

Queensland Clinical Guidelines

Translating evidence into best clinical practice

Maternity and Neonatal **Clinical Guideline**

Perinatal care of the extremely preterm baby

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Cultural acknowledgement

We acknowledge the Traditional Custodians of the land on which we work and pay our respect to the Aboriginal and Torres Strait Islander Elders past, present and emerging.

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

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

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

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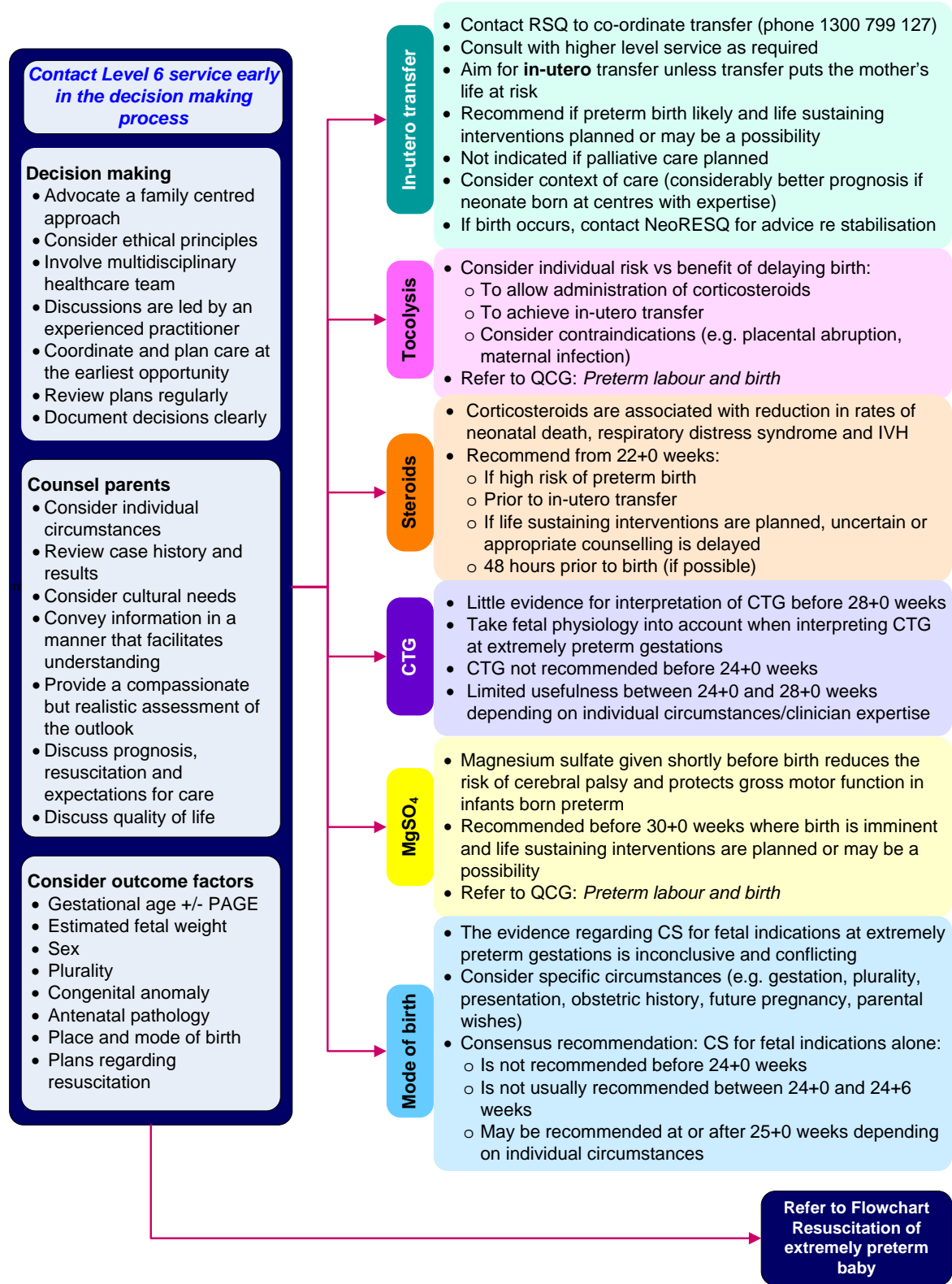


