Queensland Clinical Guidelines

Translating evidence into best clinical practice

Maternity and Neonatal **Clinical Guideline**

Perinatal care at the threshold of viability

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Disclaimer

These guidelines have been prepared to promote and facilitate standardisation and consistency of practice, using a multidisciplinary approach.

Information in this guideline is current at time of publication.

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Clinical material offered in this guideline does not replace or remove clinical judgement or the professional care and duty necessary for each specific patient case.

Clinical care carried out in accordance with this guideline should be provided within the context of locally available resources and expertise.

This Guideline does not address all elements of standard practice and assumes that individual clinicians are responsible to:

- Discuss care with consumers in an environment that is culturally appropriate and which enables respectful confidential discussion. This includes the use of interpreter services where necessary
- Advise consumers of their choice and ensure informed consent is obtained
- Provide care within scope of practice, meet all legislative requirements and maintain standards of professional conduct
- Apply standard precautions and additional precautions as necessary, when delivering care
- Document all care in accordance with mandatory and local requirements

Flow Chart: Antenatal care where birth imminent or indicated at less than 25 weeks+6 days

Inform the family that initiation of antenatal interventions does not oblige nor necessarily equate to a final decision for life sustaining interventions - especially at lower or uncertain gestations

Contact Level 6 service early in the decision making process

Decision making
- Advocate a family centred approach
- Consider ethical principles
- Ensure multi-disciplinary collaboration
- Discussions are led by an experienced practitioner
- Coordinate and plan care at the earliest opportunity
- Review plans regularly
- Document decisions clearly

Counsel parents
- Consider individual circumstances
- Review case history and results
- Consider cultural needs
- Convey information in a manner that facilitates understanding
- Provide a compassionate but realistic assessment of the outlook
- Discuss prognosis, resuscitation and expectations for care
- Discuss quality of life

Consider outcome factors
- Gestational age +/- PAGE
- Estimated fetal weight
- Sex
- Plurality
- Congenital anomaly
- Antenatal pathology
- Place and mode of birth
- Plans regarding resuscitation

In-utero transfer
- Contact QCC to coordinate transfer (phone 1300 799 127)
- Consult with higher level service as required
- Aim for **in-utero** transfer unless transfer puts the mother's life at risk
- Transfer not indicated if:
  - Birth certain or imminent at < 23+0 weeks
  - Life sustaining interventions not intended and not considered a possibility at birth
- Consider context of care (considerably better prognosis if neonate born at centres with expertise)

Tocolysis
- Consider individual risk vs benefit of delaying birth:
  - To allow administration of corticosteroids,
  - To achieve in-utero transfer
  - Consider contraindications (e.g. placental abruption, maternal infection)
- Refer to Queensland Clinical Guideline *Preterm Labour*

Steroids
- Corticosteroids are associated with reduction in rates of neonatal death, respiratory distress syndrome and IVH
- Recommend where there is a risk of preterm birth and life sustaining interventions are planned or may be a possibility
- Not indicated if birth is imminent at < 23+0 weeks

CTG
- Little evidence for interpretation of CTG at < 28+0 weeks
- Take fetal physiology into account when interpreting CTG at lower gestations
- CTG not recommended at < 24+0 weeks
- Limited usefulness after 24+0 weeks depending on individual circumstances and clinician expertise

$MgSO_4$
- $MgSO_4$ given shortly before birth reduces the risk of cerebral palsy and protects gross motor function in infants born preterm
- Recommended between 23+0 weeks and 30+0 weeks where birth is imminent and life sustaining interventions are planned or may be a possibility
- When birth is planned, commence as close to 4 hours prior to birth as possible
- Requires one-to-one midwifery care

C Section
- The evidence regarding CS for fetal indications at extremely low gestations is inconclusive and conflicting
- Consider specific circumstances (e.g. gestation, plurality, presentation, obstetric history, future pregnancy, parental wishes)
- Consensus recommendation - CS for fetal indications alone:
  - Is not recommended at < 24+0 weeks
  - Is not usually recommended between 24+0 and 24+6 weeks
  - May be recommended at ≥ 25+0 weeks depending on individual circumstances

Refer to threshold of viability resuscitation flowchart

CS Caesarean section **CTG** Cardiotocograph **IVH** Intraventricular haemorrhage **PAGE:** Prognosis for average gestational age equivalent infant framework **QCC** Queensland Emergency Medical System Coordination Centre

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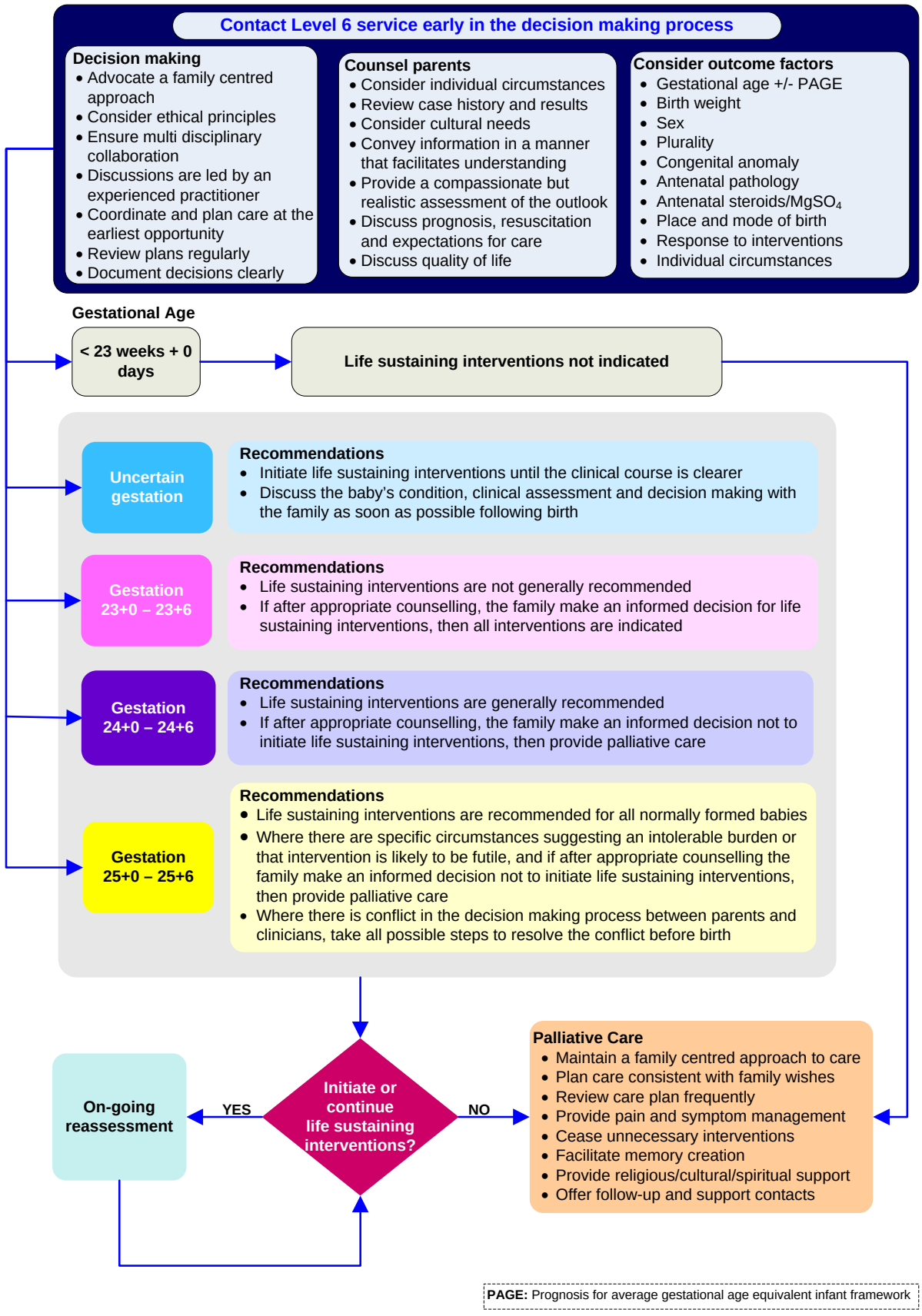
Flow Chart: Consensus approach to resuscitation at the threshold of viability in Queensland



