Māori have been exposed to colonialism, assimilationist practices, Westernisation and urbanisation. However, despite the diversity and differences among Māori whānau (families, including extended family), some traditional Māori beliefs and values are consistent across all iwi. Aotearoa is intended to be a bicultural nation, with Māori culture being of integral importance to all New Zealanders.

Te Tiriti o Waitangi, signed in 1840, is Aotearoa's founding document outlining the expected relationship between Māori and the British Crown. Te Tiriti o Waitangi is a critical document in

healthcare. It outlines that health providers have an obligation to provide care in ways that enable Māori to live, thrive and flourish as Māori, to support Māori to exercise tino rangatiratanga (self-determination over their health and wellbeing) and contribute to equitable health outcomes for Māori. [67-69]

A popular holistic Māori health approach that many Western health practitioners are familiar with encompasses four key elements: wairua (spiritual), hinengaro (psychological), tinana (physical) and whānau (family).[70] Care of pēpi (babies), tamariki (children) and rangatahi (young people) with serious illnesses and their whānau (family) should be provided that encompasses all these aspects of care within the context of the child's environment, including the whenua (lands, territory) they occupy and their community.

There are six core values that should underpin care of pēpi, tamariki and rangatahi with serious illness and their whānau: whanaungatanga, aroha, manaakitanga, kotahitanga, wairuatanga and rangatiratanga of whānau.[71] These values are critical in caring for Māori tamariki and whānau and can also be translated into high-quality palliative care to support children and families of all ages and ethnicities.

Whanaungatanga

Whanaungatanga is about establishing and maintaining meaningful relationships with both tamariki and their whānau. This begins with getting to know the pēpi, tamariki or rangatahi beyond their illness, seeking to understand and acknowledge the tamariki: their likes or dislikes, their interests, who the important people are to them and what comforts them in times of distress. Establishing a relationship with the child must also include the child witnessing warm interactions and trust between their whānau and health professionals.

Getting to know a whānau—including their beliefs and values and the way they wish to love, honour and care for their pēpi—supports the provision of quality palliative care. Establishing a strong relationship with the family and forming trusting connections is most important as this will ensure families have a sense of safety at the outset of the child's illness. Space should be offered to support families in observing cultural and spiritual rituals such as karakia (prayers, incantations, chants) and waiata (singing). Māori families often observe cultural processes and death rituals that involve processes to remove tapu (spiritual restrictions), such as kai whakanoa (consuming food to remove tapu to return people to an ordinary pre-tapu, non-restrictive spiritual state). Accommodating these processes can help families to feel safe.

Aroha

Aroha is the expression of love, empathy, affection and compassion. It guides whānau in everything they do to ensure their pēpi, tamariki, rangatahi and the wider whānau are loved, nurtured, protected and kept safe. This means that health practitioners must create spaces for families to gather so they can fully express their love for their unwell child and each other in privacy. Space must be provided for whānau to be together, particularly larger families. Whānau may wish to share a meal together or to enjoy kai rangatira (food for the esteemed) together; parents and other family members may bring speciality foods into the healthcare setting to share with the child and each other. These foods, such as seafood or foods from tribal regions, often have cultural significance and are considered a delicacy to share. Acceptance, understanding and patience among health professionals are appreciated by whānau.

Aroha is present in gentle expressions of caring and affection that produce a healing energy that fortifies and sustains whānau to care for pēpi and tamariki. At other times, aroha can be seen in emotional eruptions as families struggle to cope with the stresses of having a critically unwell child. Given that Indigenous whānau are often disproportionately overburdened with inequities, it is not surprising that emotions can quickly intensify when caring for an ill and dying child. At times like these, the aroha of health practitioners can go a long way to ensure whānau feel supported.

Manaakitanga

Manaakitanga is built on the terms mana and manaaki. Mana means prestige, control, authority, status and spiritual power; it is a supernatural force in people and objects. Everything and everyone has mana. To manaaki means to take care of children and whānau, ensuring they can reach their full potential by supporting them and showing them respect. Manaakitanga is the process of actively caring for pēpi, tamariki, rangatahi and their whānau through providing hospitality and showing kindness and generosity. Health professionals become important participants in the whānau care network—they have an integral role to play in the care of the child and whānau.[72]

Health professionals bring their own knowledge, skills and experiences to the relationship with a whānau. Whānau often remember and demonstrate trust in health professionals who show kindness, understanding and take time to really listen to both the child and their whānau, hearing their voice and perspectives. It is essential that clinicians develop a partnership and have the willingness to walk alongside the child and whānau throughout their journey. This commitment and partnership may open doors that enable whānau to feel able to access healthcare organisations and services, reducing inequities that currently exist.

Kotahitanga

Kotahitanga (unity) is a process where whānau come together as a collective and make unified decisions. This includes consideration of the child and their developmental needs, ensuring information and engagement are provided in a developmentally appropriate way. When tamariki, rangatahi, whānau and health professionals are all aligned, and on the same page, a powerful partnership and team can be developed. This approach ensures that the child remains at the centre of decision-making and the very best care can be provided to child and whānau.

Clinicians must be prepared for some discussion and debate. This is a positive and respectful process that ensures everyone has a voice and has the opportunity to hear from the child, whānau and health professionals. Bringing everyone together allows the space for past issues to be acknowledged and mamae (emotional pain) to be expressed while working towards kotahitanga (consensus through unity).

In whānau hui (family meetings), it is important to realise that silence does not always mean agreement. Whānau may feel overwhelmed or stressed and may not be able to voice their thoughts or opinion. A skilled community leader or Māori health worker who is fluent in te reo Māori (Māori language) and experienced in working with Māori communities may be helpful in supporting a whānau hui and kotahitanga processes.

Wairuatanga

Wairuatanga is Māori spirituality in all its forms. Spirituality is a critical component of care provision to any child with serious illness and their whānau. Navigating serious illness and dying is a spiritual matter for the child and their whānau.

Health professionals who provide care that acknowledges the child's physical, spiritual and psychological needs, whānau and community thereby provide care for the child's mauri (life force, vital essence) and their whānau. When health professionals demonstrate manaakitanga (hosting, caring) to children and whānau during challenging times, their aroha (love) can really support whānau to feel held and cared for. Together, these things contribute to good spiritual care.

In Māori culture, it is understood that birth and death are part of the cycle of life. The wairua (spirit) of the pēpi or child travels through the portal separating the physical and metaphysical worlds, where they will arrive at their spiritual home. Traditional whānau acknowledge Hine-Nui-Te-Po (the Goddess of the underworld), who waits to greet her children as they leave the physical realm. A pēpi or tamariki who dies passes through the ārai (veil) to the loving arms of their tīpuna (ancestors). The spirit is said to return to Hawaiki (ancient spiritual homeland), while others may reference the wairua's journey to a heavenly realm. Regardless of spiritual faith, there is a belief in the eternal wairua and its reconnection with tīpuna (ancestors). This belief brings enormous comfort to whānau, knowing their pēpi is with their tīpuna and they will see their child again.[73]

Every tamariki and whānau will have different beliefs, values and spiritual rituals that they use when a child is seriously unwell or nearing the end of life. Being able to identify spiritual concerns or distress is very important. Facilitating conversations about any worries or concerns and offering opportunities for further discussion about what the future may hold can be helpful for whānau. Discussing ACP with the child and whānau before imminent death can help prepare whānau for what lies ahead and ensuring the wishes of the child and whānau are respected.

It may be helpful to involve a local kaumātua (older man) or kuia (older woman) in these discussions. Whānau may have already established connections within their whānau or community. It is important to be mindful that Māori whānau may have lost connections with their marae (ancestral home) and tikanga (customs). At challenging times like these, whānau may look to reconnect with their Māori culture and require guidance regarding this. Every health organisation in Aotearoa should have access to Māori cultural support so whānau can be connected with appropriate spiritual and cultural support.

The practice of karakia is a critical healing resource upon which many whānau rely. Space and time should be available for karakia and waiata (singing) at the opening and closing of all whānau hui. A whānau member may conduct this, but health professionals should also be willing to lead karakia in a hui if the whānau want this. It is recommended to talk with your local Māori health team or iwi for support to identify appropriate karakia and waiata for your local area.

Rangatiratanga: Whānau

Rangatiratanga is the ability for whānau to have self-determination over their child's and whānau's wellbeing and health. This is critical in paediatric palliative care—it enables both the child and whānau to have a voice and to be cared for in a way that aligns with their beliefs, values and tikanga. It is important that assumptions are not made, and whānau are asked what is important

to them and how health professionals can support them to navigate the care of their seriously ill or dying child.

Māori tikanga at the end of life may include whānau gathering in large numbers when a child is approaching death and the journey through the ārai (veil). It is important that whānau are accommodated by having large spaces available in which to gather. This will help whānau to carry out their cultural care customs; these practices will typically include family gathering at the bedside with the child, karakia, waiata, kōrero (conversation) and, later, sharing of kai (food). Kai is usually shared away from the dying child.

Many whānau like to have water (that has been blessed) available outside their room or outside the building so they can observe the cultural practice of whakawātea (spiritual cleansing rituals). This ritual clears any unwanted spiritual energy, returning the environment and space to its original state.

After death, once the tūpāpaku (child's body) has been removed from the room, the tapu (spiritual restrictions) are lifted via karakia (prayer). This helps to free the whānau of unwanted energies associated with illness or death. Many whānau will wish to take the tūpāpaku home with them and then travel on to the whānau marae (ancestral meeting house). Tangihanga (funeral ceremony) is usually held over several days at the whānau marae and typically involves the burial of the tūpāpaku in the tribal urupā (burial site). For many whānau, this can involve significant travel to another part of Aotearoa, which can take time and incur travel costs.

Refugees and asylum seekers

Some patients from CALD backgrounds may be refugees or asylum seekers.

A refugee is defined by the 1951 United Nations Convention as:

> someone who is unable or unwilling to return to their country of origin owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion.[74]

Caring for the child of a refugee family with an LLC requires an additional level of cultural sensitivity and understanding of the associated physical and emotional trauma that families may present with.

Refugees often arrive in Australia or New Zealand following many years in refugee camps or detention. Often, they have had little access to healthcare, sometimes resulting in negative health outcomes. Refugees may feel extremely isolated, having lost their extended family, housing, income and position in society, employment, social support systems, cultural norms, religious customs and language. These issues may lead to a disconnection with cultural and religious support. However, families often seek comfort in specific rituals in the terminal phase, and we should do our best to understand and facilitate their wishes, if possible.

Associated risk factors for refugees include psychological trauma following the separation, loss or death of family and friends, leading to increased risk of mental illness, post-traumatic stress disorder, anxiety and depression. Refugee parents and siblings of a child with an LLC are at particular risk of complicated grief. Therefore, culturally sensitive psychosocial care should be

introduced early in the child's palliative care trajectory to ensure families are linked to appropriate mental health care and ongoing bereavement care following the death of a child.

Refugees and asylum seekers usually lack knowledge of our healthcare system.[75] They may have unrealistic expectations of the health system and hope we can prevent the death of their child. Alternatively, there may be trust issues regarding people in authority, including health professionals, who may have been involved in the administration of torture in their country. Consideration should also be given to literacy skills and ensuring the use of interpreters while being mindful of social and linguistic complexities.

Caring for refugee families in a holistic way involves acknowledging cultural, linguistic and health-related issues specific to each family. Collaborating with the family's refugee support workers, with the family's permission, can be beneficial when plans are being made regarding how best to manage a child's progressive illness. For further information, contact your local Refugee Health Network.[76-83]

LGBTQIA+ people and families

LGBTQIA+ refers to people who are lesbian, gay, bisexual, transgender, queer, intersex, asexual or those who have a diverse gender identity or sexual orientation. This is a diverse group of people who all have their own unique life experiences. Caring for a child who is LGBTQIA+ or belongs to an LGBTQIA+ family requires an understanding of their specific care needs—this will lead to people feeling understood, respected and included.

To understand the needs of LGBTQIA+ families, it is vital to have knowledge and understanding of the barriers LGBTQIA+ people face when accessing palliative and end-of-life care. These include:

- **Discrimination in healthcare settings:** assume that families could include LGBTQIA+ people and that they may have previously been subject to harm and discrimination within the healthcare system.
- **Heteronormativity:** this is the unconscious bias that assumes all patients are heterosexual, cisgender (not transgender or gender diverse) and endosex (not intersex).
- **Failure to recognise partners and families of choice:** this may include biological family members or may not. Families who include LGBTQIA+ parents may relate to the term 'Rainbow Family'. Healthcare providers can sometimes prioritise biological family members over a child's LGBTQIA+ parent or family members. To build trust with LGBTQIA+ families, healthcare providers must respect the identity of the child's LGBTQIA+ parents and include them in all aspects of their child's care, including any healthcare decisions that are required for the child accessing palliative care.

If you are unclear about how the existing laws on decision-making in your state apply to LGBTQIA+ parents, educate yourself so that you can provide clear advice.

For more information, you can visit LGBTIQ Health Australia

www.lgbtiqhealth.org.au

Building Community Capacity

When a child becomes seriously ill, the impact of illness is not only present for the child but also experienced throughout their family and wider network of relationships. A family's experience of living with an illness is affected in ways that can either support or compound illness, according to the health or resilience of all domains of family life: social, spiritual, psychological, emotional and the community in which they are embedded.

For families caring for a child with palliative paediatric care needs, although professional health services form a vital and often necessary part of the overall support network, it is important for professionals to remember that health is only one domain of a family's social network.[84]

'It takes a village to raise a child'—as health professionals, it is vital and beneficial for us to recognise the role played by 'other parts of the village', including schools, neighbours, friends, relatives, community groups and sports clubs. These networks, if nurtured and equipped by community enablers, can provide everyday social care, such as meal delivery, a quick shop, a listening ear or childcare support for siblings. In this way, they can play a significant role in contributing to an overall sense of health, belonging and wellbeing.

Recognising the role that all areas of community play in supporting individuals and families living with death, grief and illness is at the centre of a range of emerging approaches to palliative care.[85] Such approaches expand the approach of *family-centred care* (which is foundational across paediatrics) to encourage a further broadening of perspective to what we can call *network-centred care.* Over time, building capacity in communities through community engagement and community development will enhance the support families will be able to access through their social networks.

Exploring Examples of Capacity Building Approaches

Increasingly, the role that the wider community hold in supporting a family and child living with a LLC is not only being recognized as a key source of strength and resilience, but is being included in the broader picture of a family or child's experience of care by inter-disciplinary approaches to PPC. For example, Public Health Approaches to Palliative Care are established both internationally and domestically along with capacity building approaches under the broader banner of Compassionate Communities.[86-88] Both utilize Community Development approaches to increase the resilience of support networks, capacity, and quality of life for members of the community who are living with illness, death, or bereavement.

Further information can be found in some of the following national and international examples of Community Development Work, and their application to Palliative Care:

Community Centered Approaches to Palliative Care Resources:

- **Public Health Palliative Care International (PHPCI):** fosters networks of collaboration, support to encourage research and evaluation of health promotion in palliative care.
- **Healthy End of Life Project (HELP):** La Trobe University – an evidence based PHPC resource[89]
- **The Groundswell Project:** Compassionate Community program development, education, and advocacy organization[90]
- **Compassionate Communities:** An implementation guide for community approaches to end-of-life care[91]

Schools

Apart from the family, preschool, kindergarten, special schools and regular schools are generally the most significant part of a child's community. Schools are extremely significant learning environments not only in academic terms but also in terms of life skills. More importantly, in the context of palliative care, schools are nurturers of children's social and emotional wellbeing; they are also places where many meaningful peer relationships occur. They are also the places where the most significant extra-familial child–adult relationships tend to occur. For many families, the relationships associated with school are also a major part of the parents' social network.

Interventions in this setting generally take at least three forms:

1. renegotiating: assisting the school and family to renegotiate the nature of their relationship, particularly to recognise the need for adjustment of the nature of and time spent at school and for the increased significance of emotional care and support
2. care of the child and siblings: assisting the school to develop skills to care for the child and siblings in the palliative phase of an illness and support the siblings in their bereavement after a child has died
3. care of staff and students: assisting the school in developing skills to care for all the staff and students through the grief and anticipatory grief associated with the palliative care and death of an important member of its community.

Renegotiating the relationship with the school

As with all areas of psychosocial support in palliative care, renegotiating the relationship between the family and the school occurs most effectively if done intentionally. Consequently, it is best if the school and the family have a shared understanding of what the family needs and what the school can offer.

For schools where a student has had a long-term illness, a well-thought-out plan is often already in place, and the child's anticipated deterioration will be part of this plan. At this point, however, many schools request a meeting that includes the child's family, relevant school staff and the palliative care service to ensure the best care, as well as maximising the time the child can spend at school.

Renegotiation will vary from family to family and school to school. Some schools and families have wonderfully open and supportive relationships established long before a child commences palliative care. Others may have given the situation surprisingly little consideration and have minimal communication, coordination and intentional support in place. Some families wish to maintain their privacy during this time and may not be open to sharing many details about their child's health with the wider community. It is always important to seek consent from families regarding the type and amount of information they wish to have shared.

Schools will have varying experiences with supporting children and families with death and dying. Health professionals can help in assisting schools to identify the family's needs and may, at times, need to advocate with or on behalf of families. Many families will be able to liaise directly with the school to set goals and problem-solve the issues. At other times, it may be appropriate for the health professional to be involved in these processes.

Key considerations include:

- maintenance of important relationships (e.g., friendships with the dying child where appropriate)
- maintenance of normality and routine for the child and siblings, as much as possible
- specific support regarding particular needs
- consideration of flexible attendance arrangements or options for engagement if required
- identification of a key contact person to be in regular contact with the family.

The relationships with the child's close friends may continue at home if the child is unable to attend school, with guidance and support from school staff as well as negotiation with the family.

Examples of specific things that schools can do include:

- enable sick children to attend school flexibly, such as for their favourite classes or lunch breaks
- ensure that students keep in contact with sick children who can no longer attend school through home visits, letters, videos or the internet (e.g., video calls, email)
- have a clear plan for getting messages to siblings quickly so they feel confident that they can be contacted when needed
- keep any schoolwork or artwork completed by the child and make this available to the family; this becomes a component of memory making
- invite siblings into the child's class for activities
- consider e-learning opportunities if appropriate.

Care of the child and siblings

School staff have high levels of skill in communicating with children; however, they often find it confronting to address issues surrounding palliative care. The role of a health professional is to:

- affirm the skills possessed by the school and its importance to the family
- assist the school in communicating appropriately and with family permission with the wider school community
- assist school staff to understand palliative care issues and grief processes, including how to use this knowledge in their interactions with the child and siblings
- work with the school social worker, psychologist, chaplain or wellbeing officer to enhance sibling support, if appropriate.

The principles provided in the sections 'Psychosocial Foundations of Palliative Care', 'Grief and Anticipatory Grief' and 'Communicating with Children' form the primary content required by schools to achieve this.

Care of staff and students

How a school manages the palliative care and death of one of its students will form an important model for the student population regarding death and loss throughout their lives. School staff who are aware of this generally adopt the responsibility of normalising the experience.

Schools have the multiple responsibility of providing appropriate care to the child who is dying and their siblings and to other students and staff at the school. This is a daunting task for every school; however, by working together, schools and palliative care professionals can make a positive impact. Most schools greatly appreciate the support and guidance experienced paediatric palliative care professionals provide.

It is important to acknowledge this expertise and recognise that the health professional's role is to provide specialised input that can be used in planning care for staff and students. Much of the input is the same or similar to that provided in caring for the child and siblings.

Two of the most crucial issues are:

1. planning for how the school will communicate to staff, students and parents
2. identifying people who are likely to require increased care.

For example, in deciding how to communicate to students, and in consultation with the family's wishes and direct consent, the school must decide what information would be best communicated to the whole school on assembly and to the greater school community, as well as what should be communicated in the smaller setting of the classroom or even on an individual basis.

Generally, information that may be distressing should be communicated sensitively, allowing a more individualised response to their needs. In the classroom, a teacher is more likely to observe which students are upset, compared to in an assembly, and it is easier to give children the opportunity to ask questions and express feelings.

At a class level, there are many things that teachers can do to facilitate communication of feelings and enable children to understand what has occurred. For example, in the class of the child who has died, issues such as what to do with the child's desk can be discussed by the class and decisions made that meet the needs of the students. Similarly, students can be given opportunities to write farewell letters or tributes, have discussions and make artwork to express thoughts and feelings.

At the whole school level, decisions such as whether to have a memorial service must be made. Most schools find that memorial services and involvement in the funeral (if appropriate and acceptable to the family) are helpful events for the school community. The school could consider long-term memorials for the child (e.g., a tree planting, bench seat with associated plaque and dedications), which provide a focus for a shared acknowledgment of the school's grief and the importance of the life and death of the child to the school community. The school should always consult with the family of the child who has died about wishes for the timing and the nature of the service.

Across a school, there will be a spectrum of impacts regarding the illness and death of a student. Some students will be affected greatly, while others will only be affected minimally. With this recognition, schools should identify staff and students who may be at risk of stronger reactions to

the situation and require special care or, at least, a closer level of caring observation and support. Their needs should also be considered when planning how communication will occur in the school.

People (staff or students): who may be at increased risk are:

- those who have already experienced significant loss in their lives (e.g., the death of a loved one, divorce, trauma, refugee status)
- those who have a close relationship with the child who has died or the siblings
- those who have similar health problems themselves or in their family.

Predicting who will ultimately struggle the most with a death is impossible. Consequently, teachers must be aware of the students for whom they have responsibility and allow opportunities for them to express their feelings and concerns so that difficulties can be identified and responded to.[92] Staff should also always be responsive to signs of distress in their colleagues (*see* chapter 'Clinician wellbeing and moral distress').

Teachers supporting students at school - Paediatric Palliative Care

https://paediatricpalliativecare.org.au/resource/teachers-supporting-students-at-school/

Symptom management

This chapter aims to provide an outline of the more common symptoms experienced by children with an LLC and a guide to the possible approaches to management.

Symptom management can be broadly divided into five stages:

1. accurate history and assessment
2. identification of the cause (if possible) of each symptom
3. ongoing communication with the child and family
   - explanation of symptoms and treatment options
   - establishment of goals of therapy
4. implementation of therapy
   - treatment of underlying causes
   - pharmacological, physical, psychological and complementary therapies
5. regular review and modification of treatment and management.

To optimise quality of life, a knowledge of the underlying disease process and anticipated symptoms is required, as well as an understanding of the family dynamics and likely goals and needs of the child and family. How the care of a child and the family is approached will greatly influence the quality of the child's remaining life and the ability of the parents, siblings and friends to cope after the child's death.[93]

The approach must be individualised, considering an often-complex set of circumstances unique to each child's clinical and social or cultural situation. Hunt (1990) analysed the most common symptoms experienced by children dying from various conditions within a children's hospice, finding that more than 80% of patients had pain recorded as a symptom in the last month of life and over one-third of children experienced constipation. A more recent study found lethargy and drowsiness to be the most common symptom, more commonly experienced in the hospital ward compared to the ICU. Other symptoms experienced by dying children include dyspnoea, nausea and vomiting, excess airway secretions, dysphagia, anorexia, agitation and irritability, psychological distress, skin changes, seizures and peripheral oedema.[94, 95]

Non-pharmacological interventions for symptom management

Non-pharmacological interventions are valuable for symptom management (including pain) in paediatric palliative care. These interventions traverse physical, psychological and creative domains, have a high safety profile and are often relatively inexpensive.

A range of physical and psychological (or mind–body) therapies are used in managing various types and locations of pain. Fear, anxiety and other existential concerns will aggravate pain. Communication with the child and family about their pain and these other concerns will assist in both assessing and managing pain. These non-pharmacological (or integrative) measures can allow control to be regained and will often assist in 'total' pain relief for the child.

Developmentally targeted non-pharmacological interventions have the following benefits:

- empower parents with strategies to assist their child
- provide the child with a sense of control
- reduce fear, distress and anxiety
- teach and enhance positive coping strategies for the child and family
- offer relief from unpleasant symptoms
- assist tolerance to and reduction of the distress of pain and other symptoms.

Physical (sensory) interventions

- **Massage** and comforting touch can be provided by family and carers. Benefits include reduced stress (for the patient and caregiver), promotion of muscle relaxation, lowering of blood pressure and improvement of circulation. This can decrease pain and anxiety and improve mood and quality of life.
- **Positioning** may help to relieve muscle pain, tension and discomfort. Correct positioning and optimal repositioning support comfort and function. Specialist support and prescription of equipment for positioning can be accessed via occupational therapists or physiotherapists.
- **Fans** directed at the upper part of the face can reduce the sensation of breathlessness and are free of side effects.
- **Hot and cold packs can be** used carefully and safely to locally soothe sources of pain and provide general reassurance.
- **Vibration devices** may be used topically for procedural pain support (e.g., to reduce discomfort during cannula insertion).
- **Hydrotherapy / aqua therapy** uses low-impact and gravity-free movement in water to improve physical and mental symptoms.
- **Neurostimulation:** transcutaneous electrical nerve stimulation (TENS) may be useful for pain relief in older children. TENS uses small electrodes placed on the skin to stimulate the nerves. A physiotherapist can educate the family on how to use a TENS device.

Psychological (cognitive and emotional) interventions

Anxiety and distress can exacerbate children's physical symptoms. Common psychological interventions aim to alleviate these psychological symptoms, reducing pain intensity and improving patient quality of life.

- **Mindfulness (meditation)** is a reflective practice encompassing a moment-by-moment awareness of thoughts, feelings and body sensations. It may be a useful technique for relaxation and calming in older children and parents.
- **Talk-based therapies** can be provided by counsellors, psychologists and other trained clinicians. Examples include cognitive behavioural therapy and acceptance and commitment therapy. These interventions may be useful for older children and parents.
- **Guided imagery** is a facilitated meditation practice that can encourage relaxation and positive emotions.
- **Progressive muscle relaxation** is a guided meditation technique where the child tightens and relaxes different muscle groups progressively throughout the body, invoking a sense of relaxation and comfort.
- **Hypnosis** has various definitions but can be understood as an alternative state of awareness and attention. This state can be spontaneous or 'induced' for the purposes of accomplishing a specific therapeutic goal (e.g., reducing a discomfort, coping with stress, falling asleep more easily). Hypnotherapy combines hypnosis with talk-based therapies.[96]

Creative interventions

Creative interventions give children developmentally appropriate means to explore, understand and process the experiences they face with an LTC or LLC. They also provide distraction, joy and pleasure; through this, they can have a profound effect on symptoms, relationships and quality of life. These interventions are also important considerations in legacy creation, bereavement support and memory making.

Registered music, art, play and child life therapists may utilise the following interventions in their clinical practice:

- **Music therapy**, whether by active music making or reflective listening, has the capacity to offer joy, meaning, pleasure and 'normalcy' to the child and family and often helps to alleviate suffering.
- **Art therapy** provides the opportunity for communication and reflection through self-expression. Fostering self-expression assists individuals in exploring emotions that improve self-awareness and wellbeing, in addition to developing coping skills that may assist in reducing symptom intensity.
- **Play/child life therapy** is a kind of child-centred therapy that uses play activities, both narrative and non-verbal, to allow a child to express themselves and make sense of life experiences.

While the above interventions are commonly seen in paediatrics, there are many more with varying degrees of evidence not included here. Further interventions include:

- spiritual practices (*see* section 'Spiritual and cultural perspectives')
- virtual reality
- yoga / tai chi
- animal-assisted / pet / equine therapy
- hypnosis / hypnotherapy
- aromatherapy
- acupuncture / acupressure
- reiki therapy.

Non-pharmacological approaches to symptom management make an important contribution to the comfort and quality of life of children with palliative care needs, alongside medications. Encouraging open conversations regarding these therapies is important to enable a personalised approach to each child's symptom relief. Some therapies may be more accessible depending on where patients are geographically located.

Before initiating any of these therapies, the child's treating teams should be consulted to ensure there are no physical, psychological or practical contraindications to the therapy and to assess the benefits and burdens of these interventions for the child.

Pain

Pain is a common symptom in children with LLCs. Opioids are the cornerstone of pain management in this context, particularly during end-of-life care. Many children require opioid analgesia throughout the palliative phase of their illness.[3]

The fear of uncontrolled pain is recognised as a source of anxiety for both children and their families.[97] Anxiety and other psychosocial factors contribute to the total pain experienced by the child and family; these should be acknowledged and managed. The approach to pain management of the child and family involves knowledge of the underlying disease, understanding of the prior treatment or management, and understanding of the child and family's responses to treatment and their transition from a curative to palliative focus.

Dispelling myths about pain

Myth: *Young children and infants experience less pain than adults*.

Truth: Similar myths suggest that children tolerate pain better and rarely require opioid analgesia. Many clinical studies have challenged these 'beliefs', demonstrating that neonates, infants and children experience similar pain to adults.

Myth: *The child will become addicted to opioids.*

Truth: One of the major concerns for both family and health professionals is addiction to opioids. It is important to dispel this fear early in the treatment course. Addiction is predominantly a psychological dependence, and patients with an LTC or LLC (e.g., progressive cancer, severe cerebral palsy) who require titrated doses of morphine due to underlying or progressive pain do not become addicted to opioids.[98] Tolerance to the analgesic effect of opioids (e.g., morphine) is not a common problem, and psychological dependence in patients receiving palliative care is rare. Parents should be reassured in this regard.

Myth: *It is not appropriate to use opioids for non-cancer conditions.*

Truth: Many patients with non-cancer LLCs may benefit from a trial of carefully titrated opioid analgesia. However, patients with a non-cancer diagnosis often do not require the rapid dose escalation required by a child with a rapidly progressive cancer (e.g. solid tumour).

Myth: *Medications such as opioids will cause sedation and affect the child's quality of life.*

Truth: Temporary somnolence or sedation from opioids will usually improve within a few days of initiation because the child will develop tolerance to the central nervous system (CNS) depressant effects of morphine over time.

Myth: *Using opioids will result in respiratory depression*.

Truth: Respiratory depression can be avoided by titrating opioid doses with gradual and steady increases as needed by the patient. Like the CNS depressant effects, children will develop tolerance to the respiratory depressant effects of morphine. Relatedly, the use of opioids in adult patients with advanced chronic obstructive pulmonary disease (COPD) was found to relieve dyspnoea and improve sleep—it did not worsen respiratory failure.[99]

Myth: *Using opioids will shorten the child's life.*

Truth: Pain control does not shorten a child's life. Rather, it improves the child's quality of life and brings comfort to a child's death. It can even extend a child's life because they are not exhausted from fighting pain. The dosage can also be reduced or increased depending on how the child and disease progress. A study of adult patients found that the use of opioids and sedatives was not associated with shortened survival.[100]

Assessment of pain

Pain evaluation is the foundation of good pain management and involves a detailed pain history, examination, diagnosis of the causes and subsequent measurements of pain. Evaluating pain in a child is significantly different to evaluating an adult's pain. It depends on the child's age, developmental stage, cognition and previous life experiences. As a child's vocabulary and past experiences may be limited, obtaining qualitative and quantitative descriptions of their pain may be difficult. The use of several different parameters is often helpful in determining the position, nature and severity of pain. Simple observation of the child's activity level and behaviour compared to what is normal for them may be useful.

Any behaviour change, such as irritability, fractiousness or withdrawal, may indicate discomfort. The Face, Legs, Activity, Cry, Consolability (FLACC) scale allows observation of such parameters and has been validated as a means of measuring pain in infants and children younger than four years of age.[101] Assessment in older children can be enhanced with the use of visual analogue tools, including the Faces Pain Scale (revised):

***Pain Scale*: Faces Pain Scale - Revised - International Association for the Study of Pain (IASP)**

iasp-pain.org

These scales share a common metric (generally 0–10). Pain scores fall into three ranges:

- mild (0–3)
- moderate (4–6)
- severe (7 or more).

The Non-Communicating Children's Pain Checklist can be used for children with cognitive impairment, and there are a variety of scales used for neonates (e.g., the CRIES pain rating scale).[102, 103] The use of a body outline completed with the child and parent may also aid in determining the position of the pain, and intensity can be highlighted using different shades of colours.

Aetiology of pain

Invasion of bone and bone marrow is the most common cause of pain in children with cancer and is typical of somatic nociceptive pain.[104] Other causes of pain in the child with cancer are shown in Table 3.

In children with non-cancer diagnoses, pain is often multifactorial. Musculoskeletal causes are common in this group of patients (e.g., scoliosis, dislocated hips, osteoporosis, fractures). Pain due to dystonia, muscle spasms or gastrointestinal dysmotility is also common. Pain may also

be associated with orthotic devices and can increase around the time of orthopaedic and other surgeries. Differentiating between cerebral irritability and pain can be challenging in a child with a developmental disability.

Pain can be classified by its origins and pathway of transmission to the brain into three broad categories: nociceptive (somatic and visceral), neuropathic and nociplastic.[104, 105] The most common pain encountered in paediatric palliative care is nociceptive or neuropathic pain. Nociplastic pain arises from altered nociception despite no clear evidence of actual or threatened tissue damage causing activation of peripheral nociceptors or evidence for disease or lesion of the somatosensory system causing the pain. Patients can also experience a combination of nociceptive, neuropathic and nociplastic pain. There can also be central and peripheral components to neural signalling associated with pain. Details of these categories and the pathways are beyond the scope of this guide, but different mechanisms and pain characteristics may occur.

Table 3 **Aetiology of cancer pain**

Tumour involvement
Direct tissue / nerve damage
Bone marrow infiltration
Infiltration of tissues
Compression of tissues
Nerve compression
Raised intracranial pressure
Treatment-related
Infection due to immunosuppression
Mucositis related to chemotherapy and radiotherapy
Inflammation after surgery
Procedure-related
Venepuncture
Surgical interventions
Investigations (e.g., lumbar puncture, bone marrow aspirate)

Principles of pain management

Pain management aims to relieve pain at rest and during activity and to ensure comfort during sleep with minimal side effects. To achieve this, the same general principles of symptom management are applied.

The World Health Organization published ‘Guidelines for the Management of Chronic Pain in Children’ in 2020. The guidelines emphasises pain management as a fundamental human right. The guideline focuses on the physical, psychological and pharmacological interventions for managing primary and secondary chronic pain in children aged 0–19 years. Although they

focus on children with chronic pain, and is limited by available scientific evidence, the guidelines nevertheless offers helpful guidance for managing pain in children with LLCs (including cancer) and those receiving end-of-life care.

