Queensland Government

Care Plan for the Dying Child *(CPDC)*

Supporting care in the last days and hours of life

Facility: .....

(Affix identification label here)

URN:

Family name:

Given name(s):

Address:

Date of birth: Sex: ☐ M ☐ F ☐ I

- The CPDC aims to support compassionate, coordinated and best-practice care, but **does not replace clinical judgement**
- Care outlined in the CPDC **must be altered if it is not clinically appropriate** for the individual child/young person

Steps to Initiate the Care Plan for the Dying Child (CPDC)

**Can be initiated by nursing staff*

Medical Officer and a Registered Nurse to complete. *All 3 items must be **"Yes"** to commence the CPDC.*

1. **Has the child/young person been assessed by the Interprofessional Team (IPT) as being in the last days to hours of life?** ☐ **Yes**
2. **Does the child/young person have a current Paediatric Acute Resuscitation Plan (PARP) that states resuscitation is not to be provided?** ☐ **Yes**
3. **Does the lead medical team responsible for the child/young person's care endorse commencement of the CPDC?** ☐ **Yes**

Treating Consultant (print name):	Treating Team:	
Medical Officer (print name):	Signature:	Date: / /
Registered Nurse (print name):	Signature:	Date: / /
Nurse Practitioner (print name):	Signature:	Date: / /
Ward:	Date commenced: / /	Time commenced (24hr): :

Important Family Information

Parent/Carer (print name):	Relationship to patient:	Contact number:
Parent/Carer (print name):	Relationship to patient:	Contact number:

Other relevant information about family structure/systems:

Is the child/young person of Aboriginal and/or Torres Strait Islander origin? ☐ Yes ☐ No
If *yes*, has referral to Indigenous liaison officer been made? ☐ Yes ☐ No

Is the child/young person subject to a Child Protection Order (CPO)? ☐ Yes ☐ No
- If *yes*, contact your Hospital and Health Service (HHS) Child Protection Unit (CPU).
- Refer to *Care Plan for the Dying Child: Health Professional Guidelines, June 2019 Appendix* for further information.

Review Evidence of Advance Care Planning (ACP) Documentation

☐ My Wishes (children) ☐ Voicing My Choices (adolescent) ☐ Other documents
If yes, ensure copy is placed in medical notes ☐ Yes ☐ No

Are there any specific cultural, religious or spiritual considerations for care at end-of-life (EOL) and care after death?

Organ and Tissue Donation

Organ and tissue donation discussions should only be carried out by specially trained personnel from DonateLife Qld and the most senior treating doctor. Refer to local DonateLife team in your hospital or contact DonateLife Qld.

Care After Death

Will this death be reportable to the Coroner? If *yes*, refer to HHS policy. ☐ Yes ☐ No

Communication

Have you communicated this plan to the following: *(tick all appropriate)*

Primary treating team	☐ Yes	Digital alert - 'Care Plan for Dying Child'	☐ Yes
General Practitioner	☐ Yes	Initiate local process to share information with	☐ Yes
Other community services	☐ Yes	staff (e.g. room signage/IPT/ auxiliary)	

Specialist teams (specify): .....

Discontinuation of CPDC *(see decision-making guide on page 4 and complete only if applicable)*

Care Plan for the Dying Child document discontinued – Date: ..... / ..... / ..... Time (24hr): ..... : .....

New treatment and care options reviewed by the IPT and discussed with the parent/carer(s) as appropriate: ☐ Yes ☐ No

Document the reason for discontinuation of the CPDC and new treatment plan in the patient's medical chart.

DO NOT WRITE IN THIS BINDING MARGIN

CARE PLAN FOR THE DYING CHILD (CPDC)

v1.00 - 06/2019
SW962

Best-Practice Principles to Care for the Dying Child

This is a clinical guide and should not replace clinical judgement

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 the 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 non-essential 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); have organ and tissue donation requests 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.)

