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Care Plan for the Dying Child

Health Professional Guidelines

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Care Plan for the Dying Child: Health Professional Guidelines

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An electronic version of this document is available at:

https://clinicalexcellence.qld.gov.au/resources/clinical-pathways/care-plan-dying-child

Disclaimer:

We acknowledge the Traditional Owners of the land on which we walk, talk, work and live. We pay respects to Elders past, present and all generations of Aboriginal and Torres Strait Islander peoples now and into the future.
(Artwork produced for Queensland Health by Gilimbaa)

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Purpose of this document

The *Queensland Health Care Plan for the Dying Child Health Professional Guidelines* (Guidelines) contains information on best practice, interprofessional compassionate care for children/young people the last days and hours of life in a hospital setting. They have been developed to support both generalist and specialist clinicians providing care in the terminal phase of illness and address clinical and procedural aspects of care and communication that are relevant during this period.

The Guidelines are to be used in conjunction with the Care Plan for the Dying Child (CPDC), which is based on the fundamental principles of recognising dying, communication and decision-making.

CPDC sections

The CPDC is comprised of:

- Commencement of the Care Plan for the Dying Child,
- Best-Practice Principles to Care for the Dying Child
- Information for Health Professionals
- Interprofessional Decision-Making Guide
- Initial Assessment
- Instructions for Psychosocial Support for the Child/Young Person and their Family
- Ongoing Assessment Tool
- Instructions for Ongoing Assessment, Symptom Management and End-of-Life Care
- Record of Actions (Progress Note)
- Care after Death form

Key definitions
Interprofessional Team (IPT): Minimally consists of a Medical Officer and a Registered Nurse who are partners with the family, caring of the dying child and should involve Allied Health as appropriate
Family: This term includes any people who are important to the dying child, including parents/carer(s), sibling(s), grandparent(s), extended family, kinship relationships, girl/boyfriend, friends etc.
Child: ‘Child’ refers to everyone from birth to 18 years of age, including neonates, infants, and young persons.

Section 1: Overview and principles

The *Queensland Health Care Plan for the Dying Child Health Professional Guidelines* contains detailed information on best practice care for children/young people in the last days and hours of life. These Guidelines have been developed to support both generalist and specialist clinicians providing care in the terminal phase of illness and address broad clinical and procedural aspects of care and communication that are relevant during this period. They are to be used in conjunction with the Care Plan for the Dying Child (CPDC).

- “Child’ refers to everyone from birth to 18 years of age, including neonates and infants and young persons.

Background

The Care Plan for the Dying Person (CPDP) is a state-wide clinical tool in use across Queensland Hospital and Health Services (HHS), to ensure that holistic and evidence-based care is consistently provided to adults who are dying. The tool has been adapted to meet the needs of the paediatric population. This includes the provision of child and family centred care; promoting and protecting the best interests of the child; implications of growth and development and acknowledgement of the different model of care that operates within paediatric palliative care.

Children’s Health Queensland (CHQ) Paediatric Palliative Care Service (PPCS) received SEED (Support, Explore, Excel, Deliver) funding through the Clinical Excellence Division to develop the Care Plan for the Dying Child (CPDC) to standardise end-of-life care for children/young persons. The aim of this project was to develop a clinical tool based on contemporary interprofessional evidence-based end-of-life care. The CPDC outlined best-practice care for the child and their whole family across symptom management, medical, physical, social, spiritual, cultural and emotional domains. In addition to being a clinical tool, the CPDC suite of resources provides a framework/education resource for health professionals on how best to care for a child who is dying, supporting clinicians of all specialties and with a variety of experience in the provision of paediatric end-of-life care.

Following a substantial review process in 2017, the CPDP achieved congruence with the International Collaborative Best Care of the Dying. The vision of the Collaborative is:

> *for a world where all people experience a good death as an integral part of their individual life, supported by the very best personalised care.*(1)

To attain congruence, organisations are required to demonstrate inclusion of ten evidence based key elements of care necessary for achieving best care of the dying (Figure 1).

Figure 1: Ten key elements for best care of the dying

- Recognition that the person is in the last hours or days of life should be made by the multidisciplinary team and documented by the senior doctor responsible for the persons care
- Communication of the recognition of dying should be shared with the person where possible and deemed appropriate and with the relative or carer or advocate
- The person and relative or carer or advocate should have the opportunity to discuss their wishes, feelings, faith, beliefs, values
- Anticipatory prescribing for symptoms of pain, excessive respiratory secretions, agitation, nausea and vomiting, dyspnoea should be in place
- All clinical interventions are reviewed in the best interest of the individual person

cont.

- There should be a review of hydration needs including the commencement, continuation or cessation of clinically assisted (artificial) hydration
- There should be a review of nutritional needs including the continuation or cessation of clinically assisted (artificial) nutrition
- There should be a full discussion of the plan of care with the person where possible and deemed appropriate and with the relative or carer or advocate
- There should be regular reassessments of the person at least every four hours
- Care of the person and relative or carer or advocate immediately after death is dignified & respectful

Ellershaw J, Lakhani M. Best Care for the dying person. BMJ 2013; 347: f4428

Policy context

In 2015 the *Statewide strategy for end-of-life care 2015* (the Strategy) was endorsed by the Minister for Health and Minister for Ambulance Services. The CPDC and these Guidelines have been developed to support Hospital and Health Services (HHS) to deliver safe and high-quality care at the end of life, and to meet the objectives of the Strategy. The use of CPDC as part of a continuous quality improvement program can also assist HHS in meeting the Australian Commission on Safety and Quality in Health Care, National Safety and Quality Health Service Standards (Standard 5: Comprehensive Care).

Overview of the CPDC

The CPDC is an integrated care pathway which enables the delivery of healthcare for specific patient groups. Integrated care pathways can also be used to implement clinical guidelines and to provide a framework for audit and documentation(2). Whilst integrated care pathways are intended to standardise care and reduce variations in quality and safety, clinicians must apply their clinical skills and judgment to alter plans if they are not appropriate for the individual person.

The CPDC includes 5 sections:

- Steps to Initiate the Care Plan for the Dying Child (CPDC)
- Initial (holistic) assessment form (joint assessment by Medical, Nursing and Allied Health Staff)
- Ongoing Assessment, Symptom and Comfort Management.
- Instructions for Psychosocial Support for the Child/Young Person and their Family
- Care after Death form

The CPDC prompts good communication with the child and their family and guides care planning across physical, psychological, social and spiritual domains of care. Specific elements of care include the initiation of comfort measures, anticipatory prescribing of medications to manage common symptoms, discontinuation of inappropriate interventions, and psychological and spiritual support of the child and their family.

Recognising dying

Before the CPDC can be commenced, it is important to ensure that it is an appropriate plan of care for the child. This includes undertaking a clinical assessment to determine if the child is actively dying. It is not always easy to tell when someone is actively dying[1].

Health professionals should also consider the child's clinical history and use their clinical expertise and experience to determine if a child is likely to be dying(5). This includes considering potentially reversible causes for the child's deterioration. If there are no reversible causes, or a decision has been made not to treat them, care focused on the child's comfort should be initiated. The CPDC provides a framework for initiating the elements of care considered best practice in the last days of life.

Since any member of the healthcare team, the child themselves or a parent/carer(s) may recognise that death is imminent, HHS should foster systems that encourage individuals to confidently discuss their views with the responsible senior treating doctor, and other members of the multidisciplinary team(6).

Uncertainty is an inherent part of dying, and there are occasions when a child lives longer or dies sooner than expected. Despite this, there are signs and symptoms that can indicate when a child is likely to be in the last days or hours of life, including:

- Being bed-bound and requiring extensive nursing care (refer to the Lansky play performance scale for children less than 16 or the Australian-modified Karnofsky Performance Status for children over 16 years– see appendix 2)
- Increased "sleeping" (3) / Being poorly responsive or unconscious with limited response to verbal or physical stimuli, e.g. no longer responding to voices
- Restlessness and agitation (3)
- Eye changes (4)
- Being unable to swallow
- Noisy/rattly breathing (4) and breathing pattern changes
- Circulation changes (3) and showing signs of peripheral shutdown such as pale or mottled skin and cold hands and feet
- Incontinence (4) / Reduced or no urine output

Increased sleeping

Whilst a child dying may remain responsive, most children/young persons will spend more time asleep than awake. This increased sleeping is caused by a combination of factors. For example, the illness progression may affect their vital organs which causes increased drowsiness as well as some pain medications may contribute to increased sleep. Despite a loss of consciousness, children/young persons at this stage can still hear and feel touch. (3)

Restlessness and agitation

Some children/young persons may become confused and agitated in the last few days of life, causing them to wake from sleep and become unsettled. This is not uncommon and can be caused by anxiety and fear, increased pain, nausea, decreased levels of oxygen or changes in the blood chemistry. For children/young persons who are unable to speak at this time, displaying unsettled behaviour may be their only way of communicating that they are uncomfortable. It is important to check that there is no obvious reason for their distress, including a wet bed, do they feel cold or hot? Or does their position

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[1] **Actively dying** patients are very close to death and exhibit many signs and symptoms of near-death. They are often unresponsive at times, with significant blood pressure drops, long pauses in breathing, urinary and bowel incontinence, skin colour changes etc.

need to be changed? Gently talking to the child and reassuring them that you are there will help in reducing anxiety. Simple measures like encouraging parents to hold their child's hand and stroking their face can help make the child feel safe and secure. Playing music or videos or sharing stories or prayers may also be comforting. (3)

Eye changes

The pupils of a person who is dying may become fixed or dilated. Their eyes may become sunken or bulging and glazed. If eyes are bulging (for example, this may occur in patient with neuroblastoma), a small damp bandage placed upon the eye may provide some comfort. Eye secretions can be removed with a warm damp cloth. (4)

Noisy/rattly breathing and breathing pattern changes

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/young persons 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 and explanation to the family is essential, as the noise can be very distressing. However, the child is usually untroubled by the noise and secretions. Anticholinergic drugs (e.g. hyoscine hydrobromide or glycopyrrolate) can be used to reduce the production of secretions. For children/young persons with chronic conditions suctioning may be helpful. 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. (4)

Circulation changes

As the heart slows and the heartbeat is irregular, circulation of blood is decreased to the extremities. The child's hands, feet and face may feel cold to touch, and pale, bluish or mottled in colour. Consider having the child wear their favourite socks and using a doona or blanket over the arms and legs. Consider encouraging the parent/carer to stroke their child's face as sensation to the hands is reduced with impaired circulation. The child may also sweat profusely and feel damp to touch. (3, 4)

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 important for the family that their child's dignity is respected. (4)

Benefits of recognising the child who is dying

Whilst predicting if and exactly when a child will die can be difficult, it is important that the healthcare team supports proactive planning for the outcome the child may or will die. This includes clear communication to the dying child (if appropriate) and/or parent/carer(s) about the potential for the child to die, and shared decision making about an appropriate plan of care.

Recognising dying in a timely manner allows the dying child and their parent/carer(s) to receive individualised and coordinated care that aligns with their preferences. Failure to recognise dying and clarifying the goals of treatment can lead to poor outcomes including the continuation of potentially burdensome medical treatment in the last days of life. It can also lead to missed opportunities to understand what is important to the child and those close to them, and to provide holistic care that enhances their autonomy and wellbeing.

Managing uncertainty

If the child's prognosis is uncertain, the CPDC can still be commenced. This ensures that if the child dies despite a trial of 'active' treatment, measures to optimise their comfort have still been implemented. The child whose care is being supported by the CPDC should be reviewed regularly to ensure their treatment and care is appropriate. If the child's condition improves, the CPDC, like any plan of care can be changed or discontinued.

The child's condition and the plan of care should also be reviewed if a member of their family, a parent/carer, or another clinician express concerns about its appropriateness, and at times, a second opinion or specialist palliative care advice may be needed.

The following questions can help guide your assessment:(6)

- Is the child's functional status deteriorating (bedbound, weak, drowsy, unable to swallow or only taking sips of fluid, minimal oral intake, semi-comatose)?
- Is there a reversible cause for the deterioration such as opioid toxicity, renal failure, hypercalcemia or infection?
- Is the deterioration unexpected or a predictable consequence of an existing disease process?
- Has the child experienced a similar event/deterioration in the recent past?
- Is the child showing new physical signs suggesting that death may occur?
- What do your colleagues think?
- Have you asked the child and/or their parent/carer(s) what they think of the situation? (if appropriate)

Communication

Clear communication about the child's likely prognosis enables a collaborative and proactive approach to decision-making and care planning. Ideally, the child who is dying should be included in discussions; however, their involvement will depend upon their condition, age and their parent's wishes.

Prior to any discussions it is important to identify potential barriers to communication and take steps to overcome them. Barriers may include:

- Hearing, vision or speech impairments
- Language or cultural differences requiring a professional face-to-face or telephone interpreter or cultural guidance
- Cognitive impairment, either acute (e.g.) delirium or long term (e.g. intellectual deficits)
- Reluctance of parents to be away from their child's bedside
- Fear of causing harm by distressing the child or triggering intense emotions (7)
- Presence of siblings and parent's wishing to protect them from hearing difficult conversations
- Family structure/dynamics e.g. discord between separated parents (8)
- Parent or child's reluctance and difficulties with thinking about and discussing end of life care with health care professionals and with one another/their families (8)
- Environmental barriers, e.g. noisy outside of room due to being on an acute ward
- Clinician perception of skills deficit, distress of having no solutions (7)

- Colleagues (unintentionally) obstructing communication and disclosure as they themselves are not ready (7)
- People who may usually speak and understand English at home, may revert to their language of origin at time of illness or stress.

Family meetings

Family meetings can help facilitate a shared understanding of the child's expected prognosis, the plan of care and what to expect next. It is important to create a safe and private (if possible), environment to discuss and raise concerns. Good communication can also help to prevent potential conflict due to a lack of understanding or differing opinions. People may react in a range of ways at times of distress and heightened emotions and it is essential that responses are not taken personally but seen as a reactive response to bad news.

A health professional with appropriate experience and skills should facilitate the meeting and members of the Interprofessional team (IPT) may be present. This ensures all those involved in the child's care are informed and better able to support the dying child and their family. A useful model for health professionals in the delivery difficult news/tough conversations is SPIKES (**S**- Set up, **P**–check Perception, **I**–Invitation, **K**–give Knowledge and information, **E**–respond to Emotion, **S**–Summarise).(9) See Appendix 7 for more detailed tools on communication.

During the meeting it is important that the views of all concerned are listened to and assurance is provided that the child/young person will continue to be assessed regularly and provided with ongoing comfort cares.

Consider the child/young person's family structure to be included in the family meeting. For example, alongside parents/carers, grandparents, stepmothers and stepfathers, as well as partners of the young adult or even young adult/adult siblings may wish to be included.

More than one family meeting may be required, and all decisions leading to a change in care delivery should be clearly communicated and documented.

Other important areas of discussion may include preferences regarding organ donation and coronial involvement if relevant and clinically appropriate. Family meetings may provide an opportunity to discuss memory making, support for siblings and exploring any belief systems. Consider social media plans for young adults. (8)

Key principles of paediatric family meetings focus on making sure the 'family feel heard, the information has been understood and the family feel cared for and respected'. (10)

Conducting a family meeting for a person in the last days/hours of life

Preparation

- Identify the lead clinician who will guide the meeting, as typically this will also be the health professional who is responsible for approaching and organising with the family about the possibility of a meeting. (10)
- If appropriate obtain permission from the dying child/young person (e.g. adolescents) or the parents/carers to conduct the family meeting and to share their personal information.
- Check whether they wish to attend and who else they would like present.
- Provide parents the opportunity to hear bad news/family meetings together. (7)
- Reduce the number of healthcare professionals during challenging discussions. (11)

- Consider whether a substitute decision maker is required to attend (e.g. Child Protection or the Department of Communities, Child Safety and Disability Services (DoCCSDS).
- Consider whether an interpreter is required and arrange this in advance. In discussions of a sensitive nature, allow time prior to the meeting to discuss the purpose and prepare the interpreter of the content, as well as discussing any cultural issues that may surface (12) Access the Queensland Health 'How to work with an interpreter onsite' for further guidance at https://qheps.health.qld.gov.au/__data/assets/pdf_file/0029/627329/how_to_work_int.pdf (12)
- Choose a comfortable, quiet and private area, free from interruptions (e.g. electronic devices on silent (11)) as well as considering the convenience of the location as parents may be reluctant to be too far from the patient bedside. Ensure enough seating/sit down to conduct difficult conversations (11). The SPIKES model (9) of delivering difficult news discourages having physical barriers between the clinician and the family, as well as simple measures like ensuring tissues are nearby.
- Ensure the bedside nurse/appropriate staff are informed that a difficult conversation will take place and invite them/the healthcare professional to be involved in the family meeting if suitable.(11)
- Ensure you are up to date with the child's medical status and history, together with being aware of psychosocial information, to ensure you are prepared in advance.
- Take into account what outreach may be available or whether telehealth would be beneficial to support the interprofessional team. (10)
- Consider having a meeting of the health professionals before meeting with the family. This can help in ensuring that all health professionals attending have a shared understanding of the purpose of the meeting, and any differences in perspectives can be worked through prior to meeting with the family.

Conducting the meeting

- Ensure open and welcoming body language, shake hands, be respectful and compassionate, and do not rush. (7)
- Introduce the healthcare team members and allow family/carer(s) to introduce themselves.
- Use eye contact (if culturally appropriate) along with appropriate, non-threatening body language.
- Listen actively, using gestures such as nodding, making noises of agreement or encouragement.
- Explain the purpose of the meeting and ask participants what they would like to discuss.
- Determine what the family/carer(s) and/or dying child already know about what is happening.
- Recognise the parents/carers as experts in their child's care.(7)
- Acknowledge the discussion will be difficult to hear.(9)
- Provide updates sensitively on the dying child/young person's current medical condition and prognosis.
- Allow periods of silence (11) and acknowledge and make room for emotions to be expressed, with the SPIKES model encouraging the health professional to 'sit with it' (the emotion).(9)
- Avoid misleading information, which may foster false hope and use clear, jargon-free language.
- Take care to avoid assumptions.(7)

- Allow family/carer(s) and/or dying child to ask questions and express any concerns.
- Provide clear and honest answers to concerns raised by the family/carer(s) and/or the dying child.
- Clarify the goals of care, discuss treatment and care options and recognise they may evolve over time. (10)
- If appropriate, explain the current and expected symptoms and how they can be managed (e.g. medications, non-pharmacological strategies).(10)
- Be prepared to discuss alternative locations of care (e.g. home or hospice).(10)
- Be mindful that a discussion regarding parallel planning could be appropriate (e.g. that child may live longer than the expected hours to days) and explain the uncertainty around the timing of death (e.g. imminent, hours or days).(10)
- Inform and introduce the 'Care Plan for the Dying Child, clearly explaining its role and purpose.

  e.g. "I'd like to share with you some information about a document called the 'Care Plan for the Dying Child'. Using this will help us understand how we can provide the best care for your child at this difficult time. It involves learning about your child's wishes for their care at the end of their life and how we can best facilitate this as well as making sure they are as comfortable as they can be and don't suffer…."