Pharmacological therapy (including opioid medicines such as morphine) is often the mainstay of treatment in children's palliative care. With the prescription of the correct medicine, dose and interval, effective pain relief is possible for most patients.[106]

The World Health Organization guideline has been updated over time.[106-108]

The recommended best practice for treatment is to keep it simple and to administer the desired medication(s):

- **by the mouth:** the oral route (where possible) is convenient, non-invasive and cost-effective
- **by the clock:** regular scheduling ensures a steady blood level, reducing the peaks and troughs of as-required (p.r.n.) dosing
- **by the ladder:** enabling a stepwise approach to treatment, commencing at an appropriate symptom level with non-opioid analgesia and progressing to opioids if/when needed (*see* Figure 8).

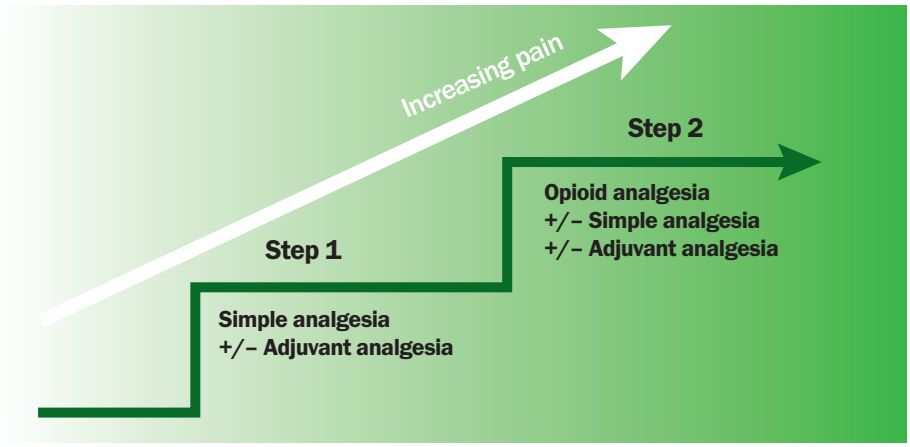

Figure 8. **Pain management ladder.**

Treatment should be individualised according to the child's pain and response to treatment and frequently reassessed and modified as required. There should be a focus on quality of life, and the ladder can be used bidirectionally (either titrating increasing doses if needed or sometimes even decreasing or weaning medicines, where possible). A multimodal approach to pain management has recently been advocated as best practice.[109]

Analgesic agents

Analgesic medications can be broadly classified into two groups:

1. primary analgesics
   - simple analgesics (paracetamol, non-steroidal anti-inflammatory drugs [NSAIDs])
   - typical opioids (oxycodone, morphine, fentanyl, hydromorphone)
   - atypical opioids (tramadol, tapentadol, buprenorphine)
2. adjuvant analgesics (or secondary analgesics)
   - antidepressants
   - anticonvulsants
   - corticosteroids
   - antihypertensives.

Treatment can be directed to both the nature and severity of pain. There may be more than one cause of pain; on occasion, the specific cause or aetiology may not be obvious. Simple analgesia can be used for mild pain and concurrently with opioids for more severe pain. Low doses of opioids can be used for moderate pain, and increased doses of opioids used for more severe pain. This approach also advocates the early introduction of adjuvant medicines for neuropathic or complex pain when appropriate. Adjuvant analgesics are medicines with a primary indication other than pain that have analgesic properties in some painful conditions. Non-pharmacological approaches (including integrating cognitive behavioural and physical interventions) should be used concurrently with pharmacological interventions.

Primary analgesics

Primary analgesics are divided into the following categories: simple analgesics and opiods (both atypical and typical).

Simple analgesics

Paracetamol (acetaminophen)

The sensory input of pain may be reduced by administrating regular paracetamol. It has a mild anti-inflammatory effect and may be useful for musculoskeletal pain in particular. It is also an effective antipyretic. Paracetamol is generally well tolerated by children and is available in oral (tablet, capsule, syrup; various concentrations available), rectal and parenteral formulations. It is the preferred non-opioid analgesic for children. Some families may already be using preparations combining paracetamol with codeine. Careful explanation regarding the use of regular paracetamol with combined agents is required to ensure adherence to recommended daily limits. It is recommended to avoid combined agents; it may be preferable to use low dose morphine syrup and regular paracetamol instead.

Paracetamol used in conjunction with an opioid is a simple example of the multimodal approach to pain management.

Care should be taken when prescribing paracetamol for chronic pain beyond an acute illness (e.g., 48–72 hours). Hepatic toxicity has been reported in children following chronic therapeutic dosing.

Non-steroidal anti-inflammatory drugs

NSAIDs are weak primary analgesic agents whose main action is to suppress inflammation via anti-prostaglandin activity. Examples include naproxen, ibuprofen and diclofenac. They are effective at reducing fever and bone pain. However, they may have significant side effects, including gastric irritation and ulceration. They may also interfere with platelet function and should be used cautiously in children who are thrombocytopenic because the risk of bleeding may be increased. Caution should also be used when prescribing these medications to children who are dehydrated, or have renal impairment or pre-existing gastric irritation. For these reasons, NSAIDs may be contraindicated for some children, although they are part of the first step of the pain management ladder.

COX-2 inhibitors, such as celecoxib, suppress the pathway that causes inflammation and pain but not that which causes gastrointestinal and platelet function. In this context, there are some clinical situations where these medicines may be considered, although there is limited safety and efficacy data in children[110] (e.g., about long-term cardiovascular effects). Aspirin is generally not prescribed to children due to its association with Reye's syndrome.

Oral opioids

Opioids are the mainstay of treatment for most patients with severe pain associated with cancer and other LLCs. If pain is not controlled with paracetamol or other simple analgesic agents, morphine is a well-established first line opioid in children. Codeine is not recommended due to its ceiling analgesic effect. Codeine can also cause significant constipation. Further, a small percentage of the population does not metabolise codeine adequately to provide effective analgesia.

Achieving the right opioid medication or dose for a child involves the following steps:

- **Initiation phase**: the starting dose in an opioid-naive child is usually calculated per kilogram of body weight (max of 50 kg; see formulary).
- **Titration phase**: the opioid dose is titrated in a stepwise approach until the correct dose is achieved (e.g., to provide the best possible analgesia for a particular child with the least associated side effects). The maximum dose increase at any one time should be equal to 30–50% of the previous total daily dose; however, experienced practitioners may increase doses more rapidly with careful monitoring and repeated pain assessments.
- **Maintenance phase**: when a particular opioid dose provides adequate relief of pain. A short-acting opioid may be converted to a long-acting opioid preparation at this point (if available or convenient for the child and family).
- In addition to a long-acting opioid preparation, additional doses for 'rescue' analgesic medication should be prescribed. A 'rescue' or p.r.n. dose is calculated as 1/6–1/10 of the total daily opioid dose.

Morphine

Morphine remains the standard against which other opioid analgesics are compared. Morphine is available in oral or enteral (mixture or syrup in various concentrations, tablets, and immediate and slow release formulations), parenteral, intrathecal and rectal preparations. Where possible, the oral or enteral route is the preferred route of administration as it is readily absorbed and tolerated by most children. Liquid or syrup morphine, in the appropriate dose, provides approximately 4–6 hours of pain relief and should be prescribed as a regular dose every four hours.

There is no role for solely p.r.n. dosing for the palliative patient with an ongoing cause of pain. End-of-dose breakthrough pain is distressing and more difficult to control as the plasma drug level falls. Continuous or long-acting preparations in this situation are preferable and will provide more effective pain relief for patients.

Severe pain that is not adequately controlled with a commencing dose of morphine orally or enterally is an indication to increase the patient's dose. Incremental increases of 30–50% per dose may be required within 24 hours, or a shorter period, if required. Once the appropriate 24-hour dose of morphine is determined, conversion to a sustained release morphine preparation is possible. The slow release preparations, available in tablet and capsule form, have a slower onset of action than immediate release morphine preparations but a longer duration of action. Although available previously, a syrup or granule preparation of morphine that can be administered orally or into nasogastric (NG) or gastrostomy tubes is no longer available in Australia and New Zealand.

A 24-hour sustained release dose of morphine is determined by calculating the total daily amount of morphine (i.e., 6 x immediate release dose). Immediate release morphine should be available for 'breakthrough pain', which may occur. The 'breakthrough' dose is equivalent to 1/6–1/10 of the total daily dose. Breakthrough pain is covered in more detail in the following pages.

If repeated doses of breakthrough morphine are required, this is an indication to increase the total daily dose of sustained release morphine to the equivalent total dose of morphine required in the preceding 24 hours. With an increase in long-acting, 'sustained release' morphine, the 'breakthrough' p.r.n. dose of morphine will also need adjustment. If greater than six breakthrough doses of opioids are required in a 24-hour period, this may be an indication to increase the background opioid dose by 50%.

Oxycodone

Oxycodone is a useful alternative to morphine and is available as tablets, capsules and syrup. It has a slightly increased potency compared to morphine in children. It may also have kappa-receptor agonist activity, which may help with neuropathic pain. Its oral bioavailability is higher than morphine (50–60%). It is available as a tablet (scored), capsules and syrup. The onset of action is approximately 20–30 minutes, making oxycodone a good option for breakthrough pain. Oxycodone may also be a good alternative to morphine when the side effects of morphine result in intolerable vomiting, pruritus or delirium. Slow release preparations of oxycodone are available in tablet form only and cannot be crushed.

Oxycodone-with-naloxone controlled release (CR) tablets are also available and provide equivalent analgesia to oxycodone CR tablets of the same oxycodone dose. The addition of the naloxone component reduces but does not eliminate constipation.

Hydromorphone

Hydromorphone is a derivative of morphine with a higher potency. The parenteral (i.e., intravenous or subcutaneous) formulation of hydromorphone is up to five times as potent as the oral formulation. Hydromorphone is available as a syrup and in tablet form.

Tramadol

Although not a pure opioid, tramadol can be effective for moderate to severe pain in older children. It is a weak mu-receptor antagonist and a serotonin and norepinephrine reuptake inhibitor. While not a first line agent, tramadol may have a role in certain situations. Care should be taken to avoid drug interactions, especially with selective serotonin reuptake inhibitors and tricyclic antidepressants. Tramadol may also lower a patient's seizure threshold.

Tapentadol

There is emerging research evidence of tapentadol's safety and efficacy in managing both acute and chronic pain in children. Tapentadol is a centrally acting synthetic analgesic combining both opioid and non-opioid activity. It comes in immediate release and sustained release formulations (tablet).[111]

Buprenorphine

Buprenorphine is a synthetic lipophilic opioid with 30–50 times the analgesic potency of morphine. Buprenorphine can be given via the parenteral, transdermal or topical and sublingual routes. Sublingual tablets of buprenorphine have a duration of action of approximately 6–8 hours. The lowest-dose patch of buprenorphine has the benefit of having a much lower morphine equivalent dose than the lowest-dose fentanyl patch and is applied every seven days. The patches are an easily administered option for low dose background opioid analgesia in a stable situation (e.g., in a child with severe neurological impairment with pain, musculoskeletal pain in a child with an LLC).[112]

In clinical practice, buprenorphine does not have a ceiling effect. However, a ceiling effect has been demonstrated for respiratory depression, resulting in an improved safety profile compared to other opioids (e.g., fentanyl). Buprenorphine's pharmacokinetic properties (e.g., faecal elimination) also allow its use in patients with renal impairment. However, buprenorphine has both opioid agonist and antagonist properties and may precipitate withdrawal symptoms in children dependent on other opioids.[113, 114]

Methadone

Methadone is a synthetic, lipid-soluble opioid. It has a chemical structure very different to that of morphine. Methadone acts on the mu-opioid receptor and antagonises the N-methyl D-aspartate (NMDA) receptor. Consequently, it is very effective at treating somatic, visceral and neuropathic pain. Methadone has a long half-life, with large inter-individual variability in its half-life (i.e., 3.8–62 hours). It can accumulate in plasma, which may cause severe somnolence that is slow to reverse. Therefore, patients must be observed closely when commencing methadone or rotating to methadone from another opioid.

Methadone also prolongs the QT interval through its effect on cardiac potassium channels. This may predispose some patients to arrhythmias, particularly when the parenteral formulation is used. Consequently, methadone is often reserved for patients receiving palliative or end-of-life

care where other methods of pain management have failed. The goals of care, including the risk of arrhythmia, should be discussed with the patient's family prior to commencing methadone.

Methadone is available in tablet and liquid formulations and has very high bioavailability (almost 100 %). The dose should be doubled when converting from parenteral to oral methadone. The starting dose for an opioid-naive patient is similar to that of morphine.[115] This frequency of dose can be continued until the patient becomes pain-free or starts to show signs of somnolence or mild sedation. At this point, the dosing frequency should be reduced to 2–3 times daily.

Calculating the dose of methadone in patients already established on another opioid is more complex.[116] This is because cross-tolerance with methadone will be low. The starting dose of methadone in this situation is usually 1/10 of the morphine equivalent dose. Because methadone has complex pharmacokinetics and is not frequently used in paediatric pain management, methadone should only be prescribed by experienced practitioners; further, it would benefit from further evaluation in clinical research settings.[116]

Parenteral opioids

If a child is unable to take drugs orally or enterally, alternative routes of drug delivery are available. MS Contin tablets can be given rectally, and morphine suppositories can be obtained. In the acute situation, subcutaneous injection of morphine is easily administered and has a rapid onset of action.

There is no role for intramuscular pethidine (or other intramuscular drugs) in the management of pain related to progressive illness.

If the oral or enteral route remains problematic, a subcutaneous opioid infusion (e.g., of morphine) is a simple and effective mode of drug delivery. Some children may already have a central venous access device (central line or port-a-cath), and morphine may be delivered intravenously through this device. Insertion of a central venous access device for pain management in certain situations may also be appropriate. Peripheral intravenous catheters may also be used, but subcutaneous delivery of opioid medications is as effective, easier to insert, less likely to tissue and need to be replaced—and thus preferable. The 24-hour dose of parenteral morphine is equivalent to 1/3 of the total oral 24-hour dose.

Fentanyl, hydromorphone, oxycodone and methadone can also be administered parenterally.

Fentanyl

Fentanyl is a lipophilic synthetic opioid and approximately 10–40 times more potent than morphine. However, it is less potent in neonates and smaller children. Like morphine, it has an affinity for the mu-opioid receptor and acts as a pure agonist. It is available in a transdermal formulation. Clinical studies in children have shown that transdermal fentanyl is an effective alternative to oral opioids, with fewer side effects (particularly constipation and nausea) and improved quality of life.[117-119] Its topical route of absorption removes the need for oral or parenteral administration.

Fentanyl is also absorbed well via the oral mucosal route providing prompt pain relief. Oral transmucosal fentanyl citrate (OTFC) lozenges and buccal tablets offer promise in providing non-invasive means of treating breakthrough pain. The use of intranasal fentanyl (using mucosal

atomiser devices) for breakthrough pain relief has been described in emergency departments, cancer pain relief and in neonates and infants.[120-122]

Refer to Appendix 7 for guidelines on commencing a subcutaneous infusion.

Side effects and precautions regarding opioids

All preparations of opioids have side effects. Constipation can be a major problem, and consideration should always be given to prescribing laxatives whenever opioids are used. Unlike many other side effects, particularly nausea and drowsiness, tolerance to constipation does not occur. Methylnaltrexone is a competitive antagonist for the mu-receptor. It works at the level of the gastrointestinal tract, does not cross the blood–brain barrier and can be administered subcutaneously.[123, 124] It has a role when children cannot tolerate or do not respond to enteral or rectal laxatives (*see* section 'Constipation').

Nausea and vomiting may occur upon initiating treatment with an opioid, and an antiemetic may be required. After administration of breakthrough doses of morphine, it is not unusual for mild drowsiness to occur; however, once a stable dose of morphine is achieved, this becomes less problematic, and children are likely to be more active and alert with good analgesic control (*see* section 'Nausea and vomiting'). Pruritus may also occur and may be relieved with the concomitant use of an antihistamine. Low dose naloxone infusions have also been used to prevent severe itch associated with opioid infusions.[125]

Opioids will cause respiratory depression only if given in an inappropriate dose, which is usually above that required for analgesia. This is particularly the case for opioid-naive patients. Extreme caution should be used in giving naloxone at a treatment dose to patients who have been receiving chronic opioid therapy, as severe pain and symptoms of opioid withdrawal may ensue.

Patients with significant renal impairment will accumulate metabolites of morphine. In this context, drowsiness and respiratory depression can occur after 24 hours. Careful supervision of dosing is required, and a lower initial dose should be prescribed and titrated according to the patient's response. Similarly, a lower initial dose should be used for children with liver failure as the bioavailability of morphine is increased in this situation.

Opioid rotation

It is possible to improve pain management by changing to a different opioid medication—this process is called opioid rotation. The usual indications for switching to an alternative opioid are:

- excessive side effects (e.g., itch, nausea, delirium) with adequate analgesia (70%)
- side effects with inadequate analgesia (17%)
- tolerance (7%).[126]

Alternatives to morphine include fentanyl, hydromorphone and sometimes methadone. A switch from one opioid to another is often accompanied by a change in the balance between analgesia and side effects.

Table 4 Conversion of morphine to fentanyl and hydromorphone assists with converting morphine to fentanyl and hydromorphone. Both background and bolus doses should be considered when switching opioids. Switching to methadone is more complex, as discussed above.

Table 4 **Conversion of morphine to fentanyl and hydromorphone**

Drug	Morphine	Fentanyl	Hydromorphone	Oxycodone
Relative potency	1	40[127]	5–7[35]	0.5–1.0
Example dose comparisons	4 mg	100 mcg (i.e., 0.1 mg)	570 mcg	2–4 mg

Opioid-resistant pain

While opioids are the gold standard for the treatment of cancer pain, not all pain is sensitive to opioids (*see* Table 5 Causes of opioid-resistant pain).

Table 5 **Causes of opioid-resistant pain**

Relative resistance
Under-dosing
Poor oral absorption
Lack of emotional support
Semi-resistant pain
Soft tissue/muscle infiltration
Bony metastases
Raised intracranial pressure
Neuropathic pain
Resistant pain
Neuropathic pain
Muscle pain

Relative resistance can be overcome by increasing the dose, improving support of the child and family or using an alternative route of drug delivery. The addition of an NSAID or paracetamol may alleviate pain related to soft tissue or bony metastases. Pelvic pain is also potentially difficult to control, and consideration of nerve blocks or palliative radiotherapy may be required.

Neuropathic pain tends to be relatively resistant to the above approaches and is due to the compression or infiltration of nerves or to neuropathy, which may be disease-related or treatment-related. For example, medications used in cancer (e.g., vincristine) and HIV therapy (e.g., didanosine, zalcitabine) can cause neuropathy. The nature of neuropathic pain has different characteristics and tends to be either spasmodic or shooting or continuous burning or piercing.

Abnormal sensations may also be present. Younger children often cannot differentiate between or precisely describe the different qualities of pain.

Breakthrough pain

When exacerbations of medium to severe pain occur against the background of otherwise reasonably well-controlled pain, this is commonly described as 'breakthrough pain'. There is a high incidence of breakthrough pain in paediatric oncology patients, with one study finding at least one episode of such pain per day in ~57% of patients.[128] This pain can last seconds to minutes and is frequently described as 'sharp' or 'shooting'. The pain may be incidental (related to movement, breathing, coughing, eating) or spontaneous with no obvious cause. Breakthrough pain can also occur in patients with non-oncology diagnoses, for similar reasons.

Management of breakthrough pain

Breakthrough pain usually requires the administration of rescue doses in addition to medications used to control baseline pain (as outlined above). If a child experiences breakthrough pain, morphine (or another parenteral opioid) may be administered as a bolus. This is usually 1/6–1/10 of the total daily dose of opioid.

The following pharmacological approaches may help in the management of persistent breakthrough pain:

- increasing the dose of a long-acting opioid
- increasing the frequency of a short-acting opioid
- replacing a short-acting opioid with a long-acting opioid
- adding a rapid onset opioid to around-the-clock medication
- adding an adjuvant analgesic.[129]

Non-pharmacological management strategies may also be appropriate and may be combined with the use of medications. This may include heat, ice or cool packs and some of the complementary therapies outlined in the section on 'Non-Pharmacological Interventions for Symptom Management'.

Paediatric pain crisis

A pain crisis in a child is an emergency and requires treatment beyond conventional means. If a child has persistent and severe pain, with close medical supervision and guidance, the dosing frequency of administration of analgesic medications can be titrated to effect (e.g., the dose can be increased, or the duration between doses reduced). At the same time, a specific diagnosis of the underlying cause should be attempted to allow more effective therapies to be implemented.

The intravenous route of administration provides rapid onset of analgesia. On occasion, the clinician may need to remain by the child's bedside to titrate incremental intravenous doses every 10–15 minutes until effective analgesia has been achieved. Alternatively, the subcutaneous route can be used to manage a pain crisis. The analgesic effects of opioids increase in a log-linear function, with incremental opioid dosing required until either analgesia is achieved or somnolence occurs. The total quantity of opioid administered to require this reduction in pain intensity is considered the opioid loading dose. A continuous infusion of opioid may need to be commenced

to maintain this level of analgesia. An alternative to a continuous infusion of opioid is intermittent parenteral opioid, especially in the context of an unpredictable pain syndrome.

Patient-controlled analgesia

A patient-controlled analgesia (PCA) is an infusion device that the patient can activate to self-administer a set bolus dose of analgesia, generally via peripheral or central intravenous access. Children as young as seven years of age can use a PCA.[130] Nurse-controlled analgesia (NCA) is appropriate for controlling pain in infants, pre-verbal children and children with severe developmental delay who cannot use a PCA. Some hospitals (where appropriate protocols exist) allow parent-controlled analgesia in younger children. Parent-controlled analgesia can also be provided in the home. Two modes can be used: bolus only or bolus plus a continuous background continuous infusion.

Additional doses of pain relief can be administered for breakthrough and incident pain in addition to a background infusion. The prompt and safe delivery of analgesia associated with this modality allows control over the wide and unexpected analgesic requirements of children. For example, there is good evidence to support the use of PCAs in patients with mucositis undergoing bone marrow transplantation.[131, 132] Adolescents have reduced sedation and morphine intake with similar pain relief when using PCAs compared to continuous infusions alone.[131] Both modes (PCA and NCA) are suited to provide analgesia where there is a significant component of 'incident pain' (e.g., pain on movement, with coughing, eating or swallowing).[128] There is also evidence to support this pain management modality in the palliative care context.[133]

The PCA device must be programmed to deliver an opioid dose at a predetermined frequency, with a maximum total dose allowed per hour. See local hospital guidelines for the initial prescription of a PCA in an opioid-naive patient. Rescue doses are kept as a proportion of the baseline opioid infusion rate and recalculated as between 50% and 200% of the hourly basal infusion rate. Bolus attempts and successful bolus administrations should be documented as part of the observations.

A PCA (or NCA) can be used to titrate analgesia safely during a pain crisis. It is possible to transition a patient back onto long-acting opioid preparations after the child's pain has stabilised and the total daily opioid requirement has become clear. A PCA can be continued at home using a computerised ambulatory infusion pump. Parent-controlled analgesia is also possible in younger children in the home setting.[134] Methadone can be administered in a PCA if the lockout interval is increased to 30–60 minutes, given its long half-life.

Adjuvant (or secondary) analgesics

Antidepressants in low doses may be useful for neuropathic pain, particularly painful paraesthesia and peripheral neuropathy. As well as having a direct analgesic effect, they potentiate opioid analgesia via adrenergic or serotonergic mechanisms. For example, a low dose of amitriptyline at night usually has an effect within 48–72 hours.

Anticonvulsants (e.g., gabapentin and pregabalin) are useful for pain related to nerve infiltration or compression, which may be periodic or spasmodic. These medications appear to have a stabilising effect on excitable cell membranes to help prevent the spread of neuronal excitation.[127] Gabapentin has been used more often in younger children recently, particularly with children with severe neurological impairment (SNI).

Clonidine may be useful for patients with refractory pain, irritability or agitation. Clonidine is a centrally acting alpha agonist antihypertensive that may be a helpful adjunct for pain, cerebral irritability and insomnia. In very unwell patients or at higher doses, hypotension may be a dose-limiting side effect. Care must be taken if stopping clonidine suddenly, as rebound hypertension can occur. Clonidine may also be a helpful adjunct when weaning opioid or benzodiazepine medicines.

Ketamine is an NMDA receptor antagonist that may be a helpful adjunct for pain and can also provide sedation in the setting of severe irritability agitation when indicated. At higher doses, ketamine is a dissociative anaesthetic. Neurostimulatory side effects, such as hallucinations, may occur with its use. A lack of evidence for the use of ketamine in adult patients receiving palliative care and concerns about the neurostimulatory side effects have led to ketamine not being used frequently in paediatric palliative care. Ketamine (and clonidine) are not commonly prescribed during end-of-life care in paediatrics but do remain pharmacologic options in difficult or refractory cases.[135]

Corticosteroids, either alone or in combination with an anticonvulsant like gabapentin or pregabalin, may also effectively reduce swelling and pain associated with nerve compression or infiltration. Corticosteroids may also alleviate some of the symptoms related to raised intracranial pressure. Low dose steroids act as anti-inflammatory drugs and may reduce bone pain. However, dosing and duration of use should be restricted as much as possible because significant side effects can occur, including excessive weight gain, gastric irritation, mood changes and increased susceptibility to infection, among many others. Acid-suppressing agents (e.g., omeprazole, lansoprazole) are usually given concurrently with corticosteroids to help with gastrointestinal tract protection.

Other drugs recognised as secondary analgesics include antispasmodics, anxiolytics and bisphosphonates. Hyoscine N-Butylbromide may be useful for bladder or bowel spasm, and low doses of diazepam may be an effective treatment for muscle spasm or myoclonus. Regular review, reassessment and an individualised approach are essential for successful treatment of pain.

Other therapies for pain

Antibiotics or antifungal agents may improve pain control when there is an underlying infection, such as cellulitis or mucositis. Consideration should be given to practical, oral anti-infective therapy in these situations. Bisphosphonates such as pamidronate and zoledronate inhibit bone reabsorption and may be useful for treating pain secondary to hypercalcaemia, disseminated bone metastases, avascular necrosis and pathological fractures related to osteoporosis.

Both chemotherapy and radiotherapy can be used as palliative treatments. The sequelae of radiotherapy (in particular) may have a potent analgesic effect in patients with cancer. One or two fractions of radiotherapy may be all that is required in an acute setting, and effects may be quite rapid. Consequently, a patient's opioid requirement may likely lessen rapidly, and drowsiness may occur in this context if the patient's regular opioid dose is continued without frequent review.[136] For this reason, dose monitoring is critical during radiotherapy treatment, and reverting from sustained release preparations of morphine to immediate release morphine should be considered.

Nerve blocks are occasionally used for children with well-defined somatic or visceral pain.[137] Spinal opioid therapy and epidural anaesthetics may be effective for pelvic pain and often allow

the reduction of high doses of oral or subcutaneous opioids that may be causing sedation. Nerve blocks may be temporary, prophylactic or permanent and should be placed by anaesthetists experienced in such pain management techniques.

There are very few well-designed clinical trials using medicinal cannabis in children. Standard treatments remain the only proven therapy for pain to date. There is a significant need for larger, high-quality studies to evaluate the potential benefits, harms and safety of the use of medicinal cannabis for the management of pain (and other symptoms) in paediatric palliative care.[138]

Sedation as a therapeutic modality for intractable pain

The use of sedation is reserved for select situations of refractory pain where conventional therapies have been unsuccessful.[139] All acceptable means of providing timely analgesia without compromising consciousness should be exhausted. This trade-off between sedation and inadequate pain relief requires the consideration of both the wishes or preferences of the child and their family. In the context of intractable pain not otherwise relieved by other measures, sedation may be considered and prescribed by an experienced practitioner—with the primary aim of relieving suffering. Ethical principles, including the principle of double effect, are important in this context. The continuation of high dose opioid infusions in these circumstances is recommended to avoid situations where a patient may have unrelieved pain but inadequate clarity to report pain perception. In this unique and uncommon setting, various medications have been used, including barbiturates, benzodiazepines, dexmedetomidine and propofol.[140]

Gastrointestinal symptoms

Oral conditions

Oral hygiene

Children with serious illnesses receiving paediatric palliative care often undergo treatments (e.g., immune-suppressant medications or therapies that adversely affect their oral health).[141] Oral hygiene at the end of life is essential because such children often also have poor oral intake and are susceptible to oral conditions, such as xerostomia, oral candidiasis (thrush) and mucositis.[142]

Regular oral hygiene can promote comfort and prevent many oral conditions.[1] Cleaning teeth twice daily with a soft toothbrush or swab and mouthwashes with chlorhexidine or chlorhexidine gel are beneficial. Gentle mouth irrigation with warm salt water (0.9% saline solution) will help remove debris and soothe the mouth. Lips can be kept moist with lip balm or paraffin. The mouth can be kept fresh by sucking ice chips as tolerated.

Xerostomia

Xerostomia or dry mouth is a common problem that can result from mouth breathing, dehydration, anxiety, medications and infection. Simple measures such as sucking ice blocks, ice cubes, frozen juices and drinks will moisten the mouth and relieve thirst. Chewing or sucking unsweetened pineapple pieces increases salivary flow and can also help clean the mouth as it contains ananase, an enzyme that breaks down protein. For children unable to manage sucking or chewing, using a swab or sponge dipped in water or unsweetened pineapple juice can be helpful. Expressed breast milk, when available, should be the first choice for performing mouth care in infants who are unable to feed orally. Where possible, fresh expressed breast milk should be used for mouth care.[143, 144]

Mucositis

Mucositis or mouth ulcers are a well-known side effect of chemotherapy and after head and neck radiotherapy. Mucositis can also arise due to poor oral hygiene, neutropenia (low white blood cell levels) and infection. Apthous ulcers are small, shallow, painful ulcers that can be relieved with simple analgesic mouthwash, such as benzydamine hydrochloride. Lignocaine viscous (local anaesthetic gel) may also be used.

Herpetic ulcers are painful, larger ulcers and can also cause significant oesophagitis. Oral acyclovir, in addition to an analgesic mouthwash, should be used. The pain of severe ulceration may require oral or parenteral morphine in combination with parenteral acyclovir to ensure absorption.

Immunosuppressed children are at risk of fungal infection. Candidiasis may present as stomatitis (inflammation of the mouth) when the obvious white plaques may not be evident. Oral nystatin, amphotericin lozenges or miconazole every 4–6 hours should be used. In children with clear localised candida infection or for whom topical treatments have been ineffective, oral fluconazole once daily may be indicated.

Mucosal bleeding can be reduced by improving mouth care and treating or preventing infection. Thrombocytopenia (low platelet levels) will aggravate bleeding, and a platelet transfusion should be considered. This will depend on the child's stage of disease. Oral tranexamic acid and topical sucralfate suspension may be beneficial.[145]

Gastroesophageal reflux disease

Gastroesophageal reflux is a common problem in paediatrics, particularly in infants and children with a neurodisability.[146] Gastroesophageal reflux disease (GORD) is usually defined by the retrograde passage of gastric contents into the oesophagus with or without regurgitation or vomiting.[147, 148] Children with reflux may present with some of the following symptoms: chronic regurgitation, irritability, excessive crying or distress episodes, poor appetite or feeding refusal, gagging, chronic cough, sleep disturbance, wheezing, stridor, grimacing and retrosternal or epigastric pain.[147] GORD can have a significant impact on the child and family's quality of life.

Non-pharmacological strategies

- thickened feeds for infants' oral feeding
- optimising position during and for 30 minutes after feeding (upright position)
- tilting cot or bed so that head is elevated when not feeding
- some children with a neurodisability and dependence on enteral feeding may require surgical intervention with a fundoplication.

Pharmacological strategies

Proton pump inhibitors (e.g., omeprazole, lansoprazole) are considered the first line treatment of GORD in children. Proton pump inhibitors help to relieve symptoms of dyspepsia and prevent acid-induced oesophageal injury. These medications are generally tolerated well by children.

Other medications that can be considered:

H_2 receptor antagonists (e.g., ranitidine): this group of medications works by reducing gastric acid secretion. They do not reduce the frequency of gastroesophageal reflux.

Prokinetic agents (e.g., metaclopramide or domperidone [see dosing and information below]). These medications can help promote gastric emptying.

Nausea and vomiting

There are many reasons why a child can become nauseated or vomit. Common causes in palliative care include:

- opioids and other drugs
- upper gastrointestinal inflammation
- raised intracranial pressure
- metabolic disturbances
- constipation
- infection.

Vomiting is initiated by the vomiting centre when it is stimulated directly or through the chemoreceptor trigger zone (CTZ), autonomic afferents from the viscera (gut organs) and higher brain centres. Antiemetic drugs have different effects on these sites, and the agent chosen should depend upon the most likely reason for nausea or vomiting (*see* Table 6). For example, drugs and metabolic disturbances act on the CTZ, and antiemetics affecting this site are indicated,

while disturbances of gastric (stomach) emptying can be helped with agents that increase gastric emptying (e.g., metoclopramide and domperidone).[145] It is important to note that children with possible bowel obstruction should avoid stimulant agents such as metoclopramide as they can aggravate the obstruction resulting in increased pain. Octreotide, administered intravenously or subcutaneously as a bolus or infusion, may relieve vomiting associated with bowel obstruction.[149]

Other causes of vomiting include severe constipation, which should be relieved with adequate treatment, as discussed below. Raised intracranial pressure that causes vomiting is usually, but not always, associated with headache. Steroids can alleviate these symptoms, but long-term steroid use is associated with excessive weight gain, changes in appearance, behavioural changes, fragile skin and, ultimately, resistance. Drugs acting on the vomiting centre can be beneficial and used instead of steroids.

If possible, the preferred route for medication is by mouth. It may be necessary to give initial doses of medication intravenously, subcutaneously or, very occasionally, rectally. Many agents that can be administered subcutaneously are compatible with morphine and, therefore, can be used in combination in infusion pumps. Further details regarding drug compatibilities are outlined in Appendix 7.

Non-pharmacological management strategies to consider include:

- chewing ginger pieces or taking ginger tablets
- sipping water, juice or flat soft drinks
- eat foods with a lot of water in them; try clear soups, ice blocks and jelly
- offering bland foods or salty foods and snacks
- altering feed regimes if the child is receiving enteral nutrition (e.g., giving continuous instead of bolus feeds)
- trial of hydrolyte or similar in replacement of milk-based feeds
- aromatherapy[150]
- hypnosis[96]
- other considerations such as access to fresh air and positioning.