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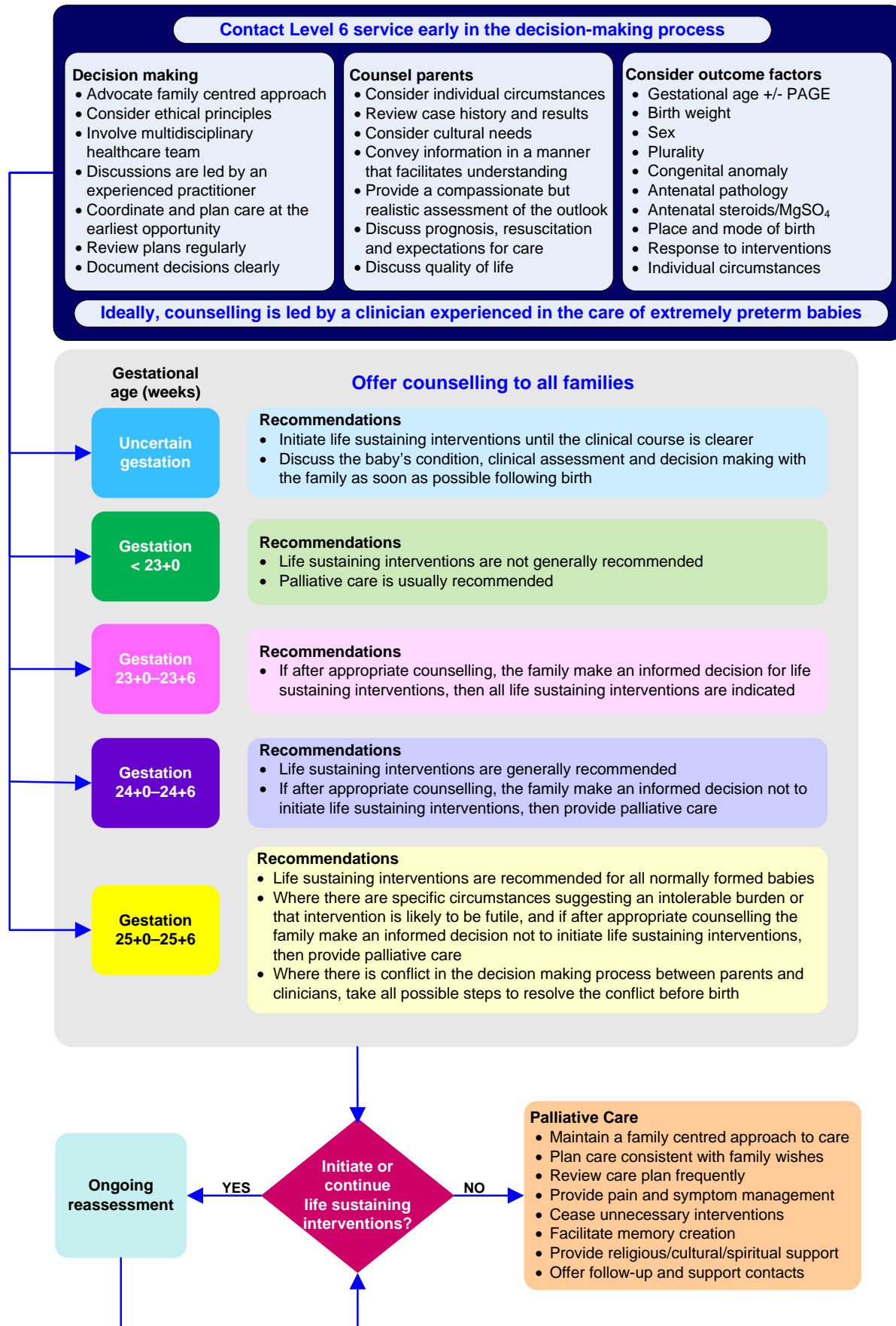
Flow Chart: Antenatal care where birth imminent or indicated at less than 25 weeks+6 days

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



CS: Caesarean section CTG: Cardiotocograph IVH: Intraventricular haemorrhage PAGE: Prognosis for average gestational age equivalent infant framework, RSQ: Retrieval Services Queensland, QCG: Queensland Clinical Guideline

Flow Chart: Queensland Consensus approach to resuscitation of an extremely preterm baby



