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Clinical Excellence Queensland

Queensland Clinical Guidelines

Translating evidence into best clinical practice

Clinical Guideline

Palliative and end-of-life care for babies

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Acknowledgement

The Department of Health respectfully acknowledges the Traditional Owners and Cultural Custodians of the lands, waters and seas across Queensland. We pay our respects to Elders past and present, while recognising the role of current and future leaders in shaping a better health system.

Disclaimer

This guideline is intended as a guide and provided for information purposes only. The information has been prepared using a multidisciplinary approach with reference to the best information and evidence available at the time of preparation. No assurance is given that the information is entirely complete, current, or accurate in every respect.

The guideline is not a substitute for clinical judgement, knowledge and expertise, or medical advice. Variation from the guideline, taking into account individual circumstances, may be appropriate.

This guideline does not address all elements of standard practice and accepts that individual clinicians are responsible for:

- Providing care within the context of locally available resources, expertise, and scope of practice
- Supporting consumer rights and informed decision making, including the right to decline intervention or ongoing management
- Advising consumers of their choices in an environment that is culturally appropriate, and which enables comfortable and confidential discussion. This includes the use of interpreter services where necessary
- Ensuring informed consent is obtained prior to delivering care
- Meeting all legislative requirements and professional standards
- Applying standard precautions, and additional precautions as necessary, when delivering care
- Documenting all care in accordance with mandatory and local requirements

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Flowchart: Model of care and principles of palliative and end-of-life care for babies

Any baby (in utero or post-natal) requiring palliative and end-of-life care

Model of care overview

Diagnosis
- Discuss—prognosis (quiet, private environment)
- Introduce—palliative care principles (early)
  - Can be concurrent with curative or disease-modifying treatment
- Support—early referral and connection
- Allocate—a key point/s of contact
  - To coordinate care and maintain communication

Condition-specific care planning
- Use multidisciplinary teams
- Update plans regularly based on:
  - Baby's condition/changes
  - Parent and family values, goals and preferences
- Plan:
  - Delivery mode
  - Location of care
  - Resuscitation plans
  - Pain and symptom management/ comfort care
  - Considerations for provision of nutrition
  - Medical Interventions
  - Spiritual and cultural considerations—blessing, naming ceremony
  - Memory making
  - Sibling support—if applicable

Palliative care
- Focus on:
  - Symptom management
  - Comfort and dignity
  - Quality of life
- Memory-making
- Reduce or withdraw of life-prolonging treatments
- Coordinate curative and palliative care approaches

End-of-life and bereavement care
- Shift focus to:
  - Comfort
  - Dignity
  - Emotional support
- Integrate bereavement planning and memory-making activities into care
- Provide ongoing support to families

Anticipatory planning
- Advance Care Planning
  - Commence early
  - Review regularly
  - Multidisciplinary input
- Parallel planning
  - Plan for ongoing care alongside end-of-life care
  - Plan for unexpected outcomes
- Investigation planning
  - Antenatal—inform prognosis, guide planning, enable early multidisciplinary care
  - Postnatal—assess condition, confirm diagnosis, guide symptom management
  - After death—inform future pregnancies, contribute to clinical knowledge

Principles
- Care begins at diagnosis (antenatally or postnatally)
- Care is:
  - Active and planned
  - Flexible and responsive
  - Holistic, integrated and supportive
  - Family-centred
  - Delivered by a coordinated, multidisciplinary team
  - Delivered across hospital, hospice, home, community and relevant Aboriginal and Torres Strait Islander community health services
- Focus on—comfort, dignity, baby's best interests
- Partner with parents and families
- Develop individualised care plans
- Respect family values
- Consistent, coordinated, and compassionate support for families
- Support:
  - Continuity, memory-making, bereavement
  - HCP through education and debriefing

HCP: Healthcare providers/professionals

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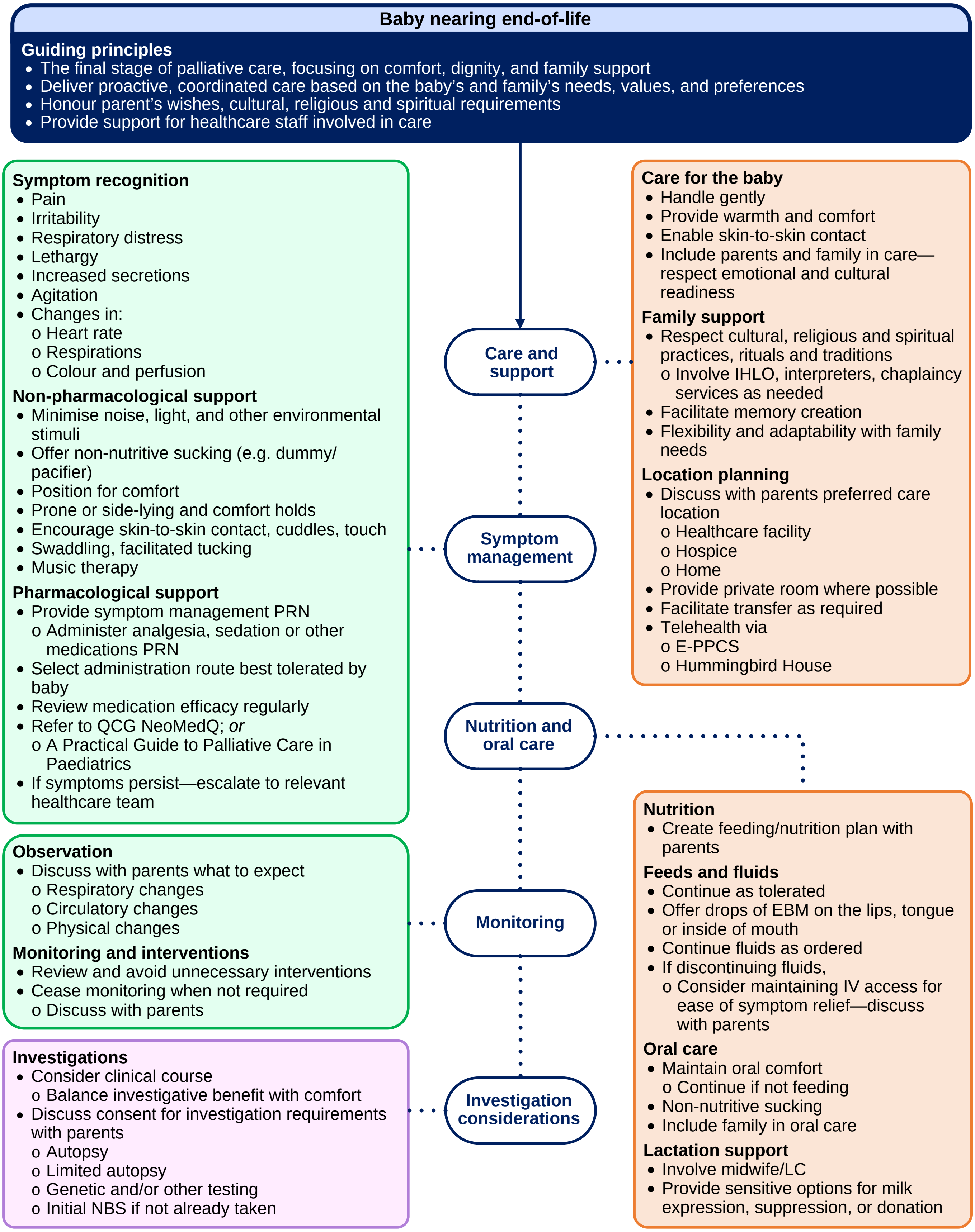
Flowchart: End-of-life care



Baby nearing end-of-life

Guiding principles

- The final stage of palliative care, focusing on comfort, dignity, and family support
- Deliver proactive, coordinated care based on the baby's and family's needs, values, and preferences
- Honour parent's wishes, cultural, religious and spiritual requirements
- Provide support for healthcare staff involved in care

Care and support

Care for the baby

- Handle gently
- Provide warmth and comfort
- Enable skin-to-skin contact
- Include parents and family in care—respect emotional and cultural readiness

Family support

- Respect cultural, religious and spiritual practices, rituals and traditions
  - o Involve IHLO, interpreters, chaplaincy services as needed
- Facilitate memory creation
- Flexibility and adaptability with family needs

Location planning

- Discuss with parents preferred care location
  - o Healthcare facility
  - o Hospice
  - o Home
- Provide private room where possible
- Facilitate transfer as required
- Telehealth via
  - o E-PPCS
  - o Hummingbird House

Symptom management

Symptom recognition

- Pain
- Irritability
- Respiratory distress
- Lethargy
- Increased secretions
- Agitation
- Changes in:
  - o Heart rate
  - o Respirations
  - o Colour and perfusion

Non-pharmacological support

- Minimise noise, light, and other environmental stimuli
- Offer non-nutritive sucking (e.g. dummy/ pacifier)
- Position for comfort
- Prone or side-lying and comfort holds
- Encourage skin-to-skin contact, cuddles, touch
- Swaddling, facilitated tucking
- Music therapy

Pharmacological support

- Provide symptom management PRN
  - o Administer analgesia, sedation or other medications PRN
- Select administration route best tolerated by baby
- Review medication efficacy regularly
- Refer to QCG NeoMedQ; *or*
  - o A Practical Guide to Palliative Care in Paediatrics
- If symptoms persist—escalate to relevant healthcare team

Nutrition and oral care

Nutrition

- Create feeding/nutrition plan with parents

Feeds and fluids

- Continue as tolerated
- Offer drops of EBM on the lips, tongue or inside of mouth
- Continue fluids as ordered
- If discontinuing fluids,
  - o Consider maintaining IV access for ease of symptom relief—discuss with parents

Oral care

- Maintain oral comfort
  - o Continue if not feeding
- Non-nutritive sucking
- Include family in oral care

Lactation support

- Involve midwife/LC
- Provide sensitive options for milk expression, suppression, or donation

Monitoring

Observation

- Discuss with parents what to expect
  - o Respiratory changes
  - o Circulatory changes
  - o Physical changes