Closure

- Thank family/carer(s) for their attendance.
- Reassure family/carer(s) that they can ask questions or seek further information at any time.
- Consider some families/carers may find written information beneficial.(7)
    - e.g. Paediatric focused carer's resources from Palliative Care Australia, available in English/Arabic/Vietnamese/Traditional or simplified Chinese, free to access at https://palliativecare.org.au/all-resources
- Document discussion outcomes and inform relevant teams on the CPDC commencement. Family meetings documented in the medical record should outline who attended, their roles/relationships as well as identifying who is responsible for following up with the family and whether further and/or a series of meetings would be helpful.(10)
- Be sensitive to whether the family/carer wants some time alone or whether they would benefit from support from a Social Worker (or other key support person after the meeting).
- If time permits, health professionals may find de-briefing and feedback on how the meeting was performed to provide future learnings and reflective practice.

Decision-making for children/young persons

End of life medical decision making is inherently difficult given the unnatural course of a child dying before their parent/carer, and subsequently decisions are incredibly difficult to reach, even in uncomplicated cases. The following scenarios and information must be handled with compassion and respect to ensure the best interests of the child, and that decision-making goals should focus on the child's comfort.

Medical decision making across the ages of 0 – 18 years can vary greatly dependent on the child's developmental age, capacity and individual/family circumstances. It is considered that the parent/legal guardian is the primary decision maker for their child however variances exist in relation to giving consent for the following:

- Parents who are themselves under 18 years old
- Children/young persons under the care of Child Protection
- Children/young person's where the Supreme Court of Queensland or the Family Court are involved
- Gillick competent (also known as 'mature minors')

Key resources
Refer to 'Part 3, Informed decision-making and consent for children and young persons', in the *Queensland Health Guide to Informed Decision-making in Healthcare (2nd edition)* for further information https://www.health.qld.gov.au/__data/assets/pdf_file/0019/143074/ic-guide.pdf
Refer to Implementation Guidelines, End-of-life care: Decision-making for withholding and withdrawing life-sustaining measures from patients under the age of 18 years, Part 1 – Legal Framework, Clinical Considerations and Decision-making Framework https://www.childrens.health.qld.gov.au/wp-content/uploads/PDF/qcycn/imp-guideline-eolc-part-1.pdf
Refer to Implementation Guidelines, End-of-life care: Decision-making for withholding and withdrawing life-sustaining measures from patients under the age of 18 years, Part 2 – Ethical Considerations and Communication https://www.childrens.health.qld.gov.au/wp-content/uploads/PDF/qcycn/imp-guideline-eolc-part-2.pdf

Guardianship

Under the *Child Protection Act 1999* or *Adoption Act 2009,* in relation to consent a person established as the guardian of the child has the same rights and responsibilities as a parent. (13)

Child Protection

Children who are placed in care will fall under the *Child Protection Act 1999.* Considerations should be made for the following;

- Custody arrangements
- Guardianship where the Chief Executive DoCCSDS or another suitable person has custody
- Foster carers
- Kinship carers

In the instances where the parent/s who do not have custody, it should be explored whether to involve them (e.g. communications) to achieve the best interests of the child in relation to good clinical care. (13)

Refer to the Department of Communities, Child Safety and Disability Services *Child Safety Practice Manual* for further guidance on medical decision making for children/young persons in care, https://www.csyw.qld.gov.au/childsafety/child-safety-practice-manual (Refer to appendix 4 for detailed information)

Supreme Court of Queensland or Family Court

The Supreme Court of Queensland and the Family Court consider the best interests of the child as the principal concern, and applications can be made (including out of hours) to ascertain consent for health care for the child if there are considerable doubts. (13)

Gillick competent

Considerations should be made for adolescents and young adults, in partnership with their families and the health care team, about whether they are Gillick competent. End of life medical decision making in this group is complex with case by case assessment warranted. See appendix 4 for Gillick competency information.

Decision making for adults

In the infrequent cases where a patient who is 18 years or above is placed on the CPDC however is under the care of a paediatric team and/or ward, the following may be applicable.

In Queensland, all adults are presumed to have capacity to make personal, health and financial decisions. If concerns about capacity to make a decision are raised, it is up to the health team to rebut the presumption, not the person to prove that they do have capacity. Furthermore, capacity is not an 'all-or-none' concept. The dying person may be able to make decisions about certain aspects of their care and treatment but not others. If the dying person lacks decision-making capacity for a decision at the time that it needs to be made and they cannot be assisted to make the decision, then it is important to identify and include their Substitute Decision-Maker (SDM).

For information about how to assess decision-making capacity and identify a person's SDM review guideline link below.

End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients. Published by the State of Queensland (Queensland Health), January 2018

End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients| End of Life (health.qld.gov.au)

Additionally, teams can refer to Social Work for assistance in identifying and engaging the person's SDM.

Evidence of advance care planning documentation

Advance Care Planning (ACP) is a person-centered approach for planning current and future health and personal care that reflects the child values, wishes, beliefs and preferences. The child may have had discussions about what is important to them with their family/carer(s) and/or chosen to document their decisions e.g.; Paediatric Statement of Choices (under development)

My Wishes (Children)
2017-11-6_AWD_MyWishes_Booklet_Update_V2_FINAL.indd (fivewishes.org)

Voicing My Choices (Adolescent and Young Adult)
Layout 1 (fivewishes.org)

If in the context of an 18-year-old patient or older, consider the need or existence of an Advance Health Directive (AHD), Enduring Power of Attorney (EPOA) or Statement of Choices. Further information can be accessed in the Care Plan of the Dying Person Guidelines available at

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Advance care plans for children aged less than 18 years are communication tools rather than legally binding documents. They often reflect a series of conversations and documentation thereof. These conversations and documents are usually dynamic and can be changed at any time based on the child/young person's clinical situation. The clinician should check the patient's medical record to determine what advance care planning has already occurred. In the integrated electronic medical record this can be found in the Advance Care Planning Tracker in The Viewer. It is important that these conversations are undertaken in a planned and co-ordinated fashion so that the child and family are not over-whelmed by too many people wanting to undertake these conversations. Conversely, it can also be problematic if no one is taking the opportunity to have these conversations at the correct time.

When a person is dying it is imperative to review whether any prior ACP discussions have occurred, and whether any documents have been completed. Electronic copies may be available on My Health Record or The Viewer, and alerts placed on the Hospital Based Corporate Information System.

These documents should be reviewed, acted on where appropriate and copies stored in the person's medical record.

The Paediatric Acute Resuscitation Plan (PARP, or equivalent documentation of a resuscitation plan in the medical record prior to the patient commencing on the CPDC, is available online at Paediatric Acute Resuscitation Plan (PARP) (health.qld.gov.au).

Further information	
Information for clinicians	Department of Communities, Child Safety and Disability Services, Child Safety Practice Manual https://www.csyw.qld.gov.au/childsafety/child-safety-practice-manual Queensland Health Guide to Informed Decision-making in Healthcare (2nd edition) - *Part 3, Informed decision-making and consent for children and young persons* https://www.health.qld.gov.au/__data/assets/pdf_file/0019/143074/ic-guide.pdf Queensland Health website for Advance care planning | Clinical Excellence Queensland | Queensland Health Or visit Care at the end of life | Queensland Health
	Queensland Health Advance Care Planning Clinical Guidelines https://www.health.qld.gov.au/__data/assets/pdf_file/0037/688618/acp-guidelines.pdf
	Queensland Health Implementation Guidelines End-of-life care: Decision-making for withholding and withdrawing life-sustaining measures from patients under the age of 18 years Part 1 https://www.childrens.health.qld.gov.au/wp-content/uploads/PDF/qcycn/imp-guideline-eolc-part-1.pdf Part 2 https://www.childrens.health.qld.gov.au/wp-content/uploads/PDF/qcycn/imp-guideline-eolc-part-2.pdf
Information for patients, carers and family members	Queensland Government website for consumers about advance care planning Or visit https://www.qld.gov.au/health/support/end-of-life Palliative Care Australia website for Teenagers and children Or visit https://palliativecare.org.au/children

Section 2: Commencement and authorisation of CPDC

To commence a child on a CPDC, the following items must be completed by a Medical Officer[2] and co-signed by a Registered Nurse:

1. The child has been assessed by the Inter-professional Team (IPT) as being in the last days to hours of life.
2. The dying child has a current Paediatric Acute Resuscitation Plan (PARP) [or equivalent note describing a resuscitation plan] which states that resuscitation is not to be provided.
3. The lead medical team responsible for the child's care endorse commencement of the CPDC.

An IPT review and decision-making guide is available on page 4 of the CPDC to assist with the assessment and authorisation process.

It is also important that the family (and child where appropriate) are provided with information about the CPDC and have the opportunity to ask questions about this document. Parents (or guardians) should be aware and give consent to their child being placed on the CPDC.

To avoid unnecessary delays in end of life care delivery, authorisation by the most senior treating doctor can be given verbally to the Medical Officer.

Following commencement, the person's General Practitioner and other relevant service providers should be contacted and informed of the person's condition and the plan of care.

Information for Health Professionals

Aim of the CPDC

- A resource to guide clinical care in the last days and hours of life to support high quality care, when death is expected, that is tailored to the individual needs of the child and their family.
- Use the CPDC in conjunction with documents or processes, such as PARP or Advanced Care Planning (e.g. Paediatric Statement of Choices, My Wishes, Voicing My Choices)
- The CPDC is comprised of:
    - Commencement of the Care Plan for the Dying Child
    - Best-Practice Principles to Care for the Dying Child
    - Guidance for Health Professionals
    - Interprofessional Decision-Making Guide
    - Initial (holistic) assessment form
    - Instructions for Ongoing Assessment, Symptom Management and End-of-Life Care
    - Instructions for Psychosocial Support for the Child/Young Person and their Family
    - Care after Death form

Clinical/Communication Requirements

- Best practice requires a coordinated Interprofessional Team (IPT) approach and effective partnerships with children and their families.
- Regular review including discussion and critical decision-making by the IPT to ensure decisions are appropriate for the individual child/young person.

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[2] **Medical Officer:** Doctor with delegated responsibility from the most senior treating doctor to make decisions related to commencing the dying child on the CPDC.

- Comprehensive and clear communication is pivotal.
- All care decisions should be communicated to the family/carer and the child/young person as appropriate.
- Invite, listen and document the views of all partners in the care of this child/young person.
- Recognise that dying is always complex, irrespective of previous diagnosis or history. Uncertainty is an inherent element of dying, and a child may live longer or die sooner than expected.
- If an Inter-Hospital Transfer occurs, the CPDC may be photocopied and transported with the child/young person, along with other documentation required as per HHS policy.

Organ and Tissue Donation

- Families may wish to consider organ/tissue donation for their child as an altruistic gift for other families/children. Organ/tissue donations are only possible in a small number of situations.
- Contact DonateLife Qld for information and support: www.donatelife.gov.au local or statewide team.

Research

- Families may wish to consider donation for research/science and post-diagnostics. Discuss options with the child's primary treating team.

Documentation Instructions

- Health professionals should document in the child's medical record as per HHS policy.
- The CPDC is a legal document and must be completed as per HHS policy Care Plan for the Dying Child (CPDC) | Queensland Health (clinicalexcellence.qld.gov.au)
- CPDC Ongoing Assessment (SW-TBA) pages are available for extended treatment Care Plan for the Dying Child Ongoing Assessment | Queensland Health (clinicalexcellence.qld.gov.au)
- All IPT staff involved in the treatment of the child must sign the signature log (page 5) upon initial entry.

Additional Resources

- **State-wide Paediatric Palliative Care Service (PPCS)**. Phone: 1800 249 648.
- Care Plan for the Dying Child: Health Professional guidelines, June 2019. Care Plan for the Dying Child (CPDC) | Queensland Health (clinicalexcellence.qld.gov.au)
- Children's Health Queensland. (2014). *"A practical guide to palliative care in paediatrics"*. www.caresearch.com.au/QuoCCA/Portals/6/Documents/A-Practical-guide-to-Palliative-Care-in-Paediatrics.pdf
- Palliative Care Australia. (2019). *"Paediatric Palliative Care Resources for Families and Health Professionals".*
- Family handouts in multiple languages on paediatric palliative care topics: www.palliativecare.org.au/children

Seek specialist paediatric palliative and/or intensive care support or a second opinion as needed.

The CPDC should not be commenced unless the most senior treating doctor agrees, and there is a consensus between the parent/carer(s), child if appropriate, and the IPT that death is likely within days or hours.

Process for discontinuing the CPDC

If the child/young person’s condition improves and the CPDC is no longer appropriate, it can be discontinued.

Some situations when this may occur:

- there is sustained improvement in conscious level, functional ability, oral intake, mobility, ability to perform self-care.
- concerns expressed regarding management plan from either the family/carer(s), child or IPT.

The decision to discontinue the CPDC should be made by the most senior treating doctor in consultation with the family/carer(s) and dying child/young person if appropriate. The reasons for the decision should be documented clearly in the child’s medical notes, along with the new treatment plan. Further consideration should be given to additional support that may be required for ongoing care management e.g. occupational therapy involvement for management of limb muscle contractures, social work or welfare support for finance and family matters, or onward referrals to psychologists’ if required.

If the child/young person’s condition deteriorates after the CPDC is discontinued a new CPDC must be commenced.

Section 3: Initial assessment

The initial assessment includes:

1. *Partnering with the child and their family*
2. *Assessment of the child’s medical and nursing care*
3. *Discussion of the plan of care*

Overarching principles of the initial assessment

- It is a joint assessment completed by Medical, Nursing and Allied Health staff
- The Initial Assessment can be completed over several conversations
- Advanced Care Planning (ACP) documents should be reviewed for relevance prior to meeting with the family
- Establish an appropriate environment and consider the impact on the child when having discussions with the family
- Prioritise the wishes, preferences and rights of the child and family in all interactions
- Consider belief systems in the timing of discussions about after death arrangements. Allow families the choice to discuss any aspects of care “later” or “afterwards”
- Specific considerations
  - Aboriginal and Torres Strait Islander language: e.g. “sad news” or “sorry business” rather than “death” or “dying” (see appendix 5)
  - Recommendations for Culturally and Linguistically Diverse (CALD) www.health.qld.gov.au/multicultural/support_tools/mcsr
  - Child Protection Order: seek advice from your HHS Child Protection Unit to determine who should be involved in completion of the Initial Assessment, and whether a Child Safety Officer is required to facilitate.

Partnering with the child and their family

For many health professionals, having open and honest discussions about death and dying with a child and their family is a difficult task. Given people's natural tendency to protect others from emotional pain, communication at the end of life requires deliberate effort to ensure best practice care.(4)

Communication with the child/young person and/or their siblings about death and dying

The International Collaborative Best Care of the Dying emphasises the importance of communication with the dying child and their family/carer(s). It is important to consider the specific information needs of the child and their family/carer(s); the different manners and styles in which they communicate, and their cultural and spiritual beliefs. Taking the time to discuss things that may be important to the dying person and their family/carer(s) will provide the IPT with valuable insight and support therapeutic interactions.

Topics that may be discussed include:

- The child and/or family's spiritual, cultural, social, emotional and practical needs:
    - Now
    - At the time of death
    - After death
- The child's preferred place of care, and ways to create a home-like environment for them.

As the child prepares to die, they may also go through a process of looking back in search of meaning. This includes saying goodbye to people and places, forgiving and being forgiven, expressing joy and gratitude, facing regrets and accepting death. It is important to take cues from the dying child and/or their family and be able to listen, help them share memories and find ways to say goodbye.

Consider the following principles and practical tips:

Principles

- Listen to the child. Gain an understanding of their world (their understanding and perceptions about their life and the lives of their family).
- Children strive to make sense of their world to gain a sense of mastery over it, and to understand how they fit into it.
- Children gather information from multiple sources including their own experiences, observations of both subtle and unsubtle cues (e.g. parent returning from meeting crying/ having been crying).
- If the family have requested support to talk about death and dying with their child it is important to clarify what they think their child knows, what words/ phases they have used in the past, and what words/phrases they would prefer you to use with their child.
- Ask if there are any specific words/phases that they don't want to be used when talking to their child.
- A health professional's role is to help families talk with their child and spend quality time with them.
- Answer the questions the child has asked but do not overwhelm them with extra details.

Practical tips

- Observe their behaviour and nonverbal responses, as cues to what may be worrying them.
- Reassure the child that the situation is not their fault.

- Use a range of activities, such as reading, drawing or writing to answer/communicate.
- Consider using specific books or videos to answer the child's questions, with the family's consent.
- Give information gradually rather than giving it all in one large session; repetition of information may be required.
- Use developmentally appropriate language.
- In cases where the family do not wish to tell their child/young person that they are dying, and the child has asked this directly to a health professional, consider the following responses:
  - "What do you think is happening?"
  - "Is this something we can talk to mum/dad about?" *(delivered sensitively)*

How do children understand death?

Children's individual experiences of death (e.g. death of pets or relatives) will impact upon their understanding of death and dying and the following age groups are only a guide (14)

- Children aged 0–2 years understand 'here' and 'not here' and whilst they can sense loss, they cannot understand death.
- Children aged 3–5 years see death as temporary and they expect the person to return.
- Children aged 6–10 years understand that death is forever and there are different causes of death. They may be curious about death, funerals and cemeteries.
- Children aged 11 and older start to perceive death as an adult would. They may look for the meaning of death and ask more questions.