Table 6 **Choice of antiemetic therapy**

Site	Aetiology	Antiemetic
Chemoreceptor trigger zone	Medications (opioids) Metabolic (hypercalcaemia)	Ondansetron Metoclopramide Prochlorperazine Haloperidol
Vomiting centre	Direct stimulation (pain, fear) Viscera (bowel obstruction) Raised intracranial pressure	Anti-anxiety medication (e.g., lorazepam) Hyoscine butylbromide Hyoscine hydrobromide Cyclizine
Gastric outlet, prokinetic	Medications (opioids) Stasis /compression	Metoclopramide (see above) Domperidone
Gastrointestinal inflammation	Gastritis (secondary to non-steroidal anti-inflammatory drugs, steroids)	Mylanta Omeprazole
Effect at all levels		Levomepromazine

Some antiemetic medications can cause dystonic reactions more commonly in children than in adults. Examples include metoclopramide, antipsychotics (e.g., haloperidol), phenothiazines (e.g., prochlorperazine, levomepromazine). These reactions are usually easily recognised, and families should be informed of such a possibility. Benztropine rapidly reverses this effect and should be available.

Medicinal cannabis for nausea and vomiting in paediatric palliative care

In recent years, legislative changes in some countries, including Australia and New Zealand, have allowed the prescription of medicinal cannabis for patients receiving palliative care. There is widespread interest within communities in the use of medicinal cannabis for managing pain, nausea and other symptoms.[151]

There is evidence that cannabinoid (CBD) and tetrahydrocannabinol (THC) products can be useful in managing nausea and vomiting and increasing appetite in children with chemotherapy-induced nausea and vomiting.[152-154] However, it is also recognised that THC increases the risk of depressive and psychotic symptoms and has an impact on both the functional and structural organisation of the developing brain. [155, 156]

Further research is required to understand the efficacy and adverse effect profile of CBD and THC products for management of nausea and vomiting in the paediatric palliative care setting.[151, 157] It is

unlikely that medicinal cannabis products will be used as first line treatment for the management of nausea and vomiting, but they may have an adjuvant or complementary role in symptom management in the future.[151, 158]

Constipation

Normal bowel function ranges from three motions a day to one motion passed every three days or up to two weeks in a breast-fed infant. Constipation refers to a significant variation from normal bowel habits. It refers to difficulty, discomfort or delay in passing a bowel motion.

- Constipation is an extremely common symptom and can contribute to abdominal pain, anorexia, nausea and vomiting, as well as overflow diarrhoea. Factors known to make constipation more likely are outlined in Table 7.
- The assessment of constipation is based upon:
- the underlying condition (including location of tumours and any neurological problems)
- food and fluid intake
- medication
- previous laxative use
- previous and current pattern of bowel habit, including frequency and consistency of stool.

Chronic constipation is common in children with an underlying neurologic impairment, usually due to poor tone and reduced mobility.

Constipation should be expected in all children receiving opioid analgesia. Opioid receptors in the gut increase the tone and non-propulsive motility in the ileum and colon.[159] Laxatives should always be prescribed with opioid medications.

The effect of laxatives is dose related, and there is large variation between individuals. If diarrhoea occurs and overflow incontinence has been excluded, the laxative treatment should be modified according to the child's needs.

Table 7 **Exacerbating factors for constipation**

Exacerbating factors
Poor dietary intake
Poor fluid intake
Immobility
Medication • Opioids
Anticholinergics • Antidepressants • Anticonvulsants
Antiemetics
Local factors • Anal fissures/infection • Haemorrhoids
Previous constipation
Electrolyte disturbance (e.g., hypercalcaemia, hypokalaemia)

Treatment and general measures

- predict and prevent
- encourage fluid and fibre intake
- encourage movement
- stop or reduce unnecessary medications
- laxative treatment

The laxative used should be based on patient preference regarding formulation, the degree of constipation and the child's stage of illness (see Table 8). Macrogols are often the laxatives of first choice, although the taste and volume can impact tolerability. Lactulose can be given to neonates and mixed with juice or cordial. However, the sweet taste can deter some older children, and it can cause bloating and cramping, particularly for children with slowed bowel activity from medications such as opioids. Poloxamer (in drops) is another option for neonates and infants. Docusate sodium as tablets is favoured in older children and adolescents, especially when they prefer tablets over liquid medications. Sodium picolsulfate is a stimulant laxative and can be administered as drops. In this context, it can be helpful if the patient is unable to tolerate oral medications or fluids and does not have a feeding tube.

Treatment for opioid-induced constipation should be directed at the large bowel to stimulate and soften the stool. For example, the combination of coloxyl with senna promotes fluid secretion, softening the stool with the coloxyl component while senna stimulates peristalsis. Care must be taken when using senna as it may cause excessive bowel spasms. Macrogol laxatives can also be very effective. An alternative to macrogol is a polyethyleneglycol laxative that does not have the salty background taste of macrogol.

In the context of opioid-induced constipation, when the response to other laxatives alone is inadequate, consider methylnaltrexone. Doses can be repeated every other day as needed.[160, 161] Methylnaltrexone is a mu-opioid receptor antagonist that acts exclusively in the peripheral tissues, including the gastrointestinal tract (increasing bowel movement and gastric emptying). While the literature suggests that it does not affect the central analgesic effects of opioids in children,[160, 161] clinical experience with adults suggests that caution must be taken as there can be some impact on the central analgesic effects of opioids.

If the stool volume or frequency remains inadequate and constipation is well established, suppositories or a small enema will be required to clear the lower bowel before a normal pattern can be established. Enemas or suppositories are best avoided in neutropenic patients. Glycerin suppositories are generally effective, especially for neonats and infants. Small volume enemas are easy to use and typically not too distressing for the child. Larger-volume enemas can lead to fluid and electrolyte disturbances, particularly in the debilitated or dehydrated child or infant. For refractory constipation, an oil retention enema can be useful. Once the constipation is relieved, prophylaxis should continue.

During the terminal phase, significant discomfort related to constipation is uncommon. As fluid and oral intake is generally decreased, oral laxatives can be discontinued. A suppository or osmotic action micro-enema may help reduce rectal discomfort arising from the urge to defecate or if there is overflow incontinence from faecal impaction.

Table 8 **Action of laxatives**

Lubricants and stool softeners
Docusate sodium: softener and promotes secretion of fluid
Stimulants/contact laxatives: Promote secretion of fluid into bowel to stimulate peristalsis
Senna, cascara
Bisacodyl: primary effect on colon within 24 hours
Osmotic: Draws fluid into bowel to soften the stool and stimulates peristalsis
Lactulose
Suppositories and enemas: Often a combination of softener and stimulant (rectal administration)
Glycerin suppository: softener
Bisacodyl: contact/stimulant

Enemas containing sodium citrate ad sorbitol (e.g., Microlax)

Non-pharmacological management strategies to consider include:

- pear or prune juice
- liquorice
- adding fibre to feeds
- sugar-free gum or lollies in generous amounts have a laxative effect
- gentle clockwise abdominal massage
- bicycling action with legs in non-mobile child
- positioning support and comfort on the toilet, use of a footstool, leaning forward with pillow support
- increasing fluids
- daily bowel chart
- attention to perianal hygiene and local anti-inflammatory or anaesthetic cream or ointment as needed.

Bowel obstruction

Bowel obstruction is rare but most commonly seen in children with incurable cancers with tumours in the abdomen or pelvis, such as lymphoma, rhabdomyosarcoma or Ewing's sarcoma. Obstruction in this setting occurs when the lumen of the bowel is sufficiently occluded to prevent the movement of intestinal contents along the gastrointestinal tract.[162] Symptoms may include severe colicky abdominal pain, abdominal distention, nausea or vomiting and constipation.

Oral or enteral feeding and medications should be discontinued, and the subcutaneous or intravenous route should be used for all medications and fluids. Consider venting or placing a free drainage bag on the child's NG tube or gastrostomy tube. Nausea and vomiting can be managed using the above guidelines, keeping in mind the cause of the nausea and vomiting. Prokinetic antiemetics (e.g., metaclopramide or domperidone) should be avoided in complete bowel obstruction as they can worsen the pain. They can be used with caution with a partial obstruction or ileus.[163]

Symptoms of bowel spasm can be reduced with the use of anticholinergic agents,[163] such as:

- hyoscine butylbromide
- hyoscine hydrobromide
- glycopyrrolate
- octreotide: may be useful to consider in discussion with a specialist palliative care service to reduce gastrointestinal secretions and vomiting
- consider using dexamethasone to reduce tumour oedema; if using dexamethasone, start a proton pump inhibitor to reduce risk of gastritis and ulceration[24]
- consider using an opiod infusion for analgesia.

Diarrhoea

Diarrhoea is characterised by an increase in the frequency and wateriness of the stool. The cause is usually evident from the history and the underlying condition. Simple measures such as discontinuing laxatives, high-fibre foods and enteric supplements will often aid management. Consideration should be given to the possibility of infectious causes of diarrhoea (e.g., rotavirus). It is also important to exclude constipation and overflow incontinence as a cause of diarrhoea because this may require increased use of laxatives.

Medication is frequently required, and loperamide is generally effective and tolerated well. If severe watery or osmotic diarrhoea is suspected, such as can occur with severe graft versus host disease of the gut and in children with HIV infection, octreotide can be helpful. Octreotide may also reduce diarrhoea refractory to other treatments. It can be administered intravenously or subcutaneously and given as a bolus or infusion.[159]

In the terminal stage, loperamide will usually be sufficient. Loperamide capsules can be dispersed in water to make a 0.2–1 mg/mL solution allowing for easier administration to children who prefer liquid formulations. Likewise, morphine (either orally or subcutaneously) can alleviate diarrhoea.

Non-pharmacological management strategies may include the provision of oral rehydration solutions instead of feeds for 24–48 hours. Sometimes, changing feed regimes from bolus to continuous feeds or to an elemental feed may reduce the volume of diarrhoea. Collaboration with the paediatric team and dietician is often required in this context.

Extra care and attention are recommended with hygiene and skin care to the perianal area, including gentle wipes, barrier cream and regular skin integrity checks in the presence of ongoing diarrhoea. There is also an increased risk of electrolyte disturbance.

Anorexia and cachexia

Anorexia or loss of appetite is common in the later stage of a child's illness and can be associated with cachexia (loss of muscle and fat). There are often multiple causes in addition to the underlying disease, including pain, nausea, constipation, drugs, anxiety, depression, oesophagitis and gastritis; addressing these is an important step in treatment.

Anorexia–cachexia syndrome is characterised by anorexia, involuntary weight loss, tissue wasting, weakness and poor physical function. It is a condition of advanced protein and calorie malnutrition that inevitably leads to death if the underlying condition cannot be treated. In children, this may be seen in growth failure rather than weight loss (usually seen in adults).[162]

The presence of anorexia–cachexia syndrome in the context of palliative care suggests an unavoidable deterioration to death. However, anorexia or cachexia together or independently can also represent a multitude of reversible causes that should be considered during the assessment and management of the child or young person (*see* Table 9).

Table 9 **Reversible causes of anorexia and cachexia**

Causes
Adverse effects of medications (including cancer-directed therapies)
Dehydration
Oral conditions • Candidiasis • Xerostomia
Gastrointestinal dysfunction • Dysphagia • Gastroesophageal reflux disease • Constipation • Intestinal obstruction
Infection • Local or systemic
Nausea and vomiting
Pain • Psychological factors • Anxiety, fear or depression

Management

A pre-emptive explanation of what can occur is essential, and providing simple advice regarding dietary habits (e.g., offering the child small, simple meals) can be very effective. This family discussion should include acknowledgement of the child and family's spiritual and cultural beliefs and explore the emotional components and meaning of their child not eating and losing weight.

Medical devices for feeding

Many children, particularly those with non-cancer LLCs, receive part or all of their nutrition via inserted medical devices. Intestinal absorption devices are nasogastric, nasojejunal, percutaneous gastrostomy and/or percutaneous jejunostomy tubes. Some children may also receive intravenous fluids, including total parenteral nutrition (TPN) via central venous, percutaneous, or intravenous lines. During end-of-life care for some children, the use of medical devices can promote comfort in the relief of hunger and thirst, and ease of administration of medication. For other children, there can be difficulties with prolonged use of devices for nutrition where the child's condition no longer tolerates this well and the experience of symptoms such as vomiting, bloating, and discomfort become significant. At this time, many children will not experience hunger or thirst. At this time, many children will not experience hunger or thirst. In a child with a relatively prolonged palliative period who is having swallowing difficulties or difficulty maintaining their weight due to insufficient

caloric intake, it may be considered beneficial to use these devices. These factors need careful consideration of the benefits and burdens of medical devices for feeding on the child's quality of life during end-of-life-care. Support for the parents and carers is also important given the meaning for parents of the provision of nutrition for their children, as well as the recognition of disease progression.

Feeding intolerance

A small group of children who receive nutrition through medical devices can develop a progressive intolerance of feeding, often seen as worsening abdominal symptoms such as reflux, vomiting, abdominal bloating, irritability and pain, which can be severe. If feed intolerance does not respond to the usual dietary modifications (e.g., changing the formula type or route, decrease in feed volume, or usual anti-reflux medications) visceral hypersensitivity should be considered.

Visceral hypersensitivity is an altered threshold to pain generation for a stimulus in the gastrointestinal tract. This means a normal stimulus (e.g., distention or pressure within the gastrointestinal tract) can result in pain, tissue inflammation or injury. For example, gastroesophageal reflux may result in the sensitisation of visceral afferent pathways with resulting visceral hypersensitivity.[164] Successful treatment often requires adjuvant analgesic medication, including gabapentinoids (gabapentin, pregabalin) and tricyclic antidepressants (amitriptyline or nortriptyline).[164, 165]

Withdrawing or withholding artificial nutrition and hydration

In situations where the continuation of life-sustaining therapies is not in the child's best interests and does not align with the agreed goals of care, it is ethically, legally and morally permissible to discontinue or not start artificial nutrition and hydration (ANH). Withdrawing or withholding ANH is not ethically, legally or morally different from other medical interventions.[166] This can be challenging to navigate, and there are important psychosocial and emotional considerations to reducing or withdrawing ANH, including parental fear of suffering, the emotional and cultural significance of feeding, and that feeding can provide comfort for parents and children.[167] It is vital to keep in mind that the goal of ANH at end of life is to promote comfort by alleviating symptoms of hunger and dehydration, particularly in children who are unable to take food or fluid orally.[168]

Children with progressive diseases can survive for significant periods with little oral intake and have minimal complaints during their last days or weeks of life. Comfort medications (e.g., morphine, benzodiazepines) are not typically additionally required due to limited nutritional intake. In fact, reduced fluid intake can sometimes lessen distressing symptoms such as nausea, vomiting, cerebral oedema, excessive secretions and urinary incontinence, while maintaining artificial hydration can aggravate such symptoms.[168, 169] Other important management considerations include mouth and skin care, pressure area care and sensitive use of clothing.

It is necessary to have a careful and sensitive discussion with the family regarding the reasons for considering reducing or withdrawing food and fluids, focused on the goal of improving distressing symptoms. It can be helpful to work with a dietician who has paediatric palliative care experience to help the family understand the changing goals. If the family remain resistant to the idea, a three-day trial reduction in feed volume of 25–50% may provide objective evidence to gain their confidence and improve rapport.

It is essential that health professionals, as well as parents, are also appropriately counselled and supported through the process to and beyond the death of the child. Both parents and health professionals may have doubts and questions about the decision to forgo ANH and will benefit from ongoing discussion within the clinical team. Consultation of clinical ethics consultation services can also be helpful in this context. Consideration should also be given to cultural influences where the provision of nutrition and food has significant meaning and where limiting nutritional intake can be a challenging concept to understand and adhere to (*see* chapter 'Clinician wellbeing and moral distress').

Respiratory symptoms

Severe respiratory symptoms are relatively common in children who are dying due to an LLC. For patients with non-cancer LLCs, during episodes of severe respiratory symptoms is often when issues around resuscitation come sharply into focus. However, it is important to recognise that for many such children, there may have been numerous previous episodes of severe respiratory symptoms from which the child has recovered well, despite predictions otherwise from treating healthcare professionals.

Whether severe respiratory symptoms occur at home or in the hospital, a common question to be addressed is whether the patient is to be 'resuscitated'. These discussions require the parents or caregivers to indicate whether their child is to be intubated and ventilated (via tube or via NIV; see below). Discussions should include the location of care at these times and whether care in an ICU or retrieval to another hospital is to be considered. It is necessary to recognise the risks and benefits of investigations, interventions and symptom management as part of the treatment plan for respiratory symptoms. There is often discussion around the extent of monitoring and what is to be done if the child's vital observations fall outside normal parameters. Many parents will also wish to monitor their child's oxygen saturation and other vital signs at home (especially at night). Monitoring equipment is not routinely provided for this in the home but is very routine in an acute setting, and the discussions in relation to these requests can be quite challenging. It is vital to validate parental concerns and reaffirm their skills at detecting or observing deterioration in their child without the presence of technology.

Dyspnoea

Dyspnoea (breathlessness or shortness of breath) is relatively common in children with LLCs. Dyspnoea may reflect deterioration or may be intermittent or reversible. At times, dyspnoea may be so severe as to constitute a palliative care emergency. Causes of breathlessness include conditions that are related to the respiratory system and those that are unrelated. The types of conditions that affect the respiratory system include infection, inflammation, fluid accumulation and problems with the muscles for breathing or the structure of the chest wall (*see* Table 10). Dyspnoea frequently occurs in conjunction with other symptoms and is almost always associated with anxiety for both child and family.

Table 10 **Causes of dyspnoea (breathlessness)**

Respiratory	Non-respiratory
• Airway obstruction: lower or upper • Chest wall deformity (e.g., severe scoliosis) • Rib fractures (with or without pneumothorax) • Respiratory muscle dysfunction, including generalised muscle weakness (e.g., spinal muscular atrophy) or phrenic nerve palsy • Pleural effusion: inflammatory, cardiac, hypoalbuminaemia • Atelectasis and mucous plugging • Asthma • Bronchiectasis • Infection • Pneumothorax • Pulmonary oedema • Interstitial lung disease (e.g., idiopathic, chemotherapy, radiation) • Pulmonary embolism • Pulmonary hypertension	• Mediastinal disease • Superior vena cava obstruction • Cardiac disease / congenital heart disease • Metabolic causes including acidosis • Cerebral causes including raised intracranial pressure • Elevated diaphragm (e.g., ascites or abdominal distension) • Anaemia • Anxiety • Pain

Emergency management of severe dyspnoea

- correct easily reversible causes
- position patient sitting up if possible
- low flow oxygen therapy if tolerated
- high flow oxygen therapy or NIV (if tolerated and appropriate)
- suction secretions if indicated (and used with care)
- determine resuscitation status and underlying disease status
- morphine parenterally, repeat after 15 minutes (if given intravenously) or 30 minutes (if given subcutaneously) if dyspnoea not settling
- Midazolam parenterally or clonazepam drops buccally for anxiety or distress (repeat as necessary).

Specific treatment of dyspnoea

Some causes are reversible with relatively simple measures. For example, a short course of antibiotics may be appropriate for managing infection, and analgesia will alleviate dyspnoea related to pain. Packed cell transfusion may be considered in individual situations when anaemia might be contributing to dyspnoea.

A course of intravenous antibiotics may be appropriate for pneumonia, but this will depend upon several factors, including parental wishes, prior performance status and disease trajectory, and ease of obtaining intravenous access. Parents often opt for enteral antibiotics for pneumonia if they have adopted a more palliative approach for their child.

High flow oxygen therapy or NIV can sometimes assist in managing a reversible cause of respiratory deterioration. In addition, these therapies can ease the distress of breathing. Their use must be balanced with potential burdens (e.g., tolerability of needing to wear a nasal or facial mask, pressure areas on the face and potential need to be managed in an ICU). High flow oxygen therapy is predominantly used in the inpatient setting.

Pleural effusions in children with non-cancer conditions are less common than in the setting of a cancer diagnosis. Management should be discussed with a respiratory paediatrician if intervention is warranted.

Respiratory symptoms can sometimes be eased for a child with a known cardiac condition by titration of medications, including diuretics. This is often done in consultation with the child's cardiologist.

Supportive measures for dyspnoea

Simple measures are often helpful for reducing the sensation of breathlessness. The child and family should be addressed in a calm and reassuring manner, as anxiety contributes to the degree of dyspnoea. Breathing exercises and relaxation techniques (perhaps with consultation from therapists) may be beneficial for an older child. Environmental considerations (e.g., increasing air flow with a portable fan and improving ventilation in the room by opening windows) are simple and often helpful steps. Positioning the child comfortably and upright in a bed or chair may also aid breathlessness. Breathlessness is often accompanied by tachypnoea and mouth breathing, which can lead to a dry and painful mouth. This can be helped by simple measures directed towards keeping the mouth and lips moist. Humidification of room air may also be beneficial.

Drug therapy

Bronchodilators

If bronchospasm is present, or if there is a history of asthma, a trial of bronchodilators is indicated. Salbutamol via a spacer or nebuliser is simple to deliver and may aid in reversible airways disease.

Corticosteroids

Corticosteroids (either inhaled or systemic) are often effective and can be used in addition to bronchodilators in children who have a component of bronchial hyper-reactivity. Prolonged steroid therapy is not generally indicated because their effect is not sustained and side effects can become significant.

Opioids

Opioids moderate the reflexive drive to breathe and decrease patient awareness of dyspnoea. At low doses, they may improve the efficiency of breathing and exercise endurance.[98] Opioids, commenced at a low dose and titrated as required, may be given as required to children with intermittent dyspnoea or regularly for those with persistent breathlessness.

The best evidence for opioid use for managing breathlessness is for morphine specifically. It is unclear whether other opioids are as effective as morphine and morphine should thus be used as the first line agent in this setting unless there is a compelling medical reason to the contrary. Oral, enteral, subcutaneous or nebulised morphine can be used. There is no proven advantage to administrating nebulised morphine; however, some children do find this route of delivery beneficial.

The dose of morphine required for the relief of dyspnoea is usually lower than that required for analgesia. Dosing intervals should be determined on the basis of severity of dyspnoea, renal function and other clinical considerations. Morphine can be combined with midazolam (*see* below) in a subcutaneous infusion to relieve respiratory and anxiety symptoms, particularly in the terminal phase.

Anxiolytics

The sensation of breathlessness can be very frightening, and a small dose of oral diazepam is often helpful in reducing associated anxiety. Clonazepam drops can also be considered. Midazolam intravenously or subcutaneously decreases anxiety, agitation and distress in the child with dyspnoea. In addition, optimising general symptoms, particularly pain, can help reduce anxiety levels.

Oxygen therapy

Many children with non-cancer diagnoses have long-term respiratory issues, with supplemental oxygen required either continuously or at times of respiratory illness. The decision to administer oxygen on increased oxygen flow rates should be made in consultation with the child's parents.

Many children have chronically low oxygen saturations, which they tolerate without respiratory distress. The decision to initiate and continue oxygen therapy in hospital should not be made based only on oxygen saturation readings but with consideration of the level of dyspnoea, tolerability of oxygen mask or nasal cannula and child and parental wishes. Some children have chronic type 2 respiratory failure, and oxygen flow rates must be considered carefully to avoid hypercarbia.

Oxygen at home

Administration of supplemental oxygen in the home setting involves additional complexities. The first issue is to determine whether supplemental oxygen will be required for a short period only (usually for end-of-life care) or likely to be a long-term requirement. Oxygen should be discontinued if there is no definite benefit noted.

Different funding pathways and equipment provision entities will probably be required for each child.

Oxygen concentrators are effective for home use and are connected to a domestic power supply (rebates may be available from electricity suppliers for these). It is advisable to notify the electricity

provider that the patient is receiving home oxygen to ensure that their power is prioritised in the event of a power outage.

The use of oxygen prior to walking to the toilet or bathing may be all that is required. The maximum flow is 5 L/min via mask or nasal prongs. Portable oxygen concentrators are available but must usually be privately purchased. Likewise, high flow oxygen therapy is not routinely provided at home in a palliative care context.

Portable oxygen cylinders allow the child and family to leave the house. Care is needed when travelling with cylinders in the car as they must be securely transported. A 'C' size cylinder lasts 2–3 hours at 2 L/min. Reservoir cannulas or pendants conserve oxygen use such that oxygen is only used on inspiration; however, these are not routinely used for children as the child's inspiratory effort may be insufficient to trigger oxygen flow.

It is important to advise parents to ensure that no-one smokes close to the patient, near the source of the oxygen or anywhere inside as there is a significant explosion risk associated with oxygen concentrators and cylinders within the home.

Cough

Many of the conditions causing dyspnoea will also produce cough. Cough results from irritation to receptors in the upper or lower respiratory tract, pleura, pericardium or diaphragm. Symptom relief may be provided by avoiding irritants or using antihistamine or anticholinergic agents for post-nasal drip or antibiotics. Simple linctus may soothe the throat or cough. Opioids, due to their central action, are the treatment of choice. If a child is already receiving morphine for pain relief, increasing the total dose may be effective.

Bronchospasm can also contribute to cough and should be treated with nebulised or inhaled salbutamol. Nebulised saline is an effective mucolytic agent, while nebulised local anaesthetic agents may be beneficial for intractable cough. Lignocaine 2% or bupivacaine 0.25% can also be used. It is vital to recognise that the gag reflex will also be impaired after this treatment; therefore, it is advisable not to eat or drink for 1–2 hours afterwards.

Non-pharmacological management strategies include humidification or using a vaporiser in the child's bedroom. Cough related to pulmonary congestion can be eased with more upright positioning. Cold drinks should be avoided as these can trigger a coughing spasm.

Heart failure and pulmonary oedema

It is rare for a child who does not have known congenital heart disease to develop left-sided heart failure or congestive cardiac failure. If this is clinically thought to be present, frusemide subcutaneously can be given and repeated 4–6 hourly, if necessary.

Acute pulmonary oedema is an emergency and should be treated with frusemide, morphine, oxygen and positioning. NIV may be helpful if available and indicated, depending upon the stage of the child's illness.

For a child with known congenital heart disease and deteriorating cardiac function, advice from the treating cardiologist may need to be obtained.

Tracheostomies and home ventilation

It is increasingly common that children with tracheostomies are referred to palliative care services. Tracheostomy issues are best guided by ear, nose and throat (ENT) surgeons and nursing staff and are beyond the scope of this document.

Children with non-cancer LTCs may have been previously commenced on home NIV (continuous positive airway pressure [CPAP], bi-level positive airway pressure [BiPAP], variable positive airway pressure [vPAP]) for sleep-disordered breathing or other indications, which may be used continuously, nocturnally or only when unwell.

Common issues arising from this intervention include:

- navigation of goals of care and escalation of intervention issues
- tolerability of NIV
- risk of aspiration
- equipment-related issues, including ill-fitting mask with leaks or pressure areas.

Expert advice should be sought from a respiratory paediatrician for issues related to home ventilation. Careful discussion with the respiratory team and family is required if decreasing the settings or cessation of ventilatory support seems appropriate due to disease progression.

It is exceptionally rare for children to have invasive ventilation at home; therefore, this topic is not covered further here.

Excess secretions

Gentle suction and physiotherapy can play a role in managing secretions for patients at all stages of palliative care. Other non-pharmacological management strategies include regular positioning changes from side to side to allow secretions to drain in combination with meticulous mouth care.

Anti-secretory medications can be used at different stages of an LLC to manage excess secretions. Consideration must be given to where carers will obtain these medications as they are not always available in community pharmacies. In the chronic phase of an LLC, such medications can be introduced with caution. Careful monitoring is required so that the secretions do not become too thick and unmanageable. Glycopyrrolate has anticholinergic properties with a selective and prolonged effect on salivary and sweat gland secretions. It can be given orally or by a feeding tube and is available in many regions as a syrup or tablet. Glycopyrrolate can be administered subcutaneously or intravenously and is compatible with morphine and midazolam when end-of-life care is provided. Atropine drops are also an option because they are readily available in community pharmacies and can be administered sublingually (commencing with one drop every 4 hours). However, atropine can cause bradycardia with repeated dosing.

Hyoscine hydrobromide can be delivered by a transdermal patch during the chronic phase of illness and also administered by subcutaneous bolus or by continuous subcutaneous infusion during end-of-life care. Hyoscine N-butyl bromide is another anti-cholinergic that is available as both a tablet and ampoule and available in community pharmacies.

Anaemia and bleeding

Anaemia

Children with incurable leukaemia almost always develop significant anaemia. One of the most common sites of metastatic disease in children with cancer is the bone marrow. Consequently, anaemia is frequently seen as a complication in children receiving palliative care for cancer diagnoses. Children with non-cancer conditions may have anaemia due to chronic disease, nutritional deficiency or blood loss from various causes.

Decisions regarding red cell transfusion should be made on an individual basis and will depend upon the geographical location, stage, life expectancy and symptoms of the child. If anaemia is interfering with the child's activity levels or causing tiredness, headache or irritability, while they are otherwise experiencing a reasonable quality of life, transfusion of packed cells may be appropriate. Packed cell transfusions can also be beneficial if the child has a special planned outing or activity arranged. However, as the disease progresses and the general activity level of the child is reduced, anaemia will be less symptomatic and any potential benefit of transfusion should be re-evaluated, especially regarding the travel required to the hospital facility for transfusions. As it becomes evident that further transfusions are not appropriate, a discussion with the family regarding the value of ongoing transfusion should be had.

Bleeding

Thrombocytopenia can be due to primary bone marrow infiltration or failure, hypersplenism or medications. Significant thrombocytopenia may lead to spontaneous or easy bleeding. Bleeding can also occur due to coagulopathy secondary to liver disease, nutritional deficiencies, disseminated intravascular coagulation or drugs (especially NSAIDs and steroids).

During curative treatments, platelet transfusions are given to children when the platelet count drops below a defined level. As the disease progresses, platelet transfusions are reserved for cases of significant bleeding, such as epistaxis, bleeding gums or gastrointestinal bleeding. The decision to transfuse with platelets should be based on each individual patient, discussed with the family and reviewed regularly.

Usually, children and parents are prepared to come to the hospital for platelet transfusions. However, as the child's disease progresses, hospital trips can be an ordeal, both physically and psychologically; therefore, the appropriateness of this should be revisited with the family in line with the interests of their child and in the context of their disease status.

Bruising and petechiae are common with thrombocytopenia and coagulopathy. Catastrophic bleeding is unusual, but active bleeding is a very distressing event for the child and family, preventing major bleeding episodes should be attempted. Subconjunctival haemorrhages are obvious and frightening, but the child and family should be reassured that such bleeds are not life-threatening or vision-threatening and do not require treatment.

In the case of epistaxis, the application of gentle pressure to the bridge of the nose or icepacks on the back of the neck will stem most episodes. Oozing from mucosal surfaces can lead to bleeding gums, dark stools, haematuria and rectal bleeding. Tranexamic acid may be given to help stabilise clots that form over the bleeding area. This can be given orally or as a mouthwash for mouth bleeds. Bleeding from ulcerated areas on the skin or perianally can typically be settled with topical

adrenaline. Sucralfate dispersed in water-soluble gel can also be used topically to control local bleeding or oozing.

For major bleeding when death is imminent, treatment should be directed at calming the family and simple supportive measures. Bleeding generally lessens as the blood pressure and cardiac output drop. The use of dark-coloured bedding and towels to disguise the extent of bleeding and disposable pads and nappies can be helpful. If the child is aware, appropriate analgesia and sedation should be administered to relieve distress. In addition, it is helpful to have medications such as morphine, midazolam and adrenaline-soaked dressings available in the home. If major bleeding is anticipated, it is helpful to have a sensitive conversation with the family about how this distressing symptom can best be managed.

Neurological symptoms

Children with SNI account for a significant proportion of children supported by palliative care services. The cause of neurological symptoms can include brain tumours as well as congenital, genetic, metabolic and traumatic conditions. Symptoms resulting from impaired nervous system dysfunction are common in paediatric palliative care.

It is also important to consider symptoms that may be related to psychological or psychiatric issues. Childhood development can influence the assessment and management of psychological issues in children with LLCs. It can also be difficult to diagnose psychological problems when somatic or neurological symptoms may be similar to symptoms of disease progression or medication side effects. It is important that clinicians concerned with quality of life and symptom management remain vigilant regarding identifying and managing (where appropriate) psychological symptoms. Certain emotional and behavioural symptoms require additional expertise and collaboration with mental health clinicians. Depression and delirium are important to consider in this context and not covered more fully in this guide. More comprehensive textbooks cover these topics, such as the *Oxford Textbook of Palliative Care for Children* (2021) and the *Textbook of Interdisciplinary Pediatric Palliative Care* (2022).

Anxiety

Many children will experience anxiety during the treatment of their LTC or LLC; when deterioration occurs, this may be exacerbated significantly. Anxiety and depression may be under-recognised in non-verbal children. The experience of poorly controlled symptoms, uncertainty, loss of autonomy, fear of the unknown, potential symptoms and suffering will cause agitation in both the child and family. Anxiety is a normal response to these issues. Communicating with the child and family will help allay some fears. Relaxation techniques, distraction, music and meditation for older children will reduce anxiety levels. Members of the allied health team can assist with the provision of some of these strategies.

Anxiolytics may also be of benefit. The use of a hypnotic (e.g., temazepam) at night will be helpful for some children and adolescents. Lorazepam is both a hypnotic and an intermediate-acting benzodiazepine that can reduce anxiety and may be helpful. Antidepressant medications such as sertraline or fluvoxamine can be helpful for anxiety, repetitive thoughts and low mood. Escitalopram is often chosen for adolescents with anxiety and panic attacks. These are usually prescribed after liaison with the psychiatry team.

Seizures

Even brief generalised seizures can be very distressing for parents to witness, and the family should be prepared for such a possibility if applicable. As with other symptoms, knowledge of the patient's history and an understanding of the natural history of the underlying disease will suggest which children may be at risk (see Table 11). Seizures may be a feature of chronic illness or may occur more acutely as part of a terminal deterioration.