PAGE: Prognosis for average gestational age equivalent infant framework

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Abbreviations

CI	Confidence interval
CS	Caesarean section
CTG	Cardiotocograph
ELBW	Extremely low birth weight
FHR	Fetal heart rate
GMFCS	Gross motor function classification system
ICF	International classification of functioning, disability and health
IV	Intravenous
IVH	Intraventricular haemorrhage
LBW	Low birth weight
$MgSO_4$	Magnesium Sulfate
NICU	Neonatal intensive care unit
NNT	Number needed to treat
NNTB	Number needed to treat to benefit
QCC	Queensland Emergency Medical System Coordination Centre
PAGE	Prognosis for gestational age equivalent
RR	Relative risk

Definitions of terms

CRIES	A neonatal pain assessment tool. An acronym of five physiological and behavioural variables: C-Crying, R-Requires increased oxygen administration, I-increased vital signs, E-expression, S-Sleeplessness.
Intolerable burden	Extreme level of suffering or impairment which is either present in the baby or may develop in the future.
Inborn	A baby born at a facility that has Neonatal Intensive Care Unit capabilities.
Family	Refers to two or more persons who are related in any way (biologically, legally, or emotionally). Patients and families define their families.[1]
Mediation	Mediation is a flexible process conducted confidentially in which a neutral person actively assists the parties in working towards a negotiated agreement of a dispute or difference, with the parties in ultimate control of the decision to settle and the terms of resolution.[2]
Multidisciplinary health care team	Membership of the health care team is influenced by the needs of the woman and her baby, availability of staff, and other local resourcing issues. The health care team may include but is not limited to: nurse/midwife, obstetrician, neonatologist/paediatrician, other specialist practitioners (e.g. palliative care, feto-maternal specialist), social worker/counsellor and dietician.
Outborn	A baby born at a facility (or at home) that does not have Neonatal Intensive Care Unit capabilities.
PIPP	A neonatal pain assessment tool. An acronym for Premature Infant Pain Profile.
Premature	Less than 37 weeks.
Psychological supports	Emotional and psychological support can be provided by a range of health professionals as appropriate to the circumstances and resources available. Providers may include (but are not limited to) social worker, counsellor, psychologist, grief counsellor, midwife, nurse, doctor).
Threshold of viability	Gestational age at which the sustainability of life is not certain. For the purposes of this guideline this is considered to be gestations between 23 weeks+0 days and 25 weeks+6 days.
Viability	Capable of living ex-utero; born alive and with such form and development of organs as to be normally capable of living.
Withholding treatment	Non-initiation of treatment that may sustain life.
Withdrawal of treatment	Cessation of life sustaining interventions.

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1 Introduction

The birth of a baby at extremely low gestational age can be a stressful experience for the parents and family. Birth at these gestations also presents enormous challenges for maternity and neonatal healthcare professionals. Although neonatal survival rates have improved dramatically over the last few decades, severe morbidity is still common.[3] Uncertainty is a feature of many decisions regarding prognosis thus complicating counselling and care provision.

As the gestational age decreases, morbidity and mortality increase dramatically. Although fewer than 1% of babies are born at less than 28 weeks gestation they account for more than half of all cases of perinatal mortality in Queensland.[4] In Queensland between 2000 and 2008, 100% of babies born at less than 22 weeks gestation died and 97.5% of babies born between 22 and 23 weeks gestation died.

1.1 The threshold of viability

Where the threshold of viability lies is the subject of much debate both nationally and internationally [refer to Appendix A Summary of initiation of treatment by gestational age]. While gestational age is an important determinant of viability all decisions regarding birth, withdrawal or withholding of care require consideration of the individual circumstances, the likely prognosis and parental preferences.[5,6,7]

For the purposes of this guideline the threshold of viability is considered to be between 23 weeks and 0 days and 25 weeks and 6 days gestational age.

1.2 Purpose of the guideline

The purpose of this guideline is to:

- Promote consistency in perinatal viability counselling
- Promote informed ethical decision-making

It is not intended to provide rules by which care at a specific gestational age is impermissible or obligatory.

1.3 Clinical standards

- Provide care in accordance with the Clinical Services Capability Framework[8]
- Maintain a family centred approach to care that incorporates psychological, spiritual and social support[9]
- Educate health professionals on outcome data relevant to the setting[10]
- Educate health professionals providing care to babies of very low gestational age in the basic principles of palliative care[2,3,11]
- Provide support (e.g. debriefing, interdisciplinary morbidity and mortality reviews or counselling) to health professionals caring for families experiencing birth at extremely low gestational age
- Promote communication skills training[12] across all health disciplines
- Use agreed definitions when preparing information on outcome and morbidity[5]

2 Communication

Open and honest communication between the family and healthcare team is the cornerstone of ethical decision-making and care provision.[13,14] Acknowledging the prognostic uncertainty and the limited evidence supporting specific interventions and care provision at very low gestational ages is an essential component of this communication. Ideally, communication commences in the antenatal period whenever possible.[13] Where this is not possible, commence discussions with the family as soon as practical after birth. Ideally discussions are led by practitioners experienced in the care of extremely premature babies.

2.1 Family centred care

Patient and family centred care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.[1,15]

Table 1. Core concepts of patient and family centred care

Core Concept[1]	Meaning
Respect and dignity	• Health care practitioners listen to and honour patient and family perspectives and choices • Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care
Information and sharing	• Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful • Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making
Participation	• Patients and families are encouraged and supported in participating in care and decision-making at the level they choose
Collaboration	• Patients and families are also included on an institution-wide basis • Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation, in health care facility design, and in professional education, as well as in the delivery of care

2.2 Ethical principles

Four commonly held broad ethical principles form a framework within which moral decision-making can occur. These principles are outlined in Table 2.

Table 2. Ethical principles

Principles	Considerations
Non-maleficence[16]	• Requires that harm not be inflicted intentionally and is closely linked to the imperative to minimise harm
Beneficence[16]	• Refers to a moral obligation to act for the benefit of others, helping them to further their important and legitimate interests, at times preventing or removing possible harm • Harm may result from treatment that in other circumstances would be clinically appropriate and beneficial. This implies a constant need to determine the levels of potential harm and benefits of life sustaining interventions, and to ensure that the benefits outweigh the harms
Autonomy[16]	• Autonomous individuals are entitled to make their own decisions and life choices • Extremely premature babies must rely on others to make decisions for them
Justice[16]	• Prescribes actions that are fair to those involved • Suggests that like cases should be treated alike and that variations in management must be justified by relevant clinical and/or evaluative conditions

2.3 Ethical and legal considerations

Critical care decisions for the baby are likely to raise a number of ethical issues. Understanding of these ethical issues may aid the appreciation and understanding of differences in opinion that arise.[2]

Table 3. Ethical considerations

Aspect	Considerations
Legal principles	• The 'best interests of the baby' is the legal principle that underpins all decisions relating to resuscitation[17] • There is no statutory or common law definition of viability or of when resuscitation should or should not be provided[17] • Australian case law has affirmed that the withdrawal of life-sustaining treatment can be in the best interests of a baby under certain conditions, and that parents were permitted to authorise and consent to withdrawal of treatment[18]
The value of human life	• There are some circumstances in which imposing or continuing treatment to sustain a baby's life results in a level of irremediable suffering such that there is no ethical obligation to act in order to preserve life[2] • Respect for the sanctity of human life is a primary consideration in clinical practice but is not absolute. Acknowledgement that death is a part of life within neonatal care is also required
Best interests	• Consideration of best interests includes an assessment of: o Pain and suffering o Inevitability of death o The quality of life o The interests of the family and other parties • The opinion of the family as to the best interests of the baby is to be considered and accounted for in any decision made in respect of the baby • The health care team is not obliged to provide interventions that are not in the best interest of the baby or to withhold beneficial intervention at the request of the family[13,19] • Society has the ethical and legal right to intervene when the family's decisions are clearly not in the best interests of the baby[20]
Withdrawing or withholding life sustaining interventions	• There is no ethical or legal distinction between withholding and withdrawal of life sustaining interventions when the decisions are motivated by an assessment of the best interests of the baby[2,12,13] • Withholding or withdrawing life sustaining intervention does not imply that a baby will receive no care. Rather it signals a change in focus towards palliative care making sure that the rest of the baby's life is as comfortable as possible[21]
Deliberately ending life	• The Australian and New Zealand Society of Palliative Medicine (ANZSPM) does not endorse euthanasia[22]
Relieving pain and causing death	• Provided the intervention is guided by the best interests of the baby, and has been agreed as a joint decision, interventions that relieve pain, suffering or distress but which incidentally shorten life are both morally acceptable[2,19] and lawful