Palliative Care Australia (14)

Consider that the child dying may be feeling anticipatory grief where they face the losses associated with their illness, e.g. becoming sick, becoming more dependant, missing out on normal activities such as school, sport and therefore a sense of isolation as friendships and relationships change, as well as adolescent's suffering the loss of their hopes and dreams for their future. (4)

Communication with the family about their dying child

It is important to ensure the needs of those close to the dying child are supported. Not all people will have family/carer(s); a situation to be taken into consideration by the IPT. This includes:

- Ensuring the child's parents/carer(s) understand and is aware that death is imminent.
- Identifying who else is important to the child and what support they require (e.g. best friend, adolescent's partner).
- Identifying specific spiritual, cultural or practical needs.
- Identifying and responding to emotional needs.
- Providing information as needed and explaining what to expect as the child deteriorates.
- Involving them in caring for the dying child if they are comfortable doing so and indicate a willingness to do so. Providing parenting opportunities (e.g. bathing) empowers the parent to nurture which positively impacts upon parent's bereavement health.

Health professionals can support family/carer(s) by encouraging them to:

- Take time to say goodbye.
- Allow family members and friends to have time alone with the child.
- Take breaks to eat/drink, shower/toilet and rest.
- Bring pictures, music and important objects from home to create a comfortable environment.
- Draw on the support of family, friends, communities (e.g. schools, churches) and the IPT.

Staff should also provide information on:

- After-hours access to the hospital/ward.
- Car parking.
- Options for families to stay overnight.
- Food and drink options, tea and coffee facilities.
- Location of hospital chapel or quiet spaces/gardens if available.
- Areas for siblings (e.g. play areas, starlight room).

Social workers and welfare workers may be able to provide assistance with emotional, social and financial matters and should be advised of any imminent death so that they can review the needs of both the dying child/young person, and their family/carer(s). Social workers are well versed in supporting people through illness, death and bereavement, and can use proven range of practical strategies to alleviate current and future issues.

Consider the following principles and practical ideas when communicating with a family:

Principles

- Active listening to hear the family's perception of the situation, especially their views on what they think their child knows about dying and what is important for them.
- Reflective listening – rephrasing your understanding of the conversation – demonstrates you are listening to their concerns.
- Some families will be very open and honest with their child/young person about dying, whilst others may not; there is no right or wrong way.
- The family knows their child best and we must be guided by them.
- Be aware of how our nonverbal communication can be interpreted by a child. Even exclusion from contact communicates something.
- Be aware of issues, such as blame, and guilt felt by either the parents or the child and sibling(s).
- It is generally accepted that a typically developing child/young person, will have a reasonably full understanding of death from approximately 7 years of age.

Practical ideas

- Provide reassurance so that they understand we are here to guide them.
- Encourage family members to answer questions as openly and honestly as possible, and that they do not need to have all the answers right now.
- Use open ended questions "what do you think your child understands about what is happening to them"?

- Has the family had previous experience with death (e.g. a family pet, grandparents/significant other passing away)? Encourage them to reflect on those experiences with their child now, and continue to use the phrases, stories, and examples they have used previously.
- Has the family/child been exposed to books that talk about the life cycle/dying? (e.g. The Invisible String by Patricia Karst)? Refer to Health Professional Guideline for further resources.
- Ask the family what words or phrases they use to explain what is happening to the child.

See also “Goal setting and future planning – the goals of care discussion” in Appendix 6.

Memory making/rituals

Refer to the QCH Memory Making guideline (located within Management of a Deceased Patient in QCH (health.qld.gov.au) Management of a Dying or Deceased patient in QCH (health.qld.gov.au)

- Memory making can be provided by any health professional. Consider referral to SW to facilitate memory making opportunities as required.
- Ensure suggestions are culturally appropriate.
- Explore with the family if there is anything, they would like to be able to do:
    - "What’s important for you to remember from today?"
    - “Are their cultural or religious traditions we can help you facilitate?”
    - “Tell me about some of things that were special for you and your sister/brother?”
    - “In the past families we have worked with have appreciated the opportunity to have photos taken with their child, is this something you would also like?”.
    - "Some parents like to rest/or cuddle with their child in bed, is this something you would like?”.
- Encourage siblings, grandparents and other significant family members to be involved in memory making.
- Some siblings like to be given special jobs that they can do so they feel involved and helpful (e.g. looking at books together, watching video/movies, or sharing stories and memories).
- Heartfelt photography (a specialist company) may be available in the hospital, where professional photographers can attend to take photos of the child and the family either before or after death.
- Bereavement boxes may be available in your hospital (e.g. Precious Wings Memory Box).
- Hand and foot moulds, and toe and fingerprint jewellery may be organised at the hospital. This can also be supported by the funeral home.
- Hand and footprints (inkless are preferable).
- Taking a lock of hair; toy/jewellery exchange.
- Drawing/writing letters to their family/loved ones.
- Support families to comfort and hold their child. This includes enabling the parent(s) to lie in the bed with their child, hold in their arms, stroking, brushing their hair, place mattresses on the floor etc.
- Bathing their child. This can be done either using a baby bath, sponge bathing or using a special bathing bowl if available in your hospital.
- Dressing their child; reassure families that they do not need to choose “forever clothes” at this time.

- Family singing to the child or playing music. Consider contacting music therapy to provide music option (e.g., sessions, recordings, CD players).

Understanding the process of dying

Families and/or the dying child/you person may wish to know the physical changes that are an expected part of the dying process. These changes may be distressing to witness. Health Professionals should normalise these physical changes and provide management strategies.

Increased sleeping:

- Most children will spend more time asleep than awake.
- Despite a loss of consciousness, children at this stage can still hear and feel touch. (3)

Restlessness & Agitation

- Some children may become confused and agitated in the last few days of life, causing them to wake from sleep and become unsettled.
- Check that there is no obvious reason for their distress, including a wet bed, do they feel cold or hot or does their position need to be changed?
- Talk gently and reassure them you are there may help to reduce anxiety.
- Encourage parents to hold/stroke their child's hand and face or cuddle can help make the child feel safe and secure.
- Playing the child's favourite music or videos or sharing stories or prayers may also be comforting.
- Assess for the presence and cause of delirium and manage appropriately (non-pharmacological approaches are often important in this context)

Noisy/rattly breathing:

- Caused by excessive secretions or difficulty clearing pharyngeal secretions. This may be distressing to witness. Family will require reassurance that this is expected and is not distressing for their child and consider postural changes or medications.

Respiration changes:

- Breathing may be rapid, shallow and irregular.
- Breathing may also slow with periods of apnoea, known as Cheyne-Stokes breathing.
- This may be distressing to witness. Family will require reassurance that this is expected and is not distressing for their child.
- These symptoms may be present for a significant period of time.

Incontinence:

- Caused by relaxation of the gastrointestinal and urinary tracts. It is important for the family that their child's dignity is respected.
- Consider a catheter, nappy/pad or disposable incontinence aid under sheet.

Loss of circulation to the extremities:

- Hands, feet and face may become cold, pale and cyanotic.
- Skin may change colour and start to look white, blue or greyish. This is caused by slow and irregular heartbeat as circulation of blood is decreased to the extremities.

- Child/young person may also sweat profusely and be damp to touch.
- Parents may wish to change the child's clothes and keep them warm with a blanket.

Eye changes:

- Pupils may become fixed and dilated; eyes may become sunken or bulging and glazed.
- If eyes are bulging, a small damp bandage may be placed upon the eye.
- Eye secretions can be removed with a warm damp cloth.
- Eye drops/lubricants or ointments (e.g. POLY VISC ® Lubricating Eye Ointment or Celluvisc ®) may be applied.
- Eye ointment may also be used to close the child's eye lids at the time of death.

Bodily fluids

- Family may find this very distressing if they are not prepared/aware of this possibility.
- There may be bodily fluids leaking from the mouth and nose, bladder, bowel and any drainage sites or openings.
- Blood may pool causing the appearance of bruising, especially on the underside of the child.
- Normalise this for the family and provide a management strategy:
    - anticipate bodily fluids by placing dark coloured sheets on the bed (where available)
    - ensure towels are easily accessible
    - place a waterproof under sheet on the parent's shoulder/lap/chest to allow cuddling
    - place a waterproof under sheet on the surface when repositioning /rolling the child/young person
    - apply a nappy or pad
    - health professionals should don Personal Protective Equipment when moving or handling the child

Bereavement risk and protective factors

Anticipatory grief

Consider that the child dying may be feeling anticipatory grief where they face the losses associated with their illness, e.g. becoming sick, becoming more dependant, missing out on normal activities such as school, sport and therefore a sense of isolation as friendships and relationships change, as well as adolescent's suffering the loss of their hopes and dreams for their future.(4) Consider that parents/carer(s), siblings, grandparents and other family/friends may experience anticipatory grief.

Bereavement

The death of a child or young person is a devastating life event for a family and often this grief extends beyond the child and their family to the family's community (e.g. school, sports clubs, churches). Bereaved parents experience a lifetime of grief as they continue to move through their deceased child's developmental and life milestones. The grief of siblings and grandparents should also be acknowledged and attended to. It is important to affirm for parents that grief is a normal, natural response to change or loss, and reassure them that every person's grief is unique. Some people are open and expressive with their grief, for example crying and wanting to talk, while others are more private, and may be reluctant to talk or prefer to keep busy. There is no correct way of reacting to loss; people will experience a range of emotions due to the circumstances and anticipation of the death.

Although grief can be very painful, most families find that with the support of their family and friends, and their own resources, they gradually find ways to integrate the loss of their child into their lives.

Protective factors are conditions or attributes (skills, strengths, resources, supports or coping strategies, previous experience of loss) in individuals that help people navigate their way through stressful life events and can mitigate or eliminate risk.

However, for a small proportion of bereaved parents the symptoms of distress following the death of a child or young person are more intense and persistent. Factors that may contribute to an increased risk of complicated bereavement include:

- A history of previous losses
- The presence of concurrent stressors such as family breakdown, compromised financial status, alcohol and/or drug dependency
- Current and/or history of physical and mental illness
- Inability or ineffective use of coping strategies such as physical self-care, accessing available support
- High pre-death distress
- Social isolation and low levels of social support
- Cause of the death e.g. suicide, trauma from accident or a sudden or unexpected deterioration/death
- Feeling of loss of control over life

It is important to note that risk factors alone do not necessarily constitute complicated bereavement risk and should be considered within context of the protective factors and each individual and family situation.

A referral to Social Work and/or Psychology or psycho-social support should be considered if available to support a family through the various transitions prior to and following the death of their child. At the early stages of responding to trauma or to a sudden or unexpected event the immediate focus should be on maintaining safety, stabilisation, practical assistance and support with communication. Ongoing bereavement support may assist a family in normalising their experience, provide psychoeducation around grief and adjustment to loss for parents and siblings of the deceased child and provide practical guidance and support around integrating into life occupations such as work and school. Always encourage the person’s family/carer(s) to ask the healthcare team for advice and support. Additional spiritual and culturally appropriate support may be organised by referring the person to an Indigenous Liaison Officer or Health Worker, spiritual carer, chaplain or cultural advisor with consent.

Siblings and grief

Children’s reactions to death and dying contrast greatly from adults and this is important when considering how siblings will respond, alongside factors like their developmental age, personality, family and belief systems influence. They may have concerns e.g. ‘Did I cause the death?’, ‘Will I die?’, ‘Who will care for me?’ and open and honestly communicating with children for their developmental level will assist in them integrating the loss of their sibling into their life. It is important to include siblings in discussions where appropriate surrounding the dying child, listening to them and normalising grief reactions for children.

Some siblings may benefit from having the opportunity to express and process their grief creatively whether it is through drawing and painting or writing a letter to their sibling.(13) Some children may have fluctuating levels of grief alternating between happiness and sadness, which can be confusing for them, but allowing and normalising their grief response is important.(7)

For further information, visit Palliative Care Australia's paediatric resource 'Siblings and grief' at

https://palliativecare.org.au/siblings-and-grief

Assessment of the child's individual medical and nursing care
Review of the child's individual medical care

When commencing the CPDC, the Medical Officer is required to document the child/young person's:

- primary diagnosis (what they are dying from)
- other relevant health history
- baseline information about their condition, including conscious state and presence of any symptoms or problems.

This assessment can inform symptom management plans and help determine the appropriateness of clinical interventions.

Medication management

In the last days of life, most people are no longer able to swallow medications. Medications aimed at long-term disease prevention and maintenance are generally no longer relevant or required. For this reason, all current medications should be assessed, and any non-essentials discontinued.

If oral medications are still required, they should be converted to a subcutaneous, dermal or sublingual route if appropriate. Whilst medications can be given intramuscularly or intravenously, these routes can be painful, and efforts should be made to avoid unnecessary discomfort in the last days of life.

Anticipatory prescribing

Anticipatory prescribing is recommended to prevent delays in treating emergent symptoms that might cause distress. It includes ensuring that medications and equipment that is likely to be needed are readily available, with prescriptions written in advance and supplies obtained.

Pro re nata (PRN) or 'as required' medications for pain, agitation, nausea and vomiting, dyspnoea and respiratory tract secretions should be available, and consideration given to injection volumes for subcutaneous routes.

A practical guide to PALLIATIVE CARE in paediatrics (caresearch.com.au) page 39 onwards Symptom management

Continuous subcutaneous infusion

In some instances, there may be a need to administer a continuous subcutaneous infusion and a syringe driver can be used for this purpose.

Not every dying person will require a continuous subcutaneous infusion. A continuous subcutaneous infusion should be considered if pain remains poorly controlled after 2 hours or if the person has required regular analgesics or other medications to control symptoms prior to entering the terminal phase. If a continuous subcutaneous infusion is used medication compatibilities should be considered and use of the device should be explained to the person's family/carer(s). A continuous subcutaneous infusion may be delivered by pumps such as the Niki T34™ pump, CADD® (Continuous Ambulatory Delivery Device) or local hospital syringe driver pump, dependant on your local HHS.

Reviewing the need for interventions

A clinical assessment should be undertaken to determine whether specific clinical interventions should be discontinued, continued or commenced. Only interventions that contribute to the child/young person's comfort or clearly benefit the child/young person should be continued or commenced. Interventions requiring review include routine blood tests, recording of vital signs, oxygen therapy (when not in the context of comfort) and dressings. Consider how to sensitively approach this topic with parents/carer(s) who may be accustomed to certain interventions for their children/young persons with chronic diseases/conditions, as this may contribute to a parent/carer(s) perception of 'abandonment' by the health care team. This transition process may be very difficult and could contribute a family's distress, however encouraging them to participate in comfort cares and symptom management can assist in the transition from acute to palliative/end of life care.

The rationale for discontinuing, continuing or commencing clinical interventions should always be discussed with the child's family/carer(s) as required and appropriate.

Note: If the child has an Implantable Cardioverter Defibrillator, it may need to be deactivated.

Allied health considerations

Although Social Work is one of the most sought out allied health support for the dying child/young person and their family/carer(s); other allied health involvement may also be considered during this period. The interprofessional team can support the dying child/young person and also the siblings, parents, grandparents etc.

All allied health professionals have a potential role in the care of the dying child/young person (e.g. social work, physiotherapy, occupational therapy, speech pathology, dietician, pharmacy, music therapy and psychology). Allied health professionals often enhance quality of life, including physically, emotionally, psychologically, cognitively or socially and can play a major part along the child/young person's palliative care journey. They can also provide assistance with developmental and functional goals.

Generally, any allied health professional may be able to assist with symptom management (both pharmacological from pharmacists and non-pharmacological), positioning, equipment, education about the death and dying process, advocacy and memory making.

- Music therapists can contribute greatly to family's experience in the last few days and hours of life by providing relaxation, symptom management, providing a spiritual connection, emotional expression and grief and bereavement support
- Occupational therapists can guide and support with non-pharmacological strategies for symptom and comfort management, facilitate parenting opportunities and the parent/child bond, developmentally appropriate education for parents/carers or directly with the dying child/siblings to support with understanding death and dying.
- Physiotherapists can assist with non-pharmacological strategies for comfort care including pain management, positioning and pressure care, respiratory care, relaxation and distraction techniques.
- Speech Pathologists can assist with communication and swallowing with a focus on quality of life and comfort.
- Dieticians can maximise quality of life related to comfort feeding.
- Psychologist can provide relaxation, mindfulness and a space for the child/young person to facilitate conversation around death and dying.

Artificial hydration and nutrition

The dying child/young person should be supported to eat and drink for as long as possible; however, a loss of interest in, and reduced need for food and drink, is a normal part of the dying process. This can be difficult to accept for families, even when they know the person is dying. Cultural perspectives on this matter should approached sensitively. It is important to explain that a lack of food and fluid is not responsible for the person's death. Good mouth care is important in managing symptoms of xerostomia (dry mouth) and nursing staff can involve the family/carer(s) in providing this care.

There is little evidence that artificial nutrition and hydration are beneficial in the last days of life. If either artificial hydration and/or nutrition are in place, however, the benefits and burdens of continuing them should be discussed with the child/young person (if appropriate) and the parents/carer(s). If continued, the decision should be periodically evaluated, and the person monitored for signs of aspiration and/or distress. Nasogastric tubes may be used for administration of medication or enteral feeding in paediatric end of life care however if there is no use for it, consider if the child finds it uncomfortable and whether it could be removed. Gastrostomy or jejunostomy tubes may be left in place and used to administer medications, instead of using subcutaneous injections(15).

If artificial fluids are continued or commenced, they should be administered subcutaneously, rather than intravenously. At times, intravenous fluids may be continued until the peripheral site extravasates (tissues). Central venous access devices (CVADs) may be already in place (e.g. from oncology treatment) and medications/hydration/nutrition are sometimes given via the existing CVAD where appropriate to avoid unnecessary pain by creating a subcutaneous route. Artificial fluids should be discontinued if the child develops signs of pulmonary, cerebral or pedal oedema.

If a decision is made to provide artificial nutrition or hydration, consider reducing the rate or volume.

Review of the child's individual nursing care

Nursing staff have an important role in optimising the physical comfort of the dying child/young person through the provision of mouth, eye, pressure area and hygiene care. An initial assessment of the child's needs should be undertaken, and plans developed to manage their unique needs.