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Information for Health Professionals

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Aim of the CPDC

- A resource to guide clinical care in the last days and hours of life to support compassionate, coordinated, high quality care, when death is expected, that is tailored to the individual needs of the child/young person and family.
- Use the CPDC in conjunction with documents or processes, such as PARP or ACP (e.g. My Wishes, Voicing My Choices, other goals documented).
- The CPDC is comprised of:
  - Comprehensive **Care Plan** *(Sections 1.0–8.0)*
  - **Steps to Initiate CPDC and Best Practice Principles to Care for the Dying Child**
  - **Initial Assessment** *(Sections 1.0, 2.0 & 3.0)*
  - **Ongoing Assessment, Symptom Management and End-of-Life Care**
  - **Instructions for Psychosocial Support** *(Section 4.0)*
  - **Care After Death** *(Sections 5.0, 6.0, 7.0, 8.0)*

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.
- Comprehensive and clear communication is pivotal.
- All care decisions should be communicated to the family* and the child/young person, as appropriate. Refer to *Health Professional Guideline* for consideration of decision making for children/young person's (e.g. Child Protection, Gillick competent).
- 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/young person may live longer or die sooner than expected.
- If an inter-hospital transfer occurs, the CPDC may be photocopied and conveyed 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/young person as an altruistic gift for other families/children. Organ/tissue donations are only possible in a small number of situations.
- Contact your local or statewide DonateLife team for information and support: www.donatelife.gov.au.

Research

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

Documentation Instructions

- Document in the child/young person's medical record as per HHS policy.
- The CPDC is a legal document and must be completed as per HHS policy.
- CPDC Ongoing Assessment (SW963) additional pages are available for extended treatment.
- All IPT staff involved in the treatment of the child/young person must provide their name and signature on page 5.

Discontinuation

- On occasion, a CPDC may be discontinued.
- In this situation, if the child/young person's condition deteriorates, a new document must be commenced.

Additional Resources

- **Statewide Paediatric Palliative Care Service (PPCS)**. Phone: 1800 249 648.
- *Care Plan for the Dying Child: Health Professional Guidelines, June 2019*.
- 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.

Definitions* (for the purposes of the CPDC document)

- **Interprofessional Team (IPT):** Minimally consists of a Medical Officer and a Registered Nurse who are partners with the family in caring for the dying child/young person, and should involve Allied Health as appropriate.
- **Family:** This term includes any people who are important to the dying child/young person, including parent/carer(s), sibling(s), grandparent(s), extended family, kinship relationships, girl/boy friend, friends etc.

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Interprofessional Decision-Making Guide

Child/young person and family communication

Assessment and clinical decision-making

The child/young person's condition indicates deterioration and potential death within days or hours

- Exclude reversible causes for the child/young person's condition
- Consider consultation with specialist (paediatric) palliative care support and/or second opinion
- The child/young person's treating consultant that death is likely within days or hours?

Meet with family and/or interprofessional (IPT) to discuss child/young person's condition

Has it been acknowledged that the child /young person is likely to die within days or hours?

NO

- If 'No' to the above, do not commence the CPDC
- Reassess the child/young person and review their plan of care in consultation with the family
- Consider a second opinion

YES

- Commence CPDC
- Complete Initial Assessment *(sections 1.0, 2.0 and 3.0)*. An advanced care plan can be used to supplement information
- Record key IPT members on page 5

Individualised care planning

Management

Complete CPDC Ongoing Assessment

- Daily clinical review by a Medical Officer
- Minimum of hourly symptom assessment and comfort observations

CPDC is discontinued

If the child/young person improves:

- IPT reviews treatment and care options with family, as appropriate
- Consider referral to Paediatric Palliative Care Service and/or second opinion

Care after death

The child/young person has died

- Refer to Care After Death form *(sections 5.0, 6.0, 7.0, 8.0)*

The statewide Paediatric Palliative Care Service is available for advice and support regarding any aspect of care, especially if symptom control is difficult – 1800 249 648.
Consider referral to Retrieval Services Queensland, if appropriate.

