

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

Symptom recognition

- Pain
- Irritability
- Respiratory distress
- Lethargy
- Increased secretions
- Agitation
- Changes in:
 - Heart rate
 - Respirations
 - 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
 - Administer analgesia, sedation or other medications PRN
- Select administration route best tolerated by baby
- Review medication efficacy regularly
- Refer to QCG NeoMedQ; or
 - A Practical Guide to Palliative Care in Paediatrics
- If symptoms persist—escalate to relevant healthcare team

Observation

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

Monitoring and interventions

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

Investigations

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

Care and support

Symptom management

Nutrition and oral care

Monitoring

Investigation considerations

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
 - Involve IHLO, interpreters, chaplaincy services as needed
- Facilitate memory creation
- Flexibility and adaptability with family needs

Location planning

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

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,
 - Consider maintaining IV access for ease of symptom relief—discuss with parents

Oral care

- Maintain oral comfort
 - 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



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

Queensland Clinical Guideline. *Palliative and end-of-life care for babies*. Flowchart: F26.82-2-V1-R31