Every effort should be made to provide this care regularly; however, nurses should use their clinical judgement to ensure care is responsive to the individual's and family's needs. There may be occasions when it is inappropriate to provide nursing care due to the person's condition. Grouping nursing interventions or activities to avoid discomfort and disturbance to the dying child and their family is advisable.

Family centred care should empower the parents/carer(s) to assist with normal parenting opportunities and assist in nursing cares where appropriate, which can have a positive impact upon bereavement health.

Mouth care

The main aims of mouth care are to keep the person's mouth both clean and moist, and the frequency of mouthcare and the products used will depend on the individuals' needs.

Keeping the person's mouth clean

Use oral hygiene sponges or swabs soaked with Normal Saline 0.9% to clean the child/young person's mouth, tongue and insides of the cheek at least four times a day or as negotiated with the child/young person and their family. Avoid using products that exacerbate a dry mouth such as Thymol or Chlorohexidine.

Keeping the person’s mouth moist

Symptoms of a dry mouth do not always indicate dehydration. The most common cause is mouth breathing. Other causes include:

- damage to salivary glands by radiotherapy, surgery or infection
- medications such as tricyclic antidepressants, antihistamines, anticholinergics and opioids.
- Oxygen use (also consider dry nares for nasal delivery of oxygen)

Encourage the child/young person to have frequent sips of fluid if possible or provide ice chips. Acidic fluids such as fruit juice can also help to stimulate saliva production.

If the child/young person is unable to manage fluids, use oral hygiene sponges or swabs soaked with water to moisten the child/young person’s mouth, tongue and insides of the cheek. Provide lip balm or paraffin for the lips and apply inside the mouth, if needed. Artificial saliva can also be used to relieve symptoms of a dry mouth and prevent associated problems.

Eye care

Towards the end of life, a child/young person’s vision may be reduced and their eye lids slightly open. Interventions to enhance the comfort of the dying child/young person, include:

- soft, indirect lights on in the room
- applying "artificial tears" to relieve dry eyes
- regular cleansing of the eyes with normal saline.

Special attention should be given to eye care if the child/family has indicated a wish to be an eye/corneal donor.

Skin integrity

The goal of pressure area care during the last days or hours of life is to maintain the person’s comfort (16). Whilst pressure area care should be provided according to local hospital policies, there may be times when it is inappropriate. The frequency of repositioning should be determined by skin inspection, assessment and the dying child/young person’s individual needs. The use of pressure-relieving aids, cushions, overlays and mattresses can help prevent discomfort and skin problems whilst minimising the need to reposition the person. Skin integrity strategies can be supported by allied health colleagues like occupational therapists or physiotherapists or wound care nurses for pressure ulcer management.

Keep the child/young person’s skin as clean and dry as possible by:

- managing incontinence and using barrier creams, if necessary
- considering the use of urinary catheters, if appropriate
- using skin cooling measures such as regular sponging with cool water and fans
- maintaining a cool environment.

Application of emollient twice a day and avoiding skin care products containing lanolin and fragrance can also help to protect the person’s skin.

Consider pruritus (e.g. opioid induced, cholestasis, uraemia or dry skin), and along with treating the underlying cause, non-pharmacological strategies include keeping fingernails short (or using mittens to cover the hands) to avoid the child from scratching, shorter bath times/use of lukewarm water, mild or low pH soaps and creams and regular emollient use.(4)

Other paediatric skin conditions to be considered include nappy rash, skin infections (e.g. cellulitis), hyperhidrosis and epidermolysis Bullosa.

Hygiene

The person’s hygiene should be maintained to optimise their comfort and dignity. This includes providing a sponge bath in bed, ensuring sheets are clean and attending to other personal hygiene needs, as required. Nursing staff should use their clinical judgement to determine when the person needs assistance as routine care may not be appropriate in every situation, or as the person deteriorates.

Discussion of the plan of care / Explanation of the care plan

Following the initial care planning phase, it is important to check that the child/young person, where appropriate and/or able, and their family/carer(s) have a full understanding of the care plan and know what to expect next. It is important to acknowledge any uncertainty that may exist, and often a multi-disciplinary and family meeting can help in this context. The CPDC will help determine the frequency and nature of medical, nursing and allied health assessments and interventions. It is important to use the CPDC as a guide, and to give parents appropriate information to make shared decisions about the management of their child/young person.

Section 4: Ongoing assessment

The Ongoing Assessment component of the CPDC forms the daily nursing care plan. It is an A3 page used for recording the outcomes of symptom assessment and comfort observations and uses, ‘track and trigger’, system to guide escalation responses to uncontrolled symptoms.

Symptom assessment and management

The CPDC contains general advice for assessing symptoms, including:

- where possible, base the assessment on the child/young person’s verbal response
- if the child/young person is unable to communicate, look for visual cues and consider the use of assessment tools as well as their parents/carer(s)
- Consider causes of escalated distress and measures to address (e.g. non-pharmacological measures like ensuring child/young person positioned comfortably, or pharmacological where appropriate, e.g. fever)
- discuss all changes to the plan of care with the child/young person and/or their family.

Important symptoms to manage at the end of life include pain, agitation/anxiety, nausea and vomiting, dyspnoea and secretions. Consider anticipating the development of these symptoms by prescribing appropriate PRN medications.

The five most common symptoms experienced by dying children and young people in Queensland are pain, irritability, dyspnoea, lethargy and secretions. (4)

Symptoms are given a ‘Symptom Rating’ of absent, mild moderate or severe, and instructions are provided about how to respond to the Symptom Rating. For example, continue with current care if symptoms are absent or consult with the nurse in charge if symptoms are moderate and not managed by the existing treatment plan.

Assessments should be performed hourly, and if any treatment or escalation is required more regular observations should occur. Ensure hourly infusion checks are attended to. This is especially important for devices like subcutaneous sites that are vulnerable to being dislodged, e.g. in the agitated patient that is moving around in bed.

If the child/young person has any symptoms present, even mild, an action to address them is required and moderate or severe symptoms require escalation.

When commencing any degree of intervention (nursing, medical or allied health), maintain communication with the dying child/young person even though they may appear to be unresponsive. Consider that their hearing could be intact in the last hours to days of their life.

Nursing staff should document their actions and outcomes in the patient's medical record.

Pain

Pain is one of the most common symptoms at the end of life for children/young person, and fear of uncontrolled pain is acknowledged as a source of anxiety for children/young person's and their parents/carer(s). (4)

Good pain management at the end of life is based on comprehensive assessment and diagnosis, careful titration of analgesics and frequent clinical review by the medical and nursing team (17).

Individuals who have been taking analgesia will require ongoing pain management in the last days of life. If their pain has previously been well controlled, it will generally continue to be controlled though ongoing monitoring is still required. Some children and young people develop new pain in the last days of life(15).

When a child/young person is poorly responsive or unconscious, pain and discomfort may be expressed as agitation. For example, the child/young person may appear restless and unable to find a comfortable position in bed or may show discomfort when being repositioned. Monitor the child/young person's behaviour and assess possible causes such as:

- Tenderness over a distended bladder
- Back pain due to immobility
- Pressure area pain
- Musculoskeletal (e.g. scoliosis)
- Infection
- Direct tissue/nerve damage (cancer pain)
- Raised intracranial pressure (cancer pain)

General measures to manage pain or discomfort include:

- repositioning
- administering analgesia prior to repositioning for 'incident pain'
- pressure-relieving aids
- hot or cold packs
- treating reversible causes such as urinary retention.
- Distraction, play, music therapy
- Touch and massage

Refer to appendix 6 for pharmacological pain management and/or consider consulting a specialist, e.g. paediatric palliative care service.

It is important to identify what pain scale is suitable for the child, based on their age and clinical stage.

The following scales can be used and are outlined in appendix 7;

- FLACC
- Faces Pain scale (FPS-R)
- Numerical Pain Rating scale
- Non-Communicating Children's Pain Checklist – Revised (NCCPC-R)

Neurological symptoms

Restlessness and irritability

Restlessness and agitation are common in the last days of life. The dying child/young person may be unable to find a comfortable position, may try to get out of bed, pluck at the sheets or air, groan and be incoherent. Possible causes include:

- physical discomfort (consider pressure areas) and poorly controlled pain
- medication toxicity
- urinary retention, faecal loading or incontinence
- infection and fever
- dehydration
- hypoxia
- anaemia
- metabolic changes
- emotional or existential distress.
- Cerebral irritability

Potentially reversible causes should be identified and managed where appropriate with the aim of optimising the person's comfort. For example, inserting a catheter to treat urinary retention.

Non-pharmacological measures should also be used, including:

- repositioning
- using soft lighting, minimising loud noise and playing soft, relaxing music
- encouraging the presence of people well known to the dying person
- encouraging family/carer(s) to provide gentle massage and touch
- checking if the child is too hot or cold and adjusting the room temperate and blankets as needed.
- Assessing and managing a full bladder (4)

There may be times when it is inappropriate to treat the underlying causes of agitation and restlessness, such as:

- when the symptoms are due to the dying child/young person's primary diagnosis (what they are dying from)
- when treatment would be burdensome and not contribute to the child's comfort.

In these situations, and when symptoms persist despite the use of non-pharmacological measures, anxiolytic and antipsychotic medications may be required(18).

Anxiety

Anxiety is commonly experienced in children and their families towards end of life.

Possible causes;

- fear of the unknown and/or of potential suffering can affect both the child/young person and their family, which is a normal response.

Non-pharmacological strategies include;

- Optimal communication techniques
- Relaxation techniques, distraction, music and meditation for older children (consider allied health support)

Pharmacological strategies;

- Hypnotics at night (e.g. temazepam or lorazepam)
- Antidepressants (following psychiatry team involvement)

Seizures

Seizures can be very upsetting, and should they be anticipated, families should be prepared for a possibility (e.g. raised intracranial pressure, intracranial haemorrhage, metabolic disturbances, infection and fever, pre-existing epilepsy). Consider if long standing orally administered anticonvulsant medication is poorly tolerated. (4) Refer to appendix 6 for further pharmacological management.

Muscle spasm and myoclonus

Immobility, pain, neuropathic spasm or cramps can lead to muscle spasms. Non-pharmacological strategies include repositioning regularly, gentle stretching, soft tissue massage and encouraging mobility if possible, which with the aim of lessening spasms and the occurrence of painful contractures. Pharmacological strategies include analgesia, with diazepam mostly used. Consider myoclonus (involuntary twitching of single or groups of muscles) in the terminal phase especially as a toxic effect of opioids with renally impaired children as the secondary toxic metabolites build up. Strategies include opioid dose reduction, alternative drugs, or midazolam to assist with myoclonus control. (4)

Gastrointestinal symptoms

Nausea and/or vomiting

Nausea and vomiting in the last days of life is usually a continuation of what has occurred in the period preceding the person’s deterioration. Where possible, previously effective medications should be continued subcutaneously. Anticipatory prescribing of antiemetics should also occur to allow immediate treatment of new symptoms.

Possible causes include (4);

- Opioids and other drugs
- Upper gastro-intestinal inflammation
- Raised intracranial pressure
- Metabolic disturbances
- Constipation
- Infection

Non-pharmacological strategies include (4);

- If able, encouraging fluids, offering bland foods
- Modifying enteral feed regime (e.g. changing to continuous from bolus, or reducing the rate)
- Trial of hydrolyte or similar for substitution of milk-based feeds

Consider assessing nausea and vomiting using the Baxter Animated Retching Faces (BARF) Nausea Assessment Scale, see appendix 6.

Oral problems

Children at the end of life can suffer from a range of oral issues including xerostomia (dry mouth), mucositis, fungal infections and mucosal bleeding.

Possible causes include (4);

- Poor oral intake and/or oral hygiene
- Prior treatment (e.g., radiotherapy, chemotherapy)
- Xerostomia caused by mouth breathing dehydration, anxiety, drugs and infection
- Immunosuppression

Strategies include (4);

- Regular mouth care (cleaning teeth, rinsing/using mouth swabs, using lip balm)
- Sucking on ice chips or similar
- Local anaesthetic gel for painful ulcers
- Pharmacological (e.g. antivirals, analgesia, antifungals, topical antifibrinolytics)
- Platelet support where appropriate

Constipation

Constipation is a common issue at the end of life for children and greatly impact upon comfort.

Possible causes/exacerbating factors include (4);

- Reduced dietary/fluid intake
- Immobility
- Medication
- Local factors
- History of constipation
- Electrolyte disturbance

Strategies include (4);

- Ensuring laxatives are given when opioids are used
- Encourage fluid and fibre intake where appropriate
- Encourage mobility
- Stop or reduce unnecessary drugs
- Laxative treatment

Respiratory symptoms

It is normal for the dying child/young person to have changes in their breathing pattern during the last days or hours of life. This includes:

- slow or irregular breathing
- periods of rapid, shallow breathing (similar to panting)
- episodes of apnoea with periods of deep, rapid breathing in between (Cheyne-Stokes Respiration)
- excessive but ineffective efforts to breathe deeply known as agonal breaths
- noisy 'rattly' breathing associated with pooling of respiratory secretions.

It is important to explain the changes in breathing pattern to the family/carer(s) and provide reassurance that it is seldom distressing to the dying child/young person.

Oxygen should not be used routinely in the last days of life to relive respiratory symptoms. This is because changes in breathing pattern are usually related to metabolic changes rather than breathlessness, and therefore supplemental oxygen usually does not improve rapid or exertional breathing patterns. The presence of an oxygen mask and tubing can also be distressing and increase agitation. Supplemental oxygen can also cause mucosal dryness, irritation and bleeding(19).

Respiratory secretions

The dying child's inability to cough effectively, or to swallow and clear secretions from the oropharynx, causes pooling of secretions in the throat. This results in rattly breathing. It is important to explain the cause of rattly breathing to the child's family/carer(s) as it can be distressing for them to hear. Reassurance should be provided that the symptom is a normal part of the dying process and is unlikely to be distressing to the dying person.

Repositioning the child into a semi-prone position may help drain pooled secretions, and if secretions are visible in the child's oral cavity, gentle suctioning with a soft, flexible catheter may be considered. Suctioning beyond the oral cavity should be avoided as it may stimulate the gag reflex and cause distress. In some instances, gentle physiotherapy may assist.

Anticholinergic medications are sometimes used to manage secretions; though, they should be given when symptoms first appear. This is because they are only effective at preventing the production of new saliva. They are not effective at treating secretions that are already pooled, or secretions due to respiratory infections or pre-existing pulmonary conditions such as lung malignancy. Continuing to use anticholinergics in these circumstances will only exacerbate a dry mouth.

Dyspnoea

Breathlessness can be a common end of life symptom in paediatrics and can signify deterioration or could stem from a reversible cause.

Possible causes include (4);

- infection
- inflammation
- fluid accumulation
- respiratory associated muscle issues or chest wall structure
- anxiety

Non-pharmacological strategies include (4);

- correct easily reversible causes

- breathing exercises/relaxation techniques for the older child
- calm and supportive care by staff
- increasing room air movement or ventilation (e.g. fans, opening windows)
- repositioning

Pharmacological strategies include (4);

- *Opioids*

Morphine is considered the first line agent for shortness of breath in the terminal phase. Opioids regulate the reflexive drive to breathe and lessens the patient awareness of shortness of breath.

- *Anxiolytics*

Diazepam and midazolam are effective agents, alongside general symptom control, particularly pain, will assist in easing anxiety. Consider that shortness of breath can be alarming and will contribute to anxiety.

- *Antipyretics*

If the child/young person appears distressed due to tachypnoea, consider checking for and treating a fever with antipyretics.

- *Oxygen*

Can be used for comfort, however, withdrawing the oxygen can be considered if there is no benefit.

- *Other*

Bronchodilators can used for bronchospasms/history of asthma, and corticosteroids if bronchial hyper-reactivity is present.

Fever

An elevated body temperature in the last days of life may cause discomfort due to associated tachycardia and tachypnoea. Potential causes include infection, dehydration, medication side effects and the underlying disease (tumour fevers). Reversing the underlying condition is generally not possible(20); however, symptomatic treatment using antipyretics, cool sponges and fans can help make the child/young person more comfortable.

Anaemia and bleeding

Anaemia can occur in children and young people with leukaemia as well as non-cancer conditions due to the metastatic bone marrow disease. Considerations surrounding red cell transfusions are made with the individual child/young person's needs in mind, life expectancy and stage. (4)

Bleeding can occur from thrombocytopenia (from bone marrow infiltration/failure, hypersplenism or medications) and coagulopathy (due to liver disease, nutritional deficiencies, disseminated intravascular coagulation or drugs). Platelet transfusions at the terminal phase should also be based around a child's individual needs. (4) Consider having nasal plugs, ribbon gauze, dark sheets/towels nearby if available for the child at risk of a massive bleed at the end of life. Pharmacological strategies for an acute distressing terminal event, like a massive bleed (alternative scenarios include upper airway obstruction, seizures) may include rapid terminal sedation (e.g. midazolam), with the aim of easing distress and anxiety for the child, and not to hasten death. (7)

Comfort assessment and management

Urinary problems

Urinary incontinence

For the older child and adolescent, loss of continence can be associated with a sense of losing dignity. It is important that sensitive language is used to discuss the needs and management of children. Other patients with chronic conditions may have longer standing incontinence issues. Neonates and infants may have management that is age appropriate and similar to those who do not have a life limiting condition.

Urinary incontinence is common in the last days of life and can be due to:

- loss of control due as a normal part of the dying process
- urinary tract infection
- bladder outflow obstruction
- reduced bladder capacity and/or local irritation.

Incontinence can be managed by:

- Using nappies/pads
- protecting skin from maceration by using skin care products and adhesive barriers
- urinary catheterisation – this should be considered carefully, as it may cause distress, bladder spasms and pain.

Urinary retention

Causes of urinary retention include:

- decreased mobility
- severe constipation
- spinal cord compression of nerves innervating the bladder
- haematuria and clot retention
- side effect of opioids/medications

Gently palpate the child's bladder to assess whether it is distended and if gentle pressure causes any distress. A bladder scanner may also be used to diagnose retention in a safe and non-invasive manner. If present, retention can be managed by inserting a catheter(15).

Bowel problems

In the last days of life faecal incontinence and diarrhoea should be managed by attending to the child's hygiene needs, and by optimising their comfort and dignity. Use soft, moist wipes for cleaning the perianal area and barrier creams to prevent excoriation.