Monitoring and interventions

- Review and avoid unnecessary interventions
- Cease monitoring when not required
  - o Discuss with parents

Investigation considerations

Investigations

- Consider clinical course
  - o Balance investigative benefit with comfort
- Discuss consent for investigation requirements with parents
  - o Autopsy
  - o Limited autopsy
  - o Genetic and/or other testing
  - o Initial NBS if not already taken

EBM: expressed breast milk; **E-PPCS:** Paediatric Palliative Care Service Telehealth; **IHLO:** Indigenous Health Liaison Officer; **IV:** intravenous; **LC:** Lactation Consultant; **NBS:** Newborn bloodspot screening; **PRN:** pro re nata/ as required; **QCG:** Queensland Clinical Guidelines

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Flowchart: After death care

No further signs of life present in baby

Guiding principles

- Care that is:
  - o Flexible and responsive
  - o Holistic in approach
  - o Integrated and supportive—end-of-life care tailored to individual family needs
- Support continuity, comfort, dignity, memory-making, and bereavement
- Focus on compassion and family-centred care throughout the journey

Care of the baby

Care of the baby

- Handle the baby's body gently and respectfully
- Disconnect all monitoring leads
- Remove lines, cannulas, tubes, tapes
  - o Discuss with coroner if uncertain about removal—in cases of reportable deaths
- Refer to local policy for cooling requirements

Family involvement:

- Support parents in ADC
  - o Hospice care is an option for ADC at parents request
- Consider location
- Quiet/ private spaces where possible
- Support memory creation
- Lead by parent wishes and pace
- Reassure parents there is no time limit

Investigation considerations

Investigations

- Identify postmortem investigation requirements in care plan and/or health record
  - o Including NBS—if initial screen not taken
- Explain purpose, process, timeframes

Autopsy

- Discuss with parents
- Consent completed

Coroners case

- If death requires coronial investigation—contact coroner
  - o If unsure, phone coroner for advice
- Lines, tubes, cannulas may be removed—unless directly related to cause of death
- Coronial investigation does not preclude parents from spending time with baby—discuss with coroner if uncertain

Administration considerations

Administration

- Complete documentation including:
  - o Cause of Death Certificate (form 9)
  - o Perinatal supplement (form 9A)—if baby less than 28 days of age
  - o Form 1A—if coronial investigation required
  - o Check local policy for procedure of transfer of deceased to the mortuary
- Notify GP and other relevant HCP
  - o Including referring obstetric, paediatric and midwifery teams if baby was retrieved as well as retrieval services

Support considerations

Bereavement support

- Recognise grief is a normal human response and differs for each individual and family
  - o May fluctuate over time
  - o Grieving is individual and respected
- Affirm parents' identities and parental role

Cultural, spiritual &/or religious

- Honour cultural, spiritual, religious preferences
- May include:
  - o Taking baby home
  - o Rituals, traditions
- Involve IHLO, interpreters, chaplaincy services as needed

Discharging baby

From hospital

- Follow local protocol
- Support transport to preferred location if required
  - o Life Extinct Form complete—to stay with baby at all times
  - o Complete required paperwork—refer to Administration above
- If not leaving hospital
  - o Follow local protocols for after-death care
- Notify relevant healthcare providers of death

From home

- Provide relevant paperwork
- Advise parents on next steps
  - o Who to contact
  - o When to contact funeral home
  - o Who is responsible for final handover

Follow-up and future pregnancies

Follow-up and support

- Offer grief and bereavement support and referrals according to parent wishes
- Facilitate follow-up
  - o Including postpartum appointments where required
- Discuss:
  - o Clinical course of baby
  - o Postmortem investigations if required

Subsequent pregnancies

- Provide information and referral for future pregnancy planning
- Acknowledge a different model of care may be required

ADC: After death care; **GP:** General Practitioner; **HCP:** Healthcare providers/professionals; **IHLO:** Indigenous Health Liaison Officer; **MO:** Medical Officer; **NBS:** Newborn bloodspot screening

Flowchart: F26.82-3-V1-R31

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Abbreviations

ADC	After death care
CSCF	Clinical services capability framework
EOL	End-of-life
E-PPCS	Telehealth Paediatric Palliative Care Service
PPCS	Paediatric Palliative Care Service
QoL	Quality of life
TOP	Termination of pregnancy

Definitions

Advance care planning	A process of reflection and discussion where preferences, values and beliefs help guide future care[1]
Anticipatory grief	Also referred to as anticipatory loss or preparatory grief, is the distress a person may feel in the days, months or even years before the death of a loved one or other impending loss.[2]
Baby	In this guideline, a baby refers to the fetus (before birth) and the newborn, from antenatal diagnosis through the perinatal and neonatal period, including ex-extremely preterm babies who may remain in a neonatal unit beyond the “neonatal” period.
Comfort care	Aims to maximise comfort for both patients and their families, near the end of life, and may include support for families and help with practical tasks, in addition to managing physical symptoms.[3]
Congenital anomaly	A physical malformation, chromosomal disorder or metabolic abnormality that is present at birth, however may only become apparent later in life.[2]
Disenfranchised grief	Grief experienced when a person's loss is not recognised, validated, or supported by society, making it challenging for the bereaved to express, process, or integrate their feelings due to a lack of acceptance or acknowledgment.[4]
E-PPCS	E-PPCS is a component of the PPCS, focusing on telehealth and aims to support families caring for a child with a life-limiting condition who reside in regional, rural, and remote areas of Queensland.
End-of-life care	Care that provides physical, emotional, and spiritual support to patients, families and carers in the period leading up to and at the time of death and includes respectful care after death.[5,6]
Life-limiting condition	Those conditions that cannot be cured and where death is likely.[7]
Life-threatening condition	Those conditions that may be cured, but where treatments may not be successful, and death may occur.[7]
Multidisciplinary approach	A team-based model where professionals and non-professionals from different disciplines work together, coordinate efforts, and communicate extensively to deliver comprehensive, holistic, and coordinated patient-centred care.[8] The team may include, but is not limited to, nurses, midwives, obstetricians, neonatologists, paediatricians, nurse practitioners, specialists (e.g. palliative care, hospice, maternal-fetal medicine), general practitioners, allied health professionals, community leaders and Elders.[2]
Palliative care	An approach focused on enhancing the quality of life for patients and their families who are facing a life-limiting and/or life-threatening illness, aiming to prevent and ease suffering through early recognition, thorough assessment, and effective management of symptoms.[5]
Parallel planning	An approach used when outcomes are uncertain, involving planning for both possible survival and potential deterioration or death. Enables open discussions about care wishes and helps coordinate services for different scenarios.[9]
Parents or baby’s family	The individual(s) who has/have the primary responsibility for the emotional and physical care of a baby—mother, father, parent, caregiver, legal guardian, primary care giver, kinship relationship, surrogate parent, birth parent.[10]
Partner/s	A person in a shared relationship with another—spouse, husband, wife, support person, de facto partner, boyfriend, girlfriend, primary emotional relationship, significant other.[10]
Perinatal palliative care	Palliative care that begins in pregnancy, is a holistic, multidisciplinary model of care for both baby and family in the event of an antenatal diagnosis of a life-limiting and/or life-threatening condition.[11]
Psychosocial issues	Problems that arise from the complex interaction between social and psychological factors, affecting a person's mental, emotional, and social well-being—can include anxiety, depression, and grief, environmental stressors (e.g. family conflict, domestic violence and financial difficulties).[12]
Trauma-informed care	Care and service delivery based on an understanding of the impact of trauma and the possibility of underlying trauma in all people. Strengths-based approach that aims to minimise risk of trauma related distress during care. Core principles include safety, trust, choice, collaboration and empowerment.
Woman/women	QCG recognise that individuals have diverse gender identities. In QCG documents, although the terms *woman* and *women* are used, these guidelines are inclusive of people who are pregnant or give birth and who do not identify as female.[10]

1 Introduction

Perinatal and neonatal palliative care, including end-of-life care, provides compassionate, holistic support to babies diagnosed with life-limiting or life-threatening conditions and their families throughout the perinatal and neonatal period.[13] Palliative care begins at diagnosis and may be provided alongside curative or disease-modifying treatments, maintaining continuity throughout the baby's journey. Through a coordinated, family-centred approach, this care upholds dignity, respect, and individual values at every stage.[14,15] Culturally safe care is fundamental; it recognises and honours diverse beliefs and practices, which are integrated into decision-making and tailored to each family's unique circumstances, needs, and values.[16,17]

1.1 Clinical standards

Table 1. Clinical standards

Aspect	Consideration
Palliative and end-of-life care principles	• Care that is active and planned from diagnosis, flexible, holistic, integrated, and supportive to individual family needs[2] • Delivered by a coordinated multidisciplinary team across hospital, hospice, home and community • Concurrent with curative treatment when appropriate[6] • Supports continuity, comfort, dignity, memory-making, and bereavement • Emphasises compassion and family-centred care throughout
Ethical and legal principles	• Focus on comfort, dignity, and the baby's best interests[18,19] • Parents are the primary decision-makers, supported with clear, transparent information[20] • Respect family values and provide multidisciplinary, collaborative care • Comply with Queensland legislation[21,22] and professional standards[23] • Acknowledge emotional and ethical challenges, supporting families and healthcare providers with compassionate care and guidance[11,24,25]
Goals	• Identify family's understanding of the baby's condition and information needs • Ascertain preferences and priorities for palliative and end-of-life care • Partner with parents and families to create individualised plans addressing physical, emotional, and cultural needs • Provide information to support informed decision-making • Initiate early referrals to establish multidisciplinary, collaborative care including for psychosocial support, medication management, non-pharmacological symptom management and nutrition
Continuity of care	• Where available, a main contact person may provide families with consistent, coordinated, and compassionate support o Seamless communication among all team members and the family o Practical supports and ongoing connection to resources and services • This key contact role may change according to care stages and service capability o Antenatal (maternal-fetal medicine, obstetrics or midwifery teams) o Postnatal (neonatology, paediatric or nursing/midwifery teams) o May also include healthcare providers from other disciplines/teams
Documentation	• Maintain comprehensive, formal documentation of care plans, decisions, and clinical rationales • Use standardised advance care planning documents[12] • Detail the agreed care plan and any changes that occur[9,12,23,2,26]
Standard care	• Refer to Queensland Clinical Guideline *Standard care*[27] for care considered 'usual' or 'standard' o Includes for example: privacy, consent, continuity of care and carer, decision making, sensitive communication, medication administration, staff education and support, culturally appropriate care