2.4 Decision-making

Table 4. Decision-making

Aspect	Considerations
Collaborative decision-making	• Collaborative decision-making[12]: o Uses a family centred approach to care o Supports decision-making in the best interests of the family[14] o Allows different parties to present their views about what they hold these interests to be o Acknowledges the responsibilities of all parties o Makes it possible for the family to raise objections to the view of healthcare professionals • Support all relevant parties wishing to participate in the decision-making to do so[12] • A multidisciplinary approach is recommended[14] to: o Ensure a range of concerns and areas of clinical care are represented[5,12] o Support continuity of care/carer in the transition through antenatal, intrapartum and neonatal care provision[12] • Discussions are led by an experienced practitioner[5,12,14,23] • Where possible facilitate regular meetings to discuss the goals of care and to establish rapport and build trust with the family
Managing conflict	• Conflict may arise particularly when there are differing cultural, religious or personal beliefs • Make every attempt to resolve conflicts or disagreements within the healthcare team or between the healthcare team and the family prior to birth • Identify key contacts and decision makers so as to minimise the risk of 'mixed messages', major changes in approach and confusion for the family[12] o Facilitate parents as a 'team' for decision-making so as to support shared responsibility • Health professionals have an obligation to support and respect their colleagues even during disagreement[12] • Consider conflict resolution/facilitated mediation if appropriate[14] • Consider involvement of an independent medical consultant[12,13] • Where all possible means of resolving disagreement between the parties has been exhausted, consider alternative decision-making processes[12] o Transfer of care[12] o Referral to clinical ethics committee or other appropriately constituted body[12,23] o Consider involvement of the courts[12] as a last resort[23]
Documentation	• Coordinate and commence a plan of care at the earliest opportunity[12,23] o Identify people to be involved with decision-making[12] o When/if transfer to a tertiary centre may be appropriate[12] o Obstetric clinical decisions[12] (e.g. administration of corticosteroids, mode of delivery, actions to be taken in the event of acute deterioration) o Decisions on resuscitation[12] (e.g. initiation based on gestational age or other criteria) • Antenatally, document all discussions[24] in the maternal health record so that other health professionals are aware of what information has been provided, the family's views, the agreed clinical approach and the rationale for decisions • Outline and document decisions in nursing and medical care plans and at daily handovers to reduce the risk of variation from the agreed plan[12] • Review and update the care plan regularly in consultation with the family as the clinical situation evolves and changes in the goals, directions or limitations occur[12]

2.5 Sharing information

Table 5. Conveying complex information

Aspect	Considerations
Preparing for discussions	• Review details of the case including[24]: o Maternal history (including past medical/obstetric history) o Presenting problem of the baby o Any investigation results or ultrasound scans • Assess the degree of diagnostic and prognostic certainty/uncertainty • Discuss the case with referring healthcare professionals • Ascertain parental knowledge, understanding, expectations, and psychological capacity for discussions • If appropriate, involve higher level services
Cultural considerations	• Use translation services if there is any doubt about the ability of all key family members to understand English[12,14,25] • Be aware that cultural and religious differences can affect clinician and parental communication styles and expectations and perspectives of viability and palliative care • It cannot be assumed that individuals will identify with all aspects of their cultural background, however anticipate specific support requirements and provide as appropriate • Involve family, religious officers or other parties as appropriate to the circumstances and in accordance with parental wishes
Conveying complex information	• Hold conversations in quiet, private and physically comfortable spaces[12] • Involve both parents at the same time wherever possible[14,25] o Involve other family members if appropriate to the individual circumstances[12] • Include a person NOT involved with giving information[12] who is able to support the family • Prepare the family by giving an indication of the seriousness of the discussion[12] • Do not assume parental knowledge or understanding o Provide a summary of the baby's situation o Give the family an early opportunity to speak so their understanding of the situation is established and their concerns heard[12] • Provide complete and unbiased information at a level appropriate for the family's level of understanding of complex issues[14,25] • Acknowledge prognostic uncertainty and where evidence for care is limited • Provide adequate time and opportunity for the family to consider the content of discussions and ask questions[14,25] • More than one conversation may be necessary and decisions may need to be altered especially if the pregnancy continues [25] • Written information may be useful as the family may forget or be unable to comprehend what they have been told at the time[14,24-26] • Taped or video recordings of the conversation (with parental consent) may be useful for later recall • Identify a key contact and decision maker so as to minimise the risk of 'mixed messages', major changes in approach and confusion for the family[12] • Refer to Section 2.6 Counselling

2.6 Counselling

The purpose of counselling is to inform the family and assist with decision-making. Common areas for discussion are outlined in Table 6.

Table 6. Areas for discussion

Discussion area	Considerations

Prognosis	• Convey a compassionate but realistic assessment of the outlook
	• Communicate information in a manner that facilitates a full understanding of the facts as they are known
	• Provide the most accurate prognostic morbidity and mortality data available[5,14,23-25]
	  o This may be hospital specific data or regional or national data as appropriate[5,24,25]
	• Discuss with the family:
	  o That the ability to give accurate short and long term prognosis for a specific baby remains limited[19,25] and is impacted by many factors (in addition to gestational age) which may not be obvious prior to or at birth[5,14]
	  o That even with resuscitation and intensive care, many babies of very low gestational age may die after birth[25,27]
	  o The possibility that even if resuscitation is attempted and is successful, there may be future situations where withdrawal of life sustaining interventions is considered[25]
	• Involve other paediatric specialists appropriate to the circumstances[12] (e.g. paediatric cardiologist or surgeon)
	• Involve receiving neonatal/obstetric units in discussions where transfer may be required (e.g. videoconference, teleconference, in-utero transfer)
	• Refer to Section 4.1 Definitions to aid parental understanding

Resuscitation	• Advise the family that if the decision is to not initiate resuscitation or if resuscitation is unsuccessful, palliative care will be provided for their baby[12,23,25] • If parental preferences regarding resuscitation are either unknown or uncertain, it is reasonable to initiate resuscitation pending further discussions[23,25]
Expectations for care provision	• Discuss/provide information on expected care as appropriate to the circumstances/decisions (e.g. appearance/condition of the baby, likely procedures/investigations, when the family will be able to hold the baby) • Refer to Queensland Clinical Guideline *Neonatal resuscitation*[28] • Refer to Queensland Clinical Guideline *Neonatal stabilisation*[29] • Provide a tour of the nursery if applicable
Continued antenatal review	• Where communication is established in the antenatal period, ensure arrangements for review and follow-up are established and communicated to all parties • Reassess the plan for care frequently if the pregnancy continues • Provide contact information for support groups/organisations • Involve social workers/psychological supports [refer to definition of terms] in discussions/follow-up

3 Factors affecting viability

Gestational age is the major factor in determining viability but other factors also impact survival and decision-making and require consideration.[14,30,31]