Table 11 **Causes of seizures**

Causes
Brain tumours: Primary, metastatic or meningeal lesions
Raised intracranial pressure
Intracranial haemorrhage
Metabolic disturbances • Hypoglycaemia • Hyponatraemia • Hypocalcaemia • Hepatic encephalopathy
Infection and fever
Pre-existing epilepsy

Treatment

Children with a history of epilepsy or previous seizures will usually be on anticonvulsants, which should be continued. However, control of seizures may be lost if the child becomes unable to tolerate medication. However, phenytoin has a relatively long half-life, and levels may not fall until several doses have been missed (see Table 12).[112]

Table 12 **Treatment of seizures**

Emergency treatment
First line: • Midazolam • Clonazepam **Second line:** Treatments include phenytoin, levetiracetam and phenobarbitone, which can be given as an intravenous or oral load Levetiracetam and phenobarbitone can both be administered subcutaneously; however, emergency management may be limited by drug volumes and dilution required (intravenous or oral routes may be preferable in this context)
Maintenance treatment: Oral
Maintenance treatment can include: • Phenytoin • Phenobarbitone • Clonazepam (including drops) • Clobazam • Levetiracetam
Continuous treatment when oral route not possible (including at end of life)
Maintenance doses of clonazepam, phenobarbitone or levetiracetam (total daily dose run over 24 hours) may be administered by subcutaneous or intravenous infusion, usually following a loading dose

Buccal or intranasal midazolam is a good first line agent for breakthrough seizure management where seizures are not controlled by prescribed anticonvulsants. It has been shown to be at least as effective as rectal diazepam in the acute treatment of seizures.[112, 170] Administration via the mouth is more acceptable and convenient and may become the preferred treatment for prolonged seizures that occur outside the hospital.[171] The buccal or intranasal dose is the same as the oral dose of midazolam used for sedation. It is helpful to have a supply of oral midazolam or rectal diazepam in the home for emergency use for fitting or agitation as they are safe and easily administered by carers. It is necessary to have a seizure management plan with clear guidelines regarding when to call for further assistance or medication advice. When prescribing midazolam, specify plastic vials if available because these will be easier to manage in such a situation. Subcutaneous or intramuscular diazepam should be avoided due to local irritation and poor drug availability. Oral clonazepam drops can be administered sublingually and may be useful for diazepam-resistant seizures. Clonazepam may increase oral secretions—this must be taken into account, especially when given regularly. If further seizures are likely, regular oral or subcutaneous

anticonvulsant therapy should be commenced. Oral phenytoin, clobazam, levetiracetam, carbamazepine or phenobarbitone can be given as maintenance therapy.

If the child is unable to tolerate oral drugs, alternative routes and drugs will be required if seizures are a possibility. Midazolam is easily prepared and can be administered subcutaneously. It is compatible with morphine and also has an anxiolytic and sedating effect. If seizures occur despite a continuous infusion, midazolam boluses can be given, followed by an increase in the dose of infused midazolam. Increasing doses will generally obtain control over seizures. Phenobarbitone, levetiracetam and clonazepam are also effective anticonvulsants and can be administered subcutaneously if necessary.

Irritability and agitation

There are many causes of irritability and agitation, many of which may be treatable (see Table 13). It is also important to consider existential (including psychological and spiritual components) causes of emotional distress that may contribute to agitation, especially in adolescents. Such assessment can also consider how best to manage carers' distress (including parents and health professionals). Reversible conditions can be managed appropriately, but cerebral irritability can be difficult to manage, with distress and inconsolability lasting for hours. Gabapentin can be considered to manage distress, anxiety and pain. It is effective for cerebral irritability, visceral hyperalgesia and autonomic dysfunction.[172] It has been shown to improve sleep quality and quantity, mood, pain, hypertonia and involuntary muscle contractions, as well as seating tolerance for children with a physical disability. It comes only as an oral preparation (capsules), but these can be split and the contents administered via NG or PEG tubes. Capsule contents taste bitter and are not tolerated well by mouth. There are minimal-to-no interactions with other medications. It is excreted renally (so the dose should be adjusted in renal impairment).

Clonidine is also very effective and tolerated well. There is also the option of a patch for controlled release when the baseline dose is known. For marked distress, levomepromazine or chloral hydrate can be used. Buccal midazolam can be used in a crisis to break the cycle of distress. However, this should not be considered for ongoing treatment of distress but rather as an option for crisis management.

In cases where irritability and behaviour disturbance are causing significant burden to the family, it can be helpful to consult with a psychiatrist for evaluation and guidance on whether psychotropic medications may be of assistance.

Non-pharmacological management strategies must always be considered:

- a calm and quiet environment
- use of schedules to create routine (and minimising boredom where possible or appropriate)
- repositioning if appropriate
- reassurance via touch and the voices of familiar people
- use of senses that are intact (e.g., reading a story or music [auditory])
- assessment and management of a full bladder, constipation, gastroesophageal reflux and other physical causes
- assessment and management of pain.

As a child approaches the end of life, hypoxia and existential distress may contribute to the acute escalation of agitation. Terminal agitation can be managed acutely with benzodiazepines; however, this may require escalating sedation with levomepromazine or phenobarbitone.

Terminal sedation should only be utilised as a measure of last resort, addressing potential contributing factors first. This includes attention to psychological issues, the environment and non-pharmacological strategies outlined above (*see* section 'Sedation as a therapeutic modality for intractable pain').

Table 13 **Sources of pain and irritability in children with neurologic impairment**

Somatic pain	
Head, eyes, ears, nose and throat	Headaches, ventriculoperitoneal shunt malfunction, otitis, corneal abrasion, sinusitis, pharyngitis, corneal abrasion, glaucoma, dental pain
Musculoskeletal	Chronic/acute musculoskeletal pain, spasticity, hip dislocation, fracture, osteomyelitis
Gastrointestinal	Gastroesophageal reflux, esophagitis, pancreatitis (associated with hypothermia and valproate), ulcer, gallstones, cholecystitis, constipation, rectal fissure, food allergy, retching and vomiting
Renal	Urinary tract infection/pyelonephritis, neuropathic bladder, obstructive uropathy, renal stones (associated with ketogenic diet and topiramate)
Respiratory	Aspiration, reactive airway, costochondritis
Genitourinary	Testicular/ovarian torsion, inguinal hernia, menstrual cramps
Skin	Pressure sore
General	Medication toxicity, sleep disturbance, obstructive apnoea
Neuropathic pain	
General neuropathic pain	Suggested by pain that appears out of proportion to an identified source or pain behaviours that develop weeks to months following surgery
Visceral hyperalgesia and central pain	Suggested by pain and/or retching associated with gastric and intestinal feedings, intestinal gas, flatus, bowel movements
Autonomic dysfunction	Suggested by sweating, increased salivation, flushing or pallor of skin, retching, vomiting, pain localised to the abdomen, agitation, arching, stiffening
Cerebral irritability	Diagnosis of exclusion: may be a feature of severe cerebral palsy and neurodegenerative conditions

Tone management: Spasticity, myoclonus and dystonia

Muscle spasms can occur due to immobility, pain, neuropathic spasms or cramps. Appropriate analgesia will reduce the protective muscle spasm effect. Low dose diazepam can also be considered if muscle spasm is causing pain. Encouraging mobility or changing position regularly in children with little energy will also reduce spasms and the development of painful contractures.

For longer-term treatment of spasms, baclofen can be considered. The main concerns with baclofen are a possible reduction in the seizure threshold and potential adverse effects on swallowing and airway protection. In addition, it takes some weeks to grade up to an effective dose. The involvement of a paediatric rehabilitation specialist or neurologist is helpful in this context. Localised spasticity can often be managed with botulinum toxin (Botox) injections. For patients with severe spasticity, an intrathecal baclofen pump can be considered.

Myoclonus is involuntary twitching involving single muscles or groups of muscles. It is a recognised toxic effect of opioids, occurring more frequently if pethidine is used.[90] It is more common in the terminal phase of illnesses and in those with underlying renal impairment, especially with the use of some opioids due to the build-up of secondary toxic metabolites. Treatment includes reduction of the dose of opioid, if possible, or changing to an alternative drug. Midazolam as a bolus or infusion is usually effective in controlling myoclonus. With some neurodegenerative conditions, it is difficult to treat completely. Longer-acting benzodiazepines such as clonazepam or clobazam may be helpful.

Dystonia as a chronic symptom is seen in children with brain injuries, including those with cerebral palsy, as well as children with metabolic and neurodegenerative conditions. This movement disorder is characterised by involuntary sustained or intermittent muscle contractions. Children with dystonia may experience contractions in opposing muscles, resulting in twisted or abnormal posturing.

Management of dystonia is usually approached in conjunction with neurologists and rehabilitation specialists. Medications commonly prescribed target three major neurotransmitter systems:

- GABAergic: diazepam, clonazepam, gabapentin, baclofen
- cholinergic: benzhexol, botulinum toxin (Botox)
- dopaminergic: levodopa.

Clonidine is also commonly prescribed; it has an unclear mechanism in dystonia management but has well-described analgesic, anxiolytic and sleep effects. Chronic dystonia can cause significant pain and psychological distress and can also be exacerbated by voluntary movement pain and psychological triggers. Concurrent management of pain, anxiety, sleep and other reversible factors is essential. Attention to positioning, equipment and massage are important aspects of dystonia management. In severe cases, surgical approaches such as deep brain stimulation and intrathecal baclofen pump insertion may also be considered.

Acute dystonic reactions are usually the consequence of antiemetics, which block central dopamine receptors. An acute dystonic crisis is characterised by facial and skeletal muscle spasms and oculogyric crises. These reactions are more common in children, especially girls, and generally occur within a few days of starting treatment and may take 24 hours to subside after ceasing the drug.

Drugs that may cause acute dystonic crisis:

- metoclopramide
- haloperidol
- levomepromazine
- risperidone / prochlorperazine.

For specific treatment, benztropine (either intramuscularly or intravenously) is recommended. This can be repeated once, but if the intramuscular route is used, allow 30 minutes to elapse before repeating. The same dose should be given orally, twice daily, for 24–48 hours to prevent recurrence.[173] Acute treatment for symptom relief can be achieved with intravenous diazepam.

Insomnia

Sleep disturbance is common in children with an LTC. The aetiology of insomnia is multifactorial and is often a combination of physical, psychological and perhaps environmental factors.

Lifestyle changes, including improved sleep hygiene and exercise, may be helpful for improving sleep. Attention to physical positioning and comfort for sleep may be needed from physiotherapy and occupational therapy teams. Nightshift staff caring for patients in the hospital and hospice settings should reduce interruptions, noise and light as much as possible. Melatonin can also be considered, particularly in children with neurological conditions and those with an altered circadian rhythm. Stronger sedative medications or psychotherapeutic agents may be required in very severe cases.[28] When depression or anxiety is a factor, consideration should be given to psychotherapy and pharmacological treatment. Amitriptyline can be helpful as a pharmacological agent for managing insomnia in terminally ill children, particularly if neuropathic pain is also present. Chloral hydrate can also be very effective. Fluvoxamine (graded up slowly) can treat anxiety and sleep. Stronger sedative medications or psychotherapeutic agents, such as nocte risperidone or quetiapine (off label) may be required in severe cases. When clinically indicated, managing persistent pain with a background infusion of opioid or oral CR opioid preparation will enhance sleep and minimise the need for breakthrough analgesia.

Fatigue

Patients may not complain of fatigue as many consider it a part of the disease process and not amenable to therapy. However, fatigue is a debilitating symptom and can significantly compromise quality of life.

Potentially reversible factors can cause fatigue and should be treated where appropriate prior to accepting fatigue as part of the terminal phase of illness. Reversible causes include:

- anaemia
- depression
- malnutrition
- dehydration
- insomnia
- medications (e.g., opioids, sedatives).

Fatigue does not respond well to pharmacological therapy. Steroids may produce an enhanced sense of wellbeing, but this is short-lived and often associated with side effects, including mood or behaviour changes and marked weight gain.

For many patients, fatigue reflects disease progression, and support should focus on helping the child and family adjust their expectations and goals. Rest may be helpful, although planned activities may improve the child's sense of wellbeing. Families should be helped to plan activities around their child's fatigue, including school attendance, which may be reduced to short periods for favourite classes at times when the child is feeling most energetic.

Renal symptoms

Kidney failure

Kidney failure (KF) is defined as an estimated glomerular filtration rate of less than 15 mL/min/1.73 m^2 and/or the requirement of kidney replacement therapy (KRT).[174] The incidence of KF in children is stable; however, the prevalence of *treated* KF is increasing worldwide.[175] This likely reflects improved survival rates of children with complex medical conditions and increased access to KRT, particularly in high income countries.[175, 176] The treatment options for children with KF are associated with reduced quality of life, significant treatment burden and increased mortality rates compared to the healthy population.[177-180] This highlights the importance of early and collaborative integration of paediatric palliative care for these children.

Children with KF have consistently been demonstrated to have a reduced quality of life compared to both well children and those with other chronic conditions.[178, 180] The symptom burden of children with KF is secondary to impaired fluid, electrolyte, haematological and hormonal homeostasis associated with kidney impairment. Symptoms include those related to fluid overload (dyspnoea, oedema), uraemia (pruritus, nausea, vomiting and anorexia, sleep disturbance), anaemia (fatigue, dyspnoea) and growth failure (related to anorexia, delayed gastric emptying, impaired growth hormone response, mineral bone disease).[181] The worst quality of life scores are reported by children on dialysis.[178] This is not only attributed to the symptoms of KF but also to the complications of their therapy.[182] Quality of life domains of significant concern include cognition (particularly school performance), emotion (both psychological health and social function) and pain.[178, 180]

Kidney replacement therapies

The treatment options for children with KF include KRT and supportive care. KRT encompasses dialysis (both peritoneal and haemodialysis) and kidney transplantation. Neither of these therapies is curative. Kidney transplantation is generally considered the gold standard KRT for most patients (especially children and adolescents) and has a median graft survival of 10–15 years.[175] This means any child with a kidney transplant will need a minimum of 2–3 kidney transplants in their (shortened) lifespan. Dialysis and transplantation are both invasive and intensive therapies, placing a significant burden on a child and their support structure.

Indications for KRT therapy in children typically include fluid overload with or without hypertension, severe electrolyte or metabolic disturbance (including hyperkalaemia, uraemia and acidosis) and, in children, poor growth. Historically, dialysis has only been offered to children as a bridge to kidney transplantation. However, with improved survival rates of extremely preterm infants, anuric

infants with congenital anomalies of the kidney and urinary tract, as well as improved survival of children with complex oncological, metabolic and genetic conditions, dialysis may be considered a component of symptom management.[183-185]

The role of palliative care in conjunction with the nephrology team

KF is an incurable LLC with increased mortality and reduced quality of life. Therefore, paediatric palliative supportive care should be considered in all children with KF, even when disease-specific therapy is being pursued. Roles for palliative care in KF include the relief of physical, psychosocial and practical suffering; improved quality of life; facilitation of advanced care directives; and direction of care discussions.[179]

One consideration in a supportive or palliative approach to KF is the use of dialysis for symptom management. Dialysis is an effective method to reduce symptoms related to fluid overload (with fluid removal), symptoms related to uraemia (with clearance), facilitate medication administration (iron and erythropoietin) and improve feeding in infants. When discussing palliative or supportive dialysis, it is important to consider the burden of these therapies and to communicate this clearly to patients and their families. For those on haemodialysis, these include requiring permanent vascular access (that may prevent activities such as showering and swimming) and regular visits to the hospital for treatment (typically 2–3 times a week), with the associated impacts on schooling and carer work capacity. For those on peritoneal dialysis, the burden of care is placed on the carers who conduct the therapy at home. When considering palliative or supportive haemodialysis, it is also essential to establish clearly that the goal of dialysis is symptom management and *not* to proceed to transplantation. For cases where the initiation of dialysis remains controversial, and there is not a clear consensus among members of the treating team and family, a time-limited trial of dialysis may be an option.[182]

Drug use for symptom management in children with kidney failure

Otherwise, supportive care in KF involves managing symptoms (both physical and psychological) via a combination of holistic and pharmacological methods.[181] It is important to consider how KF may affect the pharmacology of the medications that may be prescribed (see Table 14). Prevalent symptoms of KF include pain, agitation, pruritus, dyspnoea, nausea and fatigue; these are discussed in earlier sections of this book.

Table 14 provides a summary of pharmacological suggestions, noting that medication dosing and intervals for this patient cohort generally ***require adjustment for age/weight and kidney clearance***.[181]

Table 14 **Pharmacological options for symptom management in children with kidney failure**[181]

Drug	Recommendation	Pharmacology
Pain		
Non–opioid sensitive pain		
Paracetamol	Normal dosing but maintain minimum of 6-hour interval between doses	Predominantly hepatic metabolism to inactive metabolites. Metabolites plus less than 10% parent drug excreted in urine
Non-steroidal anti-inflammatories	Use with caution in children with kidney impairment (not on dialysis) as may worsen renal function, reducing urine output and increasing risk of issues with fluid overload Use with caution in children with kidney impairment/failure including those on dialysis as increases risk of bleeding due to platelet dysfunction	Hepatic metabolism to inactive metabolites with less than 10% of parent drug excreted unchanged in urine
Opioid-sensitive pain		
Morphine	Morphine, due to familiarity, is potentially a good option, given only on as 'as needed' basis	Metabolites and approximately 10% parent drug rely on renal clearance
Fentanyl	Fentanyl is potentially the safest option if a continuous infusion is required Start low dose and slowly titrate with close monitoring	Hepatic metabolism to inactive metabolites. 10% parent drug excreted unchanged. Excreted into urine and faeces
Methadone	Safe but for use with extreme caution and close monitoring, only under specialist supervision	Approximately 20–50% excreted in urine as metabolites or unchanged methadone. Protein binding to alpha1-acid glycoprotein may be upregulated, potentially prolonging drug half-life

Drug	Recommendation	Pharmacology
Oxycodone	Use with caution, on 'as needed basis', starting at lowest dose and titrating slowly	Hepatic metabolism to active metabolites, one of which has an affinity for the opioid receptor 40x greater than oxycodone
Hydromorphone	Not recommended as first line option Experienced clinicians may choose to use cautiously	Hepatic metabolism to hydromorphone-3-glucoronide, which is excreted in the urine
Neuropathic pain		
Gabapentin **Pregabalin**	Use with caution, starting at 50% dose with either once daily or alternate daily dosing	Renally cleared and excreted unchanged in the urine, so potential for prolonged clearance in KF
Ketamine	Start at lowest dose and titrate according to response and toxicity	Hepatic metabolism to norketamine, an active metabolite with 20–30% the potency of ketamine. Final clearance is in the urine and bile
Amitriptyline	Not recommended	1st pass metabolism to nortriptyline, a more potent metabolite, which is renally excreted
Agitation		
Haloperidol	50% dose reduction due to long half-life and potential for accumulation. Slow and considered dose titration in response to efficacy and toxicity	Significant first pass metabolism with oral absorption Metabolites not thought therapeutically relevant, although back conversion to haloperidol has been described 88–92% plasma protein bound

Drug	Recommendation	Pharmacology
Levomepromazine	Does not require dose reduction, but start at lowest recommended dose, once daily, with slow cautious titration due to potential for metabolite accumulation There is limited data regarding dosing in stage 5 chronic KD (CKD 5)	Hepatic metabolism with some clinically active metabolites that are excreted renally and faecally, with less than 5% excreted unchanged in the urine Long half-life of 15–30 hours; duration of action reported to be about 8 hours
Midazolam	For bolus dosing, no dose reduction is necessary, as long as given on an 'as needed' basis For continuous infusion, commence at lowest recommended dose and titrate slowly based on response May accumulate due to reduced metabolite excretion and an increase in free fraction through reduced protein binding	Hepatic metabolism to metabolites that are less active than the parent compound Small amounts are excreted in urine unchanged 96–97% protein bound, with significant distribution into tissue
Dyspnoea		
Morphine **Oxycodone** **Fentanyl** **Midazolam**	Opioids at 25–50% of the dose used for pain Morphine or oxycodone can be used on an 'as needed' basis Fentanyl is the preferred option for continuous infusions Midazolam may add benefit but can exacerbate drowsiness and delirium, so 'as needed' dosing is preferable	See opioids above
Nausea and vomiting		
Levomepromazine and haloperidol	See agitation above	See agitation above

Drug	Recommendation	Pharmacology
Metoclopramide	Use at 50% dose reduction due to reduced renal clearance, with accumulation and risk of extrapyramidal side effects	Hepatic metabolism to inactive metabolites, although about 20% is excreted unchanged Studies have shown accumulation in kidney impairment, with adverse effects, despite renal clearance accounting for a small amount of total clearance
Ondansetron	No dose adjustment needed as it is converted to inactive metabolites, with only small amounts excreted in the urine, so accumulation is unlikely	First pass metabolism, with 60% bioavailability following oral administration Hepatic metabolism to inactive metabolites with less than 5% excreted in urine
Pruritus		
Gabapentin **Pregabalin**	Gabapentinoids are likely to be the best options, with dose reduction and extension of dosing interval	See neuropathic pain
Secretions		
Hyoscine hydrobromide	Avoid where possible due to potential central nervous system (CNS) side effects Transdermal route less likely to be an issue, but absorption may be influenced by other complications of CKD 5 (e.g., peripheral oedema)	Uraemia may increase blood–brain barrier permeability, leading to increased drowsiness, delirium or paradoxical agitation
Hyoscine butylbromide	Use without dose reduction	Hepatic metabolism with very minimal excretion in urine Little CNS penetration
Glycopyrronium	50% dose reduction and careful titration in response to effect	Limited pharmacokinetic data available Accumulation may occur, so caution with dosing is advised

In summary, the supportive care of the child or young person with KF is challenging and complex. We recommend having both nephrology and palliative care teams working closely together to support those patients with complex symptoms or needs as early as possible. Though dialysis may be an option in select cases to assist with symptom management for end-of-life care, this must be commenced with careful consideration given that the benefit of this therapy must clearly outweigh the significant burdens and impact on the child and family's quality of life.

Dermatological symptoms

Dermatological conditions in paediatric palliative care

Dermatological conditions and symptoms are common in paediatric palliative care. Children with LLCs may have clinical manifestations of skin conditions causing distress and discomfort. The most common symptoms are pain and pruritus,[186] followed by rashes, skin ulcers and infections. These dermatological symptoms are often attributed to the underlying medical condition or complications related to treatment. Life-limiting primary dermatological diseases, such as epidermolysis bullosa (EB) and large burn wounds, negatively affect the patient's quality of life in the acute and chronic stages.[186] An interdisciplinary approach, including collaboration with a dermatologist, should be considered to manage pain or itch. A high index of suspicion is warranted for children with communication difficulties who present as being 'unsettled', necessitating a thorough assessment. Commonly occurring symptoms are discussed below.

Pruritus

Pruritus or itch is an unpleasant cutaneous sensation that provokes the desire to scratch.[186] Its presence can be very troubling for the patient and challenging for clinicians to manage. The pathophysiological mechanism of pruritus is complex. A small proportion (approximately 5%) of C-fibres, the majority (90%) of which are histamine-independent, is dedicated to transmitting the itch sensation.[187] Additionally, myelinated A-delta afferents play a role in this transmission. Chemical 'pruritogens' such as histamine, papain, kallikerin, acetylcholine and interleukin-2[186] contribute to the mechanism. Inhibitory interneurons (e.g., GABA) have also been implicated in the modulation of itch messages.[188] Neuropathic analgesics (e.g., gabapentin, pregabalin) have been shown to be efficacious antipruritic therapeutic options. Gabapentin has been found to be effective in pruritus related to uraemia,[189] cancer, opioid medication and burn injury.[187, 190]

There are numerous causes of pruritus that include dermatological conditions, systemic disease, neurologic conditions, uraemia, biliary obstruction, medication side effects, dry skin and psychological factors. Management includes a thorough history to determine the cause, a physical examination to evaluate the skin and appropriate investigations, which may include a skin biopsy. Some causes of pruritus and therapeutic options are summarised in Table 15.

Table 15 **Causes of pruritus and therapeutic options**[186]

Cause	Pathophysiology	Pharmacological management	Non-pharmacological management
Opioid	Stimulation of central mu-opioid receptors in the medullary dorsal horn Serotonin action by opiate may incite histamine release from skin mast cells	Ondansetron (5HT3 receptor antagonist) Opioid switch Droperidol (D2 receptor antagonist) Low dose naloxone alongside opioid	No specific interventions
Cholestasis	Centrally mediated increased endogenous opioid neurotransmission Bile salt accumulation and deposition in the skin	Phenobarbitone Rifampicin Cholestyramine Opioid antagonists	No specific interventions
Uraemia in end stage renal failure	Multiple theories of pathogenesis: the accumulation of uraemic toxins, cytokines, iron deficiency anaemia, raised plasma histamine levels	Gabapentin Ultraviolet-B phototherapy Topical: Gamma-linolenic acid cream, calcineurin inhibitors	Acupuncture
Xeroderma	Can cause or exacerbate pruritus Common causes include atopic eczema and ichthyosis	Topical corticosteroid Vitamin D and E Linolenic acid (some efficacy with atopic eczema)	

Other therapeutic options

Antipruritics include either sedating antihistamines (e.g., promethazine hydrochloride, trimeprazine) or non-sedating antihistamines (e.g., cetirizine or loratadine). The sedative effects can help calm any agitation associated with pruritus, particularly at night.

The use of some psychotropic medications has also been described in the alleviation of itch, such as:

- doxepin (tricyclic antidepressant)
- paroxetine (selective serotonin reuptake inhibitor)
- mirtazapine (tetracyclic antidepressant).

General measures for treating pruritus

- education about the importance of general skin care and hydration
- treatment of the underlying medical conditions
- shorter bath times (limit to 30 minutes) and the use of lukewarm water, with mild or low pH soaps and the addition of sodium bicarbonate to the bath
- use of bath oil or soap substitute (e.g., aqueous cream, bath washes, hydrating or moisturising lotions, soap-free cleansing bars)
- use shampoo substitute (e.g., oatmeal shampoos)
- keep the skin moist with regular use of emollients; there is a variety of these, such as Glycerol 10% in sorbolene cream and aqueous cream (aqueous cream strength can be varied by adding liquid paraffin, white soft paraffin or olive oil); urea-based creams are useful for very dry skin or coexisting ichthyosis
- use of wet wraps, particularly during symptom flares
- maintaining a cool ambient temperature and avoiding rapid temperature changes
- avoiding drying environments
- prevention of the child scratching (e.g., keep the fingernails short, use mittens to cover the hands)
- application of a cold object (cloth or ice) may break the cycle of scratching.

Pressure injuries

Children who are unable to reposition themselves, who are bed-bound or chair-bound, are at higher risk of developing pressure injuries. Pressure injuries or sores can develop quickly. Areas likely to develop these are boney prominences such as the heels, neck, sacrum and scalp. The risk factors that lead to pressure ulcers are poor nutritional status, conditions leading to moist skin (e.g., incontinence) and poor circulation, often related to immobility.

Preventative measures include:

- repositioning patients by lifting to avoid shearing forces every two hours for patients that are bed-bound and hourly if chair-bound
- using pressure-reducing mattresses and gel pads
- using absorbent nappies for incontinent patients
- protecting the skin using barrier creams
- avoiding letting the skin become dry; using regular moisturiser
- examining pressure areas regularly.

The management of pressure ulcers depends on the patient's prognosis. Management includes provision of appropriate analgesia depending on the severity (refer to the 'Pain' section of this book). Good wound care is also essential for wound healing and pain control. Hydrocolloid dressings are used to dress shallow ulcers. Some ulcers can become infected, requiring antimicrobial dressings, superficial debridement and wound cleansing. Deep ulcers may ooze blood or bleed; the use of tranexamic acid may be beneficial.[191]

In patients with a short life expectancy, managing accompanying symptoms of pain and odour may be more important than healing the ulcer. Odour is often well managed with the following:

- topical metronidazole gel (systemic metronidazole used in deep malodorous ulcers)
- silver sulfadiazine
- iodine cleanser
- charcoal dressings
- environmental adjustments to control odours, such as using activated charcoal in a container to absorb odour[192] or using aromatherapy such as vanilla, citrus or vinegar.

Other skin conditions

Nappy rash

Many factors contribute to dermatitis confined to the nappy area. These include excessive skin hydration, friction trauma, irritants (e.g., ammonia from urine, soaps and other creams and powders) and local fungal infection. Recommended treatments include frequent nappy changes, the use of barrier creams and treating any associated candida infections.

Skin infections

Skin infections can occur as a complication of wounds or trauma leading to localised infection, such as cellulitis. A wound swab should be taken, and appropriate antibiotic treatment should be commenced. Tinea is another common infection in children. Other uncommon skin infections include herpes zoster and herpes simplex.

Hyperhidrosis

Several causes of hyperhidrosis (excessive sweating) are seen in children with LLCs. Causes include psychological factors, familial dysautonomia, EB, heart failure, neurological, metabolic and endocrine conditions (e.g., hypoglycaemia and hyperthyroidism) and medication side effects.[193] Treating the underlying medical condition (if possible) is the preferred management strategy, as

well as supporting the family with linen changes, using absorbent drawsheets and attendance to hygiene. Anticholinergic medications can also have a role in management.[193] Support the family with linen changes and the use of absorbent drawsheets and attendance to hygiene.

Epidermolysis bullosa

EB is an inherited blistering condition with a wide spectrum of disease and prognosis. The skin and mucosa are extremely fragile. The most severe forms are junctional EB and recessive dystrophic EB. Complications (dependent on the type of EB) may include early death, formation of contractures and increased risk of developing squamous cell carcinoma.

Symptoms of EB include varying severity of pain and gastrointestinal symptoms (including gastroesophageal reflux), as well as bleeding from mucosal blistering.[3] Rare complications include the development of dilated cardiomyopathy and renal complications. Care of children with EB includes gentle baths, use of lubrication to minimise trauma and avoiding heat and high humidity—which help prevent blister formation. Broken skin should be appropriately dressed, and antibiotics should be commenced early to prevent infection.[3] Pharmacological and non-pharmacological management strategies should be used to lessen the anxiety associated with dressings, and appropriate interventions to manage pain should be used.

Perinatal palliative care

Perinatal palliative care is a compassionate approach to care that can be offered to parents who find out during pregnancy or shortly after birth that their baby has an LTC or LLC. Advances in prenatal testing and antenatal diagnosis mean that more parents are confronted with the diagnosis of an LLC in their unborn baby.[194] For parents who receive a life-limiting prenatal or prenatal diagnosis, perinatal palliative care provides the opportunity to embrace their baby's life—before and after birth. This can offer a window of opportunity to commence perinatal palliative care earlier, build relationships over a longer period and progress care planning in a less rushed manner.[194]

According to Australian definitions, the perinatal period of life begins at 20 or more completed weeks of gestation or with a birthweight of more than 400 grams and ends at 28 days after birth. Antenatal consultation (often in conjunction with maternal foetal medicine or obstetric services) can occur earlier than 20 weeks if a potential LLC is identified at that time. Perinatal deaths are those that occur prior to or during labour or birth (stillbirth) or those that occur in the neonatal period.[195, 196] Deaths in infancy are those that occur in the first year of life. Despite advances in perinatal care, deaths in the perinatal period and infancy continue to account for more than two-thirds (69%) of all deaths in children aged 0–14 years in Australia.[197]

Pregnancy is usually a time of joy, optimism and hope—when parents and families anticipate the arrival of a new baby. When parents receive the news that their unborn baby has a serious or life-threatening medical condition, or in the event of a premature delivery or unexpected diagnosis, the grief and sense of loss they experience is immense.[198] Parents and families may experience grief related to the loss of the anticipated 'normal' pregnancy and birth and the loss of their envisioned family life or the hopes and dreams they had for their child. The time that parents have with their baby may be very short and is particularly precious. Perinatal palliative care empowers families to make meaningful plans for their baby's birth, life and death and offers dignity to the baby and family in keeping with their spiritual and cultural context. Many more LGBTQIA+ families are now choosing to have children; to understand their needs, it is vital to possess knowledge around the barriers LGBTQIA+ people face when accessing pregnancy and birth care (*see* section 'LGBTQIA+ people and families').

Perinatal palliative care encounters complex ethical issues, such as navigating when the foetus' and gestational parent's interests are in conflict or the challenges of defining when life begins (*see* section 'Ethics in palliative care').

Congenital anomalies are the most common cause of perinatal deaths in Australia.[197] Some babies die in the newborn period due to complications relating to extreme prematurity or due to severe LTCs that do not respond to intensive care interventions. With advances and increased use of genetic screening and other technologies, the frequency of genetic and other potentially LLCs being diagnosed early in pregnancy is increasing.[199] However, even with an antenatal genetic or structural diagnosis, there can be broad phenotypic and functional variability, resulting in a range of clinical consequences for the child. For this reason, it is important that decision-making is individualised and considers this uncertainty.[200]

Conditions for which palliative care involvement may be appropriate include:

- major structural abnormalities in the brain (e.g., anencephaly, hydranencephaly, holoprosencephaly)
- chromosomal abnormalities (e.g., Trisomy 18 and Trisomy 13)
- severe complex congenital heart malformations (e.g., hypoplastic left heart syndrome)
- severe neuromuscular conditions
- severe renal abnormalities (+/- pulmonary hypoplasia)
- life-threatening skeletal dysplasia
- infants with life-threatening complications of prematurity.

It is vital that the palliative care approach is integrated into neonatal units for all patients, including those with extreme prematurity and LTC. The paediatric palliative care team may be well placed to assist in the management of complex cases, such as regarding symptom management, complex decision-making, navigating difficult ethical issues or planning care in the community.[201]

Perinatal palliative care presents unique challenges. Care is often planned for a baby who is not yet born, where there is likely to be a high degree of diagnostic and prognostic uncertainty.[198] Parallel planning is the process of planning for multiple scenarios, such as planning for disease-directed care alongside planning for end-of-life or comfort-focused care.[198, 202] Outcomes ranging from stillbirth to death shortly after birth or a longer time frame of survival might be considered. Parallel planning requires a multidisciplinary and comprehensive patient-centred and family-centred approach to support care in accordance with the family's cultural, religious, spiritual, social, emotional and family values. The aim is to promote shared decision-making and a partnership in care.[203, 204] Health professionals must be comfortable with a high degree of uncertainty and be willing and able to provide flexible support, potentially over an extended period.