1.2 Model of care overview

Table 2. Model of care overview

Aspect	Consideration
Diagnosis and uncertainty	• Approach discussions honestly, empathetically, and with awareness of parental readiness • Introduce palliative care principles early, even when prognosis is uncertain • Initiate psychosocial support early for emotional and practical help o Can be guided by allied health healthcare professionals as well as by community support groups as appropriate • Coordinate care continuity with a key contact throughout pregnancy and neonatal periods as well as after death
Condition-specific care planning	• Involve multidisciplinary teams tailored to the baby's needs o Early referral to allied health professionals to establish baseline goals of care • Plan delivery mode, care location, resuscitation, medical interventions, and comfort measures • Use multidisciplinary assessments covering clinical, spiritual, and community needs • Regularly review and adapt plans according to baby's condition and family preferences • Refer to Table 6. Anticipatory planning
Palliative care	• Focus on symptom management and comfort • Review and adjust interventions based on condition and goals • May include reduction or withdrawal of life-prolonging treatments after discussion and consent with parents and family • Coordinate curative and palliative approaches focusing on quality of life (QoL)
End-of-life care	• Emphasise comfort, dignity, and emotional support for baby and family • Facilitate anticipatory prescribing and integrate bereavement planning and memory-making[27] • Continue emotional and practical support for families during and after the dying process[28]
After death/ bereavement care	• Provide sensitive and culturally appropriate support to families immediately following the baby's death • Facilitate memory-making practices and rituals as desired by the family • Support families in navigating administrative processes (e.g. death certification and funeral arrangements) • Offer ongoing emotional, psychological, and spiritual support through bereavement services and community resources • Maintain continuity of care and follow-up, recognising the long-term impact of loss on families • Refer to Section 4. Supportive care

1.3 Communicating with parents

Table 3. Communicating with parents

Aspect	Consideration
Principles	• Support families through uncertainty, decision-making, and grief • Emphasise early initiation of palliative care at the point of diagnosis and continuity through bereavement • Highlight value of multidisciplinary collaboration and continuity across settings • Provide clear and compassionate conversations about palliative and end-of-life care using plain language without jargon or euphemisms[28] • Recognise flexible service models including telehealth and outreach
Communication approach	• Utilise conversation points that integrate evidence-based communication techniques to empower families, reduce confusion and distress • Promote collaborative care in line with best practice in perinatal palliative care and effective healthcare communication[29] • Families experiencing acute distress may need to hear key information more than once. o Routinely check understanding, revisit discussions, and document conversations • Refer to Table 4. Example conversation points
Parent-centred communication and supported decision-making	• Use clear, sensitive, and nonjudgmental verbal and non-verbal communication—provide consistent communication and information across the multidisciplinary team • Respect and honour family values, beliefs, and wishes • Reassure families of compassionate care during transitions • Provide private spaces for important conversations[28] • Use culturally sensitive communication to reduce anxiety[16] • Support informed parental decision-making[28] • Prepare families for the dying process and involvement options[18] o Refer to Table 12. What to expect during the dying process
Communicating when parents disagree	• Allow parents to voice opinions and concerns in a safe environment • Focus remains on the baby's best interests while supporting family dynamics • Affirm baby's right to high-quality palliative care • Facilitate open communication and revisit discussions • Engage multidisciplinary support including social workers, cultural advisors, and counsellors where appropriate and required
Communication tools	• Use visual aids, care pathways, and written summaries[30] • Provide materials in: o Multiple languages—use interpreter if required o Culturally appropriate formats[31] o Formats appropriate for those with low literacy levels, learning disabilities, acquired disabilities • Employ structured handover protocols for clear, consistent team communication[27] o Use communication tools (e.g. decision aids or digital care plans accessible to all healthcare providers)
Multidisciplinary collaboration	• Engage a multidisciplinary care team[30] and clarify roles with parents[32] o Avoid introducing parents and family to unknown/unfamiliar clinicians during important/critical meetings wherever possible • Designate a main contact person to facilitate family communication and support[33] • Collaborate with a multidisciplinary approach for continuity after discharge[14] [refer to definitions]
Regional, rural and remote guidance	• Incorporate use of telehealth and outreach programs o Telehealth Paediatric Palliative Care Service (E-PPCS) as well as Hummingbird House are available statewide services to support families in rural and remote areas [refer to Appendix A. Key contacts] • Partner with local healthcare providers and resources to access specialist palliative care services where available[14]

1.3.1 Example conversation points

Table 4. Example conversation points

Area	Example Content
Introduction	• "You might feel many emotions and have many questions after hearing about your baby's condition" • "We are here to give you clear information and to respect your family's values and wishes" • "We will work with you, so you feel involved and supported at every step"
Building rapport with families	• "What do you understand so far about your baby's condition?" • "Before I explain more, what have you been told about [baby's diagnosis/condition]?"
Principles of care planning	• "Share with us what matters most to you. What are your hopes and beliefs for your baby's care" • "Your choices guide every part of the plan. You will always be listened to" • "You can include anyone who is important to you when you talk with us"
Advance care planning and supported decision-making	• "You can make care plans to show your wishes about comfort and medical care. We update these as your choices or your baby's needs change and help with all forms and documents" • "Many parents say that in their head they understand how sick their baby is, but their heart tells them not to let go. We are all hoping things go well for your baby. It's important to also think about what we would do if things don't go so well. So we can hope for the best and plan for the rest"[34] • "Take your time to ask questions and talk about options. We respect your choices and promise to communicate clearly as you make decisions"
Roles of the care team	• "Many specialists look after your baby. We will introduce them, explain roles, and give you one or two main contacts for support and communication"
Rural and remote support	• "If you live far away, we can connect you with telehealth and local healthcare providers, so you get support close to home" • "Would you prefer to be cared for closer to home?"
Cultural engagement	• "Would you like us to include family, Elders, or an Aboriginal and Torres Strait Islander Hospital Liaison Officer for support?" • "How should we talk about your baby? Do you want us to call them by their name or something else?" • "Are there any ceremonies or cultural practices you want to do; do you need help to organise these?" • "Please share what matters most so we can honour your family's language, values, and wishes"
Anticipatory grief and emotional support	• "We can only imagine how difficult and uncertain this time is" • "It's ok to feel a wide range of emotions including grief, hope, anxiety, and sadness" • "We're here to listen, and connect you with emotional and community support"
Creating memories and meaning	• "Many families choose to make memories with their baby, like taking photos or footprints; we can talk about these options and help create moments that feel meaningful for you" • "Families have shared making these memories help give comfort in the times ahead" • "Although it's hard now, many parents look back and really value the time they spent with their baby" • "The amount of time you would like to spend with your baby is your choice; there is no right or wrong way to do this""
Ongoing communication and support	• "We'll keep reviewing your care plan together, so it meets your wishes and your baby's needs" • "You can change your decisions at any time. We continue to support you before, during, and after your baby's birth"
Conclusion	• "You are not alone on this journey" • "We respect your values and aim to provide kind care at every step • "We'll continue to support you after your baby's death, and help with any follow-up you need"

1.4 Culturally responsive care

Table 5. Culturally responsive care

Aspect	Consideration
Culturally safe care	• Respect each family's cultural, spiritual, and personal values, recognising diverse identities, family structures, and beliefs[35] • Provide inclusive, non-assumptive care that values kinship, spirituality, community, and connection to Country as central to wellbeing[15,36,37] • Support culturally and linguistically diverse, LGBTQIA+, and other marginalised groups • Acknowledge and address cultural assumptions, communication styles, and the effects of intergenerational trauma and systemic racism, especially for Aboriginal and Torres Strait Islander families[2] • Work in partnership with Aboriginal and Torres Strait Islander Community Controlled Health Organisations, recognising that standard palliative models may feel distant o Involve Aboriginal and Torres Strait Islander Health Workers, specialist palliative Aboriginal Health Workers and/or Hospital Liaison Officers in advance care planning as appropriate[5,36]
Rituals and ceremonies	• Actively support and document cultural practices, spiritual, and religious rituals throughout palliative, end-of-life and after death care—acknowledge these may differ between communities[16] • Honour traditional healers and ceremonies like smoking rituals, singing, and gatherings that support spiritual needs during and after dying
Communication	• Engage in community consultation, respecting each community's unique protocols and spokespersons for appropriate care[32,37-39] o Ask parents and families what their preferences and wishes are—do not assume based on cultural background • Respect traditions that govern naming and image use[32] • Avoid using direct terms like death or dying; euphemisms may be preferred—particularly for Aboriginal and Torres Strait Islander peoples (e.g. passing or passed away)[40] o Discuss language preferences with individual families • Initiate early, culturally sensitive conversations about care and grief, involving the whole family when appropriate • Offer spiritual and culturally sensitive grief counselling before and after death to aid family healing
Environment	• Create flexible, welcoming care environments o Honour family preferences regarding care locations and culturally significant surroundings • Consider transfer to enable birthing or dying on Country[38,41] o Work in partnership with the primary health service, families and the community[32] o Contact local hospital and health services to investigate possibilities[32] o Acknowledge the deep connection to Country of Aboriginal and Torres Strait Islander peoples • Encourage bringing in objects from Country—(e.g. leaves or plants from, sand, rocks or other objects of cultural significance)
Rural and remote cultural care	• Engage local cultural advisors, Elders, and liaison officers early in care planning process[38,42] o Where local liaison officers are unavailable, identify community-endorsed representatives • Adapt care practices flexibly to reflect the diverse cultural expressions and health beliefs within rural and remote communities[43] • Use telehealth and community networks where access is limited[44]
Education and awareness	• Adapt communication pace, style, and approaches to meet family needs, allowing extended consultation time where required[41] • Awareness of personal cultural competence—seek guidance or cultural consultation when unfamiliar with a family's values or practices[45] • Encourage open dialogue with parents and families to understand specific cultural needs and preferences[46] • Promote training in cultural humility, safety, and competence, particularly in working with Aboriginal and Torres Strait Islander families, to improve outcomes and reduce health disparities[16,42] o Include reflective practice and debriefing to address unconscious bias

2 Care planning and referral

Discussing a palliative care approach with parents and families requires sensitivity and timing. Clear communication, informed decision-making, and careful documentation support the foundation for culturally respectful, holistic care.[36] Early engagement helps tailor support to the unique values and needs of the family[47], and allows early engagement with palliative care services and planning.