Table 7. Factors influencing viability

Aspects	Considerations
Gestational age	• At very low gestational ages survival rate increases as gestational age increases o Adding even a few additional intrauterine days may be of great benefit[32] • Even relatively small discrepancies in gestational age may have major implications for survival and long-term morbidity[5] • Base gestational age on ultrasound measurements of the crown-rump length at 8–12 weeks (accuracy +/- 4 days) and/or history of the last menstrual period (accuracy -6 to +14 days)[14] • Consider the possibility of growth restriction where later ultrasound measurements suggest a younger gestational age[5] • Gestational age by obstetric dating is more accurate than estimation from physical and neurological criteria • Where gestational age is uncertain—reassess in the immediate postnatal period [refer to Table 18. Birthweight percentile values (g) for live singleton females and males]
Sex **Birth weight** **Plurality**	• Factors associated with improved survival and outcome include: o Female sex[27,31] o Singleton birth o Appropriate higher birth weight at a given gestational age[5] [refer to Table 18]
Congenital anomaly	• The outcome or prognosis associated with a significant fetal anomaly may be worsened by extreme prematurity. Examples include (but are not limited to) complex heart disease, diaphragmatic hernia, significant bowel disease • In Queensland 2000–2008, 23.3% of perinatal deaths were attributed to congenital abnormalities. Of these, 60% of perinatal deaths occurred prior to 28 weeks gestation[4]
Antenatal pathology	• Presence and/or severity of pathology influences outcomes[24]: • Poor outcome associated with (but not limited to): o Birth weight less than the 2nd centile[33] o Prolonged rupture of membranes o Severely abnormal fetal Doppler o Chorioamnionitis o Antepartum haemorrhage o Twin to twin transfusion syndrome

3.1 Gestational age equivalent infant

The Prognosis for Average Gestational Equivalent Infant (PAGE) framework is summarised here as a supplementary tool that may support usual decision-making.
It is based on the following principles[7,34]:

- Decisions about treatment should be based on the best available evidence about the prognosis for the baby
- Decisions should reflect all relevant prognostic factors and should not be based on gestational age alone
- Babies with similar prognosis should be treated similarly

Table 8. PAGE framework

<table>
<tr><th>Aspect</th><th>Consideration</th></tr>
<tr><td>Recommendation</td><td>• May be useful for expert clinicians in Neonatal Intensive Care Units with extensive experience in the care of babies at the threshold of viability
• Access to and/or knowledge of relevant data to support assessment of prognosis is required
• Consider all factors influencing viability as outlined in preceding sections.</td></tr>
<tr><td>PAGE Framework[7,34]</td><td>• Directs clinicians to:
o Gather all relevant prognostic information [refer to Section 3 Factors affecting viability]
o Estimate a baby's prognosis (if resuscitation is provided) using the best available relevant data
o Assess where a baby's prognosis sits compared with other extremely preterm infants
o Approach counselling and decision-making for that baby in a similar way to other babies with the same outlook

<table>
<tr><th>Estimated chance of poor outcome* if intensive treatment provided</th><th>PAGE#</th><th>Treatment category</th><th>Obstetric management</th></tr>
<tr><td>≥ 90%</td><td>20–22 weeks gestation</td><td>Not indicated
Life sustaining treatment should usually not be provided</td><td>Maternal focused</td></tr>
<tr><td>50–90%</td><td>23–24 weeks gestation</td><td>Optional
Life sustaining treatment should be guided by parents' wishes</td><td>Depends on parents' wishes</td></tr>
<tr><td>≤ 50%</td><td>25 weeks gestation</td><td>Usual
Life sustaining treatment should usually be provided</td><td>Maternal/fetus focused</td></tr>
</table>
*Poor outcome: refers to either death despite treatment or survival with profound impairment (Bayley score of <50 (untestable) or severe cerebral palsy (Gross Motor Function Classification Scale (GMFCS)=5)
#Weeks gestation refers to the interval of the index week (e.g. 24 weeks refers to the interval 24+0 to 24+6 weeks)</td></tr>
</table>

4 Longer term outlook

The lack of uniformity in national and international definitions of disability and severity, reporting of outcomes by birth weight versus gestational age, various ages of reporting outcomes, different assessment techniques and high attrition rates makes comparison of and interpretation of outcome data difficult.[35] Appendix C provides a summary of outcomes from selected Australian and international studies.

Significant morbidities that occur in babies 22–25 weeks gestation who survived their initial neonatal intensive care unit (NICU) admission include[2,35]:

- Cerebral palsy
- Intellectual disability
- Cognitive impairment (e.g. learning difficulties, behaviour problems)
- Sensory deficits (e.g. blindness, deafness)
- Chronic health problems (e.g. lung disease requiring home oxygen, more frequent use of health services)
- Restrictions in activities of daily living and self-care

A summary of outcomes up to 6 years of age among children born alive at different gestational ages is provided in Table 9. Summary of outcomes up to 6 years among live born children by gestational age.[36] This data should be interpreted in light of the age of the source study (EPICure 1995), changes in clinical practice that may have occurred since the study or as a result of differences in practice between the United Kingdom and Australia.

Table 9. Summary of outcomes up to 6 years among live born children by gestational age

	N (%)			
Outcome	**22 weeks**	**23 weeks**	**24 weeks**	**25 weeks**
Showed signs of life	138 (100)	241 (100)	382 (100)	424 (100)
Survived to discharge from hospital	2 (1)	26 (11)	100 (26)	186 (44)
Died by age 6 years	136 (99)	216 (90)	284 (74)	241 (57)
Lost to follow up at 6 years	0	3 (1)	25 (7)	39 (9)
Survived at 6 years with severe disability*	1 (0.7)	5 (2)	21 (5)	26 (6)
Survived at 6 years with moderate disability^	0	9 (4)	16 (4)	32 (8)
Survived at 6 years with mild disability#	1 (0.7)	5 (2)	26 (7)	51 (12)
Survived at 6 years with no impairment	0	3 (1)	10 (3)	35 (8)

Adapted from: Nuffield Council on Bioethics from Critical care decisions in fetal and neonatal medicine: ethical issues. Marlow N, Wolke D, Bracewell MA and Samara M for the EPICure Study Group (2005) Neurologic and developmental disability at six years of age after extremely preterm birth *N Engl J Med* **352**: 9–19.

**Severe disability*: likely to make a child highly dependent on caregivers, and involving one or more of the following symptoms: cerebral palsy that prevented the child from walking, severe learning difficulties, (IQ > 3 SD below mean) profound sensorineural hearing loss, or blindness.
^*Moderate disability*: child typically reaching a reasonable level of independence, and involving one or more of the following symptoms: cerebral palsy (but the child could still walk), moderate learning difficulties, (IQ 2-3 SD below mean) sensorineural hearing loss that can be corrected with a hearing aid, or impaired vision without blindness.
#*Mild disabilities*: would include mild learning problems or other impairments such as squints

4.1 Definitions to aid parental understanding

The International Classification of Functioning, Disability and Health (ICF) is endorsed for use in Australia.[37] In ICF 'disability' is an umbrella term covering impairment of body functions and structures, activity limitations and problems with involvement in life situations as influenced by the physical, social and attitudinal environmental in which the person lives.[37] The following definitions related to disability may be helpful in discussions with the family.

4.1.1 Gross Motor Function Classification System

The Gross Motor Function Classification System (GMFCS) is commonly used to describe motor skill capability.[38]

Table 10. Gross Motor Funciton Classification System

GMFCS Level	Description at 6-12 years
Level 1	• Walk indoors and outdoors and climb stairs without limitation • Can perform gross motor skills including running jumping, but speed balance and coordination are impaired
Level II	• Children walk indoors and outdoors and climb stairs holding onto a railing but experience limitations walking on uneven surfaces and inclines and walking in crowds or confined spaces
Level III	• Walk indoors or outdoors on a level surface with an assistive mobility device • Children may climb stairs holding onto a railing • Children may propel a wheelchair manually or are transported when traveling for long distances or outdoors on uneven terrain
Level IV	• May continue to walk for short distances on a walker or rely more on wheeled mobility at home and school and in the community
Level V	• Physical impairment restricts voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited • Children have no means of independent mobility and are transported

4.1.2 Intellectual disability

Arbitrary categories of mild, moderate and severe and profound levels of intellectual disability (defined by IQ score) give some guide to the level of support that may be needed. However the way a person functions in their life also depends on other factors including[39]:

- Personality and coping skills
- Other disabilities – for example, physical, social or sensory
- The amount of support offered by family, friends and the community
- What is demanded of them in different situations