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Supporting care in the last days and hours of life

(Affix identification label here)

URN:

Family name:

Given name(s):

Address:

Date of birth: Sex: ☐ M ☐ F ☐ I

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Interprofessional Team Caring for the Child/Young Person and their Family

Role	Print name	Contact Details

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Queensland Government

Care Plan for the Dying Child *(CPDC)*

Supporting care in the last days and hours of life

(Affix identification label here)

URN:

Family name:

Given name(s):

Address:

Date of birth: Sex: ☐ M ☐ F ☐ I

Initial Assessment Joint assessment by Medical Officer, Nurse and Allied Health

Overarching principles

- Initial Assessment can be completed over several conversations
- Review any completed Advanced Care Planning (ACP) documents for relevance prior to meeting with the family
- Establish an appropriate environment and consider the impact on the child/young person when having discussions with the family
- Prioritise the rights, wishes and preferences of the child/young person and family in all interactions
- Consider family's wishes, spiritual, religious and cultural beliefs 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. use "sad news" or "sorry business" rather than "death" or "dying")
  - 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/young person and their family

1.1 Provide the child/young person and their family, an explanation of the facilities and options available to them (e.g. after-hours access, staying overnight and how many family members can stay, tea and coffee facilities, toilets etc.) ☐ Yes ☐ No

1.2 Communication preferences

- What language does the family speak at home? .....
- Is an Interpreter required for the family and/or child/young person? ☐ Yes ☐ No

  Language: .....

  Interpreter contact information: .....

Name:	Role:	Signature:	Date: ... / ... / ....

1.3 Does the child/young person understand that they are dying? ☐ Yes ☐ No

- What does the child/young person know about their condition/prognosis? .....
- What language/phrasing is used to explain what is happening to them? .....

Name:	Role:	Signature:	Date: ... / ... / ....

1.4 Does the child/young person wish to participate in conversations about end-of-life care planning? ☐ Yes ☐ No

- If *no*, describe why (e.g. preferences, unable to due to age/development/condition etc.): .....

Name:	Role:	Signature:	Date: ... / ... / ....

1.5 Does the family understand that their child/young person is dying? ☐ Yes ☐ No

- What do the child/young person's family understand about their condition? Please describe preferred language/phrasing. .....
- Are there communication challenges within the family that staff should be sensitive of (e.g. parental preference for siblings, cultural considerations, family dynamics etc.)? .....

Name:	Role:	Signature:	Date: ... / ... / ....

DO NOT WRITE IN THIS BINDING MARGIN

Family name:	Given name(s):	URN:

Initial Assessment Joint assessment by Medical Officer, Nurse and Allied Health *(continued)*

Partnering with the child/young person and their family *(continued)*

1.6 Partnering with the child/young person and their family about EOL goals

- If possible, are there any family goals, special wishes or experiences that you would like us to help you achieve at this time (e.g. religious/spiritual/cultural practices, social, emotional, practical needs, environment etc.)?
  Child/Young person: .....
  .....
  .....
  .....
  Family: .....
  .....
  .....
  .....
- Who is important to you and your family at this time? Are there any limitations on visitors that you would like us to be aware of?
  .....
  .....
  .....
- What is important to you and your family in the last hours of life (e.g. religious/spiritual/cultural practices, where would you would like this to occur, who you would like to be there, special requests, music, family pets etc.)?
  Child/Young person: .....
  .....
  .....
  .....
  Family: .....
  .....
  .....
  .....
- What is important to you and your family for care after death (e.g. religious/spiritual/cultural practices, blessing/prayer, spending time at home or another location with your child/young person, funeral arrangements etc.)?
  Child/Young person: .....
  .....
  .....
  .....
  Family: .....
  .....
  .....
  .....
- Communicating this information to social networks and friends can be difficult. How can we support you to do this? (e.g. consider school, day-care, work, clubs, groups, specific staff etc.)? .....
  .....
  .....
  .....

Name:	**Role:**	**Signature:**	**Date:** ... / ... / ...

1.7 Is there anything else you would like/wish to tell us about your family? .....
.....
.....

- Is there anything else you would like to ask us? .....
  .....

Name:	**Role:**	**Signature:**	**Date:** ... / ... / ...