2.1 Guiding principles for advance care planning

Table 6. Anticipatory planning

Aspect	Consideration
Principles	• Initiate advance care planning at point of diagnosis • Guide care based on parental decisions and wishes • Recognise and validate baby antenatally and postnatally o Seek guidance from parents regarding the use of baby's name[48,49] • Offer parents the option to include support persons during discussions[2]
Advance care planning	• Develop and regularly update care plans[47,50]—make available to all healthcare providers across different settings • Enable families to express values and hopes to guide care plans • Include multidisciplinary team in advance care planning, incorporating assessments from relevant team members • Discuss and complete relevant documents : o Paediatric Acute Resuscitation Plans (PARP) or equivalent o Care Plan for the Dying Child (CPDC) • Refer to Appendix B. Quick guide to forms and care plans
Parallel planning	• Prepare families through parallel planning before birth for possible scenarios during pregnancy and after delivery[2] • Plan for ongoing care alongside end-of-life care, considering the unpredictable course of conditions by developing multiple care plans o Planning for life whilst also planning for death allows a baby's full potential to be achieved • Encourage families to explore their wishes for different circumstances • Practice proactive parallel planning by delivering end-of-life care as needed with continuation of comprehensive support from local services
Investigation planning	**Antenatal** • Conduct screening/investigation during pregnancy to identify life-limiting or life-threatening conditions or anomalies o May include ultrasound, or invasive testing (e.g. chorionic villus sampling (CVS) or amniocentesis, advanced imaging or other diagnostic procedures) • Aim to inform prognosis, guide care planning, and facilitate early involvement of palliative care and specialist teams and family support
	Postnatal • After birth, assess the baby's condition, confirm diagnosis, and guide symptom management o May include clinical examinations, blood tests, imaging, specialist consultation as well as consideration of placental histopathology • Focus on balancing investigative benefits with comfort, minimise invasive procedures unless needed for symptom relief or treatment decisions
	After death • Conducted to understand cause, identify or confirm diagnosis, and provide closure for the family, where this information is not already available, to inform future pregnancies and contribute to clinical knowledge • Can include full autopsy, limited postmortem, genetic testing, or tissue sampling, newborn bloodspot screening (NBS), advanced imaging • Requires sensitive discussion with family to obtain informed consent, respecting cultural and personal values • Inform families results from autopsies and postmortem investigations can take several months and may not yield conclusive results or diagnosis
Location planning	• For antenatal diagnosis—determine the safest and most appropriate setting for birth and subsequent care based on clinical and family needs • Consider proximity to family and support networks when choosing location • Evaluate availability of specialised equipment and healthcare providers • Refer to Table 8. Transfer and transport planning

2.2 Referral and consultation

Table 7. Referral and consultation

Aspect	Consideration
Timing	• Refer families to healthcare providers experienced in perinatal and neonatal palliative care soon after antenatal confirmation of a life-limiting or life-threatening condition[51,52] o Supports early engagement o Facilitates advance care planning[23,25] • Make prompt postnatal referrals after diagnosis or recognition of palliative care needs[2,53] • Guide timing of referral by the family's readiness and preferences for involvement of relevant services • Referral to palliative care services, or similar, does not signal withdrawal of active treatment–aims to enhance QoL and support family wellbeing
Consultation options	• Children's Health Queensland's Paediatric Palliative Care Service (PPCS) supports families statewide through a network of providers o PPCS collaborates closely with the baby's primary healthcare team, including general practitioners or paediatricians[18] o E-PPCS collaborates via telehealth to provide support to families residing in regional, rural and remote areas of Queensland[18] • Hummingbird House can provide ongoing support after hospital discharge[54] o Offer coordinated multidisciplinary statewide care and advice and family support tailored to the baby's and family's needs[55] • Refer to Appendix A. Key contacts for detailed information • Refer to Appendix B. Quick guide to forms and care plans

2.3 Transfer and transport planning

Table 8. Transfer and transport planning

Aspect	Consideration
Transfer destinations	• Facilitate transfers to a hospice, hospital closer to home, or private residence according to family wishes and clinical appropriateness[56] o Offer return to Country options for Aboriginal and Torres Strait Islander families[32] • Confirm that the receiving location can provide necessary supportive care • Make provisions for cultural, spiritual, and psychosocial needs in the receiving facility • Facilitate appropriate handover when indicated
Communication and family involvement	• Engage families early, provide clear updates, and respect readiness for information • Provide clear, compassionate explanations and regular updates on transfer plans, timing, and logistics • Respect family dynamics, cultural values, and practical needs throughout the process
Private car transfers	• Plan for private car transfers where possible and desired by parents • Assess the feasibility of transfer by car according to local policy • Provide required transport specific paperwork o Refer to Appendix B. Quick guide to forms and care plans • Coordinate logistics within the local facility and collaborate with the PPCS or Hummingbird House for transfer to home or hospice o Refer to Appendix A. Key contacts
Transport via retrieval services	• Coordinate all other transfers via Retrieval Services Queensland (RSQ) • For neonatal transfers, consult RSQ to manage logistics with: o ANTS-NQ (Advanced Neonatal Transport Service–North Queensland) o NeoRESQ (Neonatal Retrieval Emergency Service southern Queensland)—ability to perform cuddle transfers[56]
Care of the baby during transport	• Optimise symptom management, respiratory support, nutrition and availability of medications • Consider the timing and mode of transfer carefully to minimise distress

3 End-of-life care

End-of-life support in neonatal palliative care focuses on providing comfort, dignity, and compassionate support to babies and their families during their final hours.[57] Every intervention prioritises the baby's comfort and respects the family's wishes, honouring the unique bond between parents and their baby. A multidisciplinary healthcare team works closely with families to address physical, emotional, spiritual, cultural and practical needs, creating a peaceful, supportive environment during this profound time.

3.1 Comfort care and non-pharmacological symptom management

Table 9. Comfort care and symptom management

Aspect	Consideration
Principles	• Provide active, comfort-focused care that prevents and relieves distress[58] • Maintain warmth, and a soothing environment to support overall comfort[59] • Avoid interventions unlikely to improve comfort or those causing unnecessary burden or distress[60] • Review comfort plans at set intervals and when condition changes
Assessment	• Involve families as partners in symptom assessment and care decisions, inviting their observations and preferences[61] • Use validated symptom assessment tools alongside clinical judgment to monitor and evaluates symptoms[61,62] o Comfort, Observation and Symptom Assessment (COSA)[63] o Face, Legs, Activity, Cry, Consolability (FLACC) pain scale—also found in COSA o Premature Infant Pain Profile-Revised (PIPP-R)[64] o Document parental observations • Refer to Appendix B. Quick guide to forms and care plans
Symptom recognition	• Common symptoms include[30]: o Pain o Irritability o Respiratory distress or changes o Lethargy o Increase in secretions o Colour or perfusion changes • Observe for non-verbal signs of distress (e.g. changes in heart rate, respiratory changes, agitation) • Consult with paediatric palliative care specialists for symptoms refractory to initial management[54] o Refer to Table 7. Referral and consultation o Refer to Appendix A. Key contacts • Refer to Appendix C. Pain symptoms management guide and Appendix D. Non-pain symptoms management guide
Non-pharmacological methods	• Calm environment o Minimise noise, harsh lighting, and unnecessary sensory stimulation[58] • Non-nutritive sucking o Offer pacifiers or non-nutritive sucking with parental consent as a soothing measure for babies • Positioning strategies o Position to enhance comfort and alleviate symptoms (e.g. respiratory distress or secretion-related discomfort)[60] o Prone or side-lying with comfort holds • Skin-to-skin contact[65] o Encourage skin-to-skin contact between baby and parent o Reduces pain, improves breathing, fosters bonding, and supports psychological well-being • Gentle touch, sound and swaddling[65] o Use gentle touch, swaddling, facilitated tucking, and soothing voices or music therapy as calming interventions • Engage allied health including but not limited to physiotherapy or occupational therapy, for interventions o Non-invasive secretion clearance techniques o Splinting or positioning to relieve pressure areas, manage spasticity and prevent contracture pain