Table 11. Intellectual disability descriptions

Level of disability	*General* description of ability and support required[39]
Mild (IQ 50–70)	• Participates in and contributes to their family and their community • Has important relationships in his/her life • Works in either open or supported employment • May live and travel independently but will need support and help to handle money and to plan and organise their daily life • May marry and raise children with the support of family, friends and the service system • May learn to read and write
Moderate (IQ 35–50)	• Has important relationships in his/her life • Enjoys a range of activities with their families, friends and acquaintances • Understands daily schedules or future events if provided with pictorial visual prompts such as daily timetables and pictures • Makes choices about what s/he would like to do, eat, drink • May learn to recognise some words in context, such as common signs including ‘Ladies’, ‘Gents’ and ‘Exit’ • May develop independence in personal care • Will need lifelong support in the planning and organisation of their lives and activities
Severe or profound (IQ below 35)	• May recognise familiar people and may have strong relationships with key people in their lives • Has little or no speech and relies on gestures, facial expression and body language to communicate • Requires lifelong help with personal care tasks, communication and accessing and participating in community facilities, services and activities

4.2 Quality of life

Decision-making often occurs in an environment of personal distress, prognostic uncertainty, and an attempt to evaluate the baby's best interest.[12] In determining 'best interest', survival in qualitative terms (how will he or she live?) rather than merely in quantitative terms (what are his or her chances of survival) should also be considered.[14]

The following questions may be useful in assessing the foreseeable quality of life[2]

- Will the child be able to survive without permanent life support?
- Will the child be able to live outside hospital?
- Will the child be capable of establishing relationships with others?
- Will the child be likely to experience pleasure from life?

Other considerations include:

- It has been reported that health care professionals underestimate survival and overestimate likely disabilities[3]
- A quality of life which could be considered intolerable to an able-bodied person would not necessarily be unacceptable to a child who has been born with a disability
- Impairment is not incompatible with a life of quality and people with severe impairment describe a life of high quality which they are happy to be living[23,40]
- Quality of life exists on a continuum and the family vary regarding where they would choose death/no resuscitation on this continuum[26]
- Many people would perceive a loss of awareness and inability to interact as an intolerable burden not only for the future child but also for the family[12]
- The quality of the life is significantly affected by the family's ability to provide an environment within which he or she can achieve his or her full potential

5 Approach to care

There is general world-wide agreement that there are circumstances where life sustaining interventions will not be successful and therefore should not be used. Similarly it is also generally accepted that there are circumstances where non-initiation of life sustaining intensive care measures could not be ethically justified.[14]

- **If required, consult with higher level clinical services early in the decision-making process**
- Initiation of antenatal interventions in particular circumstances or at particular gestational ages is not necessarily a case of initiating 'all or no interventions'—aspects of care may be more appropriate or less appropriate given the clinical circumstances and the uncertainty of events yet to occur
- Reassess the plan for care frequently if the pregnancy continues
- Where appropriate, consider the alignment of antenatal interventions with the degree of certainty about the timing of birth and the plan for resuscitation at birth
- Involve all members of the multidisciplinary health care team in planning and decision-making

5.1 In-utero transfer

Table 12. In-utero transfer

Aspect	Considerations
Context	• Survival rates are higher in centres that deliver a high volume of very low birth weight babies and provide the highest level of neonatal care[23,41] • Inborn babies have a better prognosis than outborn babies[5,14] o Aim to achieve **in-utero** transfer unless transfer puts the mother's life at risk—this may require a higher level of acceptance of the risk of birth *en route* • Consult with higher level clinical services as early as possible, preferably the neonatal unit where the baby will be cared for • If transfer required, contact Queensland Emergency Medical System Coordination Centre (QCC) to coordinate transfer o QCC phone 1300 799 127 • If clinically appropriate, use tocolysis to allow in-utero transfer o Refer to the Queensland Clinical Guideline *Preterm labour*[42] • If birth does not occur, transfer the woman back to the referring hospital in accordance with the facility's service capabilities and the individual clinical circumstances
Recommendation	• If preterm birth is very likely and life sustaining interventions are planned or may be a possibility, recommend in-utero transfer • In-utero transfer not indicated if: o Palliative care planned o Birth certain or imminent at less than 23 weeks • If life sustaining interventions are to be initiated only if a specific gestational age achieved (e.g. interventions only if gestation reaches 24 weeks) then arrange transfer prior to the specified gestation (i.e. don't wait until 24 weeks+0 days) • If gestational age uncertain, then discuss with the receiving neonatal and obstetric unit • Inform the family that transfer does not oblige or necessarily equate to a final decision for life sustaining interventions

5.2 Antenatal corticosteroids

Table 13. Antenatal corticosteroids

Aspect	Considerations
Context	• Antenatal corticosteroids are associated with a significant reduction in rates of neonatal death, respiratory distress syndrome and intraventricular haemorrhage (IVH)[43,44] • Antenatal corticosteroid use is also associated with a reduction in necrotising enterocolitis, respiratory support, intensive care admissions and systemic infections in the first 48 hours of life compared with no treatment or treatment with placebo[43,44] • One study (n=10,541) reported a lower rate of death or neurodevelopmental impairment at 18–22 months for infants born at 23–25 weeks gestation who had antenatal exposure to corticosteroids compared with non-exposure[45] • A single dose does not appear to be associated with significant maternal or fetal adverse effects[43,44]
Recommendation*	• Recommend corticosteroids to women who are at risk of preterm birth[43] where life sustaining interventions are planned or may be a possibility • If life sustaining interventions are to be initiated only if a specific gestational age achieved, (e.g. only if gestation reaches 24 weeks) then administer corticosteroids prior to the specified gestation (i.e. don't wait until 24 weeks+0 days) • Inform the family that administration does not oblige or necessarily equate to a final decision for life sustaining interventions • Where corticosteroids are indicated, administer: o Betamethasone 11.4 mg IM o 2nd dose: Give 24 hours after initial dose, however if birth likely within 24 hours, consider repeat dose at 12 hours o Consider administration of additional dose if more than 7 days since initial dose[46]

*Refer to Australian pharmacopoeia for complete drug information

5.3 Cardiotocograph monitoring

Table 14. Cardiotocograph monitoring

Aspect	Considerations
Context	• Physiological control of FHR and resultant cardiotocograph (CTG) trace interpretation differs in the preterm compared with the term baby, especially at gestations less than 28 weeks[47] • Compared to term infants, in extremely preterm infants FHR: o Baseline is higher (average 155 bpm at 20–24 weeks)[47,48] o Baseline variability and cycling is reduced[47] o Accelerations are absent[49] or significantly reduced with lower amplitude (rise of 10 beats from baseline rather than 15)[47] o Decelerations in the absence of uterine contractions occur more frequently[48] and may represent normal development[47] o Decelerations may have lower depth and duration[47] o Variable decelerations occur more frequently intrapartum[47] • Reduced FHR reactivity has been associated with early death and severe IVH (grade III or IV) in extremely low birth weight (ELBW) infants[50] • Poor positive predictive value of CTG in addition to variation in CTG interpretation can lead to unnecessary intervention[47]
Recommendation	• Take into account fetal physiology when interpreting CTGs at less than 28 weeks gestation • Counsel women that there is limited evidence for CTG interpretation at gestations less than 28 weeks • CTG monitoring: o Is not recommended at less than 24 weeks gestation o Limited usefulness between 24 weeks and 28 weeks depending on individual circumstances

5.4 Magnesium Sulfate for neuroprotection

Table 15. Magnesium Sulfate for neuroprotection

Aspect	Considerations
Context	• Magnesium Sulfate ($MgSO_4$) given to mothers shortly before delivery reduces the risk of cerebral palsy and protects gross motor function in those infants born preterm[51] o Number needed to treat (NNT): 63 babies for one baby to avoid cerebral palsy (95% CI 44-155)[52] o NNT to benefit (NNTB): 42 babies for combined death or cerebral palsy (95% CI 24-346)[52] o The effect may be greatest at early gestational ages and is not associated with adverse long-term fetal or maternal outcome[51,53]
Recommendation*	• Recommend $MgSO_4$ to women at risk of preterm birth between 23+0 weeks and 30+0 weeks gestation where birth is imminent and life sustaining interventions are planned or may be a possibility • Where urgent birth is necessary, do not delay birth to administer $MgSO_4$[53] • If birth does not occur after giving $MgSO_4$, and preterm birth (less than 30 weeks gestation) again appears imminent (planned or expected with 24 hours), a repeat dose of $MgSO_4$ may be considered at the discretion of the obstetrician[53] Where $MgSO_4$ for neuroprotection is indicated: o Loading dose: 4 gram Intravenous (IV) (slowly over 20–30 minutes) o Maintenance: 1 gram per hour IV until birth or for 24 hours, whichever comes first o When birth is planned, commence as close to 4 hours prior to birth as possible[53] o Best effect when given for at least 4 hours within the 6 hours prior to birth o Provide one to one midwifery care o Develop or agree on local protocols for the administration and monitoring of $MgSO_4$ for neuroprotection. The regimen is the same as for severe pre-eclampsia