1.8 Psychosocial support and bereavement risk assessed: *(tick all that apply)*

☐ Refer to Social Work (wherever possible)	*Consider completing statewide Social Work Psychosocial Assessment tool*
☐ Financial stress	*Refer to Social Worker/Welfare Worker (consider supports for funeral costs)*
☐ Mental health	*Refer to Social Worker/Psychologist/CYMHS/Consultation Liaison*
☐ Sibling support/limited understanding	*Refer to Social Work/Occupational Therapy/Music Therapy*
☐ Spiritual/Cultural support	*Refer to Spiritual Carer/Chaplain/Cultural Advisor*
☐ Indigenous Health specific support needs	*Refer to Indigenous Hospital Liaison Officer/Indigenous Health Worker*

Name:	**Role:**	**Signature:**	**Date:** ... / ... / ...

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URN:

Family name:

Given name(s):

Address:

Date of birth: Sex: ☐ M ☐ F ☐ I

Initial Assessment Joint assessment by Medical Officer, Nurse and Allied Health *(continued)*

Assessment of the child/young person's medical and nursing care

2.1 The child/young person's diagnosis/review medical notes

- Primary diagnosis: .....
- Other relevant health history: .....
- Existing access and devices (e.g. subcutaneous lines, intravenous lines, feedings tubes, indwelling catheter): .....

Name:	Role:	Signature:	Date: / /

2.2 Baseline information about the child/young person's condition

☐ Alert	☐ Unable to swallow	☐ Anxiety
☐ Semi-conscious	☐ Seizures	☐ Pain
☐ Unconscious	☐ Confused	☐ Nausea/vomiting
☐ Dyspnoea/breathlessness	☐ Agitated/restless/irritability	☐ Bowel problems
☐ Respiratory tract secretions	☐ Distress	☐ Bladder problems

☐ Other: .....

Name:	Role:	Signature:	Date: / /

Symptom management is essential to ensure comfort at end-of-life (refer to *PRN Medication Guide* in Appendix of *Health Professional Guideline*)

- Pain/distress/fever
- Respiratory distress/dyspnea and/or secretions
- Nausea/vomiting/constipation
- Irritability/seizures/agitation/anxiety
- Skin care/pressure relief
- Bleeding risk

2.3 Pharmacological steps to ensure comfort

- Review and rationalise medication ☐ Yes ☐ No
- Consider alternate route for medication based on anticipated clinical decline (e.g. enteral or subcutaneous)
- PRN breakthrough medications ordered for current or expected symptoms:
  - Pain/distress/fever ☐ Yes ☐ No
  - Irritability/seizures/agitation/anxiety ☐ Yes ☐ No
  - Respiratory distress/dyspnea and/or secretions ☐ Yes ☐ No
  - Nausea/vomiting/constipation ☐ Yes ☐ No
  - Consider other anticipated symptoms related to the child/young person's disease process ☐ Yes ☐ No
- Check supply/stock of medications and place order as appropriate ☐ Yes ☐ No

Name:	Role:	Signature:	Date: / /

2.4 Non-pharmacological techniques to manage the child/young person's symptoms

- Refer to Children's Health Queensland (2014) *"A practical guide to palliative care in paediatrics"* for details on these non-pharmacological techniques
- Be guided by family recommendations regarding usual comfort care/previously successful strategies. Consider:

☐ Reposition plan (e.g. pressure mattress, pillows for comfort)	☐ Involvement of parent/carer(s) or sibling (e.g. reading books, talking to the child/young person)
☐ Skin-to-skin contact with parent/carer(s)	☐ Any spiritual comforts (e.g. meditation, prayer, rituals)
☐ Positive touch	☐ Heat pack
☐ Massage	☐ Ice chips
☐ Music/referral to Music Therapy	☐ Fan or open window (e.g. breeze access)
☐ Pet therapy	☐ Access to gardens/outdoor space
☐ Comfort toy:	

☐ Other: .....

Name:	Role:	Signature:	Date: / /

Medical/nursing interventions should be consistent with previously discussed goals of care (e.g. PARP or ACP).