3.2 Pharmacological symptom management and access

Table 10. Pharmacological symptom management and access

Aspect	Consideration
Key pharmacological principles	• Medication selection o Choose medication type, dose, route, and anticipated duration using clinical judgment and validated protocols o Prioritise comfort and symptom relief[60] • Discontinuation o Cease medications that do not contribute to comfort o Balance the risks versus benefits of ongoing treatments • Review prescribed medications regularly and adjust according to the baby's condition and comfort needs • Combine pharmacological and non-pharmacological comfort measures to optimise relief and family involvement in care
Anticipatory prescribing	• Prescribe medications in advance to manage symptoms likely to arise in the final hours or days of life • Facilitate timely and effective symptom relief by having medications readily available • Discuss the plan with the multidisciplinary team and family to promote understanding and confidence in care
Pharmacological methods*	• Refer to Queensland Clinical Guideline *Neonatal medicines*[66] or an alternative resource (e.g. A Practical Guide to Palliative Care in Paediatrics[18]) for palliative care specific drugs and dosing • Where prescribed medications are not effective, escalate to a specialist paediatric palliative care service (e.g. PPCS or Hummingbird House)
Common types of medications for symptom relief*	• Non-exhaustive list, but may include: o Simple analgesics *(e.g. Paracetamol, sucrose, non-steroidal anti-inflammatory drugs [NSAIDs])* o Opioids *(e.g. Morphine, fentanyl)* o Anxiolytics/ benzodiazepines *(e.g. Midazolam, clonazepam, clonidine)* o Anticholinergic *(e.g. Glycopyrrolate)* • Refer to Appendix C. Pain symptoms management guide and Appendix D. Non-pain symptoms management guide
Routes of administration	• Routes may be dependent on the baby's condition and size • Subcutaneous infusion—continuous infusion via syringe pump is common and effective when oral or IV access is unsuitable o Especially in community or hospice settings where IV access is not an acceptable route of administration[58,67] • Subcutaneous injection—can be used for bolus medication administration • Intravascular access—includes intravenous (IV), umbilical venous catheter (UVC), central venous line (CVL) or peripherally inserted central catheter (PICC) o Lines already in place may be used preferentially in the immediate period for symptom relief after discontinuation of life-sustaining treatment, depending on parental preference[62] o If a less invasive route is effective, avoid establishing new IV access solely for medication • Depending on the medication and condition of baby, other useful routes include oral, buccal and intranasal
Ongoing review	• Regularly review effectiveness of pharmacological interventions[61]—adjust dosing or medications based on symptom relief and side effects • Promptly identify and manage any new or escalating symptoms to maintain comfort[59] • Maintain documentation of all assessments, medication changes, family discussions, and clinical decision-making

*Refer to an Australian pharmacopeia for full details of all drugs

3.3 Nutrition, feeding and oral care

Table 11. Nutrition feeding and oral care

Aspect	Consideration
Context	• Feeding holds deep emotional and cultural significance for many parents[18] • Feeding plans are comfort-focused and not forced—options may include: o Breastfeeding o Enteral feeds using expressed breast milk (EBM), donor milk, or formula o Drops of breast milk or sucrose for comfort—even if baby has no sucking reflex[60] or an unsafe swallow • Feeding fosters comfort and emotional connection in end-of-life care
Nutrition	• Develop a feeding plan considering the baby's condition and family wishes[68] o Feeding in some form is usually possible, especially if it is an important goal for the family o Small frequent feeds can be offered for comfort—may not necessarily be nutritional o Consider involvement from speech pathology as required • Nasogastric (NG) tube feeding may be planned antenatally or re-evaluated during neonatal care based on tolerance and goals • Decision to withhold or withdraw artificial nutrition and hydration are appropriate in the context of the baby's best interests, comfort, and symptom control[60,69] o Focusing on comfort measures by choosing not to provide artificial nutrition and hydration is clinically and ethically suitable[59] o Clarify with parents—this does not mean stopping care—ongoing support for symptom management, emotional needs, and dignity continues
Oral care	• Maintain oral comfort and hygiene by gently swabbing the mouth with moistened soft swabs or clean gauze[70]—follow local protocols where available o Use sterile water or expressed breast milk (EBM) if available to clean and soothe oral tissues o Use soft white paraffin to prevent lips from drying and cracking • Non-nutritive sucking can provide oral comfort and stimulation for appropriate gestation and neurological ability[59] • Teach and support families in oral care practices to enhance closeness and caregiving[59]
Lactation support	• Provide women with sensitive, timely anticipatory guidance on lactation and management options without assuming immediate suppression[71] • Involve midwives or lactation consultants to support breastfeeding, milk expression for donation, or suppression according to parent goals[71] • Present options including[2]: o Immediate suppression by medication o Gradual suppression through expressing o Using breast milk for mementos o Donating breast milk to a milk bank or similar—if applicable locally • Offer options early and revisit as emotions and preferences change • Offer emotional support to address the psychological impact related to breastfeeding cessation and lactation choices[59,71]

3.4 What to expect

Table 12. What to expect during the dying process

Aspect	Consideration
Transparent communication	• Parents may have questions about normal physical changes near their baby's end-of-life (e.g. colour changes, altered breathing, and reduced circulation[18]) • Provide clear information about possible and/or probable changes—supports emotional preparation, and may reduce distress • Recognise that this is an incredibly difficult and confronting time for parents
Withdrawal of life-sustaining treatment	• Document and communicate all decisions regarding withdrawal of life-sustaining treatments to families[41] • Inform parents that baby may continue to breathe and have circulation for minutes, hours or days, and this can be difficult to predict • Prioritise prompt identification and management of symptoms to reduce discomfort and distress[72] • Confirm anticipatory medicines are prescribed and available o Refer to Table 9. Comfort care and symptom management o Refer to Table 10. Pharmacological symptom management and access • Support family involvement in care activities, rituals, and comfort measures to promote connection and support[73]
Circulatory changes	• Explain to parents and families that as the heart rate slows and blood circulation reduces[62] their baby may experience the following: o Colour changes (e.g. cyanosis) o Coolness of hands, feet, and face • Reassure parents and family that these symptoms can be expected during this phase[74]
Respiratory changes	• Breathing patterns may become rapid, shallow, irregular, or include infrequent gasping breaths, pauses and apnoea[18] • Noisy breathing due to secretions that the baby is unable to clear may be observed—this is common and not necessarily distressing or painful to the baby • Provide reassurance to parents and families that while irregular breathing may be upsetting to see, it is an expected part of the baby's dying process[74] and discomfort can be addressed
Additional physical changes	• May become lethargic or unresponsive as death nears[72,75] • Skin may become mottled, pale, cyanotic, or blotchy due to decreasing oxygen and circulation[75] • Eyes may remain partially open with a glassy appearance o Secretions around the eyes and mouth can be gently cleaned to maintain comfort
Uncertainty for parents and family	• Recognise families may endure repeated uncertainty and losses, o Starting with the loss of their expectations for a healthy child o Then facing the possibility of losing a child with a life-limiting condition • Remind families that the most honest answer to how long a child may live is that no one can know for sure

3.5 End-of-life care for the baby

Table 13. End-of-life care for the baby

Aspect	Consideration
Supportive care for the baby	• Handle baby gently and carefully to preserve dignity and comfort[76] • Provide warmth and comfort by wrapping, cuddling, and holding • Enable skin-to-skin contact to promote soothing and bonding • Assess comfort using validated pain tools if available[60] o Refer to Table 9. Comfort care and symptom management o Refer to Appendix B. Quick guide to forms and care plans • Transfer babies from a hospital to a hospice, a hospital closer to home or traditional Country, or a private residence for palliative and/ or end-of-life care[56] if desired by family • Promote strong communication and partnership with parents to respect their wishes about where care is delivered • Occasionally check to see if there is no heartbeat—maintaining a sensitive approach[77] o In the absence of a heartbeat, confirmation can be made by a medical officer or nurse—there is no requirement to rush this confirmation[77] o Refer to Table 15. Support in the immediate post-death period
Review interventions	• Avoid invasive procedures unless necessary[59,60] • Regularly assess the clinical context and parental wishes to guide adjustment or removal of technological supports (e.g., monitors, alarms, invasive lines, ventilation)[60] • Document care plans clearly, reflecting family wishes, advance directives, and decision-making rationales o Refer to Table 1. Clinical standards—Documentation standards o Refer to Table 6. Anticipatory planning
Location of care	**Healthcare facility** • Recognise that some parents may prefer to be cared for in a hospital where they feel most supported and familiar with the clinicians and surroundings[2], which may require transfer to a different hospital • Acknowledge the importance of continuity of care • Emphasise flexibility in care location decisions to accommodate family preferences and emotional needs[78] o Provide quiet, private rooms, where possible[60,78]—add an identifying sign/symbol to door or space so privacy may be respected o De-medicalise environment—remove non-essential equipment • Allow personalisation of the physical space with meaningful objects, photographs, music, and preferred lighting[2] • Provide opportunities to go outside, allocate near windows • Consider relaxation of visiting policies
	Hospice • Supports families through the perinatal journey with seamless coordination among hospital, community, and hospice services • Facilitates culturally safe, compassionate care that respects family preferences and cultural or spiritual practices • Provides a calm, private, and personalised setting conducive to family presence, memory-making, and end-of-life care • A multidisciplinary team which includes experienced palliative care clinicians and family support teams
	Home • Provide support and ongoing care for babies and families—general practitioners (GPs), community nurses, or specialist services (e.g. PPCS or E-PPCS)[72] • Consider spiritual and cultural supports that the family may need • If baby dies at home: o Inform parents and family about what to do and who to contact o Provide all necessary paperwork to support after death documentation—allows funeral home to take over care at a time chosen by the family

4 Supportive care

Supportive care in perinatal and neonatal palliative care provides ongoing, individualised support for families from diagnosis, through end-of-life, and into bereavement—including healthcare providers and those in rural and remote areas.[57,68] Care is offered to all families, and affirms parenthood by honouring the unique bond between parents and their baby while validating their grief.