Constipation is very common in the last days of life due to reduced peristalsis. It can lead to abdominal pain, nausea, vomiting, overflow incontinence, faecal impaction, urinary retention, and occasionally bowel obstruction and colonic perforation. Constipation can also contribute to problems such as delirium, agitated behaviour and anxiety.

Nursing staff should continue to monitor and record bowel movements and consider constipation if the person is agitated or appears to be in pain, and there are no other obvious causes for their discomfort.

Constipation may be diagnosed by examining the person for abdominal distension, tenderness and presence of abnormal bowel sounds.

Rectal laxatives can be administered to relieve constipation, and gentle abdominal massage used as a potentially effective non-pharmacological and non-invasive treatment option(21).

Medication

As death approaches, parents/carers may be concerned that the process is being accelerated or even caused by medications such as opioids. If medications are given in response to symptoms, and in doses that match their severity, there is no evidence that they will shorten the person's life(22). Despite this, it is important to acknowledge the concerns of the family and carer(s), and to provide careful explanation about the use of medications.

Providing breakthrough medication in a timely way is important from the perspectives of the child, parent and health professionals. It can be helpful to work out a team approach to how breakthrough opioid or sedative medications could be provided to the child quickly. Other strategies include maximising the background medications or the use of patient controlled or nurse-controlled analgesia.

Medication management advice for nurses includes:

- using standardised symptom management medication guidelines to treat symptoms
- if no PRN medications are charted, liaise with the Medical Officer to obtain orders in advance
- reassess the person at least one hour following treatment, and if their symptom/s are not adequately managed consider a change to the treatment plan
- monitor for the person for adverse effects
- if the person does not respond to medication within the expected timeframe, check if anything is interfering with delivery or absorption. For example, is the syringe driver working properly? Is the infusion line kinked? Is the route appropriate? Is the infusion insertion area still correctly placed and delivering medication (higher vigilance/more securement required for the agitated/restless patient)?
- if in use, syringe drivers should be checked four hourly or according to local hospital policies and procedures.

Food and fluids

Uncertainty about the dying child's nutritional requirements is a common and significant cause of distress amongst parents/carer(s). Often parents/carers fear that the child will die of starvation or dehydration and request artificial nutrition or hydration to be started or continued. There is little evidence that these are beneficial in the last days of life, and this should be sensitively explained to the person's family/carer(s). Avoid emotive language e.g. starving or dehydration. Parents/carer(s) can be taught how to provide mouth care to help manage any discomfort due to a dry mouth which also fosters parenting opportunities.

Some parents/carer(s) may continue to have concerns despite explanation and reassurance. It is important to note some cultural and religious beliefs place significant meaning upon feeding. In some instances, advice and support from someone of the same culture or faith may be useful. It may be beneficial to discuss that reducing fluids/feeds can decrease related distressing symptoms e.g. nausea and vomiting or excessive secretions. (4)

Ongoing mouth, skin and hygiene care

Skin, mouth and eye care should be provided according to the plan determined in the Initial Assessment - Review of the person's individual nursing care.

Environment

The child and family's physical surroundings can have a profound effect on their comfort in the last days of life(23). Therefore, nursing, allied health and other staff should help create a clean, calm and homely environment where the child feels safe. This includes:

- ensuring a private room where possible
- playing music that the child likes
- paying attention to lighting and temperature
- encouraging the child's family/carer(s) to personalise the dying child's space by bringing in personal objects, photos or other belongings
- ensuring access to the nurse call bell.
- Assisting with parent/family meals where appropriate
- Offering support with 'managing the room' or visitors
- Consider accessing gardens where available/appropriate

It is also important to provide sufficient seating space for family/carer(s), and overnight bedding arrangements. Consider bedding arrangements for siblings, grandparents (i.e. recliners, use of emergency nearby hospital accommodation where appropriate).

Spiritual and cultural needs

Any spiritual and cultural needs identified in the Initial Assessment should be supported as the child approaches death. This includes being receptive to new needs, providing support as required and referring to colleagues for assistance. Support for the dying child can be conveyed simply by spending time at the bedside with them and using respectful touch if appropriate. Always check in with the family/carer(s) and the dying child (if appropriate) about how they usually react or their level of comfort to touch.

When commencing any degree of intervention (nursing, medical or allied health), ensure that clear instructions are provided to the dying child, even though they may appear to be unresponsive. It is thought that hearing is the last sense to remain before death.

Support of family/carer(s)

Ongoing support for the child's parent/carer(s) and family includes:

- Ensuring they have had adequate food, drink and rest
- Checking the understanding and needs of all visitors
- Listening to worries and fears and providing age appropriate information
- Using clear language and avoiding the use of jargon and euphemisms
- Assessing bereavement risk and referring to Social Work for additional support as required.

Those close to the dying child may be concerned that when death happens it will be a painful experience. Reassurance should be provided that all efforts will be made to ensure the child's symptoms will be monitored and any concerns will be addressed in a responsive manner. Refer to section 2 Initial assessment for further information relating to communicating with the parent/carer(s) and family as well as assessing bereavement risk and protective factors.

Talking to children about terminal illness and death

Adults often feel the need to protect children from death, and they may feel that children will not understand or become upset. We can underestimate children's ability to cope. They may be more frightened by imagined events if they are not told what is happening.

Information provided to children should be simple and age appropriate. Give them time to ask questions (which may be very direct) and offer plenty of reassurance.

It is helpful for adults to share their feelings with children as this shows it is normal to feel sad when someone is terminally ill or has died.

A grieving child may express their sadness by behaviours rather than words and so advise parents of this and encourage them to advise the child's school, so that the teacher is aware of the situation. School based counsellors, guidance officers and chaplains can all be a support in this context.

A referral to Social Work can provide additional assessment, information and access to resources to assist in communicating with children. Refer to section 2 Initial Assessment for communication strategies for children, families and siblings.

Section 5: Care after death

The Care after death section includes:

- Health professional information
- Certification of death
- Care of the deceased child/young person
- Care of the bereaved family (parents, siblings and grandparents)
- Other communication
- Strategies for care after the child/young person's death is communicated

Health professional information

- Reassure the family that there is no rush; they can spend as much time with their child/young person as they require
- Religious and spiritual considerations may impact care after death (e.g. preparing/viewing the body, timeframe for burial etc.)
- Cultural consideration (e.g. a designated spokesperson may be required to inform other family members/community of the child/young person's death)
- A Medical Officer does not need to attend immediately following the death of a child/young person (see Section 6.3) unless requested by family
- Place any sensitive documents that will stay with the child/young person in a discrete envelope, as the wording/language on these documents may be confronting for family

- Upon the death of a child/young person, any Child Protection Orders will cease, and the powers, duties and responsibilities will revert to the child/young person’s parents (e.g. including after death care and arrangements)

Verification of death

Verification of death is the physiological assessment to confirm the fact of death. The clinical determinants to establish that death has occurred are:

- No palpable carotid pulse
- No heart sounds for 30 continuous seconds
- No breath sounds heard for 30 continuous seconds
- Fixed dilated pupils
- No response to centralised stimuli
- No motor (withdrawal) response or facial grimace response to painful stimuli (e.g. pinching inner aspect of the elbow)

Professional clinical judgment is required to make this determination and unique circumstances may warrant additional checks over and above the minimum guideline provided. For example, electrocardiogram showing no rhythm.

After receiving relevant education and training, the health and law professionals listed below can undertake a clinical assessment of a deceased person and verify if death has occurred:

- Medical Practitioner: A medical practitioner as defined in the Health Practitioner Regulation National Law Act 2009
- Registered Nurse: A registered nurse as defined in the *Health Practitioner Regulation National Law Act 2009*
- Paramedic: A paramedic, an ambulance officer as defined in the *Ambulance Service Act* 1991 and employed as a paramedic
- Police Officer: A police officer as defined in the *Police Service Administration Act* 1990 (only for cases of obvious death*)[3]

There are circumstances whereby a Registered Nurse, Midwife or Paramedic should not verify death. These may include, but are not limited to, unexpected, reportable or reviewable deaths. For further guidance, please refer to local hospital policies and procedures.

Life extinct forms can be found at [Life Extinct Form (health.qld.gov.au)]

The indications for coronial notification are on the Life Extinct form.

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[3] “Obvious deaths” are those where the state of the body is incompatible with life, like:
Severe incineration has caused charring and blackening of most of the body surface, with exposure of underlying tissues in some areas; or **Extensive trauma** has caused decapitation, severance of the torso, disruption of a vital organ (e.g. brain), or fragmentation of the body; or **Well established decomposition** has caused extensive discolouration of the skin, bloating of the body, and, in some cases, larval infestation and partial exposure of bones; or **advanced decomposition** has exposed most of the skeleton, so called ‘skeletal remains’.

Notifying and supporting family/carer(s)

Family and carer(s) who are present at the time of death should be supported according to their individual needs. This includes providing privacy if desired, allowing them to spend time with the child who has died, and support to carry out specific religious or cultural rituals.

The names of those present at the time of death should be documented and if no one is present the names of those informed and their relationship to the child should be documented.

Provide appropriate advice and support, answer any questions and consider bereavement support and risk as outlined in the section 2 – *Initial Assessment* of the guideline.

Certification of death

Certification of death is the process of completing the *Medical Certificate/Life Extinct* form. It is a legislative requirement that only registered medical practitioners can issue a *Medical Certificate/Life Extinct* form under Section 37 of the *Births, Deaths and Marriages Registration Act* 1996. To certify death, a registered medical practitioner is required to make a diagnosis of the cause of death, which requires specialist knowledge. Reviewable and reportable deaths to the coroner must be managed as per local hospital policies and procedures. Only registered medical practitioners can complete a death certificate.

Care of the deceased

Refer to local hospital policies and procedures for specific guidance how to care for the deceased.

Family/carer(s) may wish to be involved in washing and laying out their child. In some cases, family and carer(s) will not want staff to be present or assist with necessary cultural/religious duties relevant at/after the time of death. The period following a child's death may allow for memory making, refer to section 3 of the guideline – Initial Assessment for further details on supporting families with this .

Hummingbird House can provide care for a child after death (including acceptance of referrals after a child has died). HH has temperature-controlled rooms, specialist equipment and can also offer background information support and guidance for any health professionals supporting children families across the state.

Considerations after the child/young person has died:

Preparing the space

Whether the child has died at hospital, home, or hospice, the initial space in which a child is cared for after death can become a supportive environment for the family. Ways to initiate this include:

- Gently asking the family/carer(s) who they wish to be present., If the family/carer wish for privacy, guiding other visitors into a separate quiet space to allow this
- Supporting family/carer(s) to hold the child should they wish, allowing uninterrupted time for cuddles and space. The family/carer(s) may feel they need to seek permission and guidance to do this from a health care professional
- Playing special music provided by the family
- De-medicalising the environment as much as possible by removing machines, lines and medications from the space
- Turning down any bright lights and ensure the family have soft lighting wherever possible

- Agreeing with the family to check back at regular intervals
- Taking your time, moving slowly and remaining calm. The environment can be disturbed if health care professionals appear stressed and rushed
- Considering initial cooling of the environment and body within two hours of death. If air conditioning is available, set this to the lowest temperature. Close windows and curtains so the room is shaded from the heat of the sun
- Around two hours after death, if not already in place, considering cooling of the body. Gently prepare the family/carer(s) for this by explaining the continued care of the child. Cooling of the body can be with a cooling mat, a designated cool room, or a cooling product if available such as techni-ice. If unsure, please call Hummingbird House for advice and guidance

Location of After Death Care:

- Health professionals can advocate for families/carers to spend as much time as they need with their child/young person at hospital after they have died to grieve, perform important rituals, and say their goodbyes.
- Families/carers may choose to take the child/young person home, or to a special location after they have died. This is their right, and is legal in Queensland. The Life Extinct form must have been completed by a Medical Officer or registered nurse, and must remain with the child/young person at all times. Another option for families/carers is to transfer to Hummingbird House for after death care and holistic after death support.
- Consider contacting PPCS or Hummingbird House for any support or guidance around locations and logistics of transfer for care of the child/young person after death.

Care of the body after a child/young person has died:

- Refer to 'Understanding the process of Dying' in this guide (pp. 26-28) for expected physical changes to the child/young person's body after death
- Consider cooling mats, and use of air-conditioning or ice packs (eg: techni-ice) to cool the child/young person's body (funeral directors may be also able to assist with this). Consider the need to make the room colder if possible or using a cooling mat device.
- Some hospitals may have a 'quiet suite' or designated area for care of the deceased child/young person where room temperature can be controlled further and provide a more peaceful and private area.

Changes to a Child's Body After Death (Rigor Mortis)

- Adjust the child/young person's position after they have died to ensure their body does not stiffen unsuitably. Depending on a child's age and cause of death, stiffening will usually be present within four to six hours after death. Memory making (e.g. hand prints and moulds) are still possible after this time and specialist staff can assist with guidance on how to support this.
- Lie the child/young person's body flat on their back where possible, with legs down/straight. When possible, adjust the child/young person's head to be straight, facing directly upward if possible. Tthis also will help to minimise any fluid or excretions. You may fold small wash cloths or use small pillows to assist with this.
- Some families/carers may wish to place a favourite soft toy or rolled wash cloth under the chin to prevent the jaw relaxing into an open position.

Removal of medical tubes and devices

- Cease infusions and discuss removing tubes/devices to de-medicalise the room
- Discuss removal of medical tubes and devices (e.g. nasogastric tube, chest drain, PORT needle, insuflon, in-dwelling catheter).
- If the case is referred to the Coroner, medical tubes and devices may still be removed so long as they are retained. If unsure the coroner can be contacted to discuss any concerns. You can contact the 24-hour Coroner for advice as per HHS policy. For expected palliative care deaths requiring coronial notification (e.g. a death in care) a plan for management of medical tubes and devices can sometimes be worked out ahead of time.
- Consider applying waterproof dressings to all sites that puncture the skin
- Funeral homes will be able to surgically remove central venous devices, intrathecal baclofen pumps, pacemakers, glass eyes.

Bodily fluids

- Depending on the cause of death and other factors, support may be required to manage fluids and after death. It is important to note this is not always the case, and experienced clinicians will be able to offer support and guidance.
  - There may be bodily fluids leaking from the mouth and nose, bladder, bowel, and any drainage sites or openings.
  - Blood may pool causing the appearance of mottling or bruising to the skin especially on the underside of the child/young person.
- The child/young person's family/carer(s) may find fluids or excretions distressing if they are not prepared or aware of this possibility. Health professionals can pre-empt this concern by explaining this is not uncommon and can be managed just as a parent would in life (e.g. runny nose, pad changes). Some families/carers will be comfortable if this is normalised while others may require more assistance and reassurance. Early discussion can help to easy fears or concerns.
- Normalise changes to the body with the family and provide management strategies:
  - consider placing dark coloured sheets on the bed to anticipate bodily fluids
  - ensure towels are easily accessible
  - place a waterproof under sheet on family member/carer's shoulder/lap/chest to allow cuddling
  - place a waterproof under sheet on the surface when repositioning/rolling the child/young person
  - apply nappy or pad
  - health professionals should don Personal Protective Equipment when moving or handling the child/young person

Care after limited autopsy or tissue procurement

- Provide additional nursing cares to the sutured sites
- Bandages can be placed on incision site\

Post-Death MRI

- Refer to HHS policy

Leaving hospital

- Consider how a sensitive exit from the ward can be arranged, e.g. closing lifts to public access. Security may be able to assist with facilitating this
- In Queensland it is legal for families to transfer their child. The family will need the signed Life Extinct Form with their child if they choose this option
- The family may wish to carry their own child from the ward to their vehicle or a funeral providers' transfer vehicle
- Whether a family are self-transferring or using a funeral service provider, please explore if the vehicle can park in the ambulance bay (or similar) and notify security

Funeral Service Providers

- While there is no legal reason to have formal or public funeral ceremony, a funeral director is required by law in Queensland, to facilitate a cremation or burial.
- Families may have many questions about choosing a Funeral Service Provider. Consider informing families/carers of independent websites (such as https://www.gatheredhere.com.au/) to support their decision making and compare options. A family/carer may find it helpful to nominate a trusted family relative or friend to take on this task, allowing the family/carer(s) to be with thechild/young person.
- Financial support may be available to help with funeral costs. Consider a referral to Social Work to assist with this
- Funeral service providers will support families who wish to 'view' their child's body to visit regularly, and often include this service as standard.
- As a health professional, you may wish to consider speaking with funeral service providers as part of your professional development. This will provide opportunities to seek advice on topics such as body care and transportation options so you are prepared to support families.

Staff Support

- Following the death of this child/young person, do you need any support? Consider seeking support from colleagues and line manager. Support is available through the Employee Assistance Program (EAP).

Other communication

The person's death should be communicated to other health professionals and providers previously involved in caring for the person. Any member for the IPT can take responsibility for this communication. This should include the child's General Practitioner (GP), community nursing and local teams in the regional setting.

Complete a Death Notification Form CHQ Death Notification (health.qld.gov.au) to streamline the communication process of the deceased child/young person.

Email form: CHQ_DeathNotification@health.qld.gov.au

Section 6: Risk management considerations

The following information has been sourced from the, “Care Plan for the Dying Person - Victoria, Health Professional User Guide (2016)”(5).

Implementation and use of the CPDC must be embedded within the governance of individual HHS as part of their continuous quality improvement programs and care at end of life service provision policies and procedures.

The effective identification, analysis and management of potential and actual clinical and organisational risks associated with using the CPDC is essential to providing safe and quality care at the end of life.

Individual HHS must undertake analysis and develop risk profiles within their own strategic context and determine the type and level of risk management planning and management options to be implemented. It is also crucial that all staff receive training to accurately use and commence a person on the CPDC.

Failure to identify and minimise risk in the context of care provision at the end of life, no matter what the health care setting, can lead to:

- Significant distress to the dying person and family/carer(s) resulting in an increased risk of poor bereavement outcomes.
- Staff dissatisfaction when they do not feel supported, enabled or encouraged to deliver high quality care, whether because of a lack of:
  - organisational support from executive,
  - clinical support from their line management, such as senior Medical, Nursing and Allied Health colleagues,
  - access to education and training on symptom management, communication skills and use of the CPDC, and/or
  - access to appropriate medication, equipment and ward/unit environment privacy for the dying person and their family/carer(s).
- Complaints to the hospital/health service regarding poor care outcomes (often by bereaved family/carer(s)).
- Adverse publicity and public scrutiny (including the increasing use of social media) related to perceived poor care outcomes as a person is dying.