Once an LLC is suspected or diagnosed, the family require clear and consistent information to make informed, voluntary decisions.[205] A multidisciplinary team with the infrastructure, expertise and support to provide holistic care should be identified.[205] In the context of an antenatal diagnosis of an LLC, options available to parents may include termination or continuing the pregnancy. Parents who choose termination of pregnancy due to the diagnosis of an antenatal LLC may want to discuss palliative care options before they make their final decision. It is also essential to provide bereavement support, where possible, in this context. In some circumstances, pursuing intensive interventions (e.g., intensive care and surgical interventions) may be prioritised. Receiving these interventions is not a barrier to ongoing perinatal palliative care. In other situations, families may prefer to plan a palliative approach to care from the time of their baby's birth. Planning for the future in times of great uncertainty can be a source of comfort for some families.[198]

It is vital that all relevant teams are involved in the planning and decision-making process. This requires excellent collaboration and communication between clinicians from obstetric, midwifery, maternal foetal medicine, neonatology, paediatric and palliative care teams. This communication is integral to ensuring the family's goals of care are discussed and documented and aiming for a consistent, collaborative approach to care.[194, 204] Families benefit from having a dedicated case coordinator or consistent clinicians for support throughout their pregnancy to help establish trust, improve communication and ensure the smooth provision of care.[206]

Birth planning is an essential component of perinatal palliative care. This planning aims to optimise the baby's life while balancing the risks to the mother and baby. In creating a birth plan, palliative care goals can be clearly outlined, in addition to the standard midwifery or obstetric plan. This planning and communication are complex, and would usually occur over a series of interactions rather than at a single point in time. An acute resuscitation plan may also be completed antenatally if appropriate. Once a care plan is formulated, it should be communicated to all staff (including medical, nursing, allied health and pastoral care) and documented clearly in the maternal medical record. This is particularly important as birth may occur after hours or on weekends. It can also be useful to provide the family with written documentation, such as a copy of the birth plan or a summary from multidisciplinary team meetings (*see* section 'Advance care planning').

Key elements to consider when formulating a birth plan include:

- mode of delivery (vaginal birth versus caesarean)
- monitoring during both pregnancy and labour, recognising that monitoring will influence subsequent decision-making and interventions (e.g., consideration of a caesarean in the setting of a non-reassuring cardiotocography); the degree of monitoring should reflect the goals of care
- resuscitation planning, particularly at the time of delivery; in some situations, it will be appropriate *not* to initiate life support upon delivery
- supports for parents while in the delivery room, including consideration of support people and cultural, spiritual or religious practices
- preferred location of care, in line with the family's preferred goals of care
- family preferences for memory-making activities.

Planning for care after the baby is born might include the following approaches and interventions.

Pain and symptom management

Non-pharmacological interventions are the first line treatment for symptom management (*see* chapter 'Symptom management'). Examples include skin-to-skin or kangaroo care and swaddling.

Medication pharmacokinetics are age-dependent, and dosing may vary according to gestational age. Refer to local neonatal medication dosing guidelines (*see* Appendix 7).

Provision of nutrition

This has significant meaning to all parents; therefore, feeding should always be considered. Feeding is emotive and may have significant implications from a cultural perspective. Options may include breastfeeding or enteral feeds with expressed breastmilk, donor breastmilk or artificial formula. Drops of breast milk or sucrose can also be used for comfort, with or without the presence of a sucking reflex. In some cases, it can be helpful to discuss the appropriateness of NG tube feeding before birth so that a clear plan can be documented ahead of time. It is rare for feeding in some form not to be an option, particularly when it is an important goal of the family. Equally, the option of not providing ANH is appropriate in some situations.

Place of care

The place of care will depend upon the diagnosis and clinical situation, family preferences and geographical circumstances. Possible locations of care may include the hospital, hospice or home. Some hospitals have dedicated family rooms that are suitable for end-of-life care. Consider the physical location of families during end-of-life care and be sensitive to their proximity to other families with well babies (*see* chapter 'Place of care').

Cultural and spiritual care

It is crucial to explore with families what is important and meaningful for them. This may include baptism, spiritual rituals, specific practices around handling the body, burial or cremation and funerals (*see* section 'Spiritual and cultural perspectives').

Memory making and enhancing bond or connection

Creating opportunities for families to connect with their baby during pregnancy and following the birth is an essential element of perinatal palliative care. This may include memory-making activities such as pregnancy photography, heartbeat recording during pregnancy, family or infant photographs, footprints and handprints, plaster casts of hands or feet, a personalised cot card, breast milk donation or assembling a memory box. Equally, activities such as cuddles, bathing and dressing the baby can become important components of memory making and enhancing connection.

Consider modifying the physical environment or promoting sensory experiences to enhance the family bond and connection. This may include taking the baby outside, music, aromatherapy and facilitating experiences that hold particular significance to the family.

It is important to consider the cultural and spiritual needs of the family because some activities may not be appropriate for some families.

Autopsy

Discussion with parents regarding autopsy is recommended following stillbirth or neonatal death, particularly when there is uncertainty regarding the underlying diagnosis.[207] For some families, further genetic investigations may assist in clarifying whether their child's condition is likely to recur in future pregnancies.

Organ donation: opportunities for organ donation in infants are often limited by the child's size.[208] A request to donate tissues or organs can be discussed with the local organ donation team. Umbilical cord (stem cell) donation at birth may be possible in some centres. Practical and ethical challenges exist regarding organ donation from infants with anencephaly in Australia.[208] When organ donation is not possible, families may find meaning in planned organ or tissue donation to disease-specific research projects or biobanks (*see* chapter 'Organ and tissue donation').

Bereavement care and follow-up

Bereavement care and support for the entire family is an essential component of perinatal palliative care (see chapter 'Bereavement'). Components of bereavement care that may be unique to the perinatal palliative care setting include:

- follow-up obstetric care, including debriefing following traumatic delivery and consideration and assessment of postnatal depression
- specific considerations in multiple pregnancies, including in the setting of surviving sibling/s
- suppression of breastmilk and donation of collected breast milk
- planning for future pregnancies:
  - consideration of the implications of genetic diagnoses and arranging appropriate genetic counselling
  - obstetric model of care in future pregnancies, with the provision of trauma-informed care; ideally, this is provided in specialised pregnancy-after-loss clinics where continuity of care is provided by designated clinicians (this avoids parents needing to 'retell' their story to numerous care providers).

The dying process

Parents often wonder but may be afraid to ask about changes that may occur in their child as death approaches. The dying process is often referred to as the terminal phase of illness or end-of-life care. The body begins to shut down as major organ functions are progressively impaired. This is typically a gentle and undramatic series of physical changes, which are not medical emergencies requiring invasive interventions.

Parents need to know that these physical changes are an expected part of the dying process. It is crucial that families are supported effectively at this time. If the child is dying at home, 24-hour support (phone or in person) from experienced staff that the families know and trust is essential. Home visits by the GP, community nurse and specialist liaison nurse to assist with managing the child's symptoms are greatly appreciated by the family. This is a very emotionally draining and difficult time for the whole family. It is important to listen to parents' concerns and fears and, when necessary, offer guidance and advice on how best comfort their dying child.

It is essential that symptoms are closely monitored and that there is ongoing assessment of the effectiveness of provided therapy. Early detection of symptoms and ready availability of appropriate management of these is crucial.

Home care pack

For the child being cared for at home, the treating hospital should dispense a home care pack containing medications and other items that may be required in end-of-life care. This ensures medications are available in the home if and when the child requires them. Without a home care pack, there may be a considerable delay in obtaining medications or appropriate paediatric-sized items required for symptom relief (*see* Appendix 4). Safe storage of medications, either out of reach or in a locked box, must be discussed with the parent or carer.[209]

Circulatory and respiratory changes

As the heart slows and the heartbeat becomes irregular, blood circulation is decreased to the extremities. The child's hands, feet and face may be cold, pale and cyanotic. The child may also sweat profusely and feel damp to the touch. Parents may wish to change the child's clothes and keep them warm with a blanket or doona.

Respirations may be rapid, shallow and irregular. Respirations may also slow with periods of apnoea. This is called Cheyne-Stokes breathing and is common in the last hours or days of life. This breathing pattern is distressing for parents and siblings to witness, and they need reassurance that it is an expected part of the dying process and is not distressing for the child.

Excessive secretions, or difficulty clearing pharyngeal secretions, will lead to noisy, gurgling or 'rattly' breathing. Generally, this occurs during the terminal phase of the child's illness and is associated with a diminished conscious state. It can also be problematic for children with neurodegenerative diseases or brain stem lesions where swallowing is impaired. Positioning a child on their side or with their head slightly tilted down will allow some postural drainage—this may be all that is required. Reassurance of and explanation to the family is essential as the noise can be very distressing. However, the child is usually unaware and untroubled by the noise and secretions.

Anticholinergic medications (e.g., hyoscine hydrobromide or glycopyrrolate) can be used to reduce the production of secretions. For children with chronic conditions, a portable suction machine at home may be of benefit (*see* sections 'Respiratory symptoms' and 'Anaemia and bleeding').[186, 192, 210]

Incontinence

During the dying process, there may be a relaxation of the muscles of the gastrointestinal and urinary tracts, resulting in incontinence of stool and urine. It is important to discuss this possibility with parents, including how they wish to manage incontinence. If the child is close to death, parents are often reluctant for a catheter to be inserted to drain urine and may choose to use incontinence pads or disposable incontinence draw sheets. It is vital for the family that their child's dignity is respected. Disposable draw sheets are also helpful in cases of diarrhoea.[186, 192, 210]

Restlessness and agitation

Generally, a dying child will spend an increasing amount of time sleeping. This is partly due to progressive disease and changes in the body's metabolism but may also be due to progressive anaemia or sedation from opioids required for pain relief.

Some children remain alert and responsive until the moment of death. Others may become confused, semiconscious or unconscious for several hours or days. Restlessness and agitation during the terminal phase are not uncommon and may be due to increasing pain, hypoxia, nausea, fear or anxiety. Agitation may be the child's only way of communicating distress. A calm, peaceful environment and the presence of parents and family will assist in relieving the child's anxiety. The child's speech may become increasingly difficult to understand, and words may be confused. Even if the child is not able to communicate, they may be aware of the people around them. Hearing is the last sense to be lost, and the family should be encouraged to talk to their child. They may also like to play their child's favourite music, read stories or simply sit with and touch their child so the child knows they are not alone. These measures will assist in relieving anxiety.

However, agitation and restlessness may continue if the cause is pain, hypoxia, nausea, metabolic disturbances or unresolved psychosocial or spiritual distress (existential distress). Pain relief should be increased, which may be all required. If agitation continues, additional medications may be required. Treatment is then directed at increasing sedation. At this stage, oral medications may not be tolerated, and alternative routes of medication are essential. Midazolam can be administered via the intranasal, buccal, intravenous or subcutaneous routes. Clonazepam can be administered sublingually. Occasionally, there may also be the indication for medication to be administered rectally (e.g., diazepam or paracetamol).[186, 192, 210] See also section 'Neurological Symptoms'.

Eye changes

The pupils of a person who is dying may become fixed and dilated. Their eyes may become sunken or bulging and glazed. If eyes are bulging (which may occur in neuroblastoma), a small damp bandage placed upon the eye may provide some comfort. Eye secretions can be removed with a warm damp cloth.[186, 192, 210]

Management of symptoms via subcutaneous infusion

A continuous subcutaneous infusion of a combination of medications is simple to commence and is tolerated well by most children. A continuous subcutaneous infusion of morphine and midazolam in a syringe driver is effective for controlling pain, agitation and restlessness. A subcutaneous cannula with a side injection port should be used when starting the infusion; this enables bolus doses of medication to be given if required (*see* Appendix 2). If the child is at home, the community nurse, specialist liaison nurse or GP can commence the infusion.[209]

If bolus doses of medications are needed for breakthrough pain or increasing irritability, parents are generally able to administer bolus doses of morphine or midazolam with appropriate education and support. Doses of medication should be prepared, labelled and stored at a temperature specified by the manufacturer. Most medications should be stored below 25°C, and others must be stored in refrigerated conditions. A medication sheet should be provided to parents to record all times and doses of medication they administer.[209]

Occasionally, haloperidol or levomepromazine are required when benzodiazepines are unsuccessful in relieving agitation. Regular monitoring of the effectiveness of medication is essential, in addition to monitoring for side effects (especially dystonic reactions). Additional medications can be added to the syringe driver if needed. Morphine, hyoscine, haloperidol, metoclopramide and midazolam are all compatible and can be combined to be delivered as a subcutaneous infusion. Precipitation of medications may occasionally occur if high doses are required (*see* Appendix 7).[209]

Post-death

When a person dies, the body changes over a period of hours. The child will gradually feel cool to the touch, the skin colour will change (including the appearance of bruising), and the body will become rigid. These changes will become more obvious with time.

It is essential to inform parents that when death occurs, the child may be incontinent (i.e., urine and stool). There may also be ooze from the mouth and nose, particularly if they roll their child to undress and wash them. Parents who are unaware of these possibilities may become distressed if this occurs.

What to expect in the final days – Paediatric Palliative Care

https://paediatricpalliativecare.org.au/resource/what-to-expect-in-the-final-days/

What to do when a child dies

The death of a child is an emotionally painful experience, and no amount of preparation can entirely prepare a family for when this happens. Additionally, for many parents and carers, the death of their child will be the first death they have witnessed.

Ideally, the child has died at their or their family's preferred location of death, and they have been prepared well by a familiar member of their care team. However, whether this preparation is done before or at the time of death, being sensitive to and aware of the needs of the 'family' (i.e., their beliefs, cultural background, gender diversity and uniqueness) will be essential to enable the healthcare practitioner to best guide them through this difficult time. Please read the section on funerals, which also provides information on preparing families for what happens when their child dies.

For some parents, being prepared means knowing what will happen and what changes will occur as their child approaches death and after they die. For others, thinking or talking about their child's impending death is just too painful. It is important to reassure parents that either of these is normal. With parental permission, including the dying child or their siblings in parts of this preparation may reduce their sense of isolation and encourage the expression of their thoughts and wishes.

Most importantly, parents must be told that there is no hurry to do anything after their child dies except to spend time with them and say goodbye. They should be informed of the minimal legal requirements that must be followed—that is, that a health professional will assess their child, confirm death has occurred and complete the required documentation. It will be helpful to explain the practical tasks that must be accomplished and a time frame for doing these, which will depend on where the death has occurred and the needs of the family.

Hospital autopsies and tissue sampling after death

In some cases, a hospital autopsy may be performed for non-coronial cases to assist with understanding the cause of death or why the death occurred more suddenly than expected. This may be important for both the family and medical teams. With any patient's end-of-life care, consideration of whether an autopsy would be beneficial in understanding the disease process should be given. The family may be asked if they have any unanswered questions regarding their child's illness, and the medical staff should consider if an autopsy would assist in providing an answer. In many situations, the answer will be no. Preparation and planning for this must be done prior to the death.

There is also scope for limited autopsies (e.g., limited to brain, lung or abdominal organs) and tissue donation (e.g., cornea or heart valve). Post-mortem tissue samples may be taken for various purposes, including investigation of the underlying aetiology. Such biopsies typically must be performed in a timely manner, and samples sent to the laboratory urgently. There will be strict time requirements associated with sample collection following death, and these logistics must be explained thoroughly as part of the consent because they may also affect the place of care and time with the child's body. Typically, the metabolic or oncology service is involved in liaising with other teams and the laboratory about this process. Discussions of the issues regarding autopsy should be documented in the medical record. Some parents may also give consent for their child's

tumour (e.g., brainstem glioma) or a specific organ (e.g., brain) to be donated to the hospital for research purposes. For tissue donation, it is essential that contact has been made with the organ and tissue donation service in your state. Prior preparation, discussions and consent are paramount.

Death at home

When it is likely that a child will die at home, it is essential that a familiar member of the care team has outlined and explained to the family in advance what to expect and what is required. This may differ in different jurisdictions across the nation. In particular, parents should know whom they need to call to inform of the death and who will visit the home to complete a preliminary death certificate or 'pronunciation of life extinct form' (according to state requirements). This may be required by the funeral directors before they can move the child's body.

There may be the need for prompt action where cultural or religious rituals require specific time frames to be adhered to, or if autopsies are required or in the rare case where the death is a coronial case. Otherwise, parents should be informed that nothing needs to be done in a hurry when their child dies. This is very much a private time for family to say their individual goodbyes. Saying goodbyes and performing 'rituals' are important as they enable parents, siblings and other family members to express their love, sorrow, relief and regrets and share precious memories.

Examples of rituals that families have found helpful include washing the child for the last time, dressing the child in special clothes, taking photos, playing favourite music, praying together, touching and cuddling the child, talking to the child, taking foot and handprints, cutting a lock of hair (this must be done with parental permission) and writing a message or poem for the child.

A death certificate must be completed but not necessarily at the time of death. A doctor who has consulted the child in the past three months or who is satisfied with the cause of death must complete this; again, forward planning and pre-death identification of this person may avoid unnecessary stress at the time. This requirement may vary between jurisdictions. It will be important to know at the time whether the family want cremation or burial, as those choices may define the paperwork required. It can be a good idea to complete both burial and cremation paperwork in case the family change their mind. The death certificate is often collected by the funeral director; this may be billed as a cost to the parents.

Parents often ask if the police must be phoned once the child has died. In most cases, as the child is dying of a progressive disease and death is expected, the police do not need to be contacted. However, it is prudent to check in advance whether there are indications to notify the coroner (e.g., a child under the care of Child Safety or Protection Services) and whether any specific arrangements have been made concerning this.

Similarly, it is helpful to discuss with families whether they should call an ambulance. There is no need to call an ambulance after a child has died. In many states, if an ambulance is called prior to death, resuscitation will be attempted, irrespective of the information given by family members. It may be helpful for the family to have a copy of their current ambulance plan (available in NSW), resuscitation plan and palliative care management plan that explains the illness and expected treatments.

A funeral director will need to be called at an appropriate time for the family. Many families would have already chosen the funeral director they wish to use. Parents need to negotiate with the funeral director the time they will attend to collect the child's body. It is very important that parents remain in control of the timing and that they are not hurried. Some families may choose to keep their child's body at home for some time, including days and perhaps until the funeral. If this is the case, the family will need information and support to manage the child's body and the changes that occur post-mortem. They should be advised of changes including colour, stiffness and fluid leakage, as well as to keep the body in a room as cold as possible. A family may choose to have the body leave the home temporarily for embalming with the funeral director (see below). From a cultural or religious perspective, some families may require prompt burial or cremation, even within hours of death. Early identification of these requirements will necessitate meticulous pre-planning, including the pre-engagement of a funeral director, cultural or spiritual advice, family preparation and prompt processes for death certification.

Funeral directors are on call 24 hours a day, and parents can phone them at any time. There may be an extra cost if they attend the home after normal working hours; further, there are restricted attendance hours in some remote locations. When preparing parents for what happens at the time of death, it may be helpful to explain how the funeral director will transport their child. It is a legal requirement that a body is transported in a body bag. The funeral director can be asked to leave the child's face uncovered as they are moved to the vehicle, but they will need to close the body bag for transport. Families may like their child to leave with a doona, pillow, favourite toy or other item. These can be collected later from the funeral director. It is helpful for the GP or palliative care coordinator to be aware of parents' desires and plans before the child dies so that appropriate support can be offered at the time of death.

Death in hospital

Many of the principles discussed regarding what to do when death occurs at home also apply when death occurs in a hospital. Healthcare personnel can help create the space by taking their time, moving slowly and remaining calm. It is important that the family is given as much time as they need to perform important rituals and say their goodbyes. Some families may need to spend hours with their children before they are ready to say goodbye; others may be ready to leave soon after death. It is important for hospital staff to find the balance between respecting a family's need for privacy and identifying their need for support. A conversation with the family will clarify how present they would like you to be during this time. In the busy acute hospital setting, it may be necessary to advocate and ensure the family is allowed sufficient time to say goodbyes to the child and the staff who have cared for them. This may require some management of both time and staff. The time needed to support staff and allow for debriefing must also be considered. In non-acute settings (e.g., hospice), there is often more perceived time and space available for everyone to do this.

It is our experience that families find not taking their child home and leaving the child's body painful and distressing. Families would have travelled to the hospital and back home many times with their child during their illness. They may elect to have the funeral director collect their child's body from the ward rather than go to the hospital mortuary. Parents may also wish to walk with their child on their final journey out of the hospital to the funeral director's vehicle or mortuary viewing room. If this is their wish, a member of the care team should walk with the family and be available to support them when they leave their child's body. When walking with the child through the hospital,

staff must consider who is nearby and 'clear the way' (of other families or staff) before the child is moved from the ward. Parents may want to carry their own child for this journey, which should be assisted wherever possible.

Taking the child home from the hospital or to a hospice after death can be an option for some families. This can be discussed with sensitivity and careful consideration of the support needs of the family, community capacity, transport requirements, funeral director engagement and legal requirements such as certification.

Organ and tissue donation

It is not uncommon for parents and teenagers to ask about the possibility of organ or tissue donation as they approach the end of life. Questions regarding organ and tissue donation should be discussed with the family by a DonateLife Donation Specialist Nurse (NZ: Donor Coordinator), who has knowledge of the processes involved and can answer questions for the family and staff. In addition, post-donation follow-up is provided to the family by either the DonateLife agency or the Tissue Bank who provide information regarding how recipients will be helped through their child's donated tissue.

Organ donation can only occur if someone dies in an ICU while on mechanical ventilation. While many conditions or diagnoses mean that organ donation is not possible, there may be a possibility to donate specific tissue, such as cornea (eye tissue), heart tissue (valves), skin and bone tissue. However, the underlying condition, presence of infection, location of death and size of the child may influence whether a child would be able to donate tissue; these factors must be discussed with a Donation Specialist Nurse or Coordinator.

Mechanical ventilation is not required for someone to be able to donate tissues; in some cases, these can be retrieved up to 24 hours after death. The child does not have to die in the hospital to be a tissue donor. However, pre-planning or early discussions with DonateLife or the Tissue Bank may be helpful and make things less stressful for the family at the time of death.

In some select circumstances, children with cancer can donate samples of their tumour after they have died to further research into and scientific understanding of cancers. Families participating in this practice report benefits including meaning making, legacy creation[211] and a sense of comfort in knowing their child's suffering may help others.[212] It may be possible to donate a tumour even if the child dies at home.[213]

Family questions regarding post-mortem tumour donation should be directed to the child's oncologist for further exploration well in advance of the child's death. Palliative care clinicians may have a role in helping to facilitate the logistics of tumour donation. This may include the timely alerting of the oncology team at the time of the child's deterioration to the terminal phase, as well as ensuring that all teams involved in the child's care (including community services) are aware of the plan and processes required for post-mortem tumour donation.[213]

The procedure for tissue retrieval can be coordinated through the Donation Specialist Nurse or Coordinator, who will liaise with the Tissue Bank staff in your state, territory or region.

Further information about tissue and organ donation is available through:

http://www.donatelife.gov.au/

Alternatively, contact the DonateLife agency in your state, territory or region by phone during business hours.

Australian Capital Territory: 02 5124 5625
New South Wales: 02 8566 1700
Queensland: 07 3176 2111
Northern Territory: 08 8922 8349
South Australia: 08 8207 7117
Western Australia: 1800 950 155
Victoria: 1300 133 050
Tasmania: 03 6270 2209
New Zealand: 0011 64 963009 35

Death care arrangements

For many centuries, in societies across the world, the care of a child's body after death and the surrounding rituals (e.g., funerals and memorials) have played an important role in the grieving process by helping to acknowledge the importance of the child's life and by offering support to the family and the broader community as they grieve.

A funeral is an important event for many families and can be conducted in a range of ways. Funerals enable a family and community to express some of their emotions and thoughts about the person who has died, including how they have been affected by the person's life and death and about numerous other issues of importance to the individuals and family involved. A funeral is an event that takes place prior to the burial or cremation of a body (the body may or may not be present); it usually occurs days or weeks after a death. In contrast, a memorial is an event that typically takes place after burial or cremation and may be held many months after death. The choice of whether to hold a memorial or a funeral may be influenced by a range of considerations; however, the functional purpose of both events is quite similar.

For many people, funerals and memorials are an opportunity to commemorate the person who has died in meaningful ways, which may include expressions of cultural, faith or spiritual traditions. The child's funeral may be attended by many members of the extended family and community. This is especially the case for First Nations peoples and those with different cultural backgrounds. Specific cultural protocols may be followed to help the child's spirit journey from this world to the next.

Many Māori whānau (family, including extended family) observe tangihanga (funeral customs) at ancestral homes; this can involve people with specific cultural and pastoral skills whose role is to ensure the spiritual safety of the deceased, whānau pani (bereaved next of kin) and manuhiri (visitors) who come to pay their respects to the deceased and family. Kaumātua (elders), kai karanga (women callers), kaikōrero (speech makers) and people with pastoral knowledge and skills are there to carry out traditional death rituals at tangihanga. It is normal for tangihanga to last several days. Whānau sleep in the whare tīpuna (ancestral house) with the tūpāpaku (body); the body is never left on its own. Other whānau provide nourishment and care for the family while they are in mourning. However, it is important to acknowledge the diversity among whānau as not everyone can financially afford to host large traditional funerals, and others may prefer to conduct their death rituals at home or a church. Many urbanised whānau have lost knowledge of their death customs, and elders who could have guided these cultural processes have passed on. However, many would welcome cultural support if it were available.

For Aboriginal and Torres Strait Islander peoples, the child's funeral or Sorry Business may be attended by many members of the extended family and community, and specific cultural protocols may be followed to help the child's spirit journey from this world to the next. As with other aspects of care, it is vital to work closely with our Aboriginal and Torres Strait Islander health colleagues when supporting families during the time of Sorry Business so we can ensure that the family's cultural wishes are respected.

Choices relating to death care arrangements

In Australia and New Zealand, families typically choose to engage a professional funeral service provider to coordinate a range of activities following the death of a child. A funeral service provider

offers support with body care, completing legal paperwork, arranging a funeral or memorial service, and coordinating logistics and choices regarding body disposition, by either burial or cremation.

Health professionals should be aware that while the use of professional service providers may be the preference for many families, all families also have the right to facilitate or participate in after-death care arrangements themselves. Some families may find this participation in after-death care a supportive part of the initial grief process as it offers choice, control and a sense of personal autonomy during this time. However, other families may feel exhausted or overwhelmed or choose to outsource this care to a professional funeral service provider. Families may choose to lead their own funeral arrangements for a range of reasons, including social, spiritual, cultural or financial reasons. Wherever possible, health professionals should prioritise supporting family choices, which can be determined best through supportive pre-planning conversations (*see* below).

It is beneficial for health professionals to become informed about the range of options available to families who need to make care arrangements for a child who has died. You may choose to do this by speaking with an experienced practitioner or by meeting with a local funeral service provider as part of your ongoing professional development. In addition to supporting professional practice, becoming more informed about options, relevant regulations and available choices will directly benefit families during planning conversations, both in advance and after death.

While specific regulations relating to caring for and transporting bodies after death, as well as for burial or cremation, vary slightly across states and territories, after a child has died (where the death was expected and non-reportable), a family would usually have the right to:

- care for their child's body after death in a location of their choice (*including hospital, hospice, their home, cultural centre or a funeral service provider facility)
- arrange transport for their child's body, either themselves by private vehicle or with the assistance of a professional funeral service provider (*there are some state-based regulations guiding how transport of a body should take place; a funeral service provider will be able to provide information to support health care providers and families in this regard)
- lead arrangements for after-death care, including care of a child's body, death registration, cremation or burial plans and whether to have a funeral or memorial service. There are various regulations across the states and territories that determine the extent of family participation; however, the options available to families are often more than many will be aware of.

Some families will be familiar with these practices through existing cultural or social frameworks. In contrast, other families may be open to these choices while seeking additional advice or support from health professionals or a community death care provider, which could be a funeral director, a death doula or a cultural or spiritual elder.

When to discuss death care arrangements

It may be helpful for the health professional to offer to discuss the topic of after-death care and funerals before a child's death as part of broader planning conversations. Families may have thought about funerals privately and appreciate the opportunity to explore the options further, even though such discussions can be distressing. Families may find it helpful to have some time to think through the decisions that must be made about the funeral before the death has occurred. While

these conversations may elicit strong emotional responses, families often report that this can allay anticipatory anxiety or specific concerns (e.g., costs, options, timeframes). It may be supportive for some families to make plans and decisions in advance rather than in the period of acute grief in the hours and days after the death of the child. However, some families may not feel able to discuss funeral planning prior to a child's death and will discuss this at the time it is required. First Nations families will be familiar with consulting members of their wider community in relation to funeral arrangements and cultural protocols. However, some Māori families may be estranged from their ancestral homes and cultural protocols and may need assistance to explore, plan and prepare for what they want to happen.

Funeral costs can vary significantly, with the most significant factor usually being the choice between cremation or burial, which can vary by a factor of more than 2:1. Many Māori do not use cremation as a means of internment. However, deaths during COVID-19 lockdowns saw many whānau feel they had no choice and use cremation for the first time; unfortunately, breaking with cultural traditions in such a way caused deep distress. It can be helpful for the family to talk options through with one of the team members. Financial assistance for families in arranging the funeral may be available and should be considered with appropriate social work assessment and supports.

We are mindful that in some cultures and religions, burial must take place within a short time frame; where possible, we recommend working to support this. In addition, for Aboriginal and Torres Strait Islander families, assistance may be needed for the child to be returned to Country for their funeral.

Adolescents may wish to have the opportunity to be involved in planning their funeral; the Voicing My Choices tool provides a useful way to communicate about this (*see* section 'Advance care planning').

Families should be encouraged to do what best suits their individual needs and meets their cultural and spiritual beliefs. Some examples of decisions to consider:

- music
- cemetery plot or place for ashes
- photographs
- supportive cultural practices, which can include formal vigils
- smoking ceremonies
- releasing balloons, doves or butterflies or planting a tree
- readings
- eulogies
- inclusion of siblings
- open or private ceremony
- memorial card
- pallbearers
- public notices
- invitation of particular people to participate in special ways.

An issue that is often raised is whether children should attend funerals. The answer should be individualised, but the general rule is that attending the funeral is helpful for a child if they are given appropriate preparation and support. It is also helpful for some children to be involved directly with the funeral process. This might include choosing the clothes for the child to wear, decorating the coffin, choosing music, writing, drawing something to place in the coffin with the child, or saying something at the funeral service (in the case of older siblings or close friends). In other cultures, such as Māori, it is considered normal for children to be present at tangihanga.

Children should never be forced to attend; however, attendance often allows the child to feel included in this important family and community event and helps prevent misunderstandings about what has happened to the deceased child's body. Preparation that may be helpful for a child attending the funeral includes:

- enabling the child to ask questions about what will happen
- giving the child accurate information about what to expect.

It is especially important to prepare children for the likelihood that many people, including their mum and dad, will be very sad and might cry—but also that it is alright to cry and they will be okay. It is also important to tell them what will happen to the coffin with the child's body in it (e.g., that it will be put into the ground or curtains will close around it at the end of the funeral so it cannot be seen and then later it will be cremated).

It is essential to apply principles of good communication with children when preparing to attend a funeral. It is especially important to listen to the following questions: Why are they put into the ground? Can they feel anything? What if they're not dead? What will their ashes look like?

These questions need honest, simple, accurate and sometimes repeated answers, given in an atmosphere of care and nurture for the grieving child. Advise parents to remember to use reflective questions rather than assuming the answer that is required, as children's questions may have more than one answer. An example of a reflective question is: 'Tell me what you think and then I can tell you what I know?' The process can be quite distressing for families, especially if they have not been prepared; however, it is essential for children.

Bereavement

Grief and anticipatory grief

A simple working definition of grief is that it is cluster of thoughts, emotions, behaviours and experiences related to a loss.

Anticipatory grief is the grief that is associated with an impending or expected loss. It is a significant form of grief within palliative care. Many families will experience grief around the impact of the illness and impending death of their child and also the loss of 'normal family life' as it was before diagnosis. The death of a child also presents unique issues for grieving parents as they face their inability to protect their child and the loss of their hopes and dreams for that child's future.

As the sick child experiences losses associated with their illness, they also grieve. These include loss of their healthy self and ability to do things independently, loss of 'normal life' and routine activities (e.g., going to school, playing sports, going out with friends) and, consequently, a sense of isolation as many relationships change and diminish. They may also experience the loss of hopes and dreams for their future, particularly for adolescents.

Grief is a natural process through which people adapt to the changes in their lives that involve some kind of loss. Understandably, losses associated with the death of a loved one are of enormous significance and bring with them powerful and distressing expressions of thought, emotion, behaviour and experience.

Grief and grieving have become an issue that society is now more willing to face than in the more recent past. However, many people find it difficult to know how to communicate with a bereaved family or a family that is facing an imminent bereavement. Consequently, such families may experience (seeming) general avoidance of them or the issue that is most dominant in their lives (the death or palliative care of their child). As noted earlier, Aboriginal and Torres Strait Islander culture has a more holistic approach to health, where life and death are part of a greater journey. There are cultural beliefs and protocols that shape how the family and community will cope during Sorry Business.

Having knowledge of a range of theories of grief helps provide a clear framework for understanding grief and anticipatory grief and will enable effective work with families. Importantly, a framework that takes account of the uniqueness of each family and their social and cultural context will not only guide work with families but also can be used when working with families' support networks (*see* sections 'Indigenous and First Nations populations in Australia and New Zealand' and 'Respect for the uniqueness of each family') By sharing an appropriate understanding of grief and anticipatory grief, the anxieties and concerns of a family's support network can be reduced, enabling them to be of greater assistance to the family.

Supporting families through grief and anticipatory grief

There is an extremely broad range of normal and adaptive grief reactions, including a depth of emotional and existential pain that is difficult for most people to observe and, conversely, avoidance and suppression of emotion that can be difficult to understand. However, it is important

to be able to view the big picture and not be too quick to judge a family's expressions of grief as pathological.

Importantly, healthcare professionals must realise that it is not their role to eliminate experiences and expressions of emotional pain in the context of grief or anticipatory grief. Such a role would be impossible, and any attempt to achieve it would deny the reality of the family's experiences.

The Dual Process and Continuing Bonds are two very helpful theories of grief in the context of paediatric palliative care.

The Dual Process model of grief posits that grief is not a linear or stage-based process but rather an oscillation between loss-oriented and restoration-oriented stressors to cope with loss. For example, this model can help parents understand that it is okay to focus on activities that promote their child's quality of life in the present while, at times, they will feel very sad at the thought of their child no longer being with them in the future. After the death of the child, this model validates that it is normal to frequently feel intensely sad and yet also get on with some of the usual activities of family life, such as going to school and work.[214]

Continuing Bonds theory reassures us that when someone dies, our relationship with them does not end but slowly changes over time. The bond can remain just as strong, and some activities and rituals may help maintain the bond and honour the memories of their child after death. For example, families may have a space to keep photos and other mementos of their child, or they may set a place at the table for them or do something special on their birthday. This way of thinking can be a source of comfort to parents who fear that they and others will forget their child after death.[215]

As noted previously, we are also mindful that due to the impact of colonisation and intergenerational trauma, Aboriginal and Torres Strait Islander families experience many layers of grief during their child's Sorry Business. Importantly, we must acknowledge the cultural stories of the Dreamtime, which guide, support and comfort families during this time (*see* section 'Indigenous and First Nations populations in Australia and New Zealand').

