Palliative and end-of-life care for babies

Clinical Guideline Presentation

45 minutes

Towards CPD Hours

Clinical Excellence Queensland

Queensland Government

References:

Queensland Clinical Guideline: Palliative and end-of-life care for babies is the primary reference for this package.

Recommended citation:

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Disclaimer:

This presentation is an implementation tool and should be used in conjunction with the published guideline. This information does not supersede or replace the guideline. Consult the guideline for further information and references.

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Abbreviations

ANTS-NQ	Aeromedical Neonatal Transport Service-North Queensland
EOL	End-of-life
NeoRESQ	Neonatal Retrieval Emergency Service southern Queensland
PPCS	Paediatric Palliative Care Service
QoL	Quality of life
RSQ	Retrieval Service Queensland
TOP	Termination of pregnancy

Objectives

Identify key elements and recommendations about:

- **How to provide compassionate, family-centred care**
- Principles of palliative and end-of-life care
- Indications for palliative and end-of-life care
- Early and multidisciplinary care planning
- Symptom management and comfort care
- Family involvement and memory-making
- Bereavement support and follow-up care
- Future pregnancy care

Principles

- Care that is:
  - Flexible, responsive, consistent and holistic
  - Tailored to family needs
  - Delivered by a coordinated team across hospital, home and community settings
- Support continuity, comfort and memory-making
- Provide families with compassionate bereavement support

Model of care

Diagnosis

- Discuss prognosis
- Initiate support early, introduce palliative care principles
- Allocate key contact person

Care planning

- Involve multidisciplinary healthcare team
- Required interventions
- How to best support baby and family
  - May include delivery mode, care location, medical intervention and comfort care

Model of care continued

Palliative care

- Symptom management, comfort care and quality of life
- Review and adjust interventions according to condition of baby and goals
  - May include reduction or withdrawal of life-prolonging treatments

End-of-life care

- Comfort care, dignity and emotional support
- Bereavement planning and memory creation
- Includes after death care for baby and family

Anticipatory planning

Advance care planning

- Commence at time of diagnosis
- Develop care plan with the family
- Review and update frequently

Parallel planning

- Ongoing care alongside end-of-life care
- Plans for unexpected outcomes

Location planning

- Delivery mode and location
- Hospital, hospice or home?

Investigation planning

Antenatal:

- Informs prognosis, guides care planning, and facilitates early multidisciplinary care

Postnatal:

- Assesses baby's condition, confirms diagnosis, and guides symptom management

Post death:

- May inform future pregnancies and contribute to clinical knowledge

Referral and consultation

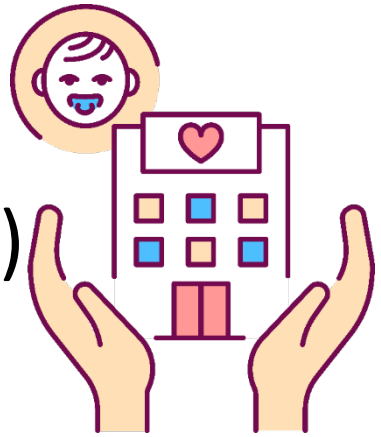
Refer babies early to palliative care services

Early referral supports:

- Early engagement
- Facilitating advanced care planning
- Assistance with coordinating care and advice including nursing, medical, and family support

Services include:

- Paediatric Palliative Care Service (PPCS)
- Hummingbird House



Transfer and transportation

Private transfer	Retrieval services
• Non-emergency transfers	• Antenatal: to return mother closer to home as appropriate
• Assess feasibility	• Neonatal transfers via ANTS-NQ / NeoRESQ
• Provide paperwork	• Coordinate via Retrieval Services Queensland (RSQ)
• Coordinate with local services, PPCS or Hummingbird House	

Comfort care

- Assess for pain and symptom management needs
- Provide comfort-focused care:
  - **Prioritise symptom relief**
  - **Avoid invasive procedures**
- Incorporate non-pharmacological interventions to maximise comfort
- Maintain warmth, and a soothing environment to support overall comfort

Symptom recognition

Symptom	Recognition
Pain	• Changes in heart rate, respiratory changes, agitation
Heart rate	• Any variation from baby's baseline ◦ Can be tachycardic or bradycardic
Respiratory distress	• Apnoea, tachypnoea, grunting, chest recession, gasping
Irritability	• Increased agitation, crying, unsettled, unable to settle
Secretions	• Increased oral secretions ◦ Especially if baby cannot swallow
Vomiting	• Increased vomiting or feed intolerance

Non-pharmacological management

- Calm environment
- Non-nutritive sucking
- Positioning strategies
- Skin-to-skin contact
- Gentle touch, swaddling and facilitated tucking
- Allied health interventions

Pharmacological management

Principles

- Select medications which prioritise comfort and symptom relief
- Discontinue medicines that do not contribute to comfort
- Escalate if symptoms not managed
- Use best route of administration best suited to baby
  - NB: IV access is unsuitable for home or hospice

