Perinatal care of the extremely preterm baby

Clinical Guideline Presentation v2.0
References:
Queensland Clinical Guideline: Perinatal care of the extremely preterm baby is the primary reference for this package.

Recommended citation:

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.

Feedback and contact details:

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Objectives

Relevant to babies born extremely preterm to identify

• Legal and ethical principles that inform care decisions
• Factors influencing survival
• Antenatal interventions that impact outcomes
• Identify key components of palliative care
Family centred care

• Respect and dignity
  ◦ Listen to, and honour family choices

• Information and sharing
  ◦ Share complete and unbiased information

• Participation
  ◦ Support parental involvement

• Collaboration
  ◦ Involvement on an institutional wide basis
# Ethical principles

<table>
<thead>
<tr>
<th>Principle</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non-maleficence</strong></td>
<td>• Do no harm/minimise harm</td>
</tr>
<tr>
<td><strong>Beneficence</strong></td>
<td>• Act for the benefit of others</td>
</tr>
<tr>
<td><strong>Autonomy</strong></td>
<td>• Make own decision and life choices</td>
</tr>
<tr>
<td></td>
<td>• Premature babies must rely on others</td>
</tr>
<tr>
<td><strong>Justice</strong></td>
<td>• Actions that are fair to those involved</td>
</tr>
</tbody>
</table>
Legal considerations

- ‘Best interests of the baby’ is the legal principle underpinning all decisions relating to resuscitation.
- No legal definition of when resuscitation should or should not occur.
- Australian case law affirms that withdrawal of life sustaining treatment can be in the best interest of the baby, and parents can consent to withdrawal of treatment.
Best interests

• Includes an assessment of:
  ◦ Pain and suffering
  ◦ Inevitability of death
  ◦ Quality of life
  ◦ Interests of family and other parties

• Healthcare team not obliged to provide or withhold interventions that are not in the best interests of the baby
Withdrawing or withholding care

• No ethical or legal distinction between withholding and withdrawal of life sustaining interventions (if decisions are made in the best interests of the baby)
• Signals a shift in focus to palliative care making sure rest of baby’s life is as comfortable as possible
Decision-making

• Parent(s) and family central to approach
• Collaborative
• Multidisciplinary
• Involve all relevant parties
• Led by an experienced practitioner
Managing conflict

• May occur within healthcare team and/or between healthcare team and family
• Attempt to resolve conflict before birth
• Identify key contacts to ensure consistent approach
• Consider conflict resolution or mediation, independent medical consultant, transfer of care, clinical ethics committee, or legal involvement (last resort)
• Commence a plan of care at the earliest opportunity
• Involve the family in care planning
• Document all discussions and decisions clearly and unambiguously
• Review and update regularly as the clinical situation evolves
Sharing information

• Prepare for discussions
  ◦ Review history
  ◦ Assess prognostic certainty
  ◦ Ascertain parental knowledge of baby’s condition

• Incorporate cultural considerations

• Provide opportunity for detailed discussion and questions

• Offer written information
Counselling

• Main purpose is to inform the family and assist with decision making
• Compassionate but realistic assessment
• Acknowledge prognostic uncertainty
• Involve others (e.g. specialities)
• Discuss expectations for care including palliative care
• Include psychological supports
Factors influencing survival

- Gestational age
- Improved outcome if:
  - Female
  - Singleton
  - Appropriate higher birth weight for gestational age
- Worsened outcome:
  - Significant fetal anomaly
  - Severe antenatal pathology
Longer term outlook

• Significant morbidities occur in babies born extremely preterm
  ◦ Cerebral palsy
  ◦ Intellectual disability
  ◦ Cognitive impairment
  ◦ Sensory deficits
  ◦ Chronic health problems
  ◦ Restrictions in activities of daily living
Quality of life

• Considers more than ‘what are the chances of survival’
• Impairment does not indicate that the life is without quality
• Exists on a continuum and people vary where they would choose death or no resuscitation
In-utero transfer

• Best survival rates: Inborn at neonatal units that manage high volumes of very low birth weight babies
• Coordinate transfer via Retrieval Services Queensland (RSQ)
• Aim for in-utero transfer unless palliative care is planned
Antenatal corticosteroids

• Recommend from 22+0 weeks where treatment is planned or may be a possibility
• Where possible, 48 hours prior to birth
• Administration does not oblige or equate to a final decision for active treatment
• Consider additional dose if more than 7 days since initial dose
Cardiotocograph (CTG)

- Take into account fetal physiology at less than 28 weeks gestation
- CTG not recommended at less than 24 weeks
- May have limited usefulness between 24 and 28 weeks gestation depending on circumstances
Magnesium sulfate

• Reduces risk of cerebral palsy
• Recommend before 30+0 weeks where active treatment is planned or a possibility and birth is imminent
  ◦ Commence as close to 4 hours prior to birth as possible
• Repeat dose may be considered if birth does not occur
Caesarean section

• Evidence lacking on optimal mode of birth
• CS not recommended for fetal indications alone at less than 24+0 weeks
• Not usually recommended between 24+0 and 24+6 weeks for fetal indications alone
• May be recommended from 25+0 weeks depending on individual circumstances
Care at birth

• If resuscitation is an option:
  ◦ Regard as an emergency
  ◦ Experienced practitioner present

• If gestation uncertain - initiate interventions until clinical course clearer

• Discuss baby’s condition with family as soon as possible

• Provide palliative care if resuscitation not planned
## Resuscitation

<table>
<thead>
<tr>
<th>Gestation</th>
<th>Life sustaining interventions</th>
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<tbody>
<tr>
<td>&lt; 23+0 weeks</td>
<td><em>Not usually recommended</em></td>
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<tr>
<td></td>
<td>• Palliative care usually recommended</td>
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<tr>
<td>23+0 - 23+6</td>
<td><em>Consider individual circumstances</em></td>
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<tr>
<td></td>
<td>• Support an informed decision by the family</td>
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<tr>
<td>24+0 - 24+6</td>
<td><em>Usually recommended</em></td>
</tr>
<tr>
<td></td>
<td>• Support an informed decision by the family for palliative care</td>
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<tr>
<td>25+0 - 25+6</td>
<td><em>Recommended</em></td>
</tr>
<tr>
<td></td>
<td>• Consider individual circumstances if an informed decision by the family is for palliative care</td>
</tr>
</tbody>
</table>

Consider other prognostic factors when making decisions
Palliative care planning

• Assess the baby’s clinical condition
• Develop a care plan with the family
  ◦ Review and update plan frequently
• Involve palliative care specialists
• Document all decisions clearly and unambiguously
Palliative care

- Involve family in newborn care
- Gastric feeding not usually recommended
- Cease unnecessary interventions, monitoring and medications
- Assess for pain and symptom management needs
- Avoid invasive procedures
- Incorporate non-pharmacological interventions
Bereavement support

- Tailor support to family needs
- Maintain a family centred approach
- Involve social worker/psychological supports
- Facilitate maternity care as required
- Facilitate memory creation
Follow-up after bereavement

• Provide information about burial and cremation
• Offer appointment to discuss events
• Provide contact information for psychological supports
• Consider needs for subsequent pregnancies
• Inform community carers (e.g. GP)