DO NOT WRITE IN THIS BINDING MARGIN

Family name:	Given name(s):	URN:

Initial Assessment Joint assessment by Medical Officer, Nurse and Allied Health *(continued)*

Assessment of the child/young person's medical and nursing care *(continued)*

2.5 The child/young person's need for interventions is reviewed by IPT ☐ Yes ☐ No

- Review and rationalise care interventions to achieve goal of comfort and support care ☐ Yes ☐ No
- Cease routine observations of vital signs (unless continuation is requested by the family)
  - families may wish to continue specific interventions that are no longer necessary but have meaning to the child/young person and their family, and will not cause harm, particularly those that have been required long-term (e.g. antibiotics, oropharyngeal suctioning, anticoagulant therapy etc.)
- Review (commence/continue/discontinue) artificial nutrition and hydration (e.g. nasogastric tube [NGT]/percutaneous endoscopic gastrostomy [PEG] feeds, total parental nutrition). All decisions must be made in the child/young person's and family's best interest. Avoid emotive language (e.g. starving, dehydration)
- Maintain oral hygiene and mouth care particularly once oral intake has ceased

Name:	**Role:**	**Signature:**	**Date:** ... / ... / ....

2.6 Nursing assessment of the following undertaken:

Mouth care: .....

.....

Eye care: .....

.....

Bowel: .....

.....

Bladder: .....

.....

Hygiene: .....

.....

Skin integrity: .....

.....

Equipment needs: .....

.....

Name:	**Role:**	**Signature:**	**Date:** ... / ... / ....

2.7 Consider additional referrals to Allied Health/Support Services for child/young person and their family: (refer to HHS policy to complete referral procedure)

Tick all that apply	Name/contact details
☐ Art Therapy	
☐ Dietitian (DT)	
☐ Hospice	
☐ Physiotherapist (PT)	
☐ Speech Pathologist (SP)	
☐ Other:	

Name:	**Role:**	**Signature:**	**Date:** ... / ... / ....

Discussion of the plan of care

3.1 Has the care plan been discussed and negotiated with the family and child/young person (as appropriate) ☐ Yes ☐ No

- Name of persons present (e.g. parent/carer(s), child/young person, other family, and health professionals):

.....

.....

Name:	**Role:**	**Signature:**	**Date:** ... / ... / ....

3.2 Offer written resources to the child/young person and their family ☐ Yes ☐ No

- Paediatric Palliative Care Resources are available through Palliative Care Australia
- Select resources appropriate to the child/young person and their family

Name:	**Role:**	**Signature:**	**Date:** ... / ... / ....

Consider ways of facilitating parenting opportunities (e.g. involvement in care, "normal" parenting activities).

Commence "*Ongoing Assessment, Symptom Management and End-of-life Care*" (SW963)

DO NOT WRITE IN THIS BINDING MARGIN

Instructions for Psychosocial Support for the Child/Young Person and their Family

4.1 Talking to families about their child/young person who is dying

Principles	Practical ideas
• Active listening to hear the family's perception of the situation, especially their views on what they think their child/young person 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/young person best and we must be guided by them • Be aware of how our nonverbal communication can be interpreted by a child/young person. Even exclusion from contact communicates something • Be aware of issues, such as blame and guilt felt by either the parents or the child/young person 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	• 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 • When parents are separated and share parental responsibility, ensure parents are given the same information • Use open ended questions "what do you think your child/young person 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/young person now, and continue to use the phrases, stories, and examples they have used previously • Has the family/child/young person 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/young person

4.2 Talking to the child/young person and/or their siblings about death and dying

Principles	Practical ideas
• Listen to the child/young person. 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/young person, it is important to clarify what they think their child/young person knows, what words/phases they have used in the past, and what words/phrases they would prefer you to use with their child/young person • Ask if there are any specific words/phases that they don't want to be used when talking to their child/young person • A health professional's role is to help families talk with their child/young person and spend quality time with them • Answer the questions the child/young person has asked but do not overwhelm them with extra details	• Observe their behaviour and nonverbal responses, as cues to what may be worrying them • Reassure the child/young person 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/young person'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/young person has asked this directly of a health professional, consider the following responses: - "What do you think is happening?" - "What has mum/dad told you?" - "Is this something we can talk to mum/dad about?" *(delivered sensitively)*