These two models can also guide healthcare professionals in supporting families experiencing anticipatory grief in the following ways:

- acknowledging and empathising with the reality of the loss that is faced
- enabling expression of and exploration of feelings, which can move between hopelessness and hope at any time
- helping overcome blocks to adjustment in the changing physical and emotional environment
- assisting in the identification and pursuit of activities that promote quality of life for their child and family.

It is not the health professional's role to make a family accept the reality of the impending death of their child nor to stop them from hoping for a cure. Rather, it is our role to gently facilitate the family's adjustment to the changes in their child's condition and prognosis and, where possible, support them in changing the goals of treatment and care. As health professionals, we must be informed by the family's own interpretation of their experience and how this is shaped by their cultural and spiritual values and beliefs.

For example, health professionals may feel that a family is 'in denial' about the severity of their child's condition—but a family may simply have developed a way of life that allows them to live day to day. Families may appear to be planning and ignoring the immediate situation; however, when this is explored more deeply, parents may say, 'I have to keep some hope alive' or 'our religious beliefs mean we must do everything we can to save our child's life'. Alternatively, families may view 'hope' in terms of a 'pain-free day' or a day 'when we didn't have to think about the future'.

Importantly, in palliative care and grief work, psychosocial support is not limited to formal psychosocial interventions (e.g., formal counselling or therapy) but extends into every interaction with a family and its social network. The skill required is to see how each interaction can assist the family's movement towards ensuring everything possible is done to manage their child's pain and ensure they are as comfortable as possible.

Bereavement support

A child's death has a profound lifelong impact on a family, and family members need recognition, acceptance and validation of their experience. Families are constantly reminded of what could have been had their child survived. Seeing other children playing, commencing school, starting high school, graduations, 21st birthdays, marriages and other events that mark the passage of life serve as reminders of what could have been and often bring about renewed pain. The death of a Aboriginal or Torres Strait Islander child also affects the whole community, and we should always be mindful of the impact of intergenerational trauma and loss.

It is vital to understand that all people, adults and children, react to the death of a family member differently. Health professionals develop relationships with the dying child and the family. This also requires acknowledgement of the personal impact of caring for the family. We are particularly mindful of the impact on Aboriginal Health Workers and rural and remote healthcare personnel who may know the family through their community. As professionals who have known the family and the child who has died, we can assist families to acknowledge and live with their experiences. This can be achieved by being available to listen to their feelings of helplessness, anger, guilt, regret, relief and sadness and by exploring lost hopes, dreams and their search for meaning.

Throughout the course of their child's life, parents will develop important relationships with staff and other families in the health care setting. Parents may wish to revisit the hospital and talk with people who knew them and their child and shared a part of their journey.

It is helpful for the treating medical practitioner to offer to meet with the family in the weeks or months after the child's death. This provides an opportunity for parents and siblings to reflect on their experience and to ask questions that may help to clarify some of the events that occurred during treatment and in the terminal phase of their child's life. Some families will receive this offer appreciatively; in contrast, other families may not wish to accept the offer at all. Aboriginal and Torres Strait Islander families may need the support of Aboriginal Health Workers to attend follow-up meetings.

As health professionals, it is important to listen carefully to bereaved parents and other family members. Each family's grief is a unique and deeply personal experience requiring flexible support from carers. It is helpful to avoid words and phrases such as 'moving on', 'closure' and 'we know

how you feel'. Once again, listening is often more healing than talking. Most parents will also value the sharing of a happy memory you have of their child that highlights their unique personality.

A real fear for some parents is that their child will be forgotten. Phone calls or cards to families at significant times (e.g., the child's birthday, the anniversary of death or other special times) are appreciated. At times, health professionals are reluctant to contact families for fear of making things worse. However, the child who has died will always be in the thoughts of their family, and knowing that others remember is important and comforting. Many hospitals now hold Annual Services of Remembrance, which constitute another important way to help families know that their children are not forgotten.

Siblings of children who have died may also have their own fears or misconceptions regarding the experience. It is important to include them in conversations and to help them create memories for the present time and into the future. A memory book created by the sibling to keep can sometimes help to alleviate such fears. It also provides an opportunity to say goodbye creatively and explore feelings through the use of drawings, photos and writings.

It is important to remember that children's expression of grief after death can appear less intense and persistent than that of adults. Siblings and other children can often be quite concrete and matter-of-fact when discussing the child's death—grieving parents can easily misinterpret this. At these times, parents will require sensitive reassurance that such behaviours are quite normal. Children may need to revisit their understanding of their sibling's death and the emotional impact of this on themselves as they grow older.

Families will experience varying degrees of emotional and physical pain in the months and years following the death of their child. It is important for health professionals to know what local bereavement services are available for families who wish to access them. Different models for providing bereavement support include individual, couples and family counselling and bereavement support groups. Each person is unique and should be encouraged to access the type of support that suits them best. Many palliative care teams now have bereavement coordinators who work with families to identify and link them in with available supports.

Clinician wellbeing and moral distress

Caring for a dying child and watching over the family's experience can affect health clinicians profoundly at physical, emotional, mental and moral levels. There is great privilege in caring for families at the end of life; however, it also creates a range of individual responses driven by many different factors. For example, long-term connections and therapeutic relationships exist for many clinicians; therefore, when a child dies, they may experience personal sadness and empathy for families. Healthcare providers may internally wrestle with balancing compassionate responses with perceived professional boundaries. Additionally, distress may arise from concerns that the 'right thing' is not being done for the patient, shaped by personal beliefs and values—known as 'moral distress'.[216] Often, there are multiple factors contributing to clinician distress. However, irrespective of the source of distress, 'caring for the carer' is essential for maintaining the health and wellbeing of the clinician and team and to support the provision of quality care to the patient and family.

This chapter discusses various strategies that can be used in response to distress that may occur for clinicians working in palliative care.

Understanding clinicians' experiences

There is a range of possible clinician experiences, such as a profound connection to purpose, meaning, values and fulfilment. However, simultaneously, these experiences may also include:

- strong emotions such as grief, fear, anger, helplessness, sadness or apathy
- questioning of values, purpose, meaning, fulfilment and lost accomplishment
- a change in cognitive processes, such as poor memory, attention, concentration and exhaustion
- behaviours such as irritability, conflict within teams, sleeplessness, social withdrawal and self-medication.

The cumulative impact of care is critical to consider. Specifically, clinicians may not have the opportunity to process, reflect or acknowledge their experience in caring for a patient and their family before a new family requires care. Additionally, the impact of care extends beyond the primary clinicians—auxiliary service roles, such as administrative and domestic services and volunteers, within organisations will also be affected. Therefore, support must not only encompass strategies for individuals but also be directed towards the whole team. Two clusters of initiatives are required: one focused upon the individual's wellbeing (traditionally considered self-care) and the other being a systems or systemic approach to the wellbeing of all. Both responses are required to design and provide both proactive and reactive support.

Responding to clinicians' wellbeing

Supports should also be **tailored to the situation(s) and the individual.** For example, clinicians involved when it was perceived to be a 'good' death by all involved may need different support than in a scenario where there was disagreement within the team, moral distress or an adverse event.

Individuals vary in the type and timing of supports they want or need. Some may prefer group support, rather than one-on-one support. Others may wish to focus on clinical aspects, and others

the emotional impacts. Some may wish to reflect and process before continuing to other tasks, whereas others may move on quickly. Consequently, support must be consultative, voluntary and enabling. Supports also enable opportunities for clinicians to come together, reflect, feel heard, process and make sense of potentially complex and distressing situations within a safe environment.[217]

Individual wellbeing strategies

All individuals have unique preferences regarding maintaining their own wellbeing. A useful frame of reference to structure these strategies is through 'recovery rituals'. Recovery rituals refer to activities that help replenish energy, tap into values and bring joy. Incorporating performance psychology[218] principles, you may consider the following kinds of recovery rituals:

- **Physical recovery:** What exercise, sleep, water and nutrition needs enable you to stay well? How do you care for your body when it is unwell? What are your body's signals for dis-ease, stress and distress?
- **Emotional recovery:** Who in your social network provides unconditional positive regard, mentorship, fun and helps problem-solve? How can you capitalise on this network? What strategies do you have when emotions like sadness, loneliness, grief, anger, powerlessness or values conflict arise? What activities bring you fun and pleasure? What possibilities might be created by connection to land and Country or time in nature?
- **Mental recovery:** Notice when rumination about work occurs.[219] What are your end-of-shift rituals that facilitate transitioning to home?[220] Consider hobbies, learning, reading, creative outlets, puzzles, journalling and activities that stimulate your mind in different ways.
- **Purpose, drivers and values recovery:** What are your personal and professional values? Why do you do this work? What matters most across all domains of your life (work, home, social, family)? Understanding these may help guide you to cultivate and enrich your life on your good, bad and hardest days. Reflecting upon personal values will also support engagement in ethical discussions when your values appear to be in tension.

Systemic wellbeing strategies

Organisations should have a range of support systems and resources that consider systems wellbeing. The system domains that may hinder or promote wellbeing within organisations include the nature of the work, processes and procedures, the role of leaders, psychological safety and the team's behaviours and beliefs about the work.[221] Specific systems initiatives that may add value include:

Education

Given the sensitive nature of palliative care practices, education about processes and practices can build competence and confidence and reduce uncertainty. Ethics education can help clinicians grapple with the moral permissibility of some end-of-life care situations, such as withdrawal of or withholding life-sustaining interventions. Education is also required to normalise the emotional responses to caring for dying patients, teach recovery rituals and help clinicians identify other sources of support available to them.

Reflective practice groups

This involves exploring initiatives for ongoing regular peer-based supervision that enable staff to come together to reflect and discuss the nature of the work. This may include normative, formative and restorative reflections; importantly, the ongoing nature of such activities provides a proactive preventative function.[222]

Post-incident support pathways

Ensure that leaders and team members have a clearly defined pathway for support options, follow-up and checking in on team members (also known as 'psychological first aid')[223] following a significant event.

Clinical reflection pathways

Sometimes referred to as debriefing, after-action reviews or death reviews should be a safe forum for team discussion, acknowledging positive outcomes and opportunities for growth, addressing unanswered questions and embedding meaning making as a team. To enable a safe environment, the rationale, timing and place of a review must be considered (prior to the review). For example, some people may not be ready to process or review a case immediately following an event. This must be balanced against ensuring all clinicians involved in the case have the opportunity to participate.

Moral and ethical case reviews

Ethical case reviews provide an opportunity for clinicians to unpack ethical concerns and acknowledge the psychological responses that arise.[217] This often involves reviewing decision points and considering options, such as asking which ethical values were upheld, balanced or traded in the process? This can be particularly important where moral distress is or was present. Clinicians are invited to reflect on the nature and accuracy of their moral judgement and consider whether the thing that constrains their action is a reasonable and/or changeable constraint.[224] Participants may be encouraged to reflect on different personal values they bring to that understanding and consider whether the decisions made (e.g., respecting a family's wishes) were ultimately morally acceptable decisions, even if not the preferred option of the participant. How participants respond to their distress should also be addressed[225] to support individual wellbeing and team morale and to avoid unhelpful tension or division within teams. This is sometimes referred to as 'splitting' where different members of the team may have polarised feelings and opinions about the care being provided to the child resulting in professional discord.

Peer support programs

Modelled on psychological first aid principles,[223, 226] appropriately trained team members may purposefully check in with peers after significant events as a caring ear and can also encourage help-seeking behaviours.

Additional supports

Various additional supports are available both within and external to the organisation, including counselling, self-paced programs, peer support and practical information. Clinicians and leaders are encouraged to connect with their organisation's wellbeing leader to find out more.

Ethics in palliative care

Many ethical issues can arise in paediatric palliative care. These include practical questions such as the following:

- Should treatments or interventions be continued or ceased? Is it more acceptable to stop some types of treatment rather than others?
- Who should decide what is best for the child or young person—the parent, the patient, the treating clinician(s) or the ethicist?
- Can or should information about the illness or its prognosis be withheld from the child or young person?

Ethical issues also include more philosophical considerations, such as attempts to characterise whether a life is worth living or debating what makes a person a person.

Clinicians' perspectives may be informed by many different ethical approaches or frameworks, as well as their own personal views, values and biases. Examples of ethical theories and frameworks include:

- virtue ethics
- Confucianism
- capability approach
- principlism
- deontology (e.g., Kant)
- consequentialism (e.g., utilitarianism)
- human rights
- ethics of care.

Similarly, children, young people and their families may have diverse ethical viewpoints, which may contrast with those of other family members or the clinicians providing their care. Open communication between clinicians, families and the child or young person can aid in minimising both immediate and longer-term distress and regret.

Ethical frameworks

The following ethical concepts are particularly relevant in paediatric palliative care and are useful frameworks to enable decision-making:

Best interests

Actions that maximally promote the good of the individual.[227] It is critical to recognise that 'best interests' is a subjective concept, related to personal values and preferences, that can change over time and context. For example, some families will believe that a particular intervention should be initiated or continued because it may extend the duration of life, while other families will not wish to pursue the same intervention because it will not improve quality of life or may have possible harms. Considering the balance of the good with possible harm of an intervention is helpful.

Harm principle

Parents or caregivers are allowed the freedom to decide for their child *except* when their choice places the child at risk of imminent harm.[228] Examples include:

- A request from a parent to provide intensive chemotherapy or stem cell transplantation to a child with relapsed and progressive disease where there is unlikely benefit, and significant risk of side effects and complications.
- A child with a late stage neurological or metabolic condition with respiratory failure where an intervention such as intubation and mechanical ventilation may not reverse underlying causes and causes pain and/or discomfort.
- A child with a LLC with a life expectancy of months to years (e.g. a neuromuscular condition) where the family have disengaged from interaction with healthcare services to the detriment of the child's overall health and wellbeing.

Zone of parental discretion

Gillam defines the zone of parental discretion (ZPD) as 'the ethically protected space where parents may legitimately make decisions for their children, even if the decisions are sub-optimal for those children' (i.e., not the absolute *best* for them).[229] The ZPD replaces the need for a *best* outcome with one that is *good enough*, accepting the family's wishes unless, on balance, the decision causes harm.

Moral distress

This involves clinician distress arising from personal concerns that what is occurring is not the 'right thing'.[216] This is covered further in the section on 'Clinician Wellbeing and Moral Distress'.

Equivalence thesis

This is the ethical theory that withholding and withdrawing treatment are morally equivalent.[230, 231] However, for some families, stopping a treatment that has already started may be more difficult than withholding treatment. Focusing on the goals of care and balancing possible benefits and burdens can be helpful in this regard.

Thinking about ethical issues in palliative care requires weighing the moral burdens and benefits of different options and considering the many possible different perspectives regarding what should be done—and then finding a path forward. Some Australian health services have specialist clinical ethics groups who provide consultations to assist clinicians and families in navigating complex ethical situations.[232] Indications for an ethics consultation include disagreement within or between families and treating teams, proposals for innovative therapies and the presence of moral distress. Specific clinical examples include whether it is appropriate to withdraw or withhold clinically assisted nutrition and hydration (CANH), ventilatory support or supportive therapies (e.g., transfusions). When there no existing formal ethics process, there may be organisational supports available or individuals with expertise in ethical thinking who can assist the clinicians involved.

Palliative care and the law

Ethical issues are frequently intertwined with legal issues, but the two require separate expertise and may provide different perspectives on the same issue. An excellent resource is End of Life Law for Clinicians (ELLC), available at https://end-of-life.qut.edu.au[233] This website and the associated online training modules are curated by the Australian Centre for Health Law Research, with information specific to each Australian state and territory for both adults and children.[233] Clinicians should be aware of the legal concepts outlined below.

Doctrine of double effect

This protects persons who provide medication with the intent of relieving pain or other symptoms from criminal responsibility for the death of the patient, even if the death is foreseeable.[233] Protections extend to doctors and those authorised by doctors to administer medication/s (e.g., nurses, carers or family members).[234] While many express personal concerns about hastening or causing death, when medications are provided at symptom relief doses (particularly opioids for pain management), precipitant death is rare in clinical practice.

Best interests

This concerns the outcome that best serves the interests of the person. This is not determined in a specified way by the officers of the court—it varies from case to case.[235]

Non-beneficial treatment

This is treatment that is 'not in the person's best interests, cannot achieve its purpose, or is not clinically indicated',[235] sometimes termed 'futile' treatment. There is no legal obligation to provide non-beneficial treatments if they are requested.

Capacity and competence

In Australian common law, capacity is the ability to 'comprehend and retain the information needed to make a decision, including the consequences of the decision; and use and weigh that information when deciding'.[236] A child or young person will be competent if 'they have sufficient understanding and intelligence to enable him or her to understand fully what is proposed'.[236] However, there is some variation across Australia. See ELLC[233] for more information regarding state-specific details, as well as further discussion of the legal concept of Gillick competence.

Requests for voluntary assisted dying

Voluntary assisted dying (VAD) is assistance from a health practitioner provided to a person seeking to end their life voluntarily.[237] ELLC provides comprehensive legal information regarding VAD, which is specific to each state and territory of Australia.[237] VAD is not an option in Australia or New Zealand for those under the age of 18, nor for those over 18 who do not have decision-making capacity. Across Australian and New Zealand jurisdictions, there are different VAD eligibility criteria and different healthcare professional responsibilities regarding provision of information about VAD. For young people with a life-limiting diagnosis or family members who seek information about VAD, sensitive acknowledgement and questioning around concerns and the goals of care should be established. Information about VAD, if requested, should be provided according to local requirements.

Quality improvement in palliative care

The quality of a health system is defined by 'the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge'.[238]

Quality health services should be:[239]

- **effective:** providing evidence-based healthcare services to those who need them
- **safe:** avoiding harm to people for whom the care is intended
- **people-centred:** providing care that responds to individual preferences, needs, and values.

Objectives should be:

- **timely:** reducing waiting times and sometimes harmful delays
- **equitable:** providing care that does not vary in quality on account of gender, sexuality, race, ethnicity, geographic location or socio-economic status (or any other factor)
- **integrated:** providing care that makes available the full range of health services throughout the life course
- **efficient:** maximising the benefit of available resources.

Principles for high-quality paediatric palliative care service provision

The needs of children and adolescents who are supported by paediatric palliative care services are individualised and unique. The following principles provide a framework to guide a model of care that supports the delivery of high-quality palliative and end-of-life service provision:[240]

- Care is child-centred, family-centred and carer-centred.
- Care provided is based on assessed need.
- Patients, families and carers have access to local and networked services to meet their needs.
- Care is evidence-based and clinically and culturally safe and effective.
- Care is integrated and coordinated.
- Care is equitable.

The National Consensus Statement specifies two broad categories of essential elements for safe and high-quality paediatric end-of-life care,[241] processes of care and organisational prerequisites (*see* Appendix 5a). Individualised patient-centred care is heavily reliant on the effectiveness of the local team. Overarching leadership and governance should be achieved through system supports to achieve high-quality care, maintained through education and improved through research. The National Palliative Care Standards (Australia) are similarly divided into 'Care Standards' (Standards 1–6) and 'Governance Standards' (Standards 7–9). These standards incorporate the unique needs of dying children and their families (*see* Appendix 5b).

Embedding a strong culture of continual quality improvement in the team is necessary to provide excellent patient care. In addition, quality improvement methodologies and the increased availability of clinical tools offer healthcare professionals a strong framework within which to

design, implement and evaluate projects or other planned initiatives to improve and sustain high-quality care for children and families.[242] The development of a platform capable of real-time clinical data capture within local e-health infrastructure is pertinent to:

- capture patient-reported measures (as feedback) of the services provided (patient, parents and siblings)
- capture occasions of service by the team and the modality utilised (face-to-face, virtual health)
- aggregate datasets for research and service planning that is needs-specific.

Data collection in paediatric palliative care

The National Palliative Care Strategy (2018), Standard 8, supports clinical service engagement in quality improvement and research to improve service provision and development.[243] A consistent approach for establishing minimum datasets is important to inform the concept of 'big health data' and guide future paediatric palliative care service delivery.[244]

The rapid progression of health information systems, including the introduction of the electronic medical record, has significantly enhanced the technology available to collect health data. Utilisation and translation of this data have great potential to generate valuable knowledge, contribute to evidence-based practice and generate research opportunities to further advance the provision of paediatric palliative care.[245]

How to optimise data collection to forecast future paediatric palliative care needs remains poorly understood. The process is complex and requires deliberate collaboration between local clinicians, chiefs of information systems and academic partnerships to bridge many of the data challenges to measure health outcomes for a population of children and families that is small, diverse and vulnerable.[246]

Domains for data collection

- individual: embedding individual patient-reported outcome measures and experiences that are useful and validated and provide meaningful information
- service delivery: measuring the efficiency, effectiveness and potential inequities in speciality paediatric palliative care service models; this may include services provided by the multidisciplinary team, funding models and staffing position requirements
- population health: utilising demographic data across differing geographical locations to project the current and future demand of specific population groups; this must emphasise the additional needs of vulnerable and priority populations (e.g., Aboriginal and Torres Strait Islander and CALD children and families).[247]

System levels at which to support quality and service improvement

Local

- development of paediatric palliative care policies, procedures and guidelines to support safe and high-quality care
- routine review of care processes provided during the end of life (death reviews, mortality and morbidity meetings)
- clinical audit reviews
- consumer engagement opportunities for patient-reported experience and outcome measures
- additional training in providing care to Aboriginal and Torres Strait Islander families through education initiatives such as the Indigenous Program of Experience in the Palliative Approach (IPEPA) and Gwandalan Palliative Care Education and Training
- clinical indicator collection to provide a method of assessing the quality and safety of care at a system level. Clinical indicators identify variation within data results and are designed to indicate potential problems that may need addressing. They are tools that can demonstrate if a standard in care is being met, which can provide evidence for accreditation. (See Appendix 6 for Australia and New Zealand Paediatric Palliative Care Clinical Indicators dataset and definitions.)
- research and publications to inform evidence and promote best practice
- professional development and training.

National

- collaboration with peak palliative care agencies (e.g., Palliative Care Australia, CareSearch, Paediatric Palliative Care Australia and New Zealand [PaPCANZ].

International

- global collaboration initiatives (e.g., International Children's Palliative Care Network).

Resources

Recommended books for further reading

This section lists resources that may be helpful to health professionals and teachers wishing to increase their knowledge regarding paediatric palliative care issues. There is also a list of storybooks that may be useful in assisting children to express their feelings associated with loss and grief. These books are only a sample of the literature available, and you may wish to look further for suitable resources.

Before recommending a book to a family, particularly a child, ensure that you read the book first. Do you think the child will understand the concepts in the book? Who has died or is dying? Is it the child themselves, a sibling, parent, friend or pet? Should the book be about an animal or a person? Is the main character of the story someone with whom the child could identify?

Further information on these topics and book loans may be available through the local children's hospital, palliative care or hospice.

Books for young children

Finn's Feather (4+ years), Rachel Noble and Zoey Abbott, 2018.

Gentle Willow: A Story for Children about Dying (5–8 years), Joyce Mills & Michael Chesworth, 1994.

I Had a Friend Named Peter: Talking to Children about the Death of a Friend (5–9 years), Janice Cohn & Gail Owens, 1987.

Beginnings and Endings with Lifetimes in Between (3–6 years), Bryan Mellonie & Robert Ingpen, 2005.

How I Feel: A Colouring Book for Grieving Children (3–8 years), Alan D. Wolfelt, 1996.

Goodbye Forever (7–9 years), Jim Boulden & Keith Eberly, 1994.

Saying Goodbye (5–10 years), Jim Boulden & Keith Eberly, 1992.

When Someone Very Special Dies (9–12 years), Marge Eaton Heegaard, 1996.

The Next Place (5+ years), Warren Hanson, 1997

When Dinosaurs Die: A Guide to Understanding Death (3–6 years), Laurene Krasny Brown & Marc Tolon Brown, 2023.

I Miss You: A First Look at Death (4–7 years), Pat Thomas, 2001.

The Invisible String (4+ years), Patrice Karst & Joanne Lew-Vriethoff, 2018.

Life Is Like the Wind (4–6 years), Shona Innes & Irisz Agocs, 2014.

The Grief Wave (4+ years), Trace Moroney, 2021.

How I Feel: Grief Journal for Kids (8+ years), Mia Roldan, 2022.

The Memory Box: A Book about Grief (4–8 years), Joanna Rowland & Thea Baker, 2017.

My Many Coloured Days (3–5 years), Dr. Seuss, 2001.

What Does Dead Mean? A Book for Young Children to Help Explain Death and Dying (4–7 years), Caroline Jay, Jenni Thomas & Unity-Joy Dale, 2012.

After Death: An Activity Book for Children (5–12 years), The Dougy Center, 2019.

The Goodbye Book, Todd Parr, 2015.

In My Heart: A Book of Feelings, Jo Witek, 2014.

A Kids Book About Death, Taryn Schuelke, 2020.

Michael Rosen's Sad Book, Michael Rosen, 2004.

Where's Jess? (2–5 years), Joy Johnson, 1982.

Books for older children and teenagers

How Teenagers Cope with Grief: Something I've Never Felt Before, Doris Zagdanski, 1990.

The Grieving Teen: A Guide for Teenagers and Their Friends, Helen Fitzgerald, 2000.

Straight Talk about Death for Teenagers, Earl Grollman, 1993.

Thoughts: A Teenager's Response to a Crisis, Darren Crewe, 1997.

The Grief Book: Strategies for Young People, Elizabeth Vercoe & Kerry Abramowski, 2004.

What on Earth Do You Do When Someone Dies?, Trevor Romain, 1999.

When a Friend Dies: A Book for Teens About Grieving and Healing, Marilyn Gootman, 2005.

Deconstruction/Reconstruction: A Grief Journal, The Dougy Centre, 2017.

Words of Comfort, Rebekah Ballagh, 2022.

Books for siblings

Two weeks with the Queen, Morris Gleitzman, 1989.

Am I Still a Sister?, Alicia Sims, 1988.

My Sibling Still: For Those Who've Lost a Sibling to Miscarriage, Stillbirth, and Infant Death, Megan Lacourrege, 2019.

You'll Always Be, Callie Fryt, 2021.

Books for parents

Shelter From the Storm– Caring for a Child with a Life-Threatening Condition, Joanne Hilden & Daniel Tobin, 2003.

Living with a Seriously Ill Child, Jan Aldridge, 2007.

A Child Dies: A Portrait of Family Grief, Joan Hagan Arnold & Penelope Buschman, 1994.

Are You Sad Too? Helping Children Deal with Loss and Death, Dinah Seibert, Judy Drolet & Joyce Fetro, 1993.

Talking About Death: A Dialogue Between Parent and Child, Earl Grollman, 1990.

After the Death of a Child: Living with Loss Through the Years, Ann Finkbeiner, 1998.

The Worst Loss: How Families Heal from the Death of a Child, Barbara Rosof, 1995.

The Bereaved Parent, Harriet Sarnoff Schiff, 1977.

Coping With Grief, Mal McKissock & Dianne McKissock, 1995.

35 Ways to Help a Grieving Child, Amy R. Barrett & Dougy Centre, 1999.

Beyond Words: Grieving When Your Child Has Died, Andrew Thompson & Tricia Irving Hendry, 2012.

By My Side: Stories for Parents Whose Child Has Died from Cancer, Dr Leigh Donovan & Redkite, 2016.

The Little Book of Loss and Grief: You Can Read While You Cry, Liz Crowe, 2014.

Books for grandparents

Grandparents Cry Twice: Help for Bereaved Grandparents, Mary Loud Reed, 2000.

When a Grandchild Dies: What to Do, What to Say, How to Cope, Nadine Galinsky, 1999.

Books for professionals

Teaching Children with Life-Limiting Illnesses: A Manual for Schools, The Children's Hospital at Westmead, 2010.

Grief In Children: A Handbook for Adults, Atle Dyregrov &Jessica Kingsley Publishers, 2008.

Loss, Change and Bereavement in Palliative Care, Pam Firth, Gill Luff & David Oliviere, 2005.

Parents and Bereavement: A Personal and Professional Exploration of Grief, Christine Young & Tracy Dowling, 2012.

Websites where books and other resources can be sourced

Innovative resources

Innovative Resources provides popular resources and conversation starters for children and teens, as well as listing books that suit children, teens, parents and professionals.

https://innovativeresources.org/

Skylight New Zealand

Skylight supports people facing any kind of tough life situation, such as change, loss, trauma or grief—whatever the cause and whatever their age. They also assist those wanting to help them.

https://www.skylight.org.nz/

Organisations and websites

Listed below are organisations and websites that may be useful to families and professionals working with them.

Information and advocacy organisations

CareSearch Palliative Care Knowledge Network

CareSearch is an online resource designed to help those needing relevant and evidenced-based information and resources about palliative care. There are sections designed specifically for health professionals and others for patients, carers and family and friends.

http://www.caresearch.com.au/

Paediatric Palliative Care Australia and New Zealand

PaPCANZ represent a strong network of health professionals, and dedicated professionals committed to the delivery of quality paediatric palliative care for all. PCA and PaPCANZ work closely to provide information, resources and educational tools and drive advocacy for health professionals, support organisations, families, carers, and young people to enhance the experience of and access to specialised paediatric palliative care in Australia.

02 6232 0700

https://paediatricpalliativecare.org.au/

Palliative Care Australia

Palliative Care Australia is the national peak body for palliative care. Palliative Care Australia represents all those who work towards high-quality palliative care for all Australians who need it. Working closely with consumers, our member organisations and the palliative care workforce, we aim to improve access to, and promote the need for, palliative care.

02 6232 0700

https://palliativecare.org.au/

Gwandalan Palliative Care

This project aims to improve access to and quality of palliative care service delivery for Aboriginal and Torres Strait Islander people throughout Australia by providing a suite of tailored education and training materials to support cultural safety within palliative care services.

1300 362 111

https://gwandalanpalliativecare.com.au/

Program of Experience in the Palliative Approach

The Program of Experience in the Palliative Approach (PEPA) forms part of the Palliative Care Education and Training Collaborative (the Collaborative). As a national palliative care project, the Collaborative takes a strategic approach to education and training of the healthcare workforce and delivers programs for priority healthcare provider groups across primary, secondary and tertiary settings.

https://pepaeducation.com/

International organisations

Children's Hospice International

https://www.chionline.org/

Together for Short Lives

http://www.togetherforshortlives.org.uk/

Paediatric Palliative and Hospice Care

https://www.nhpco.org/pediatrics/

International Children's Palliative Care network (ICPCN)

http://www.icpcn.org/

World Health Organization – Palliative Care

https://www.who.int/health-topics/palliative-care

Children and family support

Make-A-Wish Australia

Make-A-Wish Australia grants wishes to children aged 3–18 who have critical illnesses to give them hope, strength and joy.

1800 032 260

http://www.makeawish.org.au

Make-A-Wish New Zealand

Make-A-Wish New Zealand grants wishes to children aged 3–18 who have critical illnesses to give them hope, strength and joy.

0900 80 70 80

www.makeawish.org.nz

Starlight Children's Foundation

Starlight provides programs integral to the total care of seriously ill children with the aim of lifting the spirits of the child, giving them the opportunity to laugh, play and be a child again. This includes 'A Starlight Wish', which gives the whole family a break from the stress of their child's illness; fulfilled wishes provide lasting memories for the child and family. 'Livewire' (powered by Starlight) is dedicated to meeting the needs of adolescents (and their siblings) living with serious illness, a chronic health condition or disability. Livewire.org.au provides a safe and supportive online community for 10–20 year olds where members can connect and share experiences with others who understand what they are going through.

1300 727 824 (for your nearest office)

http://www.starlight.org.au

The Steve Waugh Foundation

The Steve Waugh Foundation is working to help change things for children with a rare disease by giving hope; providing medicine, equipment and treatment; supporting education and research; partnering with other similar agencies and organisations; and supporting specific projects and programs.

http://www.stevewaughfoundation.com.au/

TLC for Kids

TLC for Kids is a national charity that supports sick children and their families through the moments in hospital where fear and distress can take over. Their distraction services facilitate kids through frightening procedures and the crucial 48-hour period following any emotionally challenging situation in hospital.

1300 361 461

http://www.tlcforkids.org.au/

Variety Australia

Variety Australia empowers Australian children who are sick, disadvantaged or have special needs to live, laugh and learn. They work via providing practical equipment, programs and experiences.

http://www.variety.org.au/

Canteen Australia

Canteen is a not-for-profit providing free and tailored support to young people aged 12–25 who are affected by cancer.

1800 226 833

https://www.canteen.org.au

Canteen New Zealand

Canteen is a not-for-profit providing free and tailored support to young people aged 13–24 who are affected by cancer.

0800 2268 336

https://www.canteen.org.nz/

Koru Care New Zealand

Koru Care New Zealand is a registered charitable trust that arranges overseas trips each year for groups of ill and disabled children with the help of volunteer health professionals and caregivers.

09 523 2456

https://korucare.co.nz

Children's hospice services

Bear Cottage

Manly, Sydney, New South Wales

02 9976 8300

http://www.bearcottage.chw.edu.au/

Hummingbird House

Chermside, Brisbane, Queensland

07 3621 4364

http://www.hummingbirdhouse.org.au/

Very Special Kids

Malvern, Melbourne, Victoria

1800 888 875

http://www.vsk.org.au/

Manly Adolescent and Young Adult Hospice

Old Manly Hospital Site, Darley Road, New South Wales

02 9978 5925

https://www.nslhd.health.nsw.gov.au/manly

Rainbow Place Hospice

334 Cobham Drive, Hillcrest, Hamilton, New Zealand

07 859 1260

https://www.rainbowplace.co.nz/

Clinical support organisations

Centacare

http://www.centacarebrisbane.net.au/

Carer Gateway

1800 422 737

https://www.carergateway.gov.au

Non-cancer disease-specific organisations

Australian Leukodystrophy Support Group

1800 141 400

https://www.leuko.org.au

Cerebral Palsy League

1800 275 753

http://www.cpl.org.au/

Cystic Fibrosis Australia

https://www.cysticfibrosis.org.au/

DEBRA: Epidermolysis Bullosa

http://www.debra.org.au/

Epilepsy Australia

1300 374 537

https://www.epilepsy.org.au

Heartkids

http://www.heartkids.org.au/

Australian Mitochondrial Disease Foundation

http://www.amdf.org.au/

Mucopolysaccharide and Related Diseases Society

http://www.mpssociety.org.au/

Muscular Dystrophy Australia

http://www.mda.org.au/

Short Gut Syndrome Families' Support Group

http://www.shortgutsupport.com/

Spinal Muscular Atrophy Australia

http://www.smaaustralia.org.au/

Rare Find Foundation

https://www.rarefindfoundation.org/

Syndromes Without a Name (SWAN)

https://swanaus.org.au/

Bereavement support

Grief Australia

This organisation's website provides a range of resources about grief and how to support grieving children, adolescents and adults. It also has a collection of stories, narratives, poems and creative expressions contributed by bereaved individuals who want to share insights from their own grief journey.

http://www.grief.org.au

Australian Child & Adolescent Trauma, Loss & Grief Network

This website has key resources that can assist adults in understanding the impact of trauma, loss and grief experiences on children and young people and how to best help young people who have been affected by grief.

http://earlytraumagrief.anu.edu.au

National Centre for Childhood Grief (NCCG)

The NCCG provides free and unlimited grief counselling for bereaved children aged 3–8. They provide grief counselling to recently bereaved adults on a fee-for-service basis. The centre also provides education and training for individuals, schools and other organisations handling the grief of children and young people.

childhoodgrief.org.au

Centrelink

Centrelink offers bereavement assistance to support eligible families as they adjust to changed financial circumstances after the death of a partner, child or someone they cared for. There are a number of bereavement payments available depending on your situation and eligibility.