*Refer to Australian pharmacopoeia for complete drug information

5.5 Caesarean section for fetal indications

Table 16. Caesarean section for fetal indications

Aspect	Considerations
Context	• The optimal mode of birth for babies of very low gestational age is uncertain and controversial[32,54] • There are very few randomised controlled trials[54]— most studies are retrospective and are likely to be subject to selection bias and/or have other serious limitations [refer to Appendix B] • Preterm caesarean section (CS) is usually technically more difficult to perform and is not without risk to the baby[55] as lower segment is usually not well formed • A classical incision may be required with risks to future pregnancies including scar dehiscence, uterine rupture, placental adherence and maternal death[32] o Discuss the implications of decision with the woman • Some studies suggest CS improves survival and/or morbidity of the extremely preterm neonate[56-60] while others have not demonstrated benefit[54,60-65] • Similarly there are inconsistent results regarding CS for extremely preterm breech presentation[66] with some studies reporting reduced morbidity and/or mortality[59,62] and others reporting no difference[61,67,68]
Consensus Recommendation	• There is insufficient evidence upon which to base firm recommendations regarding CS for fetal indications at extremely premature gestational ages • Consider individual circumstances including (but not limited to): o Potential for fetal and maternal risk and benefit o Family preferences and wishes o Individual clinical circumstances (e.g. fetal presentation) • Consensus recommendations of the working party regarding CS for fetal indications: o Not recommended at less than 24+0 weeks gestation o Not usually recommended between 24+0 and 24+6 weeks gestation o May be recommended from 25+0 weeks gestation depending on individual circumstances

5.6 Care at birth

Table 17. Care at birth

Criteria	Considerations
Preparation for birth	• Whenever resuscitation is considered an option[14]: o Regard the resuscitation as an emergency o An experienced healthcare practitioner, preferably a neonatologist, should be present o All clinically accepted standard interventions are indicated as they are likely to provide more benefit than harm • Where gestational age is uncertain – it may be appropriate to initiate life sustaining interventions until the clinical course becomes clearer[6,23] • Refer to the Queensland Clinical Guideline *Neonatal resuscitation*[28] • Provide palliative care to all babies for whom resuscitation is not initiated or is not successful [25]
Condition at birth	• **Assessment of condition at the time of birth (even by experienced practitioners) may not correlate with survival to discharge**[69,70]
Reassessment	• Once life sustaining interventions are initiated, continuously re-evaluate the baby's condition and reassess the prognosis • Refer to Section 3 Factors affecting viability • Clinical assessments commonly include[24]: o Apparent maturity o Extent of bruising[19] o Heart rate o Spontaneous activity level[19] o Respiratory effort and response to resuscitation[19] o Birth weight [refer to Table 18] o Quality of the newborn skin • Discuss the baby's condition, clinical assessment and decision-making with the family as soon as possible following birth

5.6.1 Gestational age and birth weight

Table 18. Birthweight percentile values (g) for live singleton females and males[71,72]

Gestational age (weeks)	10th percentile		50th percentile		90th percentile	
	Female	*Male*	*Female*	*Male*	*Female*	*Male*
22	386	391	473	500	581	646
23	442	470	565	604	681	747
24	503	547	659	706	790	855
25	569	621	758	813	913	974
26	636	692	861	924	1049	1109

5.7 Resuscitation at birth

If resuscitation is intended, refer to the Queensland Clinical Guideline *Neonatal resuscitation*[28]
If palliative care is intended, refer to Section 6 Palliative care.

Table 19. Resuscitation at birth

Gestational age	Recommendation
Less than 23 weeks	• Life sustaining interventions are not recommended for babies of less than 23 weeks gestation • Provide palliative care if live birth occurs
23 weeks and 0 days until 23 weeks and 6 days	• Life sustaining interventions are not usually recommended • If after appropriate counselling the family make an informed decision for life sustaining interventions, then initiate resuscitation and intensive care • If parental wishes are unknown at the time of birth: o Consider the individual circumstances of the case o It may be appropriate to initiate life sustaining interventions and reassess the baby's condition when parental wishes can be ascertained
24 weeks and 0 days until 24 weeks and 6 days	• Life sustaining interventions are usually recommended • If after appropriate counselling, the family make an informed decision for palliative care, family wishes should be supported
25 weeks and 0 days until 25 weeks and 6 days	• Life sustaining interventions are recommended o It is unusual not to provide resuscitative interventions to babies born alive at 25 weeks gestation • Where there are specific circumstances suggesting an intolerable burden or that intervention is likely to be futile, and if after appropriate counselling the family make an informed decision to choose palliative care, this should be supported • Where there is conflict in the decision-making process between parents and health care professionals take all possible steps to resolve the conflict [refer to Table 4. Decision-making]

5.8 Withdrawal of life sustaining interventions

Active withdrawal of life sustaining interventions and the provision of palliative care is established practice in many Neonatal Intensive Care Units in Australia and overseas.[19]

- Make decisions in consultation with the family and in accordance with principles outlined in preceding sections
- Document decisions contemporaneously
- Refer to Queensland Clinical Guideline *Neonatal resuscitation*[28]
- Refer to Section 6 Palliative care

6 Palliative care

Palliative care focuses on the provision of dignity and respect and the relief of suffering for the baby and family. Support for the parents and extended family initially focuses on interventions for anticipatory grief and later on ensuring appropriate family bereavement.[19,73]

Table 20. Palliative care

Aspect	Considerations
Planning care	• Conduct a thorough assessment of the baby's clinical condition • Develop an agreed care plan with the family, including as appropriate to the circumstances[9,19]: o Resuscitation o Postnatal care o After death care[19] o Discuss the advantages of post-mortem examination in confirming specific pathology and for advising re future pregnancies[9,23,74] • Discuss the possibility that the baby may live for many hours or days • Review and adjust the plan at frequent intervals to ensure the goals of care are being met[11] • Include social worker/psychological supports in care planning • Involve palliative care specialists as appropriate/required[11] • Document decisions in detail to ensure a clear and unambiguous understanding by the health care team and the family[11] o Consider use of specific palliative care plans • Inform health care professionals caring for the mother of the plan[11] including the GP
Newborn care	• Handle baby gently and carefully • Provide wraps for cuddling and holding baby • Offer skin to skin contact • Offer opportunities and support the family's wishes to engage in care provision (e.g. nappy changes, bathing, cuddling/holding)
Nutrition/hydration	• Insertion of a gastric tube for feeding is not usually recommended at extremely low gestational ages but oral feeds may be considered in some circumstances (e.g. via syringe drop) • Maintain oral hygiene and comfort (e.g. moisten lips)
Review all interventions	• During the transition to palliative care, removal of technological supports may be considered (e.g. monitors and/or alarms, mechanical ventilation, removal of invasive lines and endotracheal tube) o Consider individual circumstances and parental wishes in timing these decisions o Prepare the family for the likely/possible clinical sequelae that may follow withdrawal of technological supports[19] (e.g. agitation secondary to hypoxia, tachypnoea, intercostal recession) • Where an intravenous line has previously been sited, generally, leave it in situ to assist with the administration of pain relieving medication • Supplemental oxygen may be given to provide comfort but consider administration of Morphine if the baby displays signs of shortness of breath (e.g. nasal flaring, gasping, colour changes) • Suction secretions as necessary • Review whether continued administration of individual medications (e.g. antibiotics, inotropes) contribute to the comfort of the baby [11] • Stop all unnecessary interventions and observations and actively consider interventions that increase comfort[11] • Provide sensitive emotional support and reassurance to parents throughout the dying process and afterwards