4.1 Memory making

Table 14. Creating meaningful memories

Aspect	Consideration
Principles	• Support connection, emotional healing, personalised memory making[79,80] • Offer memory-making opportunities flexibly throughout all care phases[79] • Involve families actively rather than just collecting items • Involve maternity and other bereavement services where available • Present options to family and respect any decision to decline or postpone memory-making activities[80] • Assist families to integrate memories into ongoing grief and community practices after discharge
Practical support	• Include siblings, grandparents, and extended family members where appropriate[35,80] • Facilitate cultural, spiritual, and religious end-of-life practices important to the family[81]—including but not limited to baptisms, blessings and naming ceremonies • Acknowledge that external service providers may require advance booking and may not be immediately available (e.g. religious or spiritual providers and photographers) • Document what support and activities were offered, accepted or declined
Flexibility	• Respect family readiness and pace without pressure or assumption[80,82] • Encourage family autonomy in choosing their level of involvement[2] o Re-offer memory-making opportunities if initially declined, as family's needs may evolve over time • Recognise that not all memory-making activities suit every family[81]
Creating meaningful memories	• Facilitate and support creation of tangible mementos and bonding activities tailored to the family's circumstances o Pregnancy/family photography, footprints/handprints, plaster casts o Memory boxes—provided free of charge to all Queensland Health facilities by Precious Wings [refer to Appendix A. Key contacts] o Collect personalised items (e.g. cot cards, ID bands, clothing, leads, Personal Health Record "red book") o Collect locks of hair with parental consent o Journalling, keeping a memory book, photo's • Refer to Table 5. Culturally responsive care for cultural considerations regarding the use of names and photo's for Aboriginal and Torres Strait Islander people[32]
Everyday care as memory making	• Recognise caregiving acts in memory creation[35]—skin-to-skin contact, cuddling, bathing, and dressing the baby, reading or singing, massage • These experiences nurture emotional closeness[35,80] and are a way to affirm parenthood
Sensory and environmental modification	• Enhance family bonds by modifying the care environment or offering sensory experiences: o Taking the baby outside o Playing favourite or soothing music o Using gentle lighting o Facilitating visits or rituals meaningful to the family[81] o Remove unnecessary medical equipment
Rural and remote guidance	• Coordinate telehealth for guidance, emotional support, and practical advice when in-person visits are unavailable[83] • Arrange outreach visits, when possible, to provide practical assistance • Recommend keepsake storage suited to local climate—airtight/moisture-resistant containers for humid or hot areas

4.2 Support in the immediate post-death period

Table 15. Support in the immediate post-death period

Aspect	Consideration
Physical care of the baby	• Handle baby with care, respect, and dignity • Wash and dress baby—parents may choose to do this, but may require guidance and support[77] o Remain flexible and responsive to needs of parents and family • Complete required investigations as noted in the care plan or discussed with the team and parents o Refer to Table 6. Anticipatory planning—Investigation planning • Review care plan or medical record to determine if additional post-death investigations are required—including Newborn Bloodspot Screening (NBS) if initial sample has not been collected o Refer to Queensland Clinical Guideline *Newborn bloodspot screening*[84]
Practical care	• Complete required procedural documentation according to local policy o Contact relevant services for advice if required (e.g. PPCS, Hummingbird House or Clinical services capability framework (CSCF) higher level facility){Queensland Health, 2014 #55} • Review and apply local protocols regarding cooling, storage, and transfer/transport of baby[24] (e.g. use of Techni Ice™, CuddleCots™—where available) o For resource-limited settings—utilise locally available cooling devices (e.g. air-conditioning) ▪ Techni Ice™ can be posted to regional healthcare teams by PPCS [refer to Appendix A. Key contacts] • Discuss and facilitate practical requirements for the family to take baby home, to hospice or to a significant location if desired o Complete Life Extinct Form[85] and other transport documentation o Refer to Appendix B. Quick guide to forms and care plans • Activate referral pathways or outreach support if the location is rural or has limited resources
Memory-making and after death care	• Discuss after death care early and with sensitivity[2] • Normalise after death care as a meaningful and healing memory for families, acknowledging it may initially feel unfamiliar or confronting • Offer parents choices for involvement as much or as little as they wish o Hold or spend time with the baby—give family uninterrupted time o Participate in care activities (provide clothes/mementos to stay with baby, document accordingly) o Plan alternative approaches/activities[83] o Refer to Table 14. Creating meaningful memories
Legal, administrative, and practical tasks	• Complete death certification and notification documentation o Refer to Table 24. Death certification, autopsy and auditing o Refer to Appendix B. Quick guide to forms and care plans • Notify General Practitioner (GP) and other relevant healthcare providers as required o Confirm whether the Newborn Hearing Screening and Referral form has been appropriately completed o If baby was retrieved/transferred—notify referring teams as well as relevant retrieval service • Record all actions, parental wishes, and any mementos created • Arrange follow-up contact and offer appointments to discuss findings or next steps discussions • Refer to Table 17. Follow-up care • Provide clear written and verbal explanations of processes for autopsy, reporting, and expectations • If a reportable death is suspected, preserve relevant equipment and scene as indicated o Refer to Table 23. Reportable versus non-reportable deaths

4.3 Family and bereavement support

Table 16. Family and bereavement support

Aspect	Consideration
Context	• Families often face uncertainty and complex challenges during end-of-life[2] • Grief is individual and complex—continuity of familiar carers can provide stability and reassurance • Introduce bereavement planning early to facilitate timely access to support
Recognition of parenthood	• Affirm and recognise the unique grief of parents, including anticipatory and disenfranchised grief [refer to Definitions] • Honour the parent-child bond and support parental identity[2] • Facilitate active caregiving and memory-making[2,16]
Recognition and validation of grief	• Acknowledge grief intensity, diversity and individual experiences[26,86,87] • Practice active, non-judgemental listening • Integrate culturally sensitive grief support • Offer support before and after death
Parental support	• Normalise grief as a natural and expected response[26,73] • Facilitate access to specialised grief, bereavement, and follow-up support via phone calls, home visits, or peer support groups—according to parental wishes/request • Limited bereavement support can increase the risk of negative health outcomes for parents[77] o Acknowledge all grieving styles are different and not suited to everyone o Provide information about alternative support options if parents decline further contact from healthcare providers
Family support	• Provide private spaces for grieving with access to written and verbal grief information and support services[2,26] • Recognise grief impact on siblings, grandparents, and extended family[2], and offer specific support as required[18] o To support siblings o Provide school or childcare letters as required • Respect family privacy and choice in care and bereavement settings[73]
Cultural and spiritual support	• Explore and honour the family’s cultural, spiritual, and religious needs[16] • Facilitate customary rituals or prayers and enable family-identified rituals as appropriate[16,32] • Support the choice of preferred location for end-of-life care, following relevant guidelines where able[32,62] o Refer to Table 5. Culturally responsive care
Psychosocial and practical support	• Provide ongoing psychological and culturally appropriate support[2,86] • Assist with funeral planning, death certification, and community referrals to alleviate practical burdens[26] • Offer financial, leave, and government support information as needed

4.4 Follow-up care

Table 17. Follow-up care

Aspect	Consideration
Follow-up appointments	• Facilitate post-loss appointments to discuss clinical course and investigation/autopsy findings[2,26] • Arrange appointments with relevant healthcare providers (e.g. obstetricians, neonatologists, geneticists, or bereavement counsellors)[77] • Aim for continuity by involving familiar providers where possible
Suggested follow-up timing	• Phone call within 48 hours • Review visit between 2–6 weeks (including 6-week postpartum for mother/birthing parent) • Additional review (where desired) between 3–6 months
Coordination and emotional support	• Provide ongoing emotional and psychological support[48,88,89] • Maintain standardised communication between hospital and community-based healthcare providers[2] • Assess social and emotional wellbeing at postnatal appointments
Service coordination and follow-up	• Provide reliable, coordinated follow-up and bereavement support • Respect parental wishes if they decline follow-up • Notify general practitioners, obstetric, and midwifery teams, including those from referring facilities[26] • Promote continuity through clinicians familiar with the family and baby
Rural/remote challenges	• Recognise challenges in rural and remote contexts including: o Limited access to bereavement support o Longer wait times for counselling[90] • Use telehealth, community networks, and outreach programs to extend bereavement counselling and peer support to underserved populations[2,90] o Refer to Appendix A. Key contacts

4.5 Support for healthcare providers

Table 18. Support for healthcare providers

Aspect	Consideration
Context	• Healthcare providers may experience moral distress when personal, cultural, religious, or organisational values conflict in care settings • Grief, moral distress, and secondary traumatic stress may be present but unrecognised in these contexts[91]
Emotional and professional wellbeing	• Recognise potential for burnout, compassion fatigue, and secondary traumatic stress proactively[88] o Promote team or personal debriefing and offer Employee Assistance Program (EAP) as required o Refer to Appendix A. Key contacts] • Offer confidential emotional support, promote self-care, resilience • Foster an environment that supports emotional wellbeing
Education and training	• Effective palliation of the dying infant and care of the family requires a high level of communication and interpersonal skills[77] • Support access to ongoing training on perinatal and neonatal palliative care principles, family-centred communication, cultural safety, and bereavement support[92] • Include practical skills development through case studies, simulation, and reflective practice where required and available • Emphasise interdisciplinary collaboration and role clarity • Offer accessible, flexible training options (e.g. e-learning)[25]
Organisational guidance	• Create a workplace culture of safety[93] • Recognise additional vulnerability of specific groups o Those from communities that experience racial inequality o Those who are newer to the role[93] o Those who have lived experience of pregnancy loss or child death • Support healthcare providers to use incident reporting systems so that events can be identified and followed up[93]

5 Special considerations

Healthcare providers are expected to provide compassionate, respectful, and evidence-based care with comprehensive symptom management for every baby, irrespective of the circumstances.[94,95] This includes babies born alive following termination of pregnancy, those whose parents decline participation in end-of-life care for cultural, psychological, or personal reasons, and babies from multiple births where one or more siblings survive. Recognition of the specific clinical, ethical, and psychosocial considerations associated with these situations is essential.[25] Ongoing assessment and support should also address the potential implications for parental wellbeing and future pregnancies.