In 2014, the Victorian End-of-Life Coordinating Program commissioned a stakeholder engagement exploration of potential risk considerations associated with Victorian Health Services providing care at end of life and using care at end of life integrated care pathways. Examples of those risk considerations, which are also likely to be relevant to Queensland HHS, are:

- Lack of senior management support
- Lack of clinician commitment and support
- Key stakeholders unaware of organisational care at end of life policies, including the use of care at end of life integrated care pathways
- Lack of a coordinated, planned and sustained approach to the implementation and use of care at end of life integrated care pathways
- Health professionals lack confidence and competence in care at end of life provision and implementation of care at end of life integrated care pathways including aspects such as:

  - recognition of dying
  - communicating with the dying person and their relative/friend(s)
  - how and when to initiate the care at end of life integrated care pathways
- Adverse media coverage leading to damaged HHS reputation
- Lack of consumer knowledge of ACP and care at end of life options
- Ineffective monitoring and evaluation of care provision at the end of life.

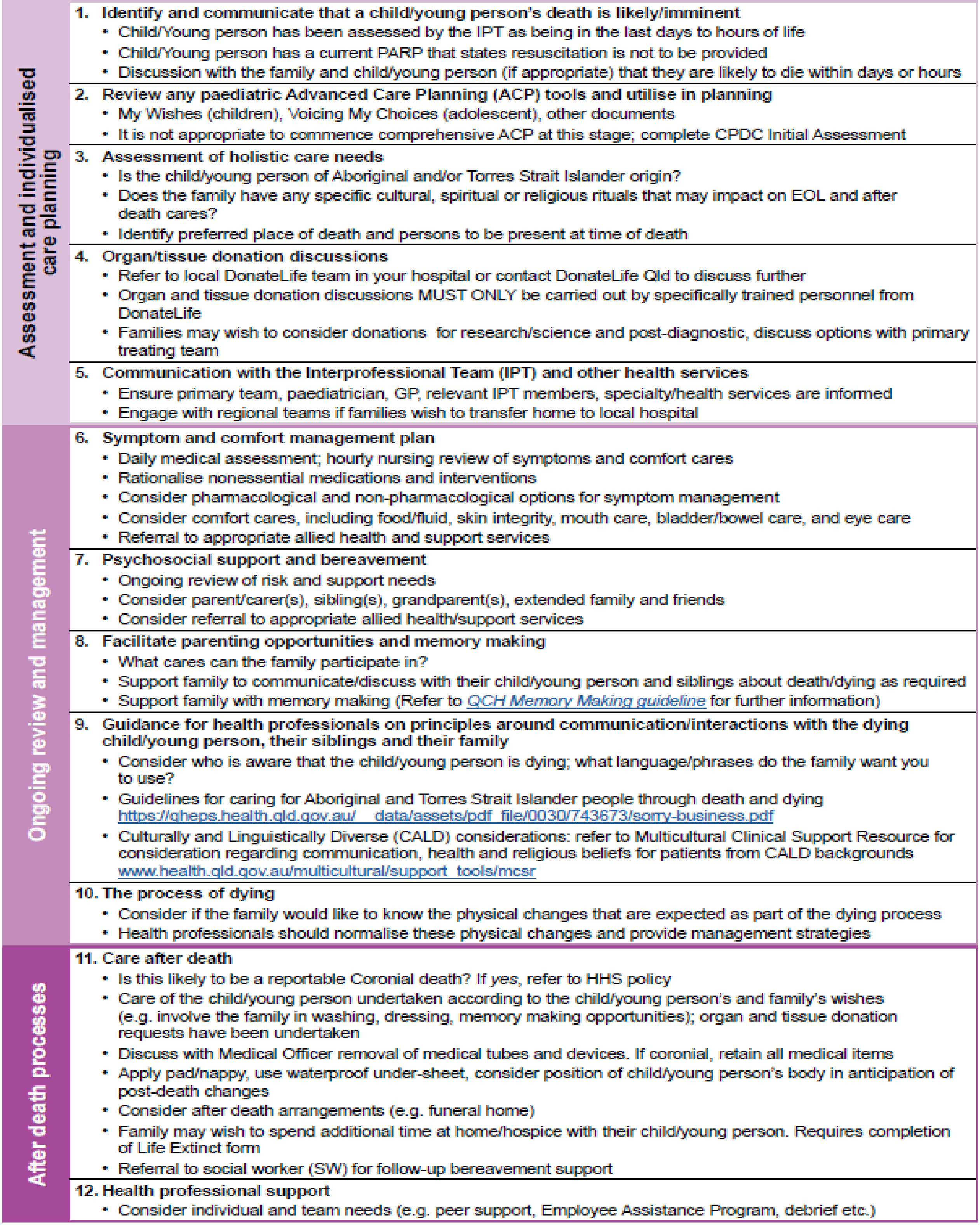
Key points

- It is important to note that this list is in no way exhaustive and the risks identified here should be considered within the context of your own HHS operational and clinical risk profiles.
- Clinical risk identification, evaluation and monitoring are a continuous process.
- Ensure the use of the CPDC is aligned within existing HHS risk management frameworks and reporting guidelines.

Guideline version and approval history

Version No.	Modified by	Amendments authorised by	Approved by
1.0	PPCWG	PPCWG	QCYCN, Clinician Collaborative

Appendix 1: Best Practice Principles to Care for the Dying Child



Assessment and individualised care planning	**1. Identify and communicate that a child/young person's death is likely/imminent** • Child/Young person has been assessed by the IPT as being in the last days to hours of life • Child/Young person has a current PARP that states resuscitation is not to be provided • Discussion with the family and child/young person (if appropriate) that they are likely to die within days or hours
	2. Review any paediatric Advanced Care Planning (ACP) tools and utilise in planning • My Wishes (children), Voicing My Choices (adolescent), other documents • It is not appropriate to commence comprehensive ACP at this stage; complete CPDC Initial Assessment
	3. Assessment of holistic care needs • Is the child/young person of Aboriginal and/or Torres Strait Islander origin? • Does the family have any specific cultural, spiritual or religious rituals that may impact on EOL and after death cares? • Identify preferred place of death and persons to be present at time of death
	4. Organ/tissue donation discussions • Refer to local DonateLife team in your hospital or contact DonateLife Qld to discuss further • Organ and tissue donation discussions MUST ONLY be carried out by specifically trained personnel from DonateLife • Families may wish to consider donations for research/science and post-diagnostic, discuss options with primary treating team
	5. Communication with the Interprofessional Team (IPT) and other health services • Ensure primary team, paediatrician, GP, relevant IPT members, specialty/health services are informed • Engage with regional teams if families wish to transfer home to local hospital
Ongoing review and management	**6. Symptom and comfort management plan** • Daily medical assessment; hourly nursing review of symptoms and comfort cares • Rationalise nonessential medications and interventions • Consider pharmacological and non-pharmacological options for symptom management • Consider comfort cares, including food/fluid, skin integrity, mouth care, bladder/bowel care, and eye care • Referral to appropriate allied health and support services
	7. Psychosocial support and bereavement • Ongoing review of risk and support needs • Consider parent/carer(s), sibling(s), grandparent(s), extended family and friends • Consider referral to appropriate allied health/support services
	8. Facilitate parenting opportunities and memory making • What cares can the family participate in? • Support family to communicate/discuss with their child/young person and siblings about death/dying as required • Support family with memory making (Refer to *QCH Memory Making guideline* for further information)
	9. Guidance for health professionals on principles around communication/interactions with the dying child/young person, their siblings and their family • Consider who is aware that the child/young person is dying; what language/phrases do the family want you to use? • Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying https://qheps.health.qld.gov.au/__data/assets/pdf_file/0030/743673/sorry-business.pdf • Culturally and Linguistically Diverse (CALD) considerations: refer to Multicultural Clinical Support Resource for consideration regarding communication, health and religious beliefs for patients from CALD backgrounds www.health.qld.gov.au/multicultural/support_tools/mcsr
	10. The process of dying • Consider if the family would like to know the physical changes that are expected as part of the dying process • Health professionals should normalise these physical changes and provide management strategies
After death processes	**11. Care after death** • Is this likely to be a reportable Coronial death? If *yes*, refer to HHS policy • Care of the child/young person undertaken according to the child/young person's and family's wishes (e.g. involve the family in washing, dressing, memory making opportunities); organ and tissue donation requests have been undertaken • Discuss with Medical Officer removal of medical tubes and devices. If coronial, retain all medical items • Apply pad/nappy, use waterproof under-sheet, consider position of child/young person's body in anticipation of post-death changes • Consider after death arrangements (e.g. funeral home) • Family may wish to spend additional time at home/hospice with their child/young person. Requires completion of Life Extinct form • Referral to social worker (SW) for follow-up bereavement support
	12. Health professional support • Consider individual and team needs (e.g. peer support, Employee Assistance Program, debrief etc.)

Appendix 2: The Lansky Play-Performance Scale for Children

The Lansky Play-Performance Scale for Children(24) is intended to offer a consistent measure of the performance status of the child with a malignancy. Consider that the original scale was designed for use in children with cancer, aged between 1 to 16 years of age and for the parent to report on.

Score	Play-performance
100	Fully active, normal
90	Minor restrictions in physically strenuous activity
80	Active, but tires more quickly
70	Both greater restriction of, and less time spent in, active play
60	Up and around, but minimal active play; keeps busy with quieter activities
50	Gets dressed, but lies around much of the day; no active play; able to participate in all quiet play and activities
40	Mostly in bed; participates in quiet activities
30	In bed; needs assistance even for quiet play
20	Often sleeping; play entirely limited to very passive activities
10	No play; does not get out of bed
0	Unresponsive

Figure 1: Based on Lansky Play-Performance Scale for Children (24)

The Australian-modified Karnofsky Performance Status

The Australian-modified Karnofsky Performance Status (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living. It is a single score between 10 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. A score of 100 signifies normal physical abilities with no evidence of disease. Decreasing numbers indicate a reduced performance status.

How to assess AKPS

1. Use the AKPS definitions to determine the initial rating on admission or commencement of an episode of care.
2. Assess at episode start.
3. Assess routinely. A minimum of daily in an inpatient setting, at each visit in a community setting or each consult.
4. Assess whenever there is a phase change
5. Assess at episode end when a patient is discharged.
6. Assessment may be conducted face to face or over the phone.
7. Record the score as assessed, which may be entered directly into the patient record or on a clinical form to be entered into relevant data systems.

KPS ASSESSMENT CRITERIA	SCORE
Normal; no complaints; no evidence of disease	100
Able to carry on normal activity; minor sign of symptoms of disease	90
Normal activity with effort; some signs or symptoms of disease	80
Cares for self; unable to carry on normal activity or to do active work	70
Able to care for most needs; but requires occasional assistance	60
Considerable assistance and frequent medical care required	50
In bed more than 50% of the time	40
Almost completely bedfast	30
Totally bedfast and requiring extensive nursing care by professionals and/or family	20
Comatose or barely rousable	10
Dead	0

Appendix 3: Gillick competency

3.1.5 How to assess whether a child or young person is Gillick competent and has capacity to consent to health care

To establish that a child or young person has capacity to consent to health care, the health practitioner can carry out an assessment to show the patient has sufficient understanding, intelligence and maturity to appreciate the nature, consequences and risks of the proposed health care, and the alternatives, including the consequences of not receiving the health care.

When assessing a child or young person's capacity, the following issues should be considered79:

- the age, attitude and maturity of the child or young person, including their physical and emotional development
- the child or young person's level of intelligence and education
- the child or young person's social circumstances and social history
- the nature of the child or young person's condition
- the complexity of the proposed health care, including the need for follow up or supervision after the health care
- the seriousness of the risks associated with the health care
- the consequences if the child or young person does not have the health care

where the consequences of receiving the health care include death or permanent disability, that the child or young person understands the permanence of death or disability and the profound nature of the decision he or she is making.

The more complex the health care or more serious the consequences, the stronger the evidence of the child or young person's capacity to consent to the specific health care will need to be. In these situations, it is recommended that the assessment is carried out by a medical practitioner.

The health practitioner documents fully in the patient's clinical record the assessment they have carried out, including the details which influenced their decision as to whether the child has capacity. 47

Maturity and intellectual development varies from one individual to another and an assessment of a child or young person's capacity is performed for each new health care decision. However, as a practical rule of thumb:

- a young person aged between 16 and 18 is most likely able to consent
- a young person aged between 14 and 16 is reasonably likely to be able consent
- a child under the age of 14 may not have the capacity to consent, except for health care that does not carry significant risk80.

A child who has the capacity to consent for a low risk, simple procedure like receiving an x-ray or suturing of a small wound, may well not have capacity to give consent to a major heart operation with greater risks and more serious consequences.

A child who is intellectually disabled may still be capable of consenting to and possibly refusing specific health care depending on the specific circumstances.

Where a child or young person does not have capacity to give consent, this does not reduce the significance of their involvement in decision-making, and health practitioners would communicate with them and involve them as much as possible in decisions about their care.

(12) Queensland Health (2017). *Queensland Health Guide to Informed Decision-making in Healthcare (2nd edition)* retrieved June 18, 2019 from https://www.health.qld.gov.au/__data/assets/pdf_file/0019/143074/ic-guide.pdf

Appendix 4: Considerations for children subject to Child Protection Orders

At the beginning of end-of-life planning for a child subject to a child protection order, please ensure you contact your local HHS Child Protection Unit or relevant Child Safety Officer for consideration around the complexities outlined below

Types of Child Protection Orders

- *Custody Orders:* Short Term (up to two years)
  The Department of Child Safety have Custody of the child and so make decisions about where the child lives and who can see the child. Parents are required to provide consent.
- *Guardianship Orders:* Short or Long Term,
  The Department of Child Safety have Custody and Guardianship of the child and so make decisions about contact arrangements and are also required to provide consent.

Both types of orders remain in place until the child passes away.

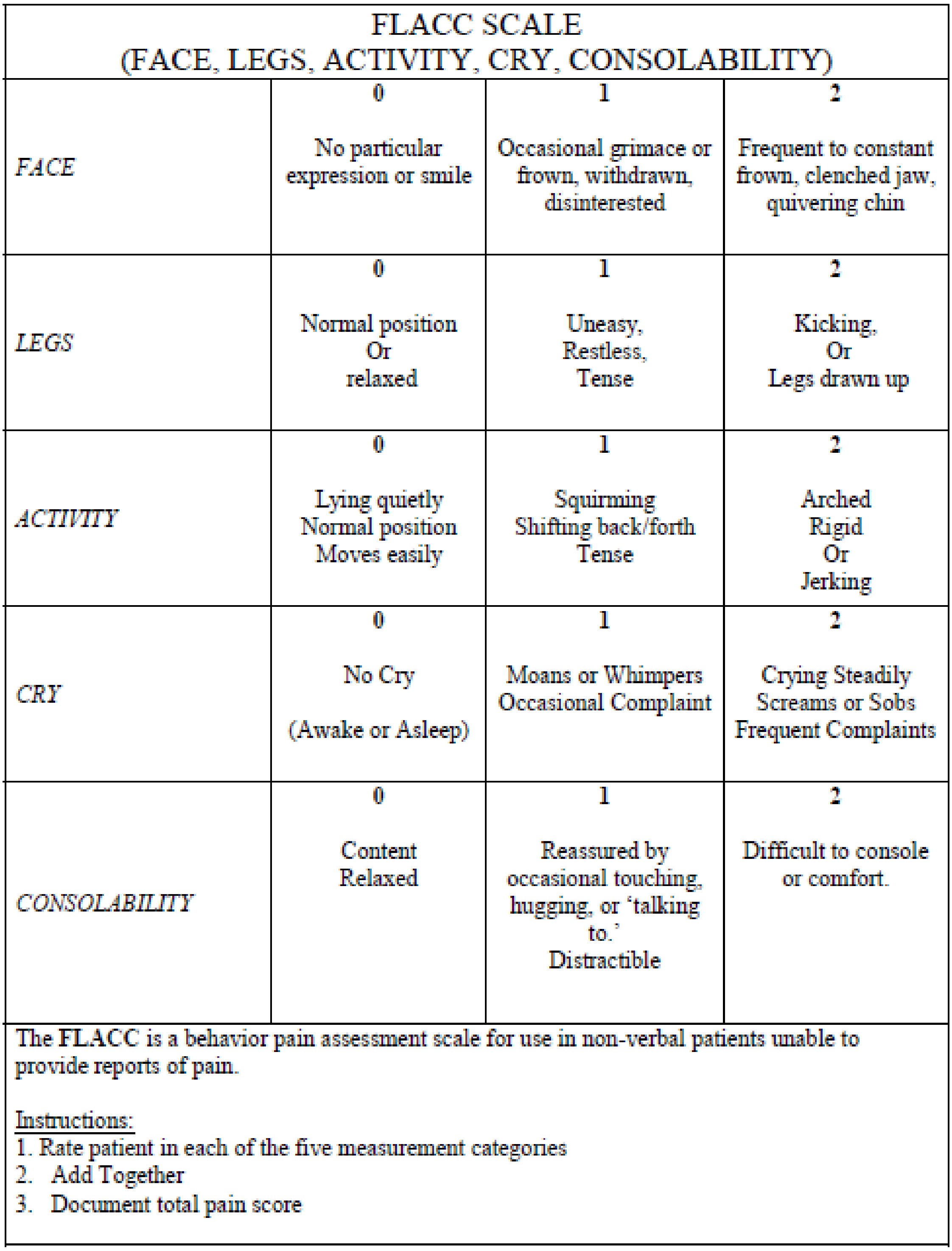
End-of-Life Planning

- All rights and responsibilities revert to the biological parents upon the death of a child, so this will need to be considered in planning discussions.
- Long-term carers may have input into end-of-life planning and decisions, however clinicians should be conscious that all rights will return to the biological parents upon the child's death. This may bring complexity if the biological parent's wishes and preferences conflict with those of the long-term carers.
- Considerations should be made around the challenges of end-of-life care taking place in the home of carers, given likely presence of biological family at this time also. Though this may be considered the location of preference for end-of-life care during initial planning discussions, the appropriateness and management of home versus hospice versus hospital should be discussed with the Child Safety Officer.
- If biological family are unable contacted or unwilling to be involved care for the child after they have died, the Department of Child Safety may take responsibility for after death care and arrangements postmortem arrangements.
- It is strongly recommended that clinicians contact their HHS Child Protection Unit and the Department of Child Safety early in the end-of-life planning process for guidance and assistance in managing the complexity of the death of children subject to Child Protection Orders.