6.1 Symptom management

Table 21. Symptom management

Aspect	Considerations	
Context	• Babies less than 800 g have been shown to receive less comfort medication than larger infants[11] • Always assess the need for pain management o Consider use of established pain scales[75,76] (e.g. CRIES, PIPP) • Avoid invasive procedures • Administer analgesics/sedation as indicated o Administer if the baby shows signs of distress or the parents perceive signs of distress o Select the route of administration that is best tolerated by the baby • Incorporate non-pharmacological interventions (e.g. minimal noise/light, stimuli, non-nutritive sucking with a dummy (pacifier), flexed position of arms and legs, massage)[77] • Refer to Section 2.3 Ethical and legal considerations	
Medication	**Route of administration**	**Starting dose**
Sucrose	Oral (directly onto tongue)	0.25 mL (optimal dose uncertain)[78]
Paracetamol[75]	Oral	15 mg/kg every 6–8 hours
	Rectal	
Morphine[75]	Oral	80–200 microgram/kg every 4 hours
	IV injection	50 microgram/kg every 4–6 hours Titrate dose as required
	SC injection	
	IV infusion	10 microgram/kg/hour
Fentanyl[75]	Intranasal (via atomiser)[79]	1.5 microgram/kg
	SC injection	1 microgram/kg every 2–4 hours
	IV injection	
	IV infusion	1 microgram/kg/hour Titrate dose as required
Midazolam[79]	Intranasal	0.2–0.3 mg/kg
	Buccal	
	IV injection	0.15–0.2 mg/kg
	IV infusion	1 microgram/kg/minute
Refer to an Australian pharmacopeia for complete drug information		

SC: Subcutaneous, **IV**: Intravenous, **mg**: milligram, **kg**: kilogram

6.2 Bereavement support

The birth and death of a baby at extremely low gestational age can be a stressful experience for the family. What comprises best practice in relation to psychosocial care in these circumstances is uncertain.[80] Care and support should be tailored to the individual circumstances and needs of the family. Patient and family comfort, human contact and creation of positive memories constitute the primary goals of care.[74]

Table 22. Bereavement care

Aspect	Considerations
Communication	• Reassure the family that their baby will continue to receive the best care possible (e.g. "We will continue to provide the best medical care possible for your baby. This will include frequent assessments by the nurse, and visits by the doctor…" • Use plain unambiguous language. For example avoid: o 'Stable' when referring to a dying baby o Euphemisms such as 'passing away' o Terms such as 'There is nothing more we can do' • Refer to Sections on counselling, sharing information
Maternity care	• If birth has occurred recently, ensure the postnatal care needs of the mother are met • Liaise with maternity clinicians for care provision o Support and facilitate continuity of care/carer
Psychosocial/ spiritual	• Maintain a family centred approach to care[9,74] • Advise the family that the duration of the dying process is variable[19] • Provide an environment conducive to family interaction[74] (e.g. room with recliners/beds, lighting that can be dimmed, outlets where music can be played, access to a kitchenette and bathroom) • Facilitate unrestricted visiting[74] • Involve the family prior to and beyond the death as appropriate to the circumstances[11] • Facilitate spiritual/religious/cultural rituals, services and support important for the family[11,74] (e.g. baptism, naming ceremony) • Involve social worker/psychological supports
Memory creation	• Facilitate memory creation/gathering before and after death consistent with the family's wishes and following consent[3,74] (e.g. identification tags, hand and footprints, digital photographs, cot cards, hair collection) • Offer options to include extended family (e.g. photographs of family groups, relatives/siblings to hold baby, video conferencing if available) • Offer option to take baby home if feasible[9] • Refer to Queensland Clinical Guideline *Stillbirth care*[81]
Follow-up	• Offer assistance with certification and registration of death[9] • Provide information on burial and cremation[9] (written or verbal as appropriate) • Consider facility initiated telephone contact after discharge • Offer a future appointment to discuss the death[9,19] with the health care team, particularly the lead health care professional • Provide contact information for psychological support (e.g. professional counselling or support groups/organisations[9]) • Consider care needs for subsequent pregnancies • Inform the regional referring centre/private midwife if applicable • Inform the General Practitioner by telephone and in writing

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Appendix A: Summary for initiation of treatment by gestational age

Source	Summary of position
NSW and ACT Consensus Statement (2006)[3]	• In an otherwise normal infant born before 23 weeks, the prospect of survival is minimal and the risk of major morbidity is so high that initiation of resuscitation is not appropriate. Maternal transfer for fetal reasons may not be justified. • At 23 weeks, active treatment may be discussed, but would be discouraged in NSW/ACT neonatal intensive care units. • In an otherwise normal infant born between 23+0 and 25+6 weeks gestation, there is an increasing obligation to treat. However, it is acceptable medical practices to not initiate intensive care if parents so wish, following appropriate counselling. • In an otherwise normal infant born as 26 weeks and above, the obligation to treat is very high, and treatment should generally be initiated unless there are exceptional circumstances.
Royal Australian College of Physicians (2008)[12]	• In the circumstance of infants with an extremely small chance of survival it may be appropriate to not offer treatment, such as with infants born at 22–23 weeks gestation, particularly if in poor condition. There is no legal obligation to offer treatment which is not medically indicated or which is futile, although taking this step in the absences of agreement should be considered only after all avenues have been exhausted. • As gestation rises and infant condition improves, the presumption of intention to treat becomes more likely. The exact point that this shift occurs will be determined partly by local conditions. For most units in Australia and New Zealand the presumption to treat exists at 24 weeks gestation, assuming a baby born in good condition and that this is in agreement with the wishes of the family.
British Association of Perinatal Medicine (2009)[24]	• If gestational age is ***certain*** and less than 23+0 (i.e. at 22 weeks) it would be considered in the best interests of the baby, and standard practice, for resuscitation not to be carried out. • If gestational age is ***certain*** at 23+0 – 23+6 (i.e. at 23 weeks) and the fetal heart is heard during labour, a professional experienced in resuscitation should be available to attend the birth. In the best interests of the baby a decision not to start resuscitation is an appropriate approach particularly if the parents have expressed this wish. However, if resuscitation is started with lung inflation using a mask, the response of the heart rate will be critical in deciding whether to continue or to stop and sensitively explain to the parents the futility of further interventions. • If gestational age is **certain** at 24+0 – 24+6 resuscitation should be commenced unless the parents and clinicians have considered that the baby will be born severely compromised. However the response of the heart rate to lung inflation using a mask will be critical in deciding whether to proceed to intensive care. If the baby is assessed to be more immature than expected, deciding not to start resuscitation may be considered in the best interest of the baby. • When gestational age is 25+0 weeks or more, survival is now considerably greater than in 1995. It is appropriate to resuscitate babies at this gestation and, if the response is encouraging, to start intensive care.
Nuffield Council on Bioethics (2012)[2]	• At 25 weeks of gestation and above, the relatively high rate of survival and the relatively low risk of severe disability are such that intensive care should be initiated and a baby admitted to a neonatal intensive care unit, unless he or she is known to be affected by some severe abnormality incompatible with any significant period of survival. • Between 24 weeks, 0 days and 24 weeks, six days of gestation, normal practice should be that a baby will be offered full invasive intensive care and support from birth and admitted to a neonatal intensive care unit, *unless* the parents and the clinicians are agreed that in the light of the baby's condition (or likely condition) it is not in his or her best interests to start intensive care. • Between 23 weeks, 0 days and 23 weeks, six days of gestation, it is very difficult to predict the future outcome for an individual baby based on current clinical evidence for babies born at this gestation as a whole. Precedence should be given to the wishes of the parents regarding resuscitation and treatment of their baby with invasive intensive care. However, when the condition of a baby indicates that he or she will not survive for long, clinicians are not legally obliged to proceed with treatment wholly contrary to their clinical judgement, if they judge that treatment would be futile. • Between 22 weeks, 0 days and 22 weeks, six days of gestation, standard practice should be not to resuscitate a baby. Resuscitation would normally *not* be considered or proposed.
American College of Obstetricians and Gynaecologists (2002)[5]	• In general, parents of anticipated extremely preterm fetuses can be counseled that the neonatal survival rate for newborns increases from 0% at 21 weeks of gestation to 75% at 25 weeks of gestation and from 11% at 401–500 g birth weight to 75% at 701–800 g birth weight. In addition females generally have a better prognosis than males. • In general, parents of anticipated extremely preterm fetuses can be counseled that infants delivered before 24 weeks of gestation are less likely to survive and those who do are not likely to survive intact. Disabilities in mental and psychomotor development, neuromotor function or sensory and communication function are present in approximately one half or extremely preterm fetuses.
Swiss Society of Neonatology (2011)[14]	• Generally, the care of preterm infants with gestational age of less than 24 weeks should be limited to palliative care measures. If a preterm infant appears significantly more mature after delivery or if previously well-informed parents insist, provisional intensive care can be started until the clinical course helps to decide for or against continuation of intensive care measures.