5.1 Considerations for other perinatal circumstances

Table 19. Other considerations for palliative and end-of-life care

Aspect	Consideration
Context	• Care for all babies during end-of-life and after death remains consistent regardless of circumstance • Acknowledge different situations require specific emotional, clinical, and cultural needs
Multiple births	• Recognise the distinct emotional and clinical needs when some or all babies from a multiple birth die[96] • Acknowledge unique grief dynamics around surviving siblings • Discuss use of symbols like the purple butterfly with parents', respecting those who may decline to avoid feeling treated differently • Affirm both individual and shared identities of deceased and living baby(ies)[2]
Stillbirth	• Care is culturally responsive and sensitive to the diverse beliefs and practices of families • Encourage family involvement in care and memory-making activities, respecting their wishes • Refer to Queensland Clinical Guideline: *Stillbirth care*[97]
Extremely preterm babies	• Consider perinatal palliative care for pre-viable preterm babies where birth is imminent • Provide comfort-focused care, balancing symptom management with family's values and preferences • Develop individualised care plans with multidisciplinary input, addressing medical, emotional, and cultural needs • Refer to Queensland Clinical Guideline: *Perinatal care of the extremely preterm baby*[98]
Babies who survive longer than anticipated	• Acknowledge that some babies may survive much longer after redirection of care o Recognise these circumstances require complex emotional support • Continuous monitoring for symptoms and management essential • Referral to PPCS or Hummingbird House, if not already, for ongoing support advised • Communicate clearly with families about prognosis, expectations, and care plans
Child Safety	• Recognise legal and protective responsibilities when babies are under the care or protection of Child Safety[22] • Understand these babies may have complex social and legal situations requiring Child Safety involvement[22] • Involve relevant authorities in care decisions alongside parents and the healthcare team • Adhere to legal mandates while providing comfort-focused care o Understand terms of guardianship/orders • Support families to visit and have opportunities for memory-making o Collaborate closely with Child Safety and the family o Refer to Queensland Clinical Guideline: *Standard care*[27]

5.2 Supporting babies when parents decline involvement

Table 20. Care considerations when parental contact is declined

Aspect	Consideration
Context	• May be influenced by geographical location, emotional distress, past trauma, cultural considerations, or personal beliefs[2,86] • Levels of involvement may vary and may reflect response to trauma, grief, cultural practices, or emotional overwhelm rather than rejection of care o Avoid assumptions, verify preferences early and review periodically o Apply trauma-informed approaches • Emotional impact is notable among clinicians caring for babies whose parents decline involvement or following pregnancy termination[99] o Refer to Table 18. Support for healthcare providers
Memory-making	• Offer opportunities for memory-making at the family's discretion[86] • Refer to Table 14. Creating meaningful memories
Communication and flexibility	• Inform parents they may change their mind at any time • Accommodate individual preferences for ongoing care and participation • Offer written information on care options, support services, and contact points[2]—recognising cultural and linguistically diverse populations • Assign a delegate to be with baby—family member, pastoral support person, or nurse/midwife caring for the baby[77] o Document delegation and any related details for future reference[77] • Maintain flexibility and respect current decisions while allowing future engagement[2,86]
Privacy and confidentiality	• Honour parental wishes relating to privacy, language preferences, and information sharing[16] • Limit discussions to the core healthcare team to protect family confidentiality and build trust[2,86]

5.3 Care of babies born alive after termination of pregnancy

Table 21. Management and support for babies born alive following termination

Aspect	Consideration
Clinical Context	• Provide individualised, non-judgmental care focused on comfort[2] • Live birth following termination of pregnancy may lead to trauma-related stress, depression, and symptoms of vicarious grief[100] • Refer to Queensland Clinical Guideline *Termination of Pregnancy*[76]
Care of the baby	• Provide care immediately after birth—based on the baby's condition, prognosis, and family wishes • Provide comfort care (e.g. warmth, gentle handling, and support for family bonding where appropriate)[101] • Manage symptoms with a focus on relieving distress o Document symptom management thoroughly o Refer to Section 3. End-of-life care for guidance on caring for baby
Care of the parents	• Recognise that some may not wish to be called parents • Acknowledge the complex emotional and psychological aspects of having a liveborn baby after termination[100] • Support access to ongoing psychological support and grief counselling[100] • Allow parents to guide direction of care and level of involvement o Refer to Section 4. Supportive care
Legal obligations in Queensland	• Liveborn babies are legal persons under Queensland law[76], regardless of gestation or circumstance • Provide care consistent with registration and professional standards (e.g. Nursing and Midwifery Board of Australia (NMBA) Registered Nurse Standards for Practice, Code of Conduct for Nurses and Midwives) • Complete birth and death registration and medical certification—required for all liveborn babies[59,91]
Ethical responsibility	• Provide care that is compassionate, non-judgmental, and upholds the baby's dignity and best interests regardless of personal beliefs[11,91] • Support both the pregnant person and baby holistically

5.4 Future pregnancy care considerations

Table 22. Considerations for future pregnancy care

Aspect	Consideration
Clinical care and coordination	• Continuity of provider for future pregnancies • Implement a multidisciplinary approach[102] • Provide pre-pregnancy advice, investigations, obstetric and midwifery care, point-of-care ultrasound, and perinatal support[2,102] • Maintain thorough documentation and referral pathways • Use a shared care plan accessible to hospital and community teams • Include clear referral triggers for early perinatal palliative care in subsequent pregnancies
Investigations for future pregnancies	• Provide information on future pregnancy planning and reproductive health • Offer genetic counselling when indicated • Review and analyse results from antenatal/neonatal investigations • Conduct investigations and risk assessments for subsequent pregnancies • Document outcomes and share with healthcare providers
Information and support	• Provide information about specialised care and support for future pregnancies[2] • Summarise previous pregnancy and baby's death circumstances • Respect and document family preferences, including naming and cultural recognition of the deceased baby • Encourage midwifery-led follow-up where possible • Offer psychological and bereavement support with trauma-informed, non-judgmental care • Address mental health concerns (e.g. anxiety, depression, disenfranchised grief, and stigma)[2,102]
Rural and remote guidance	• Use telehealth, community networks, and outreach programs to enhance access[2] • Identify and mitigate barriers faced by rural and remote families in accessing care

6 Administration and legal processes

Clear administration and legal processes help families understand what will happen after their baby's death while preserving trust in the care team. Sensitive explanations about classification, reporting requirements, certification, autopsy, and review processes support parental grieving, ensure legal and ethical obligations are met, and promote system learning to improve future care.

6.1 Reportable versus non-reportable deaths

Table 23. Reportable versus non-reportable deaths

Aspect	Consideration
Context	• Reportable deaths are defined in the State Coroners Guidelines[103], the circumstances of which are reportable under the Coroners Act 2003 o Involves deaths that are unexpected, unclear in cause, or involve trauma, suspicion, or external factors[103,104] • Non-reportable deaths are typically natural, with clear causes • Prompt and accurate classification supports legal investigations, public health monitoring, and clinical quality improvement. • Familiarity with legislation and protocols for correct death reporting and management

Reportable deaths	• If death is deemed reportable, discuss with senior clinician or medical director, prior to notifying police or coroner as required
	  o If any uncertainty, contact the coroner or experienced coronial officer for guidance
	• If unsure whether the death is reportable or whether Form 1A required, seek advice from the:
	  o Coronial Registrar during business hours
	  o On-call coroner after hours
	• Refer to Appendix A. Key contacts for contact details
	• In rural and remote areas, seek advice from a higher CSCF level facility before contacting the coroner

Reporting criteria	**Reporting to the Coroner using Form 1A**[103]
	• The treating team considers the death is due to potentially preventable conditions or complications occurring:
	  o Antenatally
	  o During birth
	  o Postnatally—delayed resuscitation or subsequent neonatal care
	• A parent expresses concerns about antenatal, labour and delivery, or neonatal management
	  o The treating clinician is uncertain whether the death is reportable

	Report deaths to police in the following circumstances[103] (Form 1–QPS)
	• These are example scenarios only:
	  o Trauma to the baby, mother/birthing parent, or fetus in utero caused by:
	    ▪ Assault
	    ▪ Motor vehicle accident
	    ▪ Fall
	    ▪ Electrocution
	    ▪ Drug overdose
	  o Death of a baby in suspicious circumstances:
	    ▪ Smothering
	  o Suspected tampering with life support equipment or medication dosage

Non-reportable deaths	• In the absence of other concerns, mandatory reporting is not required for death[65,104]:
	  o Due to extreme prematurity
	  o From managed congenital anomalies
	  o Expected from natural, medical, or prior diagnoses
	  o With appropriate medical management and no unexpected events

Responsibilities	• Document assessments and notifications accurately • Coordinate with multidisciplinary and legal teams for after death care and follow-up • If death is reportable, discuss with parents that lines, tubes etc may not be able to be removed until the case is discussed with the coroner

6.2 Death certification, autopsy and auditing

Table 24. Death certification, autopsy and auditing

Aspect	Consideration
Purpose	• Establish or clarify the cause of death, particularly when it is uncertain • Confirm clinical findings or uncover new information that may not have been apparent during life • Inform future pregnancy planning by offering reassurance or risk guidance • Contribute to system learning and prevention[2]
Legal and local protocol requirements	• Complete legal requirements for registration, certification, and mandatory reporting per local regulations[26] • Required forms include: o Cause of death certificate (CODC)—Form 9 o Perinatal Supplement (Form 9A) if baby has died within 28 days of birth o If concerns that a CODC cannot be issued, further discussion with the coroner is required [refer to Table 23. Reportable versus non-reportable deaths] • Refer to Appendix B. Quick guide to forms and care plans
Autopsy consent and support	• Parental consent is required for perinatal autopsies except coronial cases o Consent to be sought by experienced, trained clinicians o The coroner will consider family views prior to examination • Recognise the complexity and emotional difficulty of the autopsy decision • Provide thorough, non-judgmental information, allowing parents to guide timing and detail[26] • Explain to parents results from autopsy can take several months to become available o Refer to Queensland Clinical Guideline consumer information: *Autopsy examination of a baby*[105]
Cultural awareness	• Enquire sensitively about cultural, religious, or spiritual needs related to investigations • Avoid assumptions; individualise care in partnership with families and seek guidance as needed
Follow-up and communication	• Agree on timelines for communicating results before discharge with the interdisciplinary team. • Develop family-centred communication plans detailing who will share results, how, and how follow-up with parents will be managed • Document in medical records
Perinatal mortality audits	• Utilise Perinatal Society of Australia and New Zealand (PSANZ) perinatal death classifications[106] and apply as relevant in mortality audits and documentation • Utilise the perinatal mortality review toolkit[107] available from the Queensland Maternal and Perinatal Quality Council (QMPQC) via QHEPS o Complete an Australian Perinatal Mortality Clinical Audit Tool (APMCAT)[108] section 1 within 48 hours of death • Participate in formal perinatal mortality audits, including cases from rural or remote settings through collaborative audits o Complete the APMCAT section 2, Maternity Service Report, at perinatal mortality committee reviews • Refer to Appendix B. Quick guide to forms and care plans
Rural and remote	• If local autopsy services are unavailable, facilitate transport to an appropriate centre • Contact Perinatal Loss administration support officers for assistance o Central point of contact for healthcare professionals to facilitate smooth transfer of perinatal cases to and from centres within Pathology Qld o Provide ongoing support, information, and education on the perinatal autopsy process, including paperwork, transport requirements, case status updates, and estimated report turnaround times [refer to Appendix A. Key contacts] • Facilitate communication with higher CSCF level facilities teams to optimise local investigation opportunities • Consider consent via telehealth for autopsy consent—requires clear documentation