The death of all children who are subject to Child Protection Orders is reportable to Coroner

- These deaths are reported to the Coroner even if they are an expected and medically explained death. This should be clearly communicated to the Coroner upon reporting, so as not to trigger a suspicious death response inappropriately.
- Please also ensure that the Department of Child Safety is made aware at the time of the child's death. This may be done either directly to the Child Safety Officer or Service Centre involved, or through After-Hours Regional Intake Service.
- Families and carers should be advised in planning discussions that the child's death will need to be reported to the coroner and supported to understand what this response may look like.

Appendix 5: Paediatric pain assessment scales



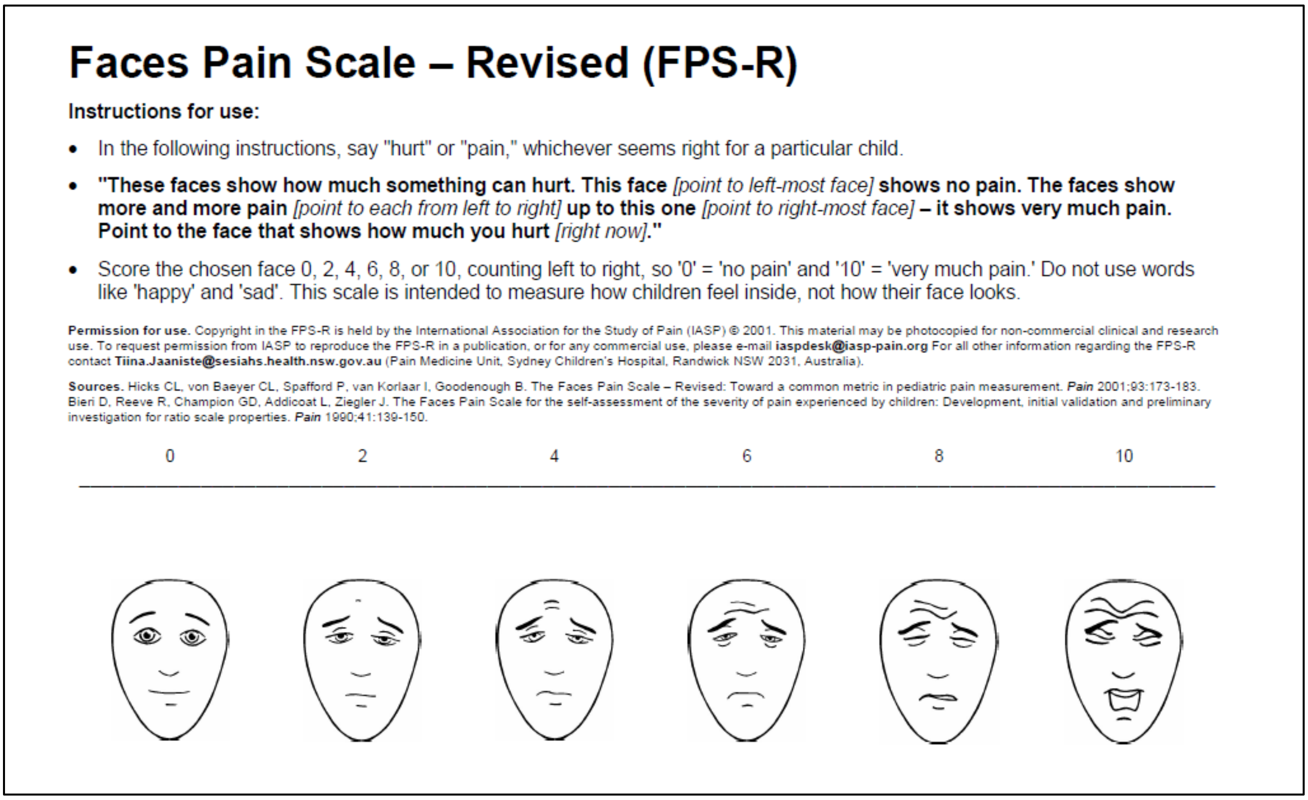
FLACC SCALE
(FACE, LEGS, ACTIVITY, CRY, CONSOLABILITY)

FACE	0 No particular expression or smile	1 Occasional grimace or frown, withdrawn, disinterested	2 Frequent to constant frown, clenched jaw, quivering chin
LEGS	0 Normal position Or relaxed	1 Uneasy, Restless, Tense	2 Kicking, Or Legs drawn up
ACTIVITY	0 Lying quietly Normal position Moves easily	1 Squirming Shifting back/forth Tense	2 Arched Rigid Or Jerking
CRY	0 No Cry (Awake or Asleep)	1 Moans or Whimpers Occasional Complaint	2 Crying Steadily Screams or Sobs Frequent Complaints
CONSOLABILITY	0 Content Relaxed	1 Reassured by occasional touching, hugging, or 'talking to.' Distractible	2 Difficult to console or comfort.

The FLACC is a behavior pain assessment scale for use in non-verbal patients unable to provide reports of pain.

Instructions:
1. Rate patient in each of the five measurement categories
2. Add Together
3. Document total pain score

(28, 29) Merkel S, Voepel-Lewis T, Shayevitz JR, et al: *The FLACC: A behavioural scale for scoring postoperative pain in young children.* Pediatric nursing 1997; 23:293-797.



Faces Pain Scale – Revised (FPS-R)

Instructions for use:

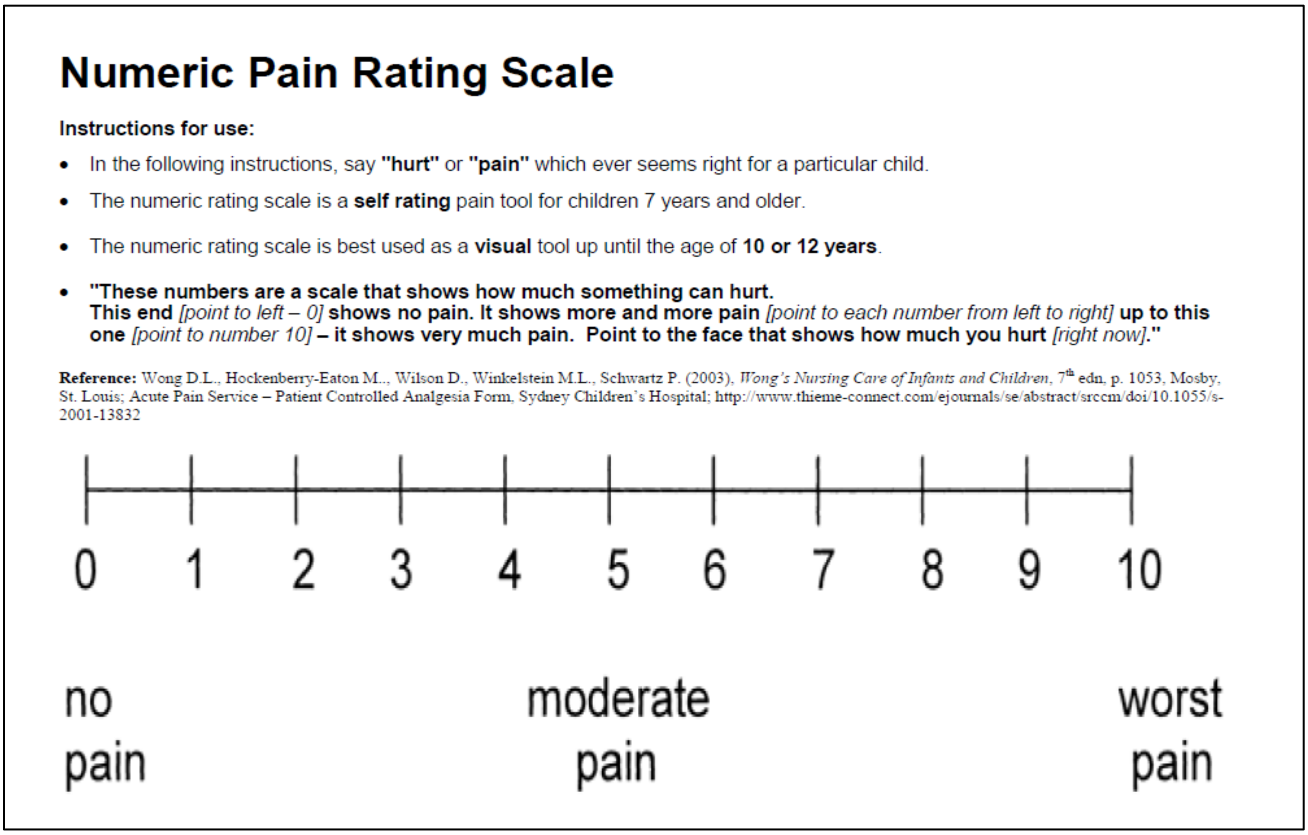
- In the following instructions, say "hurt" or "pain," whichever seems right for a particular child.
- **"These faces show how much something can hurt. This face** *[point to left-most face]* **shows no pain. The faces show more and more pain** *[point to each from left to right]* **up to this one** *[point to right-most face]* **– it shows very much pain. Point to the face that shows how much you hurt** *[right now]*.**"**
- Score the chosen face 0, 2, 4, 6, 8, or 10, counting left to right, so '0' = 'no pain' and '10' = 'very much pain.' Do not use words like 'happy' and 'sad'. This scale is intended to measure how children feel inside, not how their face looks.

Permission for use. Copyright in the FPS-R is held by the International Association for the Study of Pain (IASP) © 2001. This material may be photocopied for non-commercial clinical and research use. To request permission from IASP to reproduce the FPS-R in a publication, or for any commercial use, please e-mail **iaspdesk@iasp-pain.org** For all other information regarding the FPS-R contact **Tiina.Jaaniste@sesiahs.health.nsw.gov.au** (Pain Medicine Unit, Sydney Children's Hospital, Randwick NSW 2031, Australia).

Sources. Hicks CL, von Baeyer CL, Spafford P, van Korlaar I, Goodenough B. The Faces Pain Scale – Revised: Toward a common metric in pediatric pain measurement. *Pain* 2001;93:173-183. Bieri D, Reeve R, Champion GD, Addicoat L, Ziegler J. The Faces Pain Scale for the self-assessment of the severity of pain experienced by children: Development, initial validation and preliminary investigation for ratio scale properties. *Pain* 1990;41:139-150.

0 2 4 6 8 10

(28) Hicks CL, von Baeyer CL, Spafford PA, et al: The Faces Pain Scale-Revised: toward a common metric in pediatric pain measurement. Pain 2001 Aug;93(2): 173-83.



Numeric Pain Rating Scale

Instructions for use:

- In the following instructions, say **"hurt"** or **"pain"** which ever seems right for a particular child.
- The numeric rating scale is a **self rating** pain tool for children 7 years and older.
- The numeric rating scale is best used as a **visual** tool up until the age of **10 or 12 years**.
- **"These numbers are a scale that shows how much something can hurt.**
  This end *[point to left – 0]* **shows no pain. It shows more and more pain** *[point to each number from left to right]* **up to this one** *[point to number 10]* **– it shows very much pain. Point to the face that shows how much you hurt** *[right now]*.**"**

Reference: Wong D.L., Hockenberry-Eaton M.., Wilson D., Winkelstein M.L., Schwartz P. (2003), *Wong's Nursing Care of Infants and Children*, 7th edn, p. 1053, Mosby, St. Louis; Acute Pain Service – Patient Controlled Analgesia Form, Sydney Children's Hospital; http://www.thieme-connect.com/ejournals/se/abstract/srccm/doi/10.1055/s-2001-13832

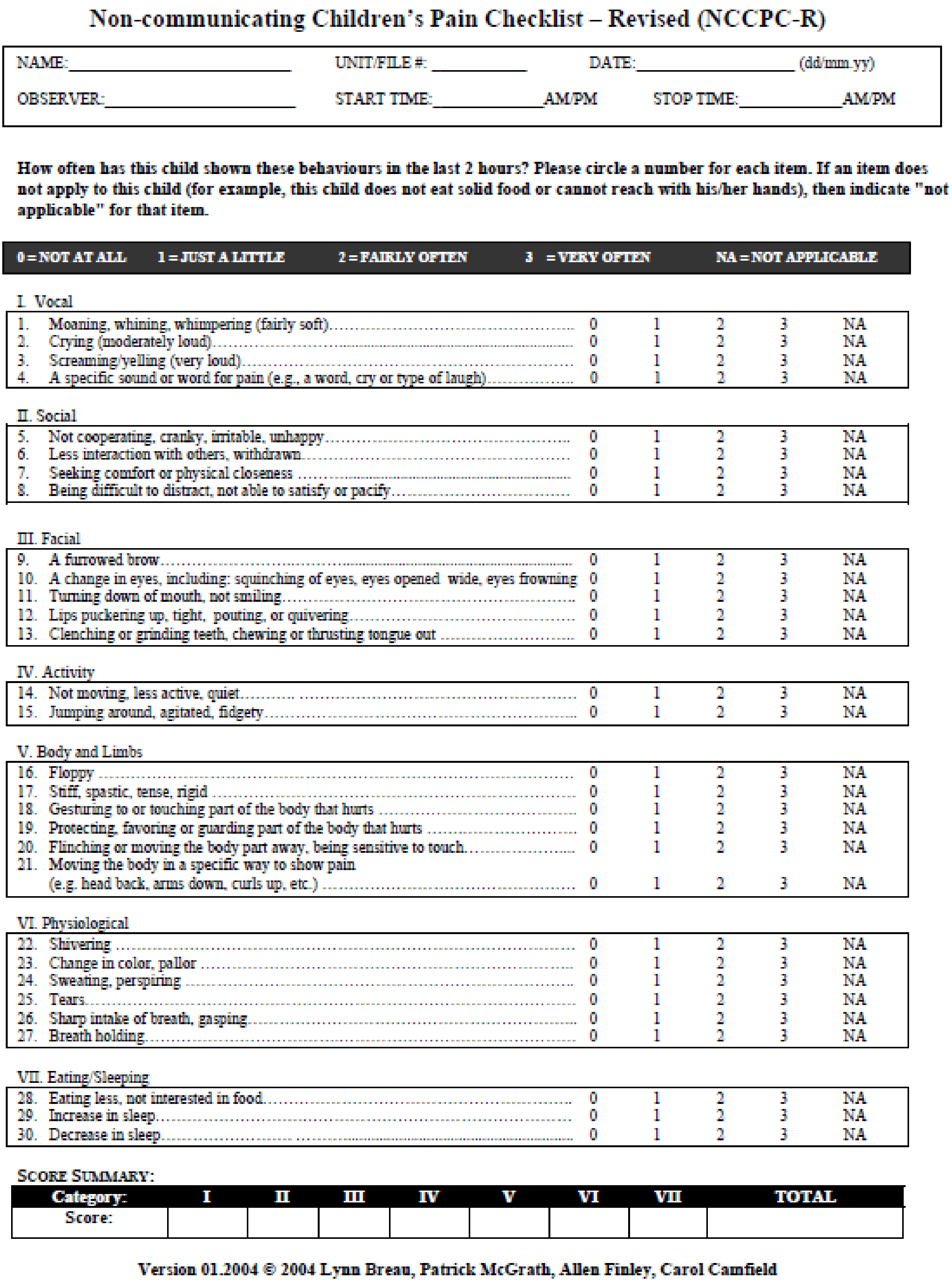
0 1 2 3 4 5 6 7 8 9 10

no pain

moderate pain

worst pain

(30)



Non-communicating Children's Pain Checklist – Revised (NCCPC-R)

NAME:______________________ UNIT/FILE #: __________ DATE:________________ (dd/mm yy)
OBSERVER:___________________ START TIME:__________AM/PM STOP TIME:__________AM/PM

How often has this child shown these behaviours in the last 2 hours? Please circle a number for each item. If an item does not apply to this child (for example, this child does not eat solid food or cannot reach with his/her hands), then indicate "not applicable" for that item.

0 = NOT AT ALL 1 = JUST A LITTLE 2 = FAIRLY OFTEN 3 = VERY OFTEN NA = NOT APPLICABLE

I. Vocal

1. Moaning, whining, whimpering (fairly soft)	0	1	2	3	NA
2. Crying (moderately loud)	0	1	2	3	NA
3. Screaming/yelling (very loud)	0	1	2	3	NA
4. A specific sound or word for pain (e.g., a word, cry or type of laugh)	0	1	2	3	NA

II. Social

5. Not cooperating, cranky, irritable, unhappy	0	1	2	3	NA
6. Less interaction with others, withdrawn	0	1	2	3	NA
7. Seeking comfort or physical closeness	0	1	2	3	NA
8. Being difficult to distract, not able to satisfy or pacify	0	1	2	3	NA

III. Facial

9. A furrowed brow	0	1	2	3	NA
10. A change in eyes, including: squinching of eyes, eyes opened wide, eyes frowning	0	1	2	3	NA
11. Turning down of mouth, not smiling	0	1	2	3	NA
12. Lips puckering up, tight, pouting, or quivering	0	1	2	3	NA
13. Clenching or grinding teeth, chewing or thrusting tongue out	0	1	2	3	NA

IV. Activity

14. Not moving, less active, quiet	0	1	2	3	NA
15. Jumping around, agitated, fidgety	0	1	2	3	NA

V. Body and Limbs

16. Floppy	0	1	2	3	NA
17. Stiff, spastic, tense, rigid	0	1	2	3	NA
18. Gesturing to or touching part of the body that hurts	0	1	2	3	NA
19. Protecting, favoring or guarding part of the body that hurts	0	1	2	3	NA
20. Flinching or moving the body part away, being sensitive to touch	0	1	2	3	NA
21. Moving the body in a specific way to show pain (e.g. head back, arms down, curls up, etc.)	0	1	2	3	NA

VI. Physiological

22. Shivering	0	1	2	3	NA
23. Change in color, pallor	0	1	2	3	NA
24. Sweating, perspiring	0	1	2	3	NA
25. Tears	0	1	2	3	NA
26. Sharp intake of breath, gasping	0	1	2	3	NA
27. Breath holding	0	1	2	3	NA

VII. Eating/Sleeping

28. Eating less, not interested in food	0	1	2	3	NA
29. Increase in sleep	0	1	2	3	NA
30. Decrease in sleep	0	1	2	3	NA

SCORE SUMMARY:

Category:	I	II	III	IV	V	VI	VII	TOTAL
Score:								

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USING THE NCCPC-R

The NCCPC-R was designed to be used for children, aged 3 to 18 years, who are unable to speak because of cognitive (mental/intellectual) impairments or disabilities. It can be used *whether or not* a child has physical impairments or disabilities. Descriptions of the types of children used to validate the NCCPC-R can be found in: Breau, L.M., McGrath, P.J., Camfield, C.S. & Finley, G.A. (2002). Psychometric Properties of the Non-communicating Children's Pain Checklist-Revised. *Pain, 99,* 349-357. The NCCPC-R was designed to be used without training by parents and caregivers (carers). It can also be used by other adults who are not familiar with a specific child (do not know them well).