Appendix B: Evidence summary related to caesarean birth

All included studies are retrospective and all attempt to find independent predictors of outcomes by using regression analysis except Alfrevic (2013) which is a systematic review of randomised controlled trials. Full citation details of studies can be found in the guideline reference list.

Studies on the effect of delivery mode on SURVIVAL of severely preterm cephalic fetuses

Negative finding: No independent effect of CS on survival
Positive finding**:** An independent effect where CS is associated with an improved survival

First Author	Year	Number	Birth weight/Gestation	Findings
Alfrevic	2013	116	<37 weeks	Negative for all
Reddy	2012	2138	24–31 weeks	Negative for all
Ghi	2010	109	25+0–32+6 weeks	Negative for all
Vimercati	2009	84	<28 weeks	Negative for all
Malloy	2008	120,542	22–31 weeks	Positive for 22-25 weeks
Wylie	2008	2466	<1500 g	Negative for all
Lee	2006	54,695	<1500 g	Positive for all
Muhuri	2006	60,364	500–1500 g	Positive for 500-749 g and 1000-1249 g
				Negative for 750-999 g and 1250-1499 g
Riskin	2004	2955	<1500 g	Negative

Studies on the effect of delivery mode on the occurrence of IVH in severely preterm fetus

Negative finding: No independent effect of caesarean birth on the occurrence of IVH
Positive finding: An independent effect of caesarean birth on the occurrence of IVH

First Author	Year	Number	Birth weight/Gestation	Findings
Ghi	2010	109	25+0–32+6 weeks	Negative
Dani	2009	218	< 28 weeks	Positive for Grade 3 IVH Vaginal birth 18% vs CS 2%
Wylie	2008	2466	<1500 g	Positive for IVH, OR 0.73 (0.55–0.97)
Riskin	2008	5033	<1500 g	Negative for IVH, OR 0.98 (0.77–1.24)
Haque	2008	213	<1250 g	Negative for IVH Vaginal birth 47.7% vs CS 46.8%

Potential limitations of retrospective studies

- Selection biases (e.g. CS may be favoured if fetus presumed viable and vaginal birth favoured if fetal condition assessed as poor)
- Small sample size
- Range of gestations/birth weights beyond the threshold of viability included, limiting applicability
- Incomplete accounting for the small/large for gestational age fetus
- Failure to distinguish between elective and emergency CS and account for the possibility of increased availability of specialised care, resources for advanced resuscitation and/or opportunity to transfer to higher level facilities
- Inability to completely account (especially from retrospective data registers) for maternal comorbidities, complications of pregnancy, labour and birth, indication for CS and other clinical factors and practices
- Inability to account for the influence of parental wishes/preferences in the decision-making process
- Immediate advantage following CS may not necessarily equate with improved long-term survival or decreased long term impairment
- Limited ability to generalise from studies involving single sites

Appendix C: Longer term outcome studies

Study Aspect	EPICure[82]	EPIPAGE[83]	EPIBEL[84]	Victorian Collab.[85]	Japanese Network[86]	NICHD[87]	VON[88]
Location	**UK**	**France**	**Belgium**	**Australia**	**Japan**	**US**	**US**
Year of birth (Follow-up age - months)	1995 (30)	1997 (24)	1999–2000 (30-42)	2005 (24)	2003–2005 (36)	1999-2004 (18-24)	1998–2003 (18–24)
23 weeks							
Mortality *n*/live births (%)	216/241 (90)	30/30 (100)	40/41* (98)	28/35 (80)	91/245 (37)	≤ 23 weeks 1225/1450 (84)	567/916 (62)
Evaluated *n*/survivors at follow-up (%)	25/25 (100)	0/0 (0)	1/1 (100)	—	119/154 (77)	22-24 weeks 816/908 (90)	214/298 (72)
Death or NDI *n*/study cohort (%)	230/241 (95)	30/30 (100)	40/41 (94)	—	156/245 (64)	≤ 23 weeks 1396/1450 (96)	679/916 (74)
CP *n*/evaluated infants (%)	—	All cases died	0/1 (0)	—	21/118 (18)	≤ 23 weeks 51/201 (25)	—
Cognitive delay *n*/evaluated infants (%)	≤ 23 weeks 22–23 weeks 7/26 (27)	All cases died	0/1 (0)	—	55/110 (50)	≤ 23 weeks MDI <70 115/191 (60) PDI < 70 77/192 (40)	—
NDI *n*/evaluated infants (%)	14/25 (56)	All cases died	0/1 (0)	—	65/114 (57)	≤23 weeks 171/193 (89)	112/214 (52)
24–27 weeks							
Mortality *n*/live births (%)	24–25 weeks 525/806 (65)	24–25 weeks 89/161 (55)	24–26 weeks 91/182* (50)	22–27 weeks 116/288 (40)	24 weeks 76/332 (23)	24 weeks 555/1238 (45)	24–25 weeks 906/3033 (30)
Evaluated *n*/survivors at follow-up (%)	24–25 weeks 279/281 (99)	—	24–26 weeks 88/91 (97)	22–27 weeks 163/172 (95)	24 weeks 180/256(70))	22-24 weeks 816/908 (90)	24–25 weeks 1229/1702 (72)
Death or NDI *n*/study cohort (%)	24–25 weeks 661/806 (82)	—	24–26 weeks 142/182 (78)	22–27 weeks 196/288 (68)	24 weeks 129/332 (39)	24 weeks 982/1238 (79)	24–25 weeks 1401/3033 (46)
CP *n*/evaluated infants (%)	22–25 weeks 50/306 (16)	—	24–26 weeks 19/77 (25)	22–27 weeks 16/163 (10)	24 weeks 14/173 (8)	24 weeks 104/609 (17)	—
Cognitive delay *n*/evaluated infants (%)	24–25 weeks 78/257 (30)	—	24–26 weeks MDI <70 22/77 (29) PDI<70 37/77 (48)	22–27 weeks 78/163 (48)	24 weeks 49/152 (32)	24 weeks MDI <70 249/567 (44) PDI <70 160/561 (29)	—
NDI *n*/evaluated infants (%)	24–25 weeks 136/279 (49)	—	24–26 weeks 51/89 (57)	22–27 weeks 80/163 (49)	24 weeks 53/142 (37)	24 weeks 284/566 (50)	24–25 weeks 495/1499 (33)

Source: Data sourced from published papers. Adapted from Ishii, N et al. 2013 Outcomes of infants born at 22 and 23 weeks gestation. Pediatrics 132(62) 2013
*Recorded births– not live births (includes intrapartum death)

Neurodevelopmental impairment (NDI) was defined as any of the following: Cerebral palsy (CP) with a GMFCS level 2 to 5, hearing impairment (defined as amplification required), visual impairment (defined as blindness with no functional vision in 1 or both eyes), or a Developmental Quotient (DQ) score <70. EPIBEL, Extremely Preterm Infants in Belgium Study Group; EPICure, study for all infants born before 26 completed weeks of gestational age in the United Kingdom and the Republic of Ireland in 1995; EPIPAGE, The Etude Epidémiologique sur les Petits Ages Gestationnels study; MDI, mental developmental index; PDI, psychomotor developmental index; VON, Vermont Oxford Network; —, data was not shown. NICHD National Institute of Child Health and Human Development

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