PAGE: Prognosis for average gestational age equivalent infant framework

Table of Contents

Abbreviations	6
Definitions	6
1 Introduction	7
1.1 Queensland data	7
1.2 Purpose of the guideline	7
1.3 Clinical standards	8
2 Communication	9
2.1 Family centred care	9
2.2 Ethical principles	9
2.3 Ethical and legal considerations	10
2.4 Decision-making	11
2.5 Sharing information	12
2.6 Counselling	13
3 Factors affecting survivability	14
3.1 Gestational age equivalent infant	15
4 Longer term outlook	16
4.1 Australia and New Zealand Neonatal Network data	16
4.2 Definitions to aid parental understanding	16
4.2.1 Severe impairment	16
4.2.2 Gross Motor Function Classification System	17
4.2.3 Intellectual disability	17
4.2.4 General description of intellectual ability and support requirements	18
4.3 Quality of life	18
5 Approach to care	19
5.1 In-utero transfer	19
5.2 Antenatal corticosteroids	20
5.3 Magnesium sulfate for neuroprotection	21
5.4 Cardiotocograph monitoring	21
5.5 Mode of birth	22
5.6 Care at birth	23
5.6.1 Gestational age and birth weight	23
5.7 Resuscitation at birth	24
5.8 Withdrawal of life sustaining interventions	24
6 Palliative care	25
6.1 Symptom management	26
6.2 Bereavement support	27
References	28
Appendix A: Summary for initiation of treatment	31
Appendix B: Evidence summary related to caesarean birth	32
Acknowledgements	33

List of Tables

Table 1. Survival to 28 days after admission to nursery during 2017–2018	7
Table 2. Clinical standards	8
Table 3. Core concepts of patient and family centred care	9
Table 4. Ethical principles	9
Table 5. Ethical considerations	10
Table 6. Decision-making	11
Table 7. Conveying complex information	12
Table 8. Areas for discussion	13
Table 9. Factors influencing viability	14
Table 10. PAGE framework	15
Table 11. Selected outcomes from ANZNN data	16
Table 12. Gross Motor Function Classification System	17
Table 13. Intellectual disability descriptions	18
Table 14. In-utero transfer	19
Table 15. Antenatal corticosteroids	20
Table 16. Magnesium sulfate for neuroprotection	21
Table 17. Cardiotocograph monitoring	21
Table 18. Caesarean section for fetal indications	22
Table 19. Care at birth	23
Table 20. Birthweight percentile values (g) for live singleton females and males ^{85,86}	23
Table 21. Resuscitation at birth	24
Table 22. Palliative care	25
Table 23. Symptom management	26
Table 24. Bereavement care	27

Abbreviations

CI	Confidence interval
CS	Caesarean section
CTG	Cardiotocograph
ELBW	Extremely low birth weight
FHR	Fetal heart rate
GMFCS	Gross motor function classification system
GP	General practitioner
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

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
Life sustaining interventions	Any method, medicine or device used to prolong life. In this guideline does not refer to interventions occurring before birth of the baby.
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
Healthcare team	Membership of the healthcare 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 a range of multidisciplinary professional including, but not limited to, nurse/midwife, obstetrician, neonatologist/paediatrician, other specialist practitioners (e.g. palliative care, maternal fetal medicine specialist), general practitioner, 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-R	A neonatal pain assessment tool. An acronym for Premature Infant Pain Profile-Revised.
Extremely preterm	In this document, refers to babies born at less than 26+0 weeks gestational age.
Psychological supports	Emotional and psychological support can be provided by a range of healthcare 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).
Withholding treatment	Non-initiation of treatment that may sustain life.
Withdrawal of treatment	Cessation of life sustaining interventions.

1 Introduction

The birth of an extremely preterm baby is a stressful experience for the parents and family. Birth at these gestations also presents enormous challenges for the healthcare team. Although neonatal survival rates have improved dramatically over the last few decades³, significant morbidity is still common.⁴ As the gestational age decreases, morbidity and mortality increase dramatically. Uncertainty is a feature of many decisions regarding prognosis thus complicating counselling and care provision.

Outcome data from many countries around the world confirm both improved survival and neurodevelopmental outcomes for extremely preterm babies. The greatest improvements in survival are seen in those at the youngest gestational ages of 22+0–23+6.⁵ While there is no single global or national consensus regarding resuscitation, there is a trend in highly resourced countries toward offering postnatal life support at these extremely preterm gestations.

Perinatal care of the extremely preterm baby will continue to evolve as new evidence, clinical practices and technologies emerge. This guideline is considered a living document and will be reviewed frequently to assess alignment with contemporary practices.