Anticipatory prescribing

Prescribing medications in advance facilitates proactive symptom management

- Have medications readily available
  - Facilitates timely and effective symptom relief
- Discuss plan with family and multidisciplinary team
  - Promotes understanding and confidence in care

Nutrition, feeding and oral care

- Feeding options:
  - Nutrition/feeding plan made in advance with parents
  - Continue as tolerated
  - Drops of breast milk for comfort—even if baby has no sucking reflex

- Decisions made in the context of best interest, comfort, and symptom control
- Maintain oral hygiene
  - Include parents and carers in oral care practices

What to expect at end-of-life

Circulatory

- Decrease in heart rate, cyanosis, cool extremities

Respiratory

- Irregular breathing, increased secretions
- Gasping

Physical

- Colour changes, lethargy, agitation

Memory-making principles

Support:

- Family connection
- Emotional healing
- Personalised memories

Offer:

- Options and adapt to family's needs

Respect:

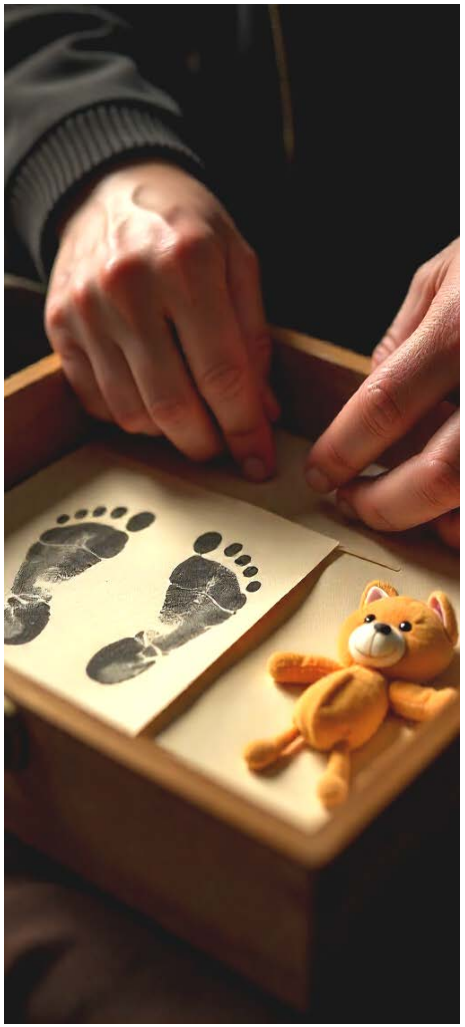
- Decision to decline or postpone

Recognise:

- Caregiving acts as part of memory creation

Memory-making suggestions

- Pregnancy and family photography
- Recording the baby's heartbeat
- Taking footprints/handprints
- Creating plaster casts of hands or feet
- Assembling a memory box with personal items
- Collecting locks of hair



If parents decline involvement

- Offer memory creation
- Involvement levels may vary
- Some parents choose not to be involved for many reasons
- Inform parents they may change their mind
- Treat baby with compassion, dignity and respect
- Give baby comfort
- Nominate surrogate carer for baby

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Babies born alive after termination

- Live born babies are legal persons under Queensland law
- Provide individualised, non-judgmental, and compassionate care immediately after birth
- Complete birth and death registrations and medical certification
- Focus on comfort, dignity, and alleviation of suffering
- Provide comfort care (e.g. warmth, gentle handling, and support for family bonding where appropriate)

After death care

- **Handle baby with care, dignity and respect**
- Remove monitoring, lines, tubing, tapes
- Parent-lead after death care and memory creation
- Support family in cultural, religious, and/or spiritual preferences including taking baby home
- Consider investigation requirements

After death considerations

Aspect	Key points
Investigations	• Full autopsy, limited postmortem • Genetic testing, or tissue sampling • Newborn bloodspot screening (NBS) • Advanced imaging
Autopsy	• Establish/clarify cause of death • Confirm clinical findings and/or uncover new information • Inform future pregnancies
Perinatal Loss Support Officers	• Facilitate transfer between centres • Provide ongoing support, information, and updates

Forms and administration

- Complete documentation
  - Including death certification
- Notify GP and other relevant healthcare providers
  - Including referring obstetric, neonatal and midwifery teams
- Provide clear written and verbal explanations of processes for autopsy, reporting, and what to expect

Bereavement support

Grief is not pathological, it's a natural response

- Recognise:
  - Significance of parenthood
  - Impact on siblings, grandparents, and extended family
- Provide access to specialised grief, bereavement, and peer support services
- Use telehealth, community networks, and outreach programs for rural and remote support

Staff support

- Staff at higher risk of:
  - **Burnout**
  - **Compassion fatigue**
  - **Ethical conflict**
  - **Secondary trauma**
- May go unrecognised
- Offer confidential emotional support
- Promote self-care
- Foster supportive environment

Follow-up

- Follow-up to discuss clinical course and investigation findings
- Communicate between hospital and community-based healthcare providers
- Assess social and emotional wellbeing at all appointments
- Provide future pregnancy planning recommendations
  - Advice and support
  - Investigation
  - Modified model of care