The NCCPC-R may be freely copied for clinical use or use in research funded by not-for-profit agencies. For-profit agencies should contact Lynn Breau: Pediatric Pain Research, IWK Health Centre, 5850 University Avenue, Halifax, Nova Scotia Canada, B3J 3G9 (lbreau@ns.sympatico.ca).

The NCCPC-R was intended for use for short or long-term pain in the child's home or in a long-term residential setting. If suspected *pain after surgery or pain due to procedures conducted in hospital* are the reason for measuring pain, the **Non-communicating Children's Pain Checklist – Postoperative Version** should be used. It can be obtained by contacting Lynn Breau. Information regarding the NCCPC-PV can be found in: Breau, L.M., Finley, G.A., McGrath, P.J. & Camfield, C.S. (2002). Validation of the Non-Communicating Children's Pain Checklist - Postoperative Version. *Anesthesiology, 96* (3), 528-535.

ADMINISTRATION:

To complete the NCCPC-R, base your observations on the child's behavior over the past **two hours**. ***It is not necessary to watch the child continuously for this period.*** However, it is recommended that the observer be in the child's presence for the majority of this time (e.g.; be in the same room with the child). Although shorter observation periods may be used, the cut-off scores described below may not apply.

Eating/Sleeping Subscale: Items on the Eating/Sleeping subscale may not occur during the two-hour observation. In this case, the rating should be based on the child's behavior over the day of the observation.

All other subscales: At the end of the observation time, indicate how frequently (how often) each item was seen or heard. This should not be based on the child's typical behavior or in relation to what he or she usually does. A guide for deciding the frequency of items is below:

0	=	Not present at all during the observation period. (Note if the item is not present because the child is not capable of performing that act, it should be scored as "NA").
1	=	Seen or heard rarely (hardly at all), but is present.
2	=	Seen or heard a number of times, but not continuous (not all the time).
3	=	Seen or heard often, almost continuous (almost all the time); anyone would easily notice this if they saw the child for a few moments during the observation time.
NA	=	Not applicable. This child is not capable of performing this action.

SCORING:

1. Add up the scores for each subscale and enter below that subscale number in the Score Summary at the bottom of the sheet. Items marked "NA" are scored as "0" (zero).
2. Add up all subscale scores for Total Score.
3. Check whether the child's score is greater than the cut-off score.

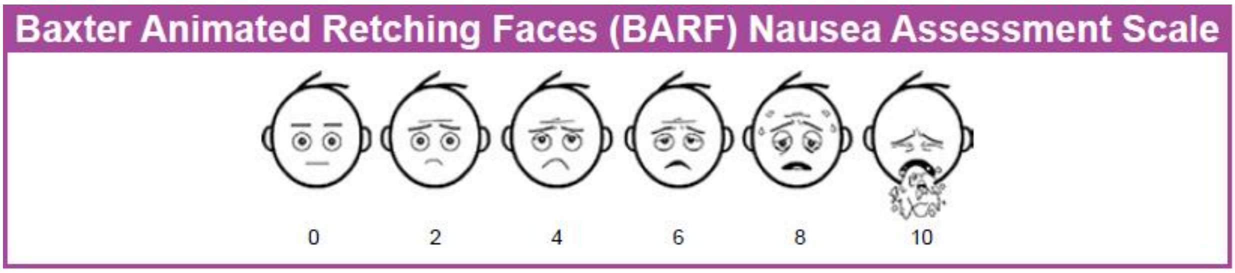
CUT-OFF SCORE:

Based on the scores of 71 children aged 3 to 18 (Breau, McGrath, Camfield & Finley, 2002), a **Total Score of 7 or more** indicates a child has pain. This was accurate in the study group 84% of the time. A Total Score of 6 or less indicates a child does not have pain. This was correct in the study group 77% of the time.

USE OF CUT-OFF SCORES:

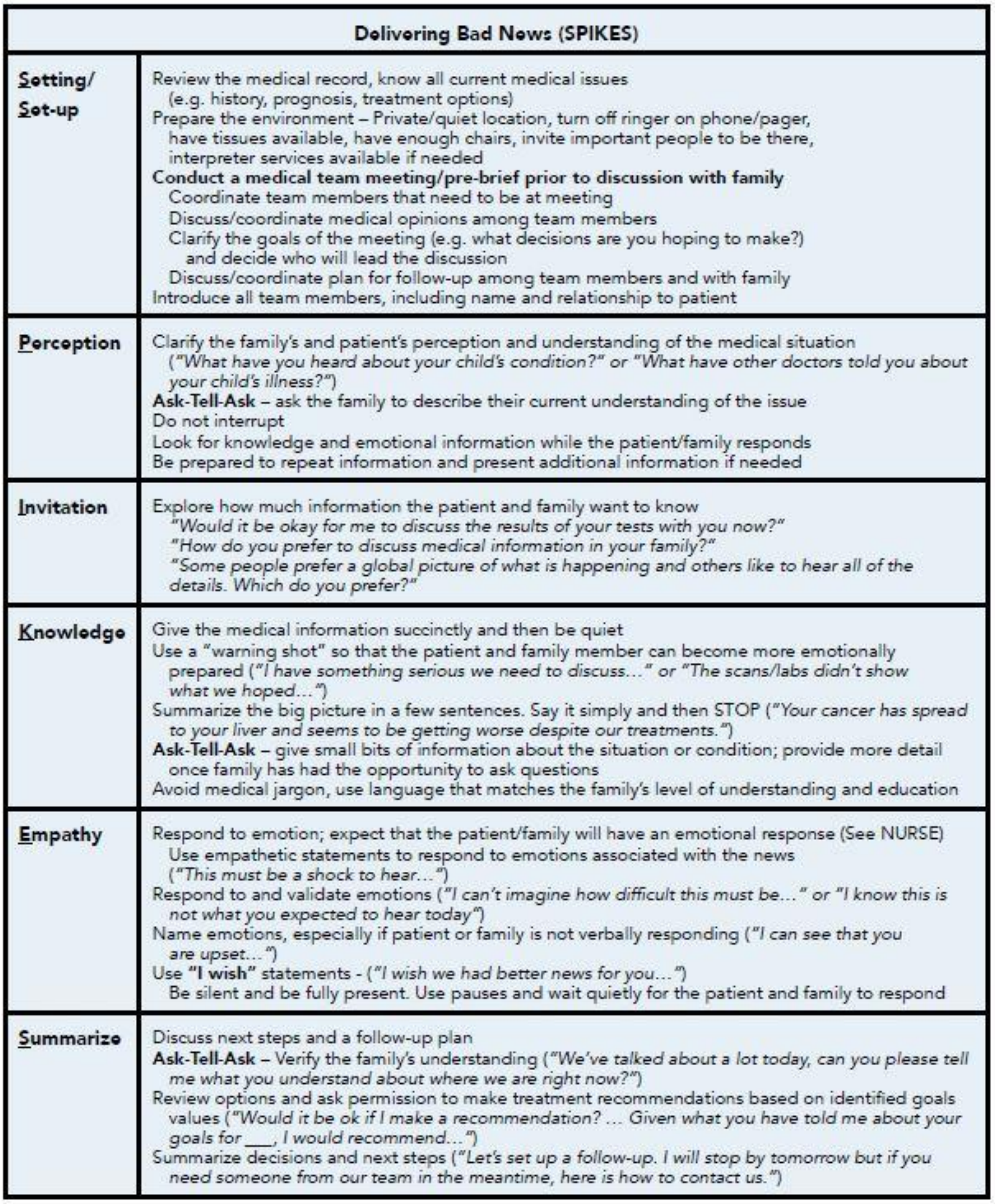
As with all observational pain tools, caution should be taken in using cut-off scores because they may not be 100% accurate. They should not be used as the only basis for deciding whether a child should be treated for pain. In some cases children may have lower scores when pain is present. For more detailed instructions for use of the NCCPC-R in such situations, please refer to the full manual, available from Lynn Breau: Pediatric Pain Research, IWK Health Centre, 5850 University Avenue, Halifax, Nova Scotia Canada, B3J 3G9 (lbreau@ns.sympatico.ca).

Appendix 6: Paediatric nausea and vomiting scale

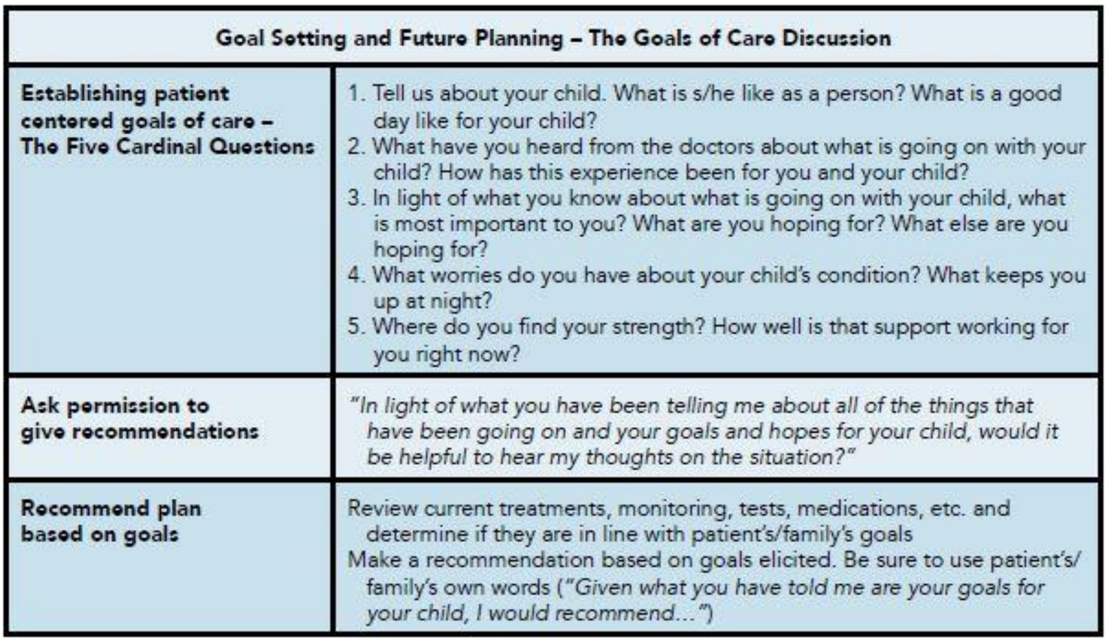


Reference: Baxter AL, Mehenoor F, Baxter WV et al: Development and Validation of a Pictorial Nausea Rating Scale for Children: Pediatrics June 2011; 127(6): 1542-9

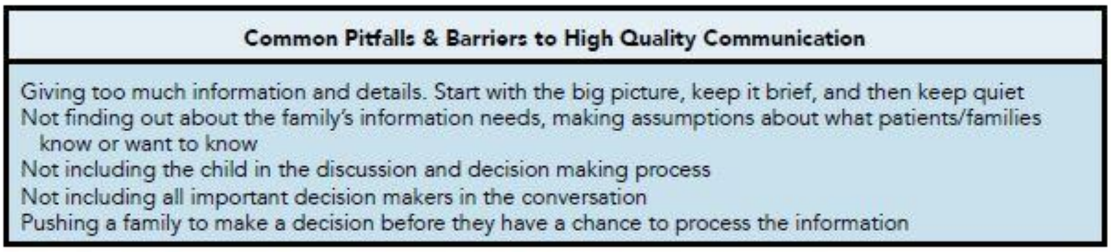
Appendix 7: Communication Guides



Delivering Bad News (SPIKES)	
Setting/ Set-up	Review the medical record, know all current medical issues (e.g. history, prognosis, treatment options) Prepare the environment – Private/quiet location, turn off ringer on phone/pager, have tissues available, have enough chairs, invite important people to be there, interpreter services available if needed **Conduct a medical team meeting/pre-brief prior to discussion with family** Coordinate team members that need to be at meeting Discuss/coordinate medical opinions among team members Clarify the goals of the meeting (e.g. what decisions are you hoping to make?) and decide who will lead the discussion Discuss/coordinate plan for follow-up among team members and with family Introduce all team members, including name and relationship to patient
Perception	Clarify the family's and patient's perception and understanding of the medical situation (*"What have you heard about your child's condition?" or "What have other doctors told you about your child's illness?"*) **Ask-Tell-Ask** – ask the family to describe their current understanding of the issue Do not interrupt Look for knowledge and emotional information while the patient/family responds Be prepared to repeat information and present additional information if needed
Invitation	Explore how much information the patient and family want to know *"Would it be okay for me to discuss the results of your tests with you now?"* *"How do you prefer to discuss medical information in your family?"* *"Some people prefer a global picture of what is happening and others like to hear all of the details. Which do you prefer?"*
Knowledge	Give the medical information succinctly and then be quiet Use a "warning shot" so that the patient and family member can become more emotionally prepared (*"I have something serious we need to discuss…" or "The scans/labs didn't show what we hoped…"*) Summarize the big picture in a few sentences. Say it simply and then STOP (*"Your cancer has spread to your liver and seems to be getting worse despite our treatments."*) **Ask-Tell-Ask** – give small bits of information about the situation or condition; provide more detail once family has had the opportunity to ask questions Avoid medical jargon, use language that matches the family's level of understanding and education
Empathy	Respond to emotion; expect that the patient/family will have an emotional response (See NURSE) Use empathetic statements to respond to emotions associated with the news (*"This must be a shock to hear…"*) Respond to and validate emotions (*"I can't imagine how difficult this must be…" or "I know this is not what you expected to hear today"*) Name emotions, especially if patient or family is not verbally responding (*"I can see that you are upset…"*) Use **"I wish"** statements - (*"I wish we had better news for you…"*) Be silent and be fully present. Use pauses and wait quietly for the patient and family to respond
Summarize	Discuss next steps and a follow-up plan **Ask-Tell-Ask** – Verify the family's understanding (*"We've talked about a lot today, can you please tell me what you understand about where we are right now?"*) Review options and ask permission to make treatment recommendations based on identified goals values (*"Would it be ok if I make a recommendation? … Given what you have told me about your goals for ___, I would recommend…"*) Summarize decisions and next steps (*"Let's set up a follow-up. I will stop by tomorrow but if you need someone from our team in the meantime, here is how to contact us."*)



Goal Setting and Future Planning – The Goals of Care Discussion	
Establishing patient centered goals of care – The Five Cardinal Questions	1. Tell us about your child. What is s/he like as a person? What is a good day like for your child? 2. What have you heard from the doctors about what is going on with your child? How has this experience been for you and your child? 3. In light of what you know about what is going on with your child, what is most important to you? What are you hoping for? What else are you hoping for? 4. What worries do you have about your child's condition? What keeps you up at night? 5. Where do you find your strength? How well is that support working for you right now?
Ask permission to give recommendations	*"In light of what you have been telling me about all of the things that have been going on and your goals and hopes for your child, would it be helpful to hear my thoughts on the situation?"*
Recommend plan based on goals	Review current treatments, monitoring, tests, medications, etc. and determine if they are in line with patient's/family's goals Make a recommendation based on goals elicited. Be sure to use patient's/family's own words (*"Given what you have told me are your goals for your child, I would recommend…"*)



Common Pitfalls & Barriers to High Quality Communication
Giving too much information and details. Start with the big picture, keep it brief, and then keep quiet Not finding out about the family's information needs, making assumptions about what patients/families know or want to know Not including the child in the discussion and decision making process Not including all important decision makers in the conversation Pushing a family to make a decision before they have a chance to process the information

Source: Quick Communication Reference Guide, St Jude Children's Research Hospital

Glossary of terms

Child:	'Child' refers to everyone from birth to 18 years of age, including neonates and infants and young persons.
Family:	This term includes any people who are important to the dying child, including parents/carer(s), sibling(s), grandparent(s), extended family, kinship relationships, girl/boyfriend, friends etc.
Interprofessional Team (IPT):	Minimally consists of a Medical Officer and a Registered Nurse who are partners with the family, caring of the dying child and should involve Allied Health Care Team as appropriate
Medical Officer:	Doctor with delegated responsibility from the most senior treating doctor to make decisions related to commencing the dying child on the CPDC.
Nurse Practitioner:	A nurse practitioner is a registered nurse educated and authorised to function autonomously and collaboratively in an advanced and extended clinical role. *(Australian Nursing and Midwifery Advisory Council).* [37]
Paediatric Acute Resuscitation Plan (ARP)	The PARP is a medical order signed by the most senior doctor available and designed to provide clinical direction in the event of a patient's acute deterioration. The document records resuscitation planning outcomes following discussion with the family and child/young person if appropriate, and other members of the multidisciplinary team.
Paediatric Statement of Choices	The Paediatric Statement of Choices form focuses on a person's wishes and choices for health care into the future. An advance care plan, including the Statement of Choices, will only be used if a child/young person is unable to make or communicate their decisions.

Abbreviations

ACP	Advance care planning
AKPS	Australian-modified Karnofsky Performance Status
CPDC	Care Plan for the Dying Child
CSCI	Continuous subcutaneous infusion
IPT	Interprofessional team
HHS	Hospital Health Service
MET	Medical Emergency Team
PARP	Paediatric acute resuscitation plan
PRN	Pro re nata

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