Prevention of preterm birth remains a focus for healthcare in Queensland. However, where birth at extremely preterm gestational age is unavoidable, individualised care led by experienced clinicians and informed by the best available evidence and contemporary healthcare practices³ is essential.

1.1 Queensland data

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.⁶

In Queensland in 2017 and 2018, none of the 77 babies born alive at 20–21 weeks gestation were admitted to a nursery and all died. At 22–23 weeks gestation, 42% of all liveborn babies were admitted to a nursery and 58% of these survived to 28 days. At 24–25 weeks gestation, 93% of all liveborn babies were admitted to a nursery and 78% of these survived to 28 days. Refer to Table 1. Survival to 28 days after admission to nursery during 2017–2018

Table 1. Survival to 28 days after admission to nursery during 2017–2018

Gestation (weeks)	20–21	22–23	24–25
Total born alive (<i>n</i>)	77	103	145
Born alive AND admitted to nursery <i>n</i> /total born alive (%)	0 (0)	43/103 (42)	134/145 (93)
Admitted to nursery AND survived to 28 days <i>n</i> /admitted (%)	—	25/43 (58)	105/134 (78)

Nursery: includes Special Care Nursery (SCN) or Neonatal Intensive Care Nursery (NICU)
Source: Perinatal Data Collection extract 2020

1.2 Purpose of the guideline

The purpose of this guideline is to:

- Promote consistency in perinatal counselling
- Promote family-centred 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; instead it is designed to place emphasis on individual factors that influence the complicated and nuanced healthcare decisions that are to be made.

1.3 Clinical standards

Table 2. Clinical standards

Aspect	Consideration
Clinician support	<ul style="list-style-type: none"> • Educate the healthcare team on outcome data relevant to the setting⁷ • Educate the healthcare team providing care to extremely preterm babies in the basic principles of palliative care^{4,8} • Provide support (e.g. debriefing, interdisciplinary morbidity and mortality reviews or counselling) to the healthcare team caring for families experiencing the birth of an extremely preterm baby • Promote communication skills training⁹ across all health disciplines
Model of care	<ul style="list-style-type: none"> • Provide care in accordance with the Clinical Services Capability Framework¹⁰ • Maintain a family centred approach to care that incorporates psychological, spiritual and social support¹¹
Standard practice	<ul style="list-style-type: none"> • Refer to the Queensland Clinical Guideline: <i>Standard care</i>¹² • Use agreed definitions when preparing information on outcome and morbidity¹³

2 Communication

Open and honest communication between the family and healthcare team is the cornerstone of ethical decision-making and care provision.^{14,15} Ideally, discussions are led by clinicians experienced in the care of extremely premature babies. Acknowledging the prognostic uncertainty is an essential component of this communication. Whenever possible, communication commences in the antenatal period.¹⁴ Where this is not possible, commence discussions with the family as soon as practical after birth.

2.1 Family centred care

Patient and family centred care is an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families.^{1,16}

Table 3. Core concepts of patient and family centred care

Core Concept ¹	Meaning
Respect and dignity	<ul style="list-style-type: none"> Healthcare 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	<ul style="list-style-type: none"> Healthcare 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	<ul style="list-style-type: none"> Patients and families are encouraged and supported to participate in care and decision-making at the level they choose
Collaboration	<ul style="list-style-type: none"> Patients and families are also included on an institution wide basis Healthcare leaders collaborate with patients and families in policy and program development, implementation, and evaluation, in healthcare 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 4.

Table 4. Ethical principles

Principles	Considerations
Non-maleficence¹⁷	<ul style="list-style-type: none"> Requires that harm not be inflicted intentionally and is closely linked to the imperative to minimise harm
Beneficence¹⁷	<ul style="list-style-type: none"> 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
Autonomy¹⁷	<ul style="list-style-type: none"> Autonomous individuals are entitled to make their own decisions and life choices Extremely premature babies must rely on others to make decisions for them
Justice¹⁷	<ul style="list-style-type: none"> 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 ethical issues. Understanding of these ethical issues may aid the appreciation and understanding of differences in opinion that arise.²