Services Australia also has social workers who may be able to assist with claiming, counselling and support during times of grief.

136 150

https://www.servicesaustralia.gov.au/

The Compassionate Friends

The Compassionate Friends offers support during the grief and trauma that follows the death of a child at any age and from any cause for bereaved parents, siblings and grandparents The Compassionate Friends offer a range of free services to bereaved parents and families including:

- branches across Queensland
- support group meetings
- country support groups
- telephone and email support
- grief information and library
- newsletters
- annual Candlelight Remembrance Service
- annual Grief and Loss Seminar.

http://www.tcfaustralia.org.au/

Medicare Better Access Initiative

The Better Access initiative provides Australians with access to mental health professionals through Medicare. To receive a Medicare rebate for mental health services, there must be a referral to a mental health professional by an appropriate medical practitioner (GP, psychiatrist or paediatrician). The doctor must first make an assessment that the services of a mental health practitioner are needed. The costs will vary depending on the length of the session and the fee being charged by the professional.

www.health.gov.au/mentalhealth-betteraccess

Griefline

Griefline supports anyone experiencing grief, providing access to free telephone support and facilitating online forums and support groups.

1300 845 745

https://griefline.org.au/

Hope Again – Young People Living After Loss

Hope Again is the youth website of Cruse Bereavement Support. It is a safe place where you can learn from other young people, how to cope with grief and feel less alone. The website has information about their services, a listening ear from other young people and advice for any young person dealing with the loss of a loved one.

https://hopeagain.org.uk

Reachout.com

Reachout.com is Australia's leading online youth mental health service and provides an online support space for adolescents dealing with grief and loss. The service offers:

- expert information on how adolescents can tackle life's challenges and become mentally fit and resilient
- real-life stories of grief and loss
- forums
- videos.

http://au.reachout.com/Tough-Times/Loss-and-grief

SANDS

SANDS provides miscarriage, stillbirth and newborn death support. It aims to facilitate healthy grieving following the death of a baby through miscarriage, stillbirth, newborn death or termination for medical purposes.

http://www.sands.org.au/

Red Nose

Red Nose provide a range of services, including:

- a 24-hour bereavement support line
- face-to-face and telephone counselling for parents, siblings and extended family
- workshops
- support meetings
- information kits and potential funeral funding assistance.

https://rednose.org.au

Child & Youth Grief Network

The Children and Youth Grief Network (CYGN) is a collaboration of 7 organisations that aim to provide education, information and resources related to supporting children and youth that are grieving the dying or death of someone they care about.

https://www.youtube.com/channel/UCQvwAsW5s8NokNuMSByJOsA

GriefLink

Information about the grief of Aboriginal and Torres Strait Islander people: Australia's First Peoples.

https://grieflink.org.au/factsheets/grief-of-indigenous-people/

Skylight New Zealand

Skylight supports people facing any kind of tough life situation of change, loss, trauma or grief, whatever the cause and whatever their age. They also assist those wanting to help them.

0800 299 100

http://www.skylight.org.nz/

Young Minds

Young Minds is a leading UK charity that provides information on improving the emotional wellbeing and mental health of children and young people. Their website provides resources that may be helpful in assisting your child/children during their grief.

http://www.youngminds.org.uk/

Child Bereavement UK

Child Bereavement UK helps children and young people (up to the age of 25) and families to rebuild their lives when a child grieves or when a child dies.

http://childbereavementuk.org/for-schools/primary-schools/

Center for Good Mourning (USA)

The Center for Good Mourning provides support and assistance given to bereaved children and families in Arkansas through education, program development and grief support programs. Their website includes resources and a regular newsletter.

https://www.archildrens.org/center-for-good-mourning

The Dougy Centre

The Dougy Centre is a USA-based resource that provides support in a safe place where children, teens, young adults and their families grieving a death can share their experiences. Their website provides resources for parents, teachers and others helping children in grief.

http://www.dougy.org/

Clinical resources

Oxford Textbook of Palliative Care for Children, Ann Goldman, Richard Hain & Adam Rapoport & Michelle Miering, 2021.

Really Practical Handbook of Children's Palliative Care: For Doctors and Nurses Anywhere in the World, Justin Amery, 2016.

Textbook of Interdisciplinary Pediatric Palliative Care, Joanne Wolfe, Pamela S. Hinds & Barbara M. Sourkes, 2022.

Paediatric Palliative Care Clinical Guidelines

https://starship.org.nz/health-professionals/paediatric-palliative-care-clinical-guidelines/

Local resources

This page has been designed for individual organisations to develop a local resource list. If you are aware of local health professionals with an interest and/or experience in palliative care, record their names here for future reference.

Paediatrician/s

Community Nursing Service/s

General Practitioner/s

Local Hospital (Paediatric Ward)

Local Hospice/Palliative Care group/s

Social Work Services

Other

Appendix 1

Appendix 1
Symptom management plan

Created On:

Patient identifier: Patient name: DOB:

Weight: Date weight taken:

Diagnosis:

Adverse drug reaction history:

Instruction for parents/carers caring for their child with changing symptoms

NIKI Pump Infusion
**Delete if not applicable*

PAIN
Non-medicine options **Personalise to child*

Regular pain medicines

Medicine name	Dose	Product strength/form
	Give _____ (tablets/capsules/mL) (_____ mg) Enter frequency and times and any administration instructions	

Additional medicines for when regular medicines are not working

For MILD PAIN give		
Medicine name	**Dose**	**Product strength/form**
	Give _____ (tablets/capsules/mL) (_____ mg) Enter frequency and times and any administration instructions	

Appendix 1

For MODERATE / SEVERE PAIN –
*May need separate section for moderate and one for severe pain

Medicine name	Dose	Product strength/form
	Give _____ (tablets/capsules/mL) (_____mg) Enter frequency and times and any administration instructions	

Call _____ for further advice if ongoing pain despite above

RESPIRATORY / SHORTNESS OF BREATH

Non-medicine options

Medicine name	Dose	Product strength/form
	Give _____ (tablets/capsules/mL) (_____mg) Enter frequency and times and any administration instructions	

SEIZURES

Regular medications

Medicine name	Dose	Product strength/form
	Give _____ (tablets/capsules/mL) (_____mg) Enter frequency and times and any administration instructions	

Appendix 1

INCREASED SECRETIONS / Chest Health		
Non-medicine options		
Medicine name	**Dose**	**Product strength/form**
	Give _____ (tablets/capsules/mL) (_____ mg) Enter frequency and times and any administration instructions	

NAUSEA AND VOMITING		
Non-medicine options		
Medicine name	**Dose**	**Product strength/form**
	Give _____ (tablets/capsules/mL) (_____ mg) Enter frequency and times and any administration instructions	

Additional medicines for when regular medicines are not working

Medicine name	Dose	Product strength/form
	Give _____ (tablets/capsules/mL) (_____ mg) Enter frequency and times and any administration instructions	

Appendix 1

CONSTIPATION		
Non-medicine options		
Medicine name	**Dose**	**Product strength/form**
	Give _____ (tablets/capsules/mL) (_____ mg) Enter frequency and times and any administration instructions	

ANXIETY / SLEEP / IRRITABILITY/ AGITATION		
Non-medicine options		

Regular anxiety / sleep medicines

Medicine name	Dose	Product strength/form
	Give _____ (tablets/capsules/mL) (_____ mg) Enter frequency and times and any administration instructions	

Additional medicines for when regular medicines are not working

Medicine name	Dose	Product strength/form
	Give _____ (tablets/capsules/mL) (_____ mg) Enter frequency and times and any administration instructions	

Appendix 1

OTHER SYMPTOM (e.g., cough, bleeding, muscle tightness / cramps, delirium, itch, fatigue)		
Non-medicine options		
Medicine name	**Dose**	**Product strength/form**
**Delete if not applicable*	Give _____ (tablets/capsules/mL) (_____ mg) Enter frequency and times and any administration instructions	

If above measures do not relieve symptoms, please contact the Paediatric Palliative Care Team:

Completed by (name and designation): _____

Date: _____

DO NOT USE IF MORE THAN 12 MONTHS FROM WHEN CREATED

NOTE: This Symptom Management Plan is not a complete record of patient's regular medicines.

Appendix 2
Guidelines for continuous subcutaneous infusions[248]

BD Saf-T-IntimaTM and BD BodyGuardTM T Pump*

*Some services may use alternative pumps. There are 3 different versions of syringe pumps: the NIKI PUMP™, T34™ and BD BodyGuard™ T. Throughout this procedure, the term 'NIKI pump' will be used to refer to all 3 devices.

For a detailed guide, seek further information from your paediatric palliative care team.

Purpose

To deliver high-quality palliative care to infants, children and young adults by enabling healthcare professionals to safely and competently use a subcutaneous infusion to help manage pain and other symptoms.

Relief of symptoms towards the end of life when the oral administration of medications is not optimal or appropriate.

Allows multiple medications to be given via a single infusion. No need for repeated injections or multiple oral medications.

Background information

While the route of choice for medications in the paediatric palliative care setting is enteral (e.g., oral, NG or PEG), this is not always possible. Many medications are well absorbed subcutaneously, and this route removes the need for intravenous infusions or intramuscular injections.[249] Continuous subcutaneous infusions of medications using a portable syringe driver can provide good symptom control. Combinations of drugs are sometimes used to control several symptoms. A significant advantage of continuous subcutaneous infusion is that plasma levels of drugs are more stable, and good symptom control can be achieved without the peaks and troughs that result from intermittent drug administration.

At times, it may be appropriate to use the child's central venous access device (central line or port), if present, to administer medications by infusion.

Indications

- When medications are unable to be given by another route (e.g, enteral or intravenous)
- Due to nausea/vomiting, dysphagia, mal-absorption, gastrointestinal obstruction
- Patient no longer responsive to enteral medications
- Reduced level of consciousness/severe weakness

Key points

- Use an aseptic technique to prepare and set up the infusion.
- More than one drug can be mixed and administered in the same syringe. Where more than 2 drugs are required to manage multiple symptoms (e.g., pain, secretions and nausea), care must be taken to ensure compatibility, particularly with higher doses of midazolam. Check compatibility with a pharmacist. Common drugs delivered in combination are listed in Appendix 3.
- Dexamethasone may be added to the infusion (for dosing, see Appendix 3) to assist with extending the longevity of the subcutaneous infusion site.
- Consider the need for 2 subcutaneous devices if bolus medication is required or anticipated.
- Normal saline or water for injection (WFI) are the preferred diluents for most medications. Dilute the drug as much as possible to reduce risk of irritation and preserve the insertion site for infants or delicate sites; minimal volumes of 10 mL are usually well tolerated.
- Select the most appropriate injection site with adequate subcutaneous tissue (*see* Figure A2). Rotate the site with each insertion.
- Catheter of choice is the **BD Saf-T-Intima**™ 24 gauge with Y-arm/port. This catheter can remain in place for as long as the site remains free of complications. After 2 weeks, consider rotation of the insertion site to avoid after-hours replacement or complications.
- The **NIKI Pump** portable syringe driver is suitable for continuous subcutaneous infusions. A loading dose of the medication (e.g., analgesia, anticonvulsant) may be required at the start of the infusion to ensure therapeutic drug levels are reached quickly.

Subcutaneous cannula BD Saft-T- Intima™ and Site Selection

A subcutaneous cannula device BD Saf-T-Intima™ 250 (*see* Figure A1) is used to allow medications to be delivered under the skin, avoiding multiple injections. The medication is absorbed into the body via the small blood vessels in the fatty layer of the skin. BD Saf-T-Intima™ can be used for continuous infusion and or bolus medication delivery.

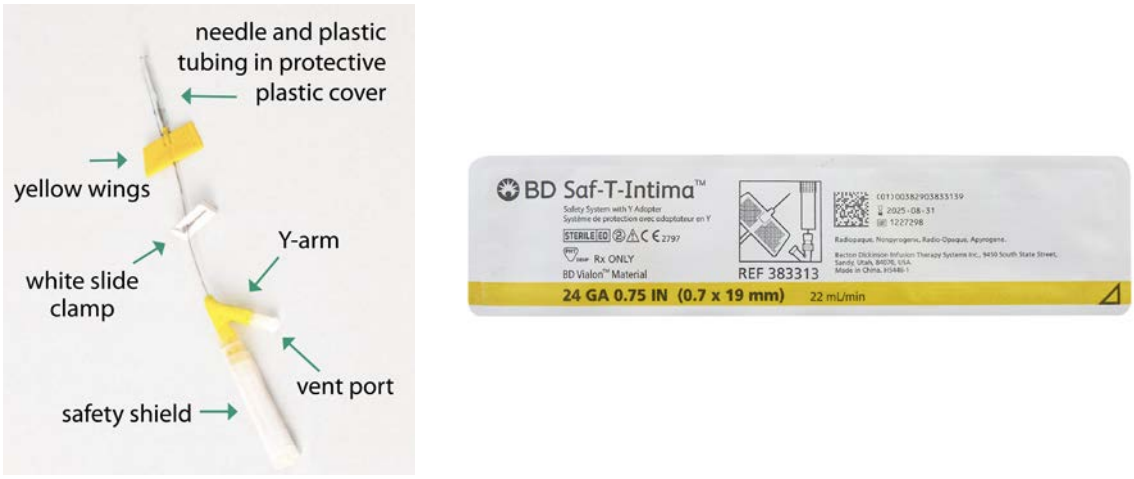

Figure A1. BD Saf-T-Intima™.

Appendix 2

As illustrated in Figure A2, the preferred sites in children are abdomen, upper thigh, upper arm (where there is more subcutaneous tissue).

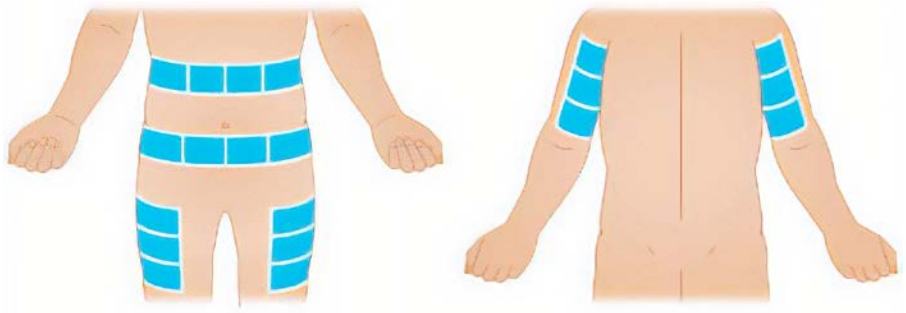

Figure A2. Preferred sites.[250]

Avoid:

- bony prominences, as there is less subcutaneous tissue and absorption will be reduced
- joints, as it is more likely to be uncomfortable and easier to dislodge
- oedematous, infected, broken or bruised skin
- sites in contact with wheelchair harnesses or seatbelts
- areas of poor circulation or sites recently irradiated
- nappy area.

Equipment:

- topical anaesthetic cream (EMLA/LMX4) or ice if cream is not tolerated or available
- BD Saf-T-Intima 24g (yellow) indwelling catheter
- NIKI PUMP (inc. lock box and key)
- 9-volt spare battery (non-rechargeable)
- BD™ syringe or other luer lock syringe compatible with pump, of size required for ordered volume
- prescribed medication and diluent
- minimum volume extension set
- needleless access device (NAD) injection port
- a selection of smaller-size syringes and drawing up needles to draw each ordered medicine to dose required
- sodium chloride 0.9% 10 mL ampoules as required for infusion (sterile WFI occasionally required if medication used is not compatible with sodium chloride)
- alcohol swabs
- transparent dressing (6 cm x 7 cm)
- small piece of Hypafix™ or similar tape
- brown additive label ‘For subcutaneous use only’ for both line and syringe
- non-sterile gloves.

1. Prepare medication syringe

PROCEDURE	ADDITIONAL INFORMATION
Prepare equipment and prescribed medication using a clean technique and in accordance with hospital or home care protocols	
Syringe size & dilution: Volume of undiluted, prepared drug(s): **≤ 10 mL**: 10 mL syringe can be diluted with up to 10 mL volume **≤ 20 mL**: 20 mL syringe can be diluted with up to 18 mL volume **> 20 mL**: 30 mL syringe can be diluted with up to 22 mL volume 50 mL syringe can be diluted with up to 33 mL volume	Check compatibility of diluent as some drugs require water for injection (WFI) or 5% dextrose Note: with 50 mL syringe, the volume will not be accommodated in the locked box
Prepare the syringe for the infusion as ordered, complete medicine label	Label according to hospital policy
Attach extension set line to the syringe	Do not use a needleless access device (NAD) between syringe and tubing
DO NOT PRIME THE LINE	The pump will be used in a later step to prime the extension set line
Protect end of extension set with a cap until ready to attach to BD Saf-T-IntimaTM	

NOTE: always change the extension set at the syringe when the medication infusion order changes. The volume of the extension set may be up to 2 mL in length and therefore take several hours to infuse.

2. Insertion of BD Saf-T-Intima catheter

PROCEDURE	ADDITIONAL INFORMATION
Explain procedure to child/parent and gain consent	
Choose appropriate site and apply topical anaesthesia 45–60 minutes before procedure	Ice applied, as tolerated, for 5 minutes can also be used
Collect equipment Open the BD Saf-T-Intima™ package	
Perform hand hygiene and don personal protective equipment (PPE)	
Inspect the BD Saf-T-Intima™, remove clamp, inspect the integrity of the needle tip	
Prime BD Saf-T-Intima™, remove the Y-arm port, attach a NAD and prime with sodium chloride 0.9%	
Remove topical anaesthesia with soap and water Perform hand hygiene	
Clean skin with 0.5–2% chlorhexidine in 70% alcohol or an alcowipe and **allow to air dry**	
Apply gloves (non-sterile)	
Remove the protective plastic covering the needle	Ensure the sloping edge (needle bevel) of the needle is on top
Pinch the skin between thumb and forefinger	Ensures subcutaneous tissue is identified
Grasp the BD Saf-T-Intima™ wings with bobble-surface facing down towards patient	
Insert the BD Saf-T-Intima™ into the subcutaneous tissue, advancing the total length of the catheter at a 20–45° (degree) angle to the skin surface This should be done in one quick, smooth movement with the bevel facing up Realise the wings and flatten against the patient's skin	If blood is visible in the cannula, remove and insert a new cannula in another site, at least 3 cm from previous site

PROCEDURE	ADDITIONAL INFORMATION
Secure the BD Saf-T-Intima™ by applying transparent dressing, ensuring the insertion site is valuable and wings are full enclosed	Ensure the dressing is totally adhered to the skin to prevent bacteria from entering insertion site
Hold the yellow Y-arm firmly in one hand With your other hand, hold the white safety shield/mechanism Pull back in a straight continuous smooth motion The safety shield and needle separate from the canula	This is important, otherwise you may pull the plastic tubing out of the patient, instead of just the needle Check the needle entry site to ensure the plastic tubing has stayed under the skin
Discard the safety shield with its needle into the sharps container	
Remove brown bung Replace the injectable bung with NAD	
Apply pieces of Hypafix™ to secure the BD Saf-T-Intima™ and dressing	
Dispose of equipment, remove gloves and perform hand hygiene	
Check all lines are secure	

Appendix 2

3. Setting the NIKI Pump infusion

If you have not used a NIKI pump before or need support, please seek assistance from your palliative care service.

Generic online training is available:
https://www.caresearch.com.au/eolcareracf/tabid/6027/Default.aspx

Talk to your state paediatric palliative care team for more specific information.

PROCEDURE	ADDITIONAL INFORMATION
Insert battery into NIKI Pump by sliding the compartment cover at the back of the driver	
Switch the pump ON : wait for the pump to pre-load	The machine will calibrate itself
Measure the drawn-up syringe against the NIKI Pump and press either or to align actuator to the syringe plunger	Do not attempt to manually move the actuator as this can damage the device
The pump will display 'LOAD SYRINGE' Lift the barrel arm clamp and align the syringe in place with numbers facing operator Lower the clamp	If syringe not aligned correctly, the screen will alert which sensor is incorrect
The NIKI Pump will automatically detect which syringe is loaded Use the keys to confirm syringe brand and size and press to confirm	
Check and review data on screen: Volume, Duration, Rate Confirm settings displayed on the screen and press	The pump should automatic be set to run over a 24 hr period. If the rate is not 24 hrs, contact your local paediatric palliative care team
Start infusion? **DO NOT start infusion: you need to prime the extension set**	Use the NIKI pump to prime the extension set
Press to start the 'Purge/Prime' process	NOTE: on subsequent days, the extension set will not need to be primed

PROCEDURE	ADDITIONAL INFORMATION
Screen will display 'Purge. Disconnect patient' Press  to confirm	
Prime the extension set by pressing  and holding. When purge is completed, wait for the next screen to display	Visually see fluid move down the line and exit the end extension set. 2 mL is the maximum purge volume
Reconfirm syringe brand and confirmation by pressing 	
Confirmed revised infusion. Press  to resume Check and review data on screen: Volume, Duration, Rate Confirm settings displayed on the screen and press 	Because the extension set has been primed with medication, the pump will not run for a full 24 hrs. The infusion will finish approximately 2 hours early. This will occur only on the day an extension set must be primed. On subsequent days, the NIKI pump will run for the full 24 hrs, as the extension set will not need to be primed The rate will remain constant
The screen will display 'start infusion?' Press  to confirm	The NIKI pump will not be running
Pause the NIKI pump while you complete the remainder steps of the setup process Press  to pause the pump	The infusion will pause for 2 minutes before alarming. After 2 minutes, the NIKI pump will alarm again. Complete process if you are not ready to start infusion

4. Connection NIKI pump to a BD Saf-T-Intima™ and commence infusion

PROCEDURE	ADDITIONAL INFORMATION
Perform hand hygiene and don appropriate PPE	
Clean one of the NAD connected to the BD Saf-T-Intima™ and sounding area with an alcohol wipe	
Kink the BD Saf-T-Intima™ tubing and remove the NAD Attach the extension set and NIKI pump	
To resume the NIKI Pump once connected to the BD Saf-T-IntimaTM , press 	Once the infusion has started, time remaining and rate will be displayed on the screen. The bottom line will rotate between the brand/ size of syringe and 'Pump delivering'
Activate the keypad lock by pressing and holding the info/  key until a bar is displayed moving from left to right Hold the key until bar is full and beep is heard to confirm lock activates	Press and hold  key to unlock the pump
Place NIKI pump in lockbox and place in the protective pouch if appropriate	

Observation and Documentation:

1. Refer to local medication-specific protocols for frequency of observations. These may be modified in the end-of-life setting. Discuss with the primary treating team or palliative care team if unsure.
2. Site appearance: observe and document at least 4-hourly monitoring for irritation, inflammation, excessive redness, tenderness, presence of a haematoma or leaking at the insertion site.
3. Syringe/line contents appearance: observe and document absence of clouding, crystallisation or colour change.
4. Monitor infusion delivery, including infusion rate setting, volume remaining (correlate the volume remaining with the time remaining), volume infused.
5. Check battery status (shown as a percentage on the NIKI pump display panel). Ensure there is at least 40% battery life. If in doubt, change the battery.
6. Check parents know whom to contact if they experience problems with the infusion.
7. Document any problem(s) noted and action taken.

At completion of infusion or when removing the subcutaneous infusion device:

Ensure disposal of any remaining syringe contents per hospital/community hospice service protocols.

For more information, online education and a picture step- by-step guide see:

https://www.caresearch.com.au/eolcareracf/tabid/6027/Default.aspx

Please note this is an adult-focused resource so they may be variances within the paediatric setting.

Appendix 3
Syringe drivers: Medications and compatibilities

The most commonly used medications in paediatric palliative care can often be combined and administered subcutaneously via the one syringe driver. An analgesic and an anxiolytic are the most common combination, but an antiemetic, anticonvulsant or anti-secretion medication are also commonly used. The requirements for each child will vary, and the prescription should be assessed and written on an individual basis.

Infusions are generally administered over 24 hours to maintain medication compatibility and minimise microbiological contamination. Syringes should regularly be inspected visually for discolouration and precipitation.

The following medications can usually be combined in an infusion if indicated:

- midazolam
- morphine (or other opioid e.g., hydromorphone, methadone)
- metoclopramide (or other antiemetic e.g., cyclizine, levomepromazine)
- glycopyrrolate or hyoscine hydrobromide.

Multiple medications often must be combined in a single infusion to optimise patient care; however, where possible, this should be limited to three or four medications.

The use of two syringe drivers may be needed if medication incompatibilities exist, such as phenobarbitone, which must be administered via separate infusion as it is not compatible with other medications.

Some medications may be suitable to administer as a bolus injection rather than a continuous infusion, such as those with a long duration of action (e.g., clonazepam, dexamethasone).

As well as the infusion, breakthrough doses generally should be available and are usually administered as a bolus via a separate subcutaneous cannula. However, phenobarbitone administration via bolus should be avoided due to its acidic pH, which can cause tissue necrosis.

Some medications **should not** be administered subcutaneously, including antibiotics, diazepam, chlorpromazine and prochloperazine, as they can more often cause skin reactions at the injection and infusion sites.

Diluent:

Sodium chloride 0.9% and WFI are the most commonly used diluents. Sodium chloride 0.9% is preferred to prevent site reactions and discomfort. WFI must be used for cyclizine and should be considered if incompatibility is suspected.

Depending on the volume of medication, minimal dilution may be required to make the syringe to volume.

Site management:

Infusion site reactions can occur with some medications, such as midazolam, cyclizine, ketamine and methadone. Consider the following to reduce or prevent site irritation:

- further dilute medication with diluent
- change diluent (i.e., use sodium chloride 0.9% rather than WFI)
- change to less irritant medication
- add dexamethasone 0.5–1.0 mg to infusion or inject directly into infusion site before flushing and commencing infusion; doses over 1 mg do not provide any extra benefit and often contribute to incompatibility.

The following references provide specific medication compatibility information:

Dickman A, Schneider J. The syringe driver: continuous subcutaneous infusions in palliative care. 4th ed. Oxford: Oxford University Press, 2016.

Charlesworth S. Palliative care formulary. 7th ed. London: Pharmaceutical Press, 2020.

Safer Care Victoria. Syringe driver compatibility: guidance document. Victoria: Safer Care Victoria, 2021.

Alternatively, you can also liaise with a pharmacist.

Appendix 4
Contents of home care pack

To facilitate early treatment of symptoms and ensure the availability of specific medications, it is advisable that families living away from their treating hospital are given a home care pack. This pack should contain medications and equipment that may be required for general symptom relief and end-of-life care.

Contents for consideration:

- medical summary of current condition and goals of care
- copy of any relevant care plans where applicable (e.g., Paediatric Resuscitation Plan [PARP], ACP / Goals of Care documents)
- symptom management plan
- medication supply related to symptom management plan
- end-of-life care medication suggestions, including opioid (morphine), benzodiazepine (midazolam), anticholinergic (hyoscine hydrobromide [in parenteral formulation]), antiemetic (metoclopramide)
- contact details of relevant health professionals including an after-hours contact plan
- storage container (e.g., tackle box) to store equipment
- equipment for commencing subcutaneous infusion via BD BodyGuard T Pump or intermittent dose via a BD Saf-T-Intima™ (*see* Appendix 2)
- spare subcutaneous access devices, drawing up needles, syringes, alcohol swabs
- spare batteries for the infusion pump
- 1 mL syringes for bolus doses
- bungs/stoppers and labels
- Emla® cream or similar
- WFI and 0.9% sodium chloride
- sharps container
- syringe driver, with details of who can set up and commence, as well as a troubleshooting plan.

Appendix 4

Equipment for home care

Listed below is equipment that may assist in caring for the child at home:

- hospital bed if appropriate
- pressure relief mattress as prescribed or recommended by an occupational therapist (e.g., over lay, gel-pad, ripple or alternating air)
- incontinence supplies (e.g., disposable draw sheets, nappies)
- bed pan, urinal and commode
- bluey (disposable absorption pad)
- wheelchair or buggy, walking aids, manual handling belt, slide sheets, wedge, hoist
- TENS machine (if used prior)
- oxygen concentrator
- portable oxygen cylinder
- portable suction, disposable suction catheters and spare cannister (if applicable)
- mouth care equipment e.g., Toothettes
- NG feeding equipment (including spare tube)
- specimen jars (urine and faeces)
- consider the need for appropriate indwelling urinary catheter (IDC), particularly if spinal cord complications are a risk
- consider extra supplies that may be required if bleeding is a risk (e.g., dark towels).

Appendix 5a

Overview of the 10 essential elements in the National Consensus Statement: Essential elements for safe and high-quality paediatric end-of-life care

Appendix 5b
National Palliative Care Standards (5th ed., 2018)

OVERVIEW

Standard 1	Initial and ongoing assessment comprehensively incorporates the person's physical, psychological, cultural, social, and spiritual experiences and needs.
Standard 2	The person, their family and carers work in partnership with the team to communicate, plan, set goals of care and support informed decisions about the care plan.
Standard 3	The person's family and carers needs are assessed and directly inform provision of appropriate support and guidance about their role.
Standard 4	The provision of care is based on the assessed needs of the person, informed by evidence and is consistent with the values, goals and preferences of the person as documented in their care plan.
Standard 5	Care is integrated across the person's experience to ensure seamless transitions within and between services.
Standard 6	Families and carers have access to bereavement support services and are provided with information about loss and grief.
Standard 7	The service has a philosophy, values, culture, structure and environment that supports the delivery of person-centred palliative care and end-of-life care.
Standard 8	Services are engaged in quality improvement and research to improve service provision and development.
Standard 9	Staff and volunteers are appropriately qualified, are engaged in continuing professional development and are supported in their roles.

Adapted from *The National Palliative Care Standards Factsheet*.[242]

Appendix 6
Paediatric Palliative Care Clinical Indicators

Section 1: Demographics

1. What is the patient's CI #: .....
2. Date of birth: .....
3. Date of death: .....
4. Age at time of death
   - ☐ Less than 1 week: Age in days .....
   - ☐ Less than 1 month: Age in weeks .....
   - ☐ Less than 1 year: Age in months .....
   - ☐ Greater than 1 year: Age in years .....
5. Referral type
   - ☐ Antenatal
   - ☐ Paediatric
6. Post code of the PPC service (hospital/hospice): .....
7. Postcode of the patient's home residence: .....
8. Postcode of death location: .....
9. Location of patient death
   - ☐ Hospital
   - ☐ Home
   - ☐ Hospice
   - ☐ Other (e.g. residential facility) Specify .....
10. Was this the location of death the EOL Location Goal identified by the family?
    - ☐ Yes
    - ☐ No
    - ☐ Unknown
11. Diagnosis group
    - ☐ Cardiovascular
    - ☐ Gastrointestinal
    - ☐ Genetic
    - ☐ Metabolic
    - ☐ Neurology
    - ☐ Oncology
    - ☐ Respiratory
    - ☐ Other Specify .....
12. Has another sibling/s in the family been diagnosed with the same illness?
    - ☐ Yes
    - ☐ No

Section 2: Clinical Indicators

1. Was the referral timely?
   - ☐ Yes
   - ☐ No
   - ☐ Unsure
2. Length of engagement with palliative care team
   - ☐ Less than 24 hours
   - ☐ Less than 1 week
   - ☐ Less than 1 month
   - ☐ 1-3 months
   - ☐ 3-6 months
   - ☐ 6-12 months
   - ☐ > 1 year Specify # years .....

3. Intensity of engagement with the palliative care team (tick all that apply)

☐ Multiple consults (inpatient/outpatient/home) ☐ Weekly or more frequent consults

☐ Monthly consults ☐ One off consult with family and team

☐ Advice for treating team and no contact with the family

4. Mode of consultations (tick all that apply)

☐ Face to face ☐ Telecommunications (telephone/videoconference/text)

☐ Email

5. Palliative Care Consultations provided? (tick all that apply)

☐ Inpatient ☐ Outpatient ☐ Home ☐ Community health

☐ School ☐ Other (e.g. other tertiary facility) Specify .....

6. Pop-up intervention &/or education provided to local health providers

☐ Yes ☐ Not required

7. Multidisciplinary assessment completed? (medical/nursing/allied health)

☐ Yes ☐ No (please discuss as part of the Death Review)

8. Information resources for families? (health provider contacts/brochures/factsheets)

☐ Yes ☐ No ☐ Not applicable

9. Links with other health providers established (select all that apply)

☐ GP ☐ Community Nursing ☐ Community Palliative Care

☐ Community Paediatric Team ☐ Paediatrician ☐ NDIS providers

☐ Other Specify ..... ☐ None above applicable

10. Were respite needs met?

☐ Yes ☐ No ☐ Not required

11. Specific practices and beliefs of the family were identified while caring for the patient?

☐ Yes (please select all that apply)

☐ Cultural ☐ Religious ☐ Spiritual

☐ No (please discuss as part of the Death Review)

12. Sibling needs identified

☐ Yes ☐ No ☐ Not applicable

13. Equipment needs/medical supplies identified

☐ Yes ☐ No ☐ Not applicable (go to Q 15)

14. Equipment/medical supplies provided in a timely manner

☐ Yes (go to 15) ☐ No (please select all that apply)

- ☐ Funding issues ☐ Equipment not available
- ☐ Parent/carer decisions/circumstances
- ☐ Other (e.g. home design) Please specify .....