4.3 Memory making/rituals *(refer to the QCH Memory Making guideline for further information)*

- 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/young person, is this something you would also like?"
  - "Some parents like to rest/or cuddle with their child/young person 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/young person and the family either before or after death
- Bereavement boxes may be available in your hospital (e.g. Precious Wings)

Instructions for Psychosocial Support for the Child/Young Person and their Family *(continued)*

4.3 Memory making/rituals *(continued)*

- Hand and foot moulds, and toe and finger print jewellery may be organised at the hospital. This can also be supported by the funeral home
- Hand and foot prints (inkless is 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/young person. This includes enabling the parent(s) to lie in the bed with their child/young person, hold in their arms, stroking, brushing their hair. Consider placing mattresses on floor or another bed beside the child's/young person's bed (if room allows).
- Bathing their child/young person. This can be done either using a baby bath, sponge bathing or using a special bathing bowl if available in the hospital
- Dressing their child/young person; reassure families that they do not need to choose "forever clothes" at this time
- Family singing to the child/young person or playing music. Consider contacting music therapy to provide music options (e.g. sessions, recordings, CD players)

4.4 Understanding the process of dying

- Families 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

Physical changes	Principles	Practical ideas
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/young person • Consider postural changes or medications • Consider some gentle background music to diffuse sound if noisy/rattly breathing is distressing to the family
Respiration changes	• Breathing may be rapid, shallow and irregular • Breathing may also slow with periods of apnoea, known as Cheyne-Stokes breathing • These symptoms may be present for a significant period of time	• This may be distressing to witness. Family will require reassurance that this is expected and is not distressing for their child/young person
Incontinence	• Caused by relaxation of the gastrointestinal and urinary tracts	• It is important for the family that their child/young person's dignity is respected • Consider a catheter, nappy/pad or disposable incontinence 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 • Caused by slow and irregular heartbeat as circulation of blood is decreased to the extremities • May also sweat profusely and be damp to touch	• Parents may wish to change the child/young person'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/young person's eye lids at the time of death
Bodily fluids	• 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/young person	• Family may find this very distressing if they are not prepared/aware of this possibility • 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 easy 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/young person

Queensland Government

Care Plan for the Dying Child *(CPDC)*

Supporting care in the last days and hours of life

(Affix identification label here)

URN:

Family name:

Given name(s):

Address:

Date of birth: Sex: ☐ M ☐ F ☐ I

Care After Death

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 5.3)* 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 back to the child/young person's parents (e.g. including after death care and arrangements)

Certification of Death

5.1 Is this death reportable to the Coroner? If *yes*, refer to HHS policy ☐ Yes ☐ No ☐ N/A

Name:	**Role:**	**Signature:**	**Date:** / /

5.2 Notify HHS Child Protection Unit, if subject to Child Protection Order ☐ Yes ☐ No ☐ N/A

Name:	**Role:**	**Signature:**	**Date:** / /

5.3 Is Life Extinct form required? ☐ Yes ☐ No ☐ N/A

- This form allows mortuary staff, funeral directors and police to remove and transport a person who is deceased
- This form can be completed by a Registered Nurse or a Medical Officer
- When a Cause of Death Certificate exists *(see Section 5.4)*, a Life Extinct form is not required

Name:	**Role:**	**Signature:**	**Date:** / /

5.4 Cause of Death Certificate (Form 9) completed within 48 hours according to HHS policy ☐ Yes ☐ No

- Ensure that all carbon copies are appropriately distributed
- For perinatal deaths (within 28 days of birth), complete additional Perinatal Supplement (Form 9A) ☐ Yes ☐ No ☐ N/A

Name:	**Role:**	**Signature:**	**Date:** / /

5.5 Death notification process completed as per HHS policy ☐ Yes ☐ No

Name:	**Role:**	**Signature:**	**Date:** / /

Care of the deceased child/young person

6.1 Care of the deceased child/young person undertaken according to child/young person's and family's wishes, and hospital policies and procedures

- Consider the following, as appropriate:

☐ Spiritual/cultural rituals as per Initial Assessment
☐ Advanced Care Plan/family goals as per Initial Assessment
☐ Discuss with family about removing medical tubes/devices
☐ Offer assistance with washing/dressing
☐ Cooling mat to preserve the child/young person's body
☐ Lowering room air-conditioning (if applicable)
☐ Music Therapy (if applicable)
☐ Transfer to quiet suite/room to spend additional time
☐ Transfer to home, hospital mortuary, hospice or other location to spend additional time
☐ Memory making offered (e.g. lock of hair, inkless hand and foot prints, photography, memory box)
☐ Facilitate extended family to participate in cares or in specific rituals
☐ Support for sibling/extended family

Name:	**Role:**	**Signature:**	**Date:** / /

6.2 Organ and tissue donation requests have been undertaken as per previous discussions ☐ Yes ☐ No

- If *no*, consider escalating to your team leader

Name:	**Role:**	**Signature:**	**Date:** / /

6.3 Have after death arrangements have been made? ☐ Yes ☐ No

- If *no*, consider referral to Social Worker, Bereavement Service or Spiritual Care Advisor to support this process

Name:	**Role:**	**Signature:**	**Date:** / /

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Family name:	Given name(s):	URN:

Care After Death *(continued)*

Care of the bereaved family (parents, siblings and grandparents)

7.1 Person(s) present at time of death: .....

.....

.....

.....

- If family member is not present, have they been notified? ☐ Yes ☐ No
  Name of person informed: ..... Relationship: .....

Name:	Role:	Signature:	Date: ... / ... / ...

7.2 The family can express an understanding of what they will do next? ☐ Yes ☐ No

- Consider whether the family have a support person/advocate to manage ongoing communications
- The family are given relevant supporting information and/or bereavement referral (if applicable):
  ☐ Parent/carer(s) ☐ Sibling(s) ☐ Grandparent(s)

Name:	Role:	Signature:	Date: ... / ... / ...

Other communication

8.1 The child/young person's death is communicated (as appropriate) to:

☐ Primary treating team ☐ Paediatrician ☐ Specialist teams
☐ General Practitioner ☐ Members of the Interprofessional Team ☐ School/Day Care (consent required)
☐ Community Service Providers ☐ Auxiliary staff (e.g. food services, ward, admin)

Name:	Role:	Signature:	Date: ... / ... / ...

Strategies

Care after the child/young person has died

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/young person
- Normalise this for the family and provide a management strategy:
  - anticipate bodily fluid by placing dark coloured sheets on the bed (where available)
  - ensure towels are easy accessible
  - place a waterproof under sheet on parent'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

Rigor mortis:
- Adjust the child/young person's position after they have died to ensure their body does not stiffen unsuitably
- Lie the body flat, where possible, with legs down/straight
- Place a favourite soft toy or rolled blanket under their chin, to prevent jaw relaxing into the 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, insufflon, in-dwelling catheter etc.)
- If the case is referred to the Coroner, medical tubes and devices may still be removed so long as they are retained. You can contact the 24 hour Coroner for advice as per HHS policy
- 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

Care after limited autopsy or tissue procurement:
- Additional nursing cares to the site
- Bandage placed

Post-Death MRI:
- Refer to HHS policy

Leaving hospital:
- Close lifts to public access (if able)
- Security may be able to facilitate a sensitive exit from the ward
- Consider if family or funeral home transportation can park in the ambulance bay (or similar) and notify security

Family considerations after the child/young person has died

Spending time with their child/young person:
- Health professionals can advocate for families to spend as much time as they need with their child/young person after they have died
- It is important that the family is given as much time as they need to perform important rituals and say their goodbyes
- Families may choose to take their child/young person home or to a special location after they have died. They will require the Life Extinct form to be completed by a Medical Officer or registered nurse, which must remain with the child/young person at all times
- Consider the family may want to carry their own child from the ward
- Consider cooling mats, and use of air-conditioning or dry ice to cool the child/young person's body (funeral homes may be able to assist with this)

Funeral homes:
- Financial support may be available to families. Consider referral to SW/Welfare
- Funeral homes may allow families to visit regularly, daily in some cases

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

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