Table 5. Ethical considerations

Aspect	Considerations
Legal principles	<ul style="list-style-type: none"> • The 'best interests of the baby' is the legal principle that underpins all decisions relating to resuscitation¹⁸ • There is no statutory or common law definition of viability or of when resuscitation should or should not be provided¹⁸ • 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^{19,20}
The value of human life	<ul style="list-style-type: none"> • 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 life² • 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	<ul style="list-style-type: none"> • Consideration of best interests includes an assessment of: <ul style="list-style-type: none"> ○ Pain and suffering ○ Inevitability of death ○ The quality of life ○ 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 healthcare 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^{14,21} • Society has the ethical and legal right to intervene when the family's decisions are clearly not in the best interests of the baby²²
Withdrawing or withholding life sustaining interventions	<ul style="list-style-type: none"> • 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^{9,14} • 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 possible²³
Deliberately ending life	<ul style="list-style-type: none"> • The Australian and New Zealand Society of Palliative Medicine (ANZSPM) does not endorse euthanasia²⁴
Relieving pain and causing death	<ul style="list-style-type: none"> • 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 acceptable²¹ and lawful

2.4 Decision-making

Table 6. Decision-making

Aspect	Considerations
Collaborative decision-making	<ul style="list-style-type: none"> • Collaborative decision-making⁹: <ul style="list-style-type: none"> ○ Uses a family centred approach to care ○ Supports decision-making in the best interests of the family¹⁵ ○ Allows different parties to present their views about what they hold these interests to be ○ Acknowledges the responsibilities of all parties ○ Makes it possible for the family to raise objections to the view of healthcare team • A multidisciplinary approach is recommended¹⁵ to: <ul style="list-style-type: none"> ○ Ensure a range of concerns and areas of clinical care are represented^{9,13} ○ Support continuity of care/carer in the transition through antenatal, intrapartum and neonatal care provision⁹ • Discussions are led by an experienced practitioner^{9,13,15,25} • Where possible facilitate regular meetings to discuss the goals of care and to establish rapport and build trust with the family
Managing conflict	<ul style="list-style-type: none"> • 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 family⁹ <ul style="list-style-type: none"> ○ Facilitate parents as a 'team' for decision-making to support shared responsibility • The healthcare team have an obligation to support and respect their colleagues even during disagreement⁹ • Consider conflict resolution/facilitated mediation if appropriate¹⁵ • If conflict occurs, consider involvement of an independent medical consultant^{9,14} • Where all possible means of resolving disagreement between the parties has been exhausted, consider alternative decision-making processes⁹ <ul style="list-style-type: none"> ○ Transfer of care⁹ ○ Referral to clinical ethics committee or other appropriately constituted body^{9,25} ○ Consider involvement of the courts⁹ as a last resort²⁵
Documentation	<ul style="list-style-type: none"> • Coordinate and commence a plan of care at the earliest opportunity^{9,25} <ul style="list-style-type: none"> ○ Identify people to be involved with decision-making⁹ ○ When/if transfer to a tertiary centre may be appropriate⁹ ○ Obstetric clinical decisions⁹ (e.g. administration of corticosteroids, mode of delivery, actions to be taken in the event of acute deterioration) • Decisions on resuscitation⁹ (e.g. initiation based on gestational age or other criteria) • Antenatally, document all discussions²⁶ in the maternal health record so that all members of the healthcare team 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 plan⁹ • 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 occur⁹

2.5 Sharing information

Table 7. Conveying complex information

Aspect	Considerations
Preparing for discussions	<ul style="list-style-type: none"> • Review details of the case including^{26,27}: <ul style="list-style-type: none"> ○ Maternal history (including past medical/obstetric history) ○ Presenting problem of the baby ○ Any investigation results or ultrasound scans • Assess the degree of diagnostic and prognostic certainty/uncertainty • Discuss the case with referring healthcare team • Ascertain parental knowledge, understanding, expectations, and psychological capacity for discussions • If appropriate, involve higher level services
Cultural considerations	<ul style="list-style-type: none"> • Use translation services if there is any doubt about the ability of all key family members to understand English^{9,15,28} • Be aware that cultural and religious differences can affect clinician and parental communication styles and expectations and perspectives of viability and palliative care²⁷ • 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
Setting	<ul style="list-style-type: none"> • Hold conversations in quiet, private and physically comfortable spaces⁹ • Involve both parents at the same time wherever possible^{15,28 27} <ul style="list-style-type: none"> ○ Involve other family members if appropriate to the individual circumstances⁹ • Include a person not involved with giving information⁹ who is able to support the family
Promote parental understanding	<ul style="list-style-type: none"> • Prepare the family by giving an indication of the seriousness of the discussion⁹ • Do not assume parental knowledge or understanding <ul style="list-style-type: none"> ○ Provide a summary of the baby's situation ○ Give the family an early opportunity to speak so their understanding of the situation is established and their concerns heard⁹ • Elicit the factors the parents deem most important in making decisions about their baby (e.g. best interests, pain and suffering, giving their baby a fighting chance, faith in a higher power, likelihood of disability²⁹) • Provide complete and unbiased information at a level appropriate for the family's level of understanding of complex issues and priorities^{15,28}, including the potential for disability • Acknowledge prognostic uncertainty and where evidence for care is limited • Present the family with the choices they need to make in a clear and accurate way²⁷
Conveying complex information	<ul style="list-style-type: none"> • Provide adequate time and opportunity for the family to consider the content of discussions and ask questions^{15,28} • More than one conversation may be necessary and decisions may need to be altered, especially if the pregnancy continues²⁸ • Written information, pre-recorded material may be useful as the family may forget or be unable to comprehend what they have been told at the time^{15,26,28} • Identify a key contact and decision maker so as to minimise the risk of 'mixed messages', major changes in approach and confusion for the family⁹ • Refer to Section 2.6 Counselling