15. Family Goals and Advance Care Planning identified and reassessed as needed

☐ Yes ☐ No (please discuss as part of Death Review)

16. Difficult symptoms discussed with family

☐ Yes ☐ No ☐ Not applicable

17. Written palliative care management plan for health providers and/or family?

☐ Yes ☐ No

18. End of life/ Advance Care Planning documentation completed?

☐ Yes (please select type)

- ☐ Resuscitation Plan (or similar) ☐ Ambulance Form
- ☐ Other Please specify

☐ No

19. Family access to after-hours support if needed for end of life?

☐ Yes

☐ No (please select why)

☐ Not available ☐ Unexpected death ☐ Other Please specify

20. Preferences for location of end of life care discussed

☐ Yes ☐ No (please discuss as part of Death Review)

21. Access to the right location at the right time

☐ Yes ☐ No (please discuss as part of Death Review)

22. Family were offered an opportunity to meet/debrief with the palliative care service following their child's death

☐ Yes ☐ No Please comment

23. Bereavement follow up provided?

☐ Yes ☐ No ☐ Family declined

24. Death Review

☐ Yes ☐ No

Appendix 7
Commonly used drugs and doses

Note: gastrointestinal (GI), intramuscular (IM), intranasal (IN), intravenous (IV), nasogastric (NG), per oral (PO), per rectum (PR), subcutaneous (SC), sublingual (SL), transdermal (TD), water for injection (WFI), when required (PRN), Special Access Scheme – Australia (SAS), Special Authority – New Zealand (SA).

Table A1 **Commonly used drugs and doses**

Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Amitriptyline Tablets: 10 mg, 25 mg, 50 mg	**Neuropathic pain** **Assist sleep**	PO: 0.2–1 mg/kg at night	Starting dose: 50 mg/day Maintenance dose: 150mg/day	
Atropine Eye drops: 0.5 %, 1 %	**Secretion management**	SL: 10–19 kg: 1 drop Q6h prn 5–18 yrs (> 20 kg): 1–2 drops Q4–6h prn		Eyedrop solution can be administered SL
Baclofen Tablets: 10mg, 25mg Liquid 1mg/ml	**Spasticity**	PO: 1–10 yrs: initially 0.75 mg/kg/day in 3 or 4 divided doses 10–18 yrs: Initially 5 mg three times daily Increase gradually if needed and tolerated	< 8 yrs: 40 mg/ day 8–10 years: 60 mg/day 10–18 yrs: 100 mg/day	

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Appendix 7

Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Benzatropine Tablets: 2 mg Amp: 1 mg/mL	**Dystonic reactions** **Drug-induced extrapyramidal side effects**	PO: < 12 yrs: 0.02–0.05mg/kg once or twice daily > 12yrs: 1–2 mg twice daily IV / IM: < 12 yrs: 0.02 mg/kg/dose stat. > 12 yrs: 1–2 mg/dose stat. Repeat after 15 min if required	2 mg/dose	
Buprenorphine SL tablet 200 mcg Transdermal patch 5 mcg/hr 10 mcg/hr 15 mcg/hr 20 mcg/hr 25 mcg/hr 30 mcg/hr 40 mcg/hr	**Pain**	Dose by titration or as per existing opioid needs SL: > 6 yrs and 16–25 kg: 100 mcg Q6–8h prn 25–37.5 kg: 100–200 mcg Q6-8h prn 37.5–50 kg: 200–300 mcg Q6–8h prn > 50 kg: 200–400 mcg Q6–8h prnTD: Suggested starting dose: 15–30 kg: 5 mcg/hr patch weekly 31–50 kg child: 10 mcg/hr patch weekly	40 mcg/hour	TD: analgesic concentrations are generally reached in 12–24 hrs, but levels can continue to rise for up to 54 hrs
Carbamazepine Tablets: 100 mg, 200 mg, 400 mg Controlled release tablets: 200 mg, 400 mg Liquid: 20 mg/mL	**Seizures** **Neuropathic pain**	PO 2.5 mg/kg/dose twice daily or 5 mg/kg/dose at night Increase if necessary, every 3–5 days by 2.5–5 mg per day, daily doses divided in 2 or 3 doses, to 5–10 mg/kg/dose Q8–12h	Starting dose: 200 mg Maintenance dose: 2 g/day	Controlled release tablets should be given every 12hrs

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Chloral hydrate Liquid: 100 mg/mL 200 mg/mL	**Sedation** **Agitation** **Status Dystonicus**	PO / PR: 10–20 mg/kg/dose Q6h prn Can use higher doses (up to 50 mg/kg) with care	2g/dose	PO: Dilute with water or juice to reduce gastric irritation PR: Dilute dose with equal volume of olive oil to avoid irritation
Chlorpromazine Tablets: 10 mg, 25 mg, 100 mg Liquid: 5 mg/ mL, 10mg/ml, 20mg/mL Amp: 25 mg/mL	**Agitation** **Nausea**	PO / IV: 0.5 mg/kg/dose Q6–8h prn	< 5 yrs: 40 mg/ day >5 yrs: 75 mg/day	
Clonazepam Tablets: 0.5 mg, 2 mg Liquid: 2.5 mg/mL 1 drop = 100 mcg 25 drops = 1 mL Amp: 1 mg/mL + diluent	**Agitation** **Anxiety** **Seizures** **Dyspnoea**	PO / SL: < 10 yrs: 0.01–0.05 mg/kg/day divided in 2 or 3 doses > 10 yrs: 0.5 mg/dose Q8-12h Increase if necessary, every 3 days Status epilepticus: IV / SC: 0.05 mg/kg stat Repeat if required Can be administered as continuous infusion	Starting dose for children: 0.5 mg/dose Maintenance dose: 0.2 mg/ kg/day for children 20 mg/day for adults IV: 1 mg/ dose	Prescribe oral liquid as number of drops and mg to reduce errors (1 drop contains 0.1 mg). Has been associated with hypersalivation in children. The blue dye in the oral liquid may stain teeth or saliva Clonazepam is absorbed by PVC; for SC infusion, use non-PVC tubing.

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Clonidine Tablets: 25 mcg, 100 mcg, 150 mcg Amp: 150 mcg/mL Transdermal Patch (SAS): 2.5 mg (100 mcg/day) 5 mg (200 mcg/day) 7.5 mg (300mcg/day)	**Pain** **Dystonia** **Irritability** **Sedation** **Anxiety**	PO / IV / SC: 0.5–4 mcg/kg/dose Q6-8h Can be administered as continuous infusion TD dose conversion: (> 10kg): PO / IV 75- 150 mcg/day: use 2.5 mg patch weekly PO / IV 150–250 mcg/day: use 5 mg patch weekly	PO: 5 mcg/kg/ dose	Conversion to Patch: Apply patch on Day 1. Day 1: give 100% of PO/IV dose Day 2: give 50% of PO/IV dose Day 3: give 25% PO/IV dose Day 4: patient will only need patch
Codeine Tablets: 15 mg, 30 mg, 60mg Liquid: 5mg/mL	**Analgesic**	PO: 0.5–1 mg/kg/dose Q4–6h prn	60 mg/dose	Many children's hospitals in Australia and New Zealand have removed codeine from their formularies
Cyclizine Tablets: 50 mg Amp: 50 mg/mL	**Nausea**	PO / IV / SC: 1 month – 5 yrs: 0.5–1 mg/kg three times daily prn 6–11 yrs: 25 mg three times daily prn 12–17 yrs: 50 mg three times daily prn Can be administered as continuous infusion	< 12 yrs: 25 mg/dose ≥ 12 yrs: 50 mg/dose	IV injection to be given over 3–5 minutes Only compatible with WFI

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Dexamethasone Tablets: 0.5 mg, 1mg 4 mg Oral liquid 1 mg/mL Amp: 4 mg/mL,	**Cerebral oedema** **Spinal cord compression** **Anti-inflammatory** **(peripheral nerve compression, pain, bowel obstruction)** **Nausea** **SC site irritation / preservation**	PO / IV / SC: Seek specialist advice: A single bolus dose of 1–2 mg/ kg can be given initially, then 0.25= 0.5 mg/kg/dose Q6–12h PO / IV / SC: 0.1–0.25 mg/kg/dose Q6–12h Can be administered as continuous infusion PO / IV / SC: 0.1–0.25 mg/kg/dose Daily - Q8h. Can be administered as continuous infusion Inject 0.5–1 mg directly into infusion site, via the cannula to be used Flush with sodium chloride 0.9%, then connect the syringe driver and commence	16 mg/dose 8 mg/dose 8 mg/dose	Can also be added to syringe for infusion, if compatible with medications
Diazepam Tablets: 2 mg, 5 mg Liquid: 1 mg/mL Amp: 5 mg/mL Enema (compounded): 5 mg/2.5mL, 10 mg/2.5mL	**Anxiety Muscle spasm** **Seizures**	PO / IV: Initially 0.1 mg/kg/dose Q8h prn Increase dose as needed and tolerated IV: 0.1–0.3 mg/kg/dose stat PR: 0.3–0.5 mg/kg/dose Repeat at 15–30 minute intervals if required	Starting dose: 5 mg/dose Maintenance dose: 40 mg/day IV: 10 mg/dose PR: 20 mg/dose	

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Diclofenac Tablets: 12.5 mg, 25 mg, 50 mg Enteric coated tablets: 25mg, 50 mg Capsules: 12.5 mg, 25 mg Liquid (sachet): 50 Controlled release tablets: 75 mg Amp: 25mg/ml Suppositories: 25 mg, 50 mg, 100 mg	**Anti-inflammatory**	PO / PR: 0.5–1 mg/kg/dose Q8–12h prn	50 mg/dose	Avoid with thrombocytopenia
Docusate sodium Tablets: 50 mg, 120 mg	**Constipation**	PO: 3–6 yrs: 50 mg Q8h prn 6–12 yrs: 50–120 mg Q8h prn >12 yrs: 100–150 mg Q8h prn	< 12 yrs: 240 mg/day > 12 yrs: 500 mg	< 3 yrs: consider poloxamer drops
Docusate sodium with Sennoside b Tablets: 50 mg/8 mg	**Constipation**	PO: 6 yrs: 1–2 tablets nocte	6–12 yrs: 2 tablets/day > 12 yrs: 4 tablets/day	
Domperidone Tablets: 10 mg Liquid: 1 mg/ml	**Nausea GI stasis**	PO: 0.2–0.4 mg/kg/dose Q6–8h	20 mg/dose	

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Fentanyl Amps: 10mcg/ml, 20mcg/ml 50mcg/mL 100 mcg/2 mL, 500 mcg/10 mL 500 mcg/50ml 1000mcg/50ml TD Patch: 12 mcg/ hr, 25 mcg/hr, 50 mcg/hr, 75 mcg/ hr, 100 mcg/hr Lozenge: 200 mcg, 400 mcg, 600 mcg, 800 mcg,SL Tablet: 100 mcg, 200 mcg, 300 mcg, 400 mcg, 600 mcg, 800 mcg	**Pain**	Dose by titration or as per existing opioid needs IV / SC bolus: < 1 yr: Initially 0.15–0.25 mcg/kg/dose every 0.5–1 hr 1–18 yrs: Initially 0.25–0.5 mcg/kg/dose every 0.5–1 hr IV /SC infusion: < 1 yr: Initially 0.15–0.5 mcg/kg/hr 1–18 yrs: Initially 0.25–1 mcg/ kg/ hrTD patch: Dose by titration or as per existing opioid need > 2 yrs: apply patch every 3 days PO lozenge: Initially 200 mcg over 15 minutes; repeat once only if analgesia is inadequate after finishing the first lozenge, titrate to effective dose. Wait 4 hours between treatment of pain episodes. SL tablet: Initially 100 mcg Q2- 4h (depends on product), titrate to effective dose.	Adjust dose according to response, no maximum	Three transmucosalformulations currently available in Australia (sublingual tablet (Abstral®), orally disintegrating tablet (Fentora®) and lozenges (Actiq®). Refer to product information for dosing and administration.
Gabapentin Tablets: 600 mg, 800 mg Capsules: 100 mg, 300 mg, 400 mg' Liquid: 100 mg/ml	**Neuropathic pain** **Itch**	PO: 5–10 mg/kg/dose Daily – Q8h Increase dose as needed and tolerated	Starting dose: 300 mg Maintenance dose: 60 mg/kg/day or 3.6 g	Increase dose over days Day 1: daily Day 2: Q12h Day 3: Q8h

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Glycopyrronium Tablets: 1 mg (SAS) Amp: 0.2 mg/mL	**Reduce secretions**	PO: 40–100 mcg/kg/dose Q6–8h prn IV / SC: 4–10 mcg/kg/dose Q6–8h prn Can be administered as continuous infusion	IV / SC: 400 mcg/dose PO: 2 mg/dose	Injectable solution can be given orally
Haloperidol Tablets: 0.5 mg, 1.5 mg, 5 mg Liquid: 2 mg/mL Amp: 5 mg/mL	**Agitation / Delirium** **Nausea / Vomiting** **Intractable hiccups**	PO / IV / SC: 0.01–0.02 mg/kg/dose Q8–12h Increase dose as needed and tolerated Can be administered as continuous infusion	Starting dose: 0.5 mg/dose Maintenance dose: 10 mg/day	Children and adolescents may be at greater risk of acute dystonic reactions than adults
Hydromorphone Immediate release Tablet: 2 mg, 4 mg, 8 mg Liquid (SAS): 1 mg/mL Amp: 2mg/mL,10mg/mL, 50 mg/mL	**Pain**	PO: Initial dose: 30–60 mcg/kg/dose Q3–4h IV / SC: Initial dose: 10–20 mcg/kg/dose Q3–4h Can be administered as continuous infusion Initial dose: 2 mcg/kg/hr Breakthrough doses should be calculated at 1/6 of the total daily infusion	Starting dose: PO: 2 mg IV / SC: 0.5 –1 mg/dose Increase dose as required – no max dose	
Hyoscine N-Butylbromide Tablet: 10 mg, 20 mg Amp: 20 mg/mL	**Antispasmodic (genitourinary, GI)** **Reduce secretions**	PO / IV / SC: 1 month – 5 years: 0.3–0.5 mg/kg/dose Q6-8h prn 6–11 yrs: 10 mg Q6-8h prn 12–17 yrs: 10-20mg Q6-8h prn Can be administered as continuous infusion	20 mg/dose	

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Hyoscine Hydrobromide Tablets : 0.15 mg, 0.3 mg Amp: 400 mcg/mL Patch: 1.5 mg (SAS & SA)	**Reduce secretions**	PO: 2–7 yrs: 0.075 mg/dose Q6h prn 7–12 yrs: 0.15–0.3 mg/dose Q6h prn > 12 yrs: 0.3–0.6 mg/dose Q6h prn IV / SC: 10 mcg/kg/dose Q6h prn Can be administered as a continuous infusion TD: < 3 yrs: ¼ patch Q72h 3–9 yrs: ½ patch Q72h > 9 yrs: 1 patch Q72h Apply patch to hairless area behind ear	PO: 2–7 yrs: 0.3 mg/24 hrs 7–12years: 0.6 mg/24 hrs > 12 yrs: 1.2 mg/24 hrs IV / SC: 600 mcg/ dose	
Ibuprofen Tablets: 200 mg, 400 mg, 600 mg Chewable tablets: 100mg Capsules: 100mg, 200 mg, 400 mg Chewable capsules: 100mg Controlled release tablets: 300mg, 600mg, 800 mg Liquid: 20 mg/mL, 40 mg/mL Amp: 5 mg / ml, 10 mg / ml	**Anti-inflammatory**	PO: 5–10 mg/kg/dose Q6–8h prn	400 mg/ dose	Avoid with thrombocytopenia

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Appendix 7

Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Ketamine Amp: 100 mg/ml	**Neuropathic pain** **Refractory pain**	Ketamine should only be commenced by practitioners experienced in its use IV / SC: 100 mcg/kg/dose Q6h prn Can be administered as a continuous infusion; initial dose: 20–40 mcg/kg/hr	Max starting dose: 10 mg/dose Adjust dose according to response	
Lactulose Liquid: 0.67 g/mL	**Constipation**	PO: 1–12 months: 2.5 mL twice daily prn 1–5 yrs: 2.5–10 mL twice daily prn 5–18 yrs, 5–20 mL twice daily prn	Adjust dose according to response	
Levetiracetam Tablets: 250 mg, 500 mg, 750 mg, 1000 mg Liquid: 100 mg/mL Amp: 100 mg/mL	**Seizures**	PO /. IV / SC: 1–6 months: 7 mg/kg twice daily > 6 months: 10 mg/kg twice daily Increase dose if required For breakthrough seizures: PO / IV / SC: 10–20 mg/kg Repeat dose if required Can be administered as continuous infusion	Starting maintenance dose: 500 mgMaximum daily dose: 60 mg/ kg/ day or 3 g/ day	Increase maintenance dose every 2 weeks if required
Levomepromazine (SAS) Tablet: 25 mg, 100 mg Amp: 25 mg/mL	**Nausea / vomiting** **Terminal restlessness/ sedation**	PO / IV / SC: > 2 yrs: 0.05–0.1 mg/kg/dose Daily - q8h prn Increase dose if needed, as tolerated Can be administered as continuous infusionIV / SC: 0.35 mg/kg/day as a continuous infusion Increase dose if needed	3 mg/kg/ day or 200 mg/day	

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Loperamide Capsule/tablet/ orally disintegrating tablets: 2 mg	**Diarrhoea**	PO: 0.1–0.2 mg/kg/dose 3-4 times a day or with each bowel motion until settled	2 mg/dose 16 mg/day	
Lorazepam Tablets: 0.5mg, 1 mg, 2.5 mg Amp: 4mg/mL	**Anxiety** **Anticipatory nausea/ vomiting** **Dyspnoea**	PO / SL / IV: 0.02–0.05 mg/kg/dose Q8–24h prn	4 mg/dose	
Macrogol 3350 and electrolytes Powder (for oral liquid)	**Constipation**	PO: Movicol Junior®: 1–12 months: 0.5–1 sachet daily 1–6 yrs: 1 sachet daily 6–12 yrs: 2 sachets daily Movicol: 2 yrs: 0.5 sachet daily > 12 yrs: 1 sachet daily Osmolax ® 2–6 yrs: 8.5 g scoop daily > 6 yrs: 17g scoop daily	Adjust dose according to response	Mix powder in water or clear fluids prior to consumption
Melatonin Immediate release products are not marketed in Australia. Controlled release tablets: 1 mg, 2 mg, 3 mg, 5 mg	**Sleep disturbance**	PO: 2 –3 mg at night (30–60 minutes before bedtime)	10 mg/dose	Increase dose every 1–2 weeks

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Methadone Tablets: 5 mg, 10 mg Liquid: 2 mg/mL, 5 mg/mL, 10 mg/mL Amp: 10 mg/mL	**Complex pain**	Methadone should be commenced by practitioners experienced in its use. The dose and frequency prescribed is tailored to individual clinical contexts and previous opioid exposure, with careful monitoring for delayed toxicity Dose by titration or as per existing opioid needs PO: 50–100 mcg/kg/dose Q6–12h IV / SC: 50 mcg/kg/dose Q6–12hr Can be administered as continuous infusion Use short-acting opioid as breakthrough	Starting dose: PO: 5 mg/dose IV / SC: 2.5 mg/dose Increase dose as required – no max dose (see comments)	Adjuvant doses are usually commenced at the lower dose range. Dose adjustments should be made cautiously and no more frequently than every 7 days
Methylnaltrexone Amp: 12 mg/ 0.6mL	**Opioid induced constipation**	SC: < 38 kg: 0.15 mg/kg 38–62 kg: 8 mg > 62kg: 12 mg Give once; can repeat after 24 hrs then every second day if needed	Maximum 1 dose per day	
Metoclopramide Tablets: 10 mg Liquid: 1 mg/mL Amp: 5mg/ml	**Nausea and vomiting**	PO / IV / SC: 0.1–0.2 mg/kg/dose Q6–8h prn Can be administered as continuous infusion	10 mg/dose 30mg/day	Children and adolescents may be at greater risk of acute dystonic reactions than adults

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Midazolam Amp: 5mg/5ml, 5mg/ml, 5mg/3ml, 50mg/10ml Plastic: 5 mg/mL	**Seizures**	**Status epilepticus:** Buccal / IN: 0.3 mg/kg stat (max 10 mg) Repeat after 5–10 minutes if required IV / SC: 0.1–0.2 mg/kg/dose Repeat after 5–10 minutes if required **Seizure control at end of life:** IV or SC continuous infusion: Initial dose: 1–3 mg/kg/24 hrs Increase dose if needed, as tolerated Breakthrough doses can be administered	10-15mg/dose or 50mg/day- Higher doses can be used in refractory cases	Consider other therapy if needing doses > 50 mg/day Plastic ampoules can be used buccally and intranasally
	Premedication/ procedural sedation	**Procedural sedation**: Buccal / IN: 0.3 mg/kg/dose (max 10 mg) PO: 0.25–0.5 mg/kg/dose (max 15 mg)		
	Agitation Dyspnoea Anxiety	**Agitation/Anxiety** Buccal / IN: 0.3 mg/kg stat (max 10 mg) IV / SC: 0.025–0.05 mg/kg/dose Q1h prn Can be administered as continuous infusion Initial dose: 0.25–1.5 mg/kg/24 hrs Increase dose if needed, as tolerated Breakthrough doses can be administered		

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Morphine Immediate release tablets: 10 mg, 20 mg, 30 mg Liquid: 1 mg/mL, 2 mg/mL, 5 mg/mL, 10 mg/mL Controlled release tablets: 5 mg, 10 mg, 15 mg, 30 mg, 60 mg, 100 mg, 200 mg Controlled release capsules: 10 mg, 20 mg, 30mg, 50 mg, 60 mg, 90mg, 100 mg,120 mg Amp: Morphine sulphate: 5 mg/mL, 10 mg/mL, 15 mg/mL, 30 mg/mLAmp: Morphine hydrochloride: 10 mg/mL, 20mg/mL	**Pain** **Dyspnoea**	PO: <1 month: 0.025–0.05 mg/kg/dose Q6–8h prn 1–6 months: 0.1–0.2 mg/kg/dose Q4–6h prn > 6 months: 0.2–0.5 mg/kg/dose Q4h prn Controlled release: calculate total daily oral morphine dose and give half every 12 hrs SC / IV: <1 month: 0.025 mg/kg/dose Q6–8h prn 1–6 months: 0.05–0.1 mg/kg/dose Q4–6h prn > 6 months: 0.1–0.2 mg/kg/dose Q4h prn Can be administered as continuous infusion Initial dose: <1 month: 0.12 mg/kg/24 hrs 1–6 months: 0.24 mg/kg/24 hrs > 6 months: 0.48 mg/kg/24 hrs Breakthrough doses should be calculated at 1/6 of the total daily infusion30-50% of analgesic doses	Starting dose: PO: 5–10 mg/doseIV / SC: 2.5–5 mg/dose Infusion: 20 mg/day Increase dose as required – no max dose	
Naloxone Amp: 400 mcg/mL 20 mcg/ml (neonatal) Nasal Spray: 1.8 mg/0.1ml	**Acute respiratory depression/ excessive sedation related to opioids** **Itch**	IV/SC/IM: 1–10 mcg/kg Repeat after 2–3 minutes if no responseIV/SC: 0.5–1 mcg/kg hourly Repeat as needed Can be administered as continuous infusion	100 mcg/dose	Caution in children receiving chronic opioid therapy as may induce pain crisis and/or withdrawal

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Octreotide Amp: 50 mcg/mL, 100 mcg/mL, 500 mcg/mL	**Bowel obstruction** **Intractable diarrhoea** **Secretory diarrhoea** **Acute variceal bleeding**	IV / SC: 1–2 mcg/kg/dose Q8–12h Dose can be increased as required and as tolerated Can be administered as continuous infusion	Starting dose: 50 mcg/ doseMaxi-mum mainte-nance dose: 50 mcg/hr or 1,200 mcg/day	
Olanzapine Tablets: 2.5 mg, 5 mg, 7.5 mg, 10 mg Orally disintegrating tablet/wafer: 5 mg, 10 mg, 15 mg, 20 mg	**Nausea and vomiting** **Agitation**	PO: < 12 yrs: start at 1.25 mg at night > 12 yrs: start at 2.5 mg at night Dose can be increased as required and as tolerated	20 mg/day	
Omeprazole Tablets (enteric coated): 10 mg, 20 mg Capsules (enteric coated): 10 mg, 20 mg, 40 mg Liquid: 2 mg/ml Amp: 40mg (powder)	**Antacid Reflux** **Oesophagitis / gastritis**	PO/IV: 0.5–1 mg/kg/dose Q12h – daily	40 mg/dose	
Ondansetron Tablets: 4 mg, 8 mg Orally disintegrating tablet/wafers: 4 mg, 8 mg Liquid: 4 mg/5 mL Amp: 4 mg/2mL & 8 mg/4 mL	**Nausea and vomiting**	PO / IV / SC: 0.15 mg/kg/dose Q8h prn Can be administered as continuous infusion	8 mg/dose	

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Oxycodone Immediate release Tablets: 5 mg Capsules: 5 mg, 10 mg, 20 mg Liquid: 1 mg/mL Suppository: 30 mg Controlled release tablets: 5 mg, 10 mg, 15 mg, 20 mg, 30 mg, 40 mg, 60mg, 80 mg Controlled release tablets (oxycodone/naloxone): 2.5mg/1.25mg, 5mg/2.5mg, 10mg/5mg, 15mg/7.5mg, 20mg/10mg, 30mg/15mg, 40mg/20mg, 60mg/30mg, 80mg/40mg Amp: 10 mg/mL, 50 mg/mL	**Pain**	PO: 0.1–0.2 mg/kg/dose Q4h prn IV / SC: 0.05–0.1 mg/kg/dose Q4h prn Can be administered as continuous infusion Increase dose if needed, as tolerated Controlled release: calculate total daily oral oxycodone dose and give half every 12 hrs Breakthrough doses should be calculated at 1/6 of the total daily dose or infusion	Starting dose: PO: 10 mg/dose IV / SC: 5 mg/dose Increase dose as required – no max dose	
Paracetamol Tablet/capsule: 500 mg Controlled release tablets: 665 mg Liquid: 24 mg/mL, 48 mg/mL, 50 mg/mL, 100 mg/mL Suppository; 125 mg, 250 mg, 500 mg Amp: 10mg/mL	**Analgesic** **Antipyretic**	< 1 month: PO / PR: 15 mg/kg/dose Q6–8h prn IV: 10 mg/kg/dose Q6h prn > 1 month: PO / PR / IV: 15 mg/kg/dose Q4–6h prn	< 1 month: IV: 40 mg/kg/day PO / PR: 60 mg/kg/day1 month:60 mg/kg/day 1 gram/dose	

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Phenobarbital Tablets: 15 mg, 30 mg Liquid: 3 mg/mL 10mg/ml Amp: 200 mg/mL	**Seizures** **Refractory agitation** **Terminal sedation**	PO / IV / SC: 2.5–5mg/kg/dose Q12 – daily Loading dose: IV / SC / IM: 20 mg/kg Can be administered as continuous infusion	600 mg/ day Loading dose: 1 gram/dose	Oral liquid contains ethanol 9.6% Alcohol-free liquids may be prepared at hospital and compounding pharmacies
Phenytoin Chewable tablets: 50 mg Capsules: 30 mg, 100 mg Liquid: 6 mg/mL Amp: 50 mg/mL	**Seizures**	PO / IV: 3-5 mg/kg/day in 2 or 3 divided doses Loading dose for status epilepticus: IV: 15–20 mg/kg (can be given orally divided in 3 parts every 2 hours)	<12yrs: 300mg/day >12yrs: 600mg/day	
Poloxamer Liquid: 100 mg/mL	**Laxative**	PO: < 6 months: 0.3 mL Q8h 6–18 months: 0.5 mL Q8h > 18 months: 0.8 mL Q8h		
Pregabalin Capsules: 25 mg, 50mg, 75 mg, 100mg, 150 mg, 200mg, 300 mg Liquid: 20 mg/ml	**Neuropathic pain**	PO: 1 mg/kg/dose Q12h – daily	6 mg/kg/ day (higher doses used in epilepsy)	Increase dose slowly Day 1–3: daily Day 4–6: Q12h Day 7: increase by 1 mg/kg every 3-7 days until effect
Prochlorperazine Buccal tab 3mg Tablets: 5 mg Amp: 12.5 mg/mL	**Nausea and vomiting** **Vertigo**	PO / IV: > 2 yrs: 0.25 mg/kg/dose Q8–12h prn	10 mg/dose	Children and adolescents may be at greater risk for acute dystonic reactions than adults

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Appendix 7

Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Promethazine Tablets: 10 mg, 25 mg Liquid: 1 mg/mL Amp: 25 mg/mL	**Nausea and vomiting** **Antihistamine Itch** **Sedation**	PO / IV: > 2 yrs: 0.125–0.5 mg/kg/dose Q6–8h prn	100 mg/day	Children and adolescents may be at greater risk for acute dystonic reactions than adults
Senna Tablet/chocolate square: 7.5 mg, 12 mg	**Constipation (Stimulant laxative)**	PO: 2–6 yrs: 3.75–7.5 mg at night 6–12 yrs: 7.5–15 mg at night > 12 yrs: 7.5–30 mg at night	30 mg/day	
Sodium Picosulfate Drops: 7.5 mg/mL Liquid: 5mg/ml	**Constipation** **(Stimulant laxative)**	PO: 1 month – 4 yrs: 0.25 mg/kg at night 4–18 yrs, 2.5–5 mg at night Increase if needed and tolerated	10 mg	1 drop contains 0.5 mg sodium picosulfate
Tapentadol Immediate release tablets: 50 mg Controlled release tablets: 50 mg, 100 mg, 150 mg, 200 mg, 250 mg	**Pain**	PO: Immediate release: > 2 yrs (> 16 kg): 1.25 mg/kg/dose Q4h prn Controlled release: calculate total daily oral tapentadol dose and give half every 12 hrs	100 mg/dose 600mg/day	
Tramadol Immediate release capsules: 50 mg Oral liquid: 10 mg/mL, 100 mg/mL Controlled release tablets: 50 mg, 100 mg, 150 mg, 200 mg Amp: 50 mg/mL	**Pain**	PO / IV: Immediate release: 1 yr: 1–2 mg/kg/dose Q6h prn > PO: Controlled release: calculate total daily oral tramadol dose and give half every 12 hrs	100 mg/dose	Caution when prescribing and administering tramadol liquid oral due to its high concentration (NOTE Australia product: 1 drop = 2.5 mg)

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Drug and formulation	Indication	Route, dose and frequency	Maximum dose	Notes
Tranexamic Acid Tablets: 500 mg Amp: 100 mg/mL	**Antifibrinolytic for bleeding**	PO: 15–25mg/kg/dose Q8–12h Mouthwash: 500 mg tablet dissolved in 5–10 mL water and use as mouthwash then spit out every 6 hrs IV: 10 mg/kg Q8–12h	Oral: 1.5g/ dose IV: 1 g/dose	

The drugs included are those commonly used for symptom management. This information is designed to be a dose guide only. Each patient's dose requirements may vary and should be adjusted based on the clinical situation. Readers should also refer to more comprehensive texts on palliative care for further information on drugs, indications, and side effects. All care has been made to ensure that doses are accurate, but the user is advised to check these carefully and to consult the above references and the text of this guide for potential toxicities. Contact with an experienced pharmacist is also advisable. The authors shall not take responsibility for any errors in publication of drug doses or in drug administration.

Special Access Scheme (SAS) medicines unavailable in Australia may be imported via the Therapeutic Goods Administration (TGA). Applications need to be made to the TGA and the medicines sourced from overseas suppliers.

Special Authority (SA) is an application process in Aotearoa New Zealand in which a prescriber requests government subsidy on a Community Pharmaceutical for a particular person. Section 29 of the Medicine Act deals with the supply of unapproved medicines to medical practitioners for the treatment of a named patient under their care.

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Contributors to the 1st edition (cancer conditions; 1999):

Dr Helen Irving (1st–4th editions), Kris Liebke (1st & 4th eds), Dr Liane Lockwood, Michelle Noyes (1st & 4th eds), Delma Pfingst (1st & 2nd eds), Tim Rogers and Drew Craker.

Additional contributors to the 2nd edition (cancer conditions; 2009):

Dr John Collins (2nd & 3rd eds), Dr Anthony Herbert (2nd–4th eds), Peter Barclay, Elizabeth Heiner, Carol Quayle, Sara Fleming (2nd–4th eds), Dr Marianne Philips (2nd–4th ed), Jess Jamieson, Andrew Thompson and Dr Peter O' Regan.

Project Coordinators:

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Additional contributors to the 3rd edition (both cancer and non-cancer conditions; 2014):

Project Coordinators:

Natalie Bradford and Lee-anne Pedersen (3rd ed, & contributor 4th ed).

Other Contributors:

Dr Lucy Cooke (3rd & 4th eds), Dr Simon Cohen, Leigh Donovan, Dr Ross Drake (3rd & 4th eds), Jude Frost, Alyson Gundry (3rd & 4th eds), Dr Deidre Hahn, Rachael Lawson, Dr Martha Mherekumombe (3rd & 4th eds), Suzanne Momber (3rd & 4th eds), Carol O'Ryan, Cindy Paardekooper, Andrew Paton, Jo Ritchie, Dr Sharon Ryan, Dr Susan Trethewie and Dr Peter Trnka.

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Clinical Expert Advisory Panel (CEAP): Dr Anthony Herbert, Dr Helen Irving, Dr Marianne Phillips, Dr Kirsten Ball, Nora O'Loughlin, Julie Anania and Alison McLarty.

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Project Coordinators (Palliative Care Australia)

Hannah Skipsey, Samara Rodway, Toni Rice and Annette Vickery.

Other contributors:

Alison Bowers, Angela Delaney, Clare Radford, Dr Bronwyn Sacks, Dr Deborah Gilmour, Dr Kathryn Leadbeater, Dr Maggie Mei Ki Winters, Dr Melissa Weimers, Dr Molly Williams, Dr Rachel Kermond, Dr Rowena Lalji, Dr Sherina Mubiru, Dr Shirleen Balbir-Singh, Dr Sid Vemuri, Elham Day, Elizabeth Shepherd, Dr Freya Nichols, Gemma Auburn, Hannah Morgan, Dr Jenny Hynson, Kelly Anderson, Dr Kirsty-Leah Goymour, Leah Rotin, Lorenz Pilkington, Dr Monica Cooper, Rebecca May, Shontelle Thomas, Sue Cowen, Tanya Quinn, Tina Coco, Dr Ursula Sansom-Daly, Dr Trisha Prentice, Kerry Gordon, Brittany Klee, Debbie Rando, Dr Amanda Evans and Dr Tess Moeke-Maxwell.

Peer Reviewers:

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Palliative Care Australia
pca@palliativecare.org.au

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