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Appendix A. Key contacts (A–Z)

Service	Provision	Contact
Children's Health Queensland Bereavement Service	• Offers compassionate and culturally safe care for families after the loss of their child. • Can support extended family, friends, schools and your community • Monday–Friday 8 am to 4:30 pm	**Ph: 1800 080 316** **email:** bereavement.ppcs@health.qld.gov.au
Coroner/ coronial registrar	• If uncertain after discussion with senior clinician or Medical Director: o Phone during office hours ▪ Unsure whether to issue Form 9 ▪ Unsure if there is a need for Form 1A o Phone any time – after hours: ▪ Need for urgent direction about scene preservation	Office hours **Ph: (07) 3738 7050** After Hours **Ph: (07) 3738 7166**
Employee Assistance Program (EAP)	• Free, professional and confidential counselling services • Available for Queensland Government employees and their immediate family members	EAP **page on QHEPS**
Hummingbird House	• Provides outreach and telehealth support to families in rural or remote areas • Referrals via their clinical care team and online referral form • Referrals are reviewed by a multidisciplinary paediatric palliative care panel and made using a detailed referral form with parental consent	**Ph: 07 3621 4364**
Paediatric Palliative Care Service (PPCS)	• Involve the PPCS team as needed • Referral required from a GP or paediatrician; more information is available through the hospital's website • Referrals are made using a detailed referral form with parental consent	**Ph: 1800 249 648**
Perinatal Loss Administration Support Officers for Pathology Queensland (PQ)	• Central point of contact for healthcare professionals, facilitating the smooth transfer of perinatal cases to and from dedicated perinatal autopsy centres within PQ • Provide ongoing support, information, and education on the perinatal autopsy process, including paperwork, transport requirements, case status updates, and estimated report turnaround times	**email:** autopsysupportPQ@health.qld.gov.au **Ph: (07) 3646 4898** *or* **(07) 5202 2580**
Precious Wings	• Provides memory boxes to all Queensland Health facilities free of charge	**email:** info@preciouswings.org
Retrieval Services Queensland (RSQ)	• Provides 24-hour telehealth, coordination, and emergency medical advice for critically unwell, high acuity patients in Queensland • They are available for clinical coordination and aeromedical transfer support • Contact made by referring healthcare clinician	**Ph: 1300 799 127**
Rural Health Connect	• Mental health support for anyone Australia wide who has been impacted by perinatal loss • Confidential psychological support via video calls • Psychologists with a special interest in perinatal loss • Referrals via GP or self-referral	**Ph: 0427 692 377** **Fax: (07) 4573 1100**

Appendix B. Quick guide to forms and care plans

Form		Provision	Available
Referral	**Perinatal Antenatal Neonatal Palliative Care (PAN-PC) Referral Form**	• Referral for PPCS and Hummingbird House • Form to be emailed to: o nurses@hummingbirdhouse.wmq.org.au o ppcs@health.qld.gov.au	**QHEPS (SW1080)**
Care plans	**Paediatric Acute Resuscitation Plan** (PARP)	• Outlines resuscitation wishes • Regularly reviewed as circumstances change • Tailor to individual needs of the baby and family	**QHEPS and PPCS (SW267)**
	Care Plan for the Dying Child (CPDC)	• Guides clinical care in the last days of life • Alter the care outlined in the CPDC if it is not clinically appropriate for the individual baby and family	**QHEPS (SW962)**
	Care After Death: CPDC	• Care plan and checklist for after death care	**QHEPS (SW1293)**
Pain assessment	**COSA** (Comfort, Observation and Symptom Assessment)	• Provides clear framework for individualised care and comfort for dying babies and children • Covers pain and symptom management • Outlines management strategies and considerations • Includes FLACC pain scale	**QHEPS (SW963)**
	PIPP-R (Premature Infant Pain Profile-Revised)	• Pain scale for extremely premature infants • Based on behavioural, physiological and contextual factors	**Individual HHS via QHEPS**
Transport	**Life Extinct Form**	• Allows mortuary staff, funeral directors and police to remove and transport a person who is deceased • Can be completed by a Registered Nurse/Midwife or a Medical Officer	**Individual HHS via QHEPS**
	Letter for transport	• Seatbelt exemption letter o Name of baby and who baby is travelling with o Why they are transporting baby—home or hospice • Contact PPCS or Hummingbird House if support or template required	**Template from Hummingbird House or PPCS**
Death certificates	**Form 9*** (Cause of death certificate)	• Complete within 48 hours of death • All carbon copies appropriately distributed per local HHS policy • To be completed by a Medical Officer	**Individual HHS via QHEPS or electronically***
	Form 9A* (Perinatal Supplement)	• For perinatal deaths (within 28 days of birth) • Can only be completed by a Medical Officer.	
Coronial forms	**Form 1A*** (Medical practitioner report of death to coroner)	• Advise the family of progression to the coroner • Complete Form 1A + Form 9 + progress notes • Body can be moved to mortuary • Do NOT report to police	**Coroners Court of Qld or QHEPS**
	Form 1 (Police report of a death to a coroner)	• Only completed by Queensland Police Service (QPS) • Advise the family of patient transfer to State Mortuary and of the potential for autopsy • Complete Life Extinct Form • Do **NOT** issue Form 9 CODC	**QPS responsibility**
Audit tools	**Perinatal mortality review kit**	• Key resource to support the consistent review of perinatal mortality	**QMPQC via QHEPS**
	Australian Perinatal Mortality Clinical Audit Tool	• Complete within 48 hours of death • Provides for the provision of clinical data relevant to perinatal death	
	Maternity Service Report	• Complete this section at perinatal mortality committee review • Provides for the provision of PSANZ classifications and contributing factor data in relation to the maternity service report	

*Must be registered through the Registry of Births, Deaths and Marriages (RBDM) Service Provider Portal to create, certify and submit Form 9, 9A and 1A electronically

Appendix C. Pain symptoms management guide

Pain scale	Management*
All types of pain	**Non-pharmacological management:**
	• Skin-to-skin contact[1]
	o Stabilises vital signs
	o Reduces stress hormones; ideal for ongoing mild discomfort
	• Non-nutritive sucking[2]
	• Swaddling/facilitated tucking[3]
	o Provides containment
	o Use prone/side-lying if tolerated
Mild	**Non-pharmacological management:**
	• Environmental:
	o Dim lights
	o Soft voices
	• Familiar scents/sounds
	o Parents heartbeat
	o Familiar voices
	Pharmacological management:
	• Simple analgesia
	o Sucrose
	o Paracetamol
Moderate–severe	**Non-pharmacological management:**
	• Layer with physical techniques for noticeable agitation
	• Breastfeeding or small comfort feeds if appropriate for goals of care[1]
	• Massage or music therapy to distract and soothe[3]
	Pharmacological management:
	• Give breakthrough PRN relief
	• Commence regular non-opioid and/or opioid medication (PO/IV/subcut)
	• Opioid (PRN or scheduled, if due)
	o Morphine
	• Review number of PRN doses, optimise/titrate dosing as required
Continued, uncontrolled	**Non-pharmacological management:**
	• Combine containment holds, sucrose[4]
	• Position for comfort[4]
	• Provide warmth[4]
	• Minimal stimulation—avoid procedures[4]
	Pharmacological management:
	• Optimise dose of scheduled and PRN non-opioid and opioid medications
	• Continuous (subcut/IV) infusion plus breakthrough PRN
	o Morphine
	• Escalate for continued, increased pain
	• Review number of PRN doses, optimise/titrate dosing as required
	• Consider opioid switch
	o Consult with PPCS

*Refer to an Australian pharmacopeia and/or QCG NeoMedQ for full details of all drugs

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Appendix D. Non-pain symptoms management guide

Symptom	Management
Respiratory distress	**Non-pharmacological management:**
	• Positioning[1]
	• Fans—gentle airflow toward face stimulates nerves to reduce breathlessness[2]
	• Feed adjustments—try smaller, more frequent feeds
	• Uninterrupted direct contact with parent
	• Consider reducing the use of artificial fluids that may contribute to fluid overload
	Pharmacological management*:
	• Opioid (PRN or scheduled)
	o Morphine
	o Midazolam
Agitation	**Non-pharmacological management:**
	• Skin-to-skin contact (kangaroo care)[2]
	• Swaddling and positioning—gently wrap baby or use facilitated tucking/prone/side-lying[3]
	• Non-nutritive sucking[4]
	• Dim lights, reduce noise[5]
	• Provide warmth, gentle handling, and family/familiar voices[6]
	Pharmacological management*:
	• Sucrose
	• Midazolam
	o Bolus PRN, scheduled dosing or continuous infusion
	o Optimise dose of scheduled and PRN orders
	• Consider adjunct sedative
	o Consult with PPCS
Secretions	**Non-pharmacological management:**
	• Gentle suctioning[3]
	• Positioning[2,3]
	o Side-lying or prone positioning facilitates secretion drainage
	o Avoid supine position
	• Gentle chest physiotherapy[1]
	Pharmacological management*:
	• Glycopyrronium bromide (glycopyrrolate)
Vomiting	**Non-pharmacological management:**
	• Vent gastric tube if in situ
	• Feeding adjustments[7]:
	o Smaller, more frequent feeds
	o Slower-flow teats if bottle feeding
	o Milk adjustment/change
	o Reduce feeds if vomiting worsens distress more than hunger
	• Positioning and handling
	Pharmacological management*:
	• Convert enteral medications to IV/subcut as able

*Refer to an Australian pharmacopeia and/or QCG NeoMedQ for full details of all drugs

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