2.6 Counselling

The purpose of counselling is to inform the family and assist with their decision-making. Involve the multidisciplinary healthcare team in discussions.

Table 8. Areas for discussion

Discussion area	Considerations
Prognosis	<ul style="list-style-type: none"> • 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^{13,15,25,26,28} <ul style="list-style-type: none"> ○ This may be hospital specific data or regional or national data as appropriate^{13,26,28} • Discuss with the family that: <ul style="list-style-type: none"> ○ The ability to give accurate short and long term prognosis for a specific baby remains limited^{21,28} and is impacted by many factors (in addition to gestational age) which may not be obvious prior to or at birth^{13,15} ○ Even with resuscitation and intensive care, many extremely preterm babies may die after birth^{28,30} • Involve other paediatric specialists as appropriate to the circumstances⁹ (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 4.2 Definitions to aid parental understanding
Resuscitation	<ul style="list-style-type: none"> • Advise the family that if their decision is to not initiate resuscitation, or if resuscitation is unsuccessful, palliative care will be provided for their baby^{9,25,28} • If parental preferences regarding resuscitation are either unknown or uncertain, it is reasonable to initiate resuscitation pending further discussions^{25,28} • Discuss the possibility that even if resuscitation is attempted and is successful, there may be future situations where withdrawal of life sustaining interventions is considered²⁸
Clinical course	<ul style="list-style-type: none"> • Offer information about events that may impact the clinical course, future decisions and/or outcomes (e.g. sepsis, cranial ultrasound and IVH, feeding, necrotising enterocolitis, lung function and respiratory support) • Acknowledge the potential for both clinical improvement and deterioration after birth <ul style="list-style-type: none"> ○ Refer to Table 9. Factors influencing viability
Expectations for care provision	<ul style="list-style-type: none"> • Discuss/provide information on expected care as appropriate to the circumstances/decisions/parental preferences (e.g. appearance or condition of the baby, likely procedures/investigations, when the family will be able to hold the baby) • Refer to Queensland Clinical Guideline <i>Neonatal resuscitation</i>³¹ • Refer to Queensland Clinical Guideline <i>Neonatal stabilisation</i>³² • Provide a tour of the nursery if applicable
Continued antenatal review	<ul style="list-style-type: none"> • 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
Emotional wellbeing	<ul style="list-style-type: none"> • Acknowledge the range of emotions that may be experienced by family members (e.g. joy at the birth as well as distress, disempowerment, grief, anger, self-blame, hopelessness)²⁷ • Offer referral for psychological support

3 Factors affecting survivability

Gestational age is the major factor in determining survivability but other factors also impact survival and decision-making and require consideration.^{15,33,34} Seek advice from an experienced practitioner.

Table 9. Factors influencing viability

Aspects	Considerations
Gestational age	<ul style="list-style-type: none"> • At extremely preterm gestations survival rate increases as gestational age increases <ul style="list-style-type: none"> ◦ Adding even a few additional intrauterine days may be of great benefit³⁵ • Even relatively small discrepancies in gestational age may have major implications for survival and long-term morbidity¹³ • 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)¹⁵ • Consider the possibility of growth restriction where later ultrasound measurements suggest a younger gestational age • 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 <ul style="list-style-type: none"> ◦ Refer to Table 20. Birthweight percentile values (g) for live singleton females and males • 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^{25,36}
Sex Birth weight Plurality	<ul style="list-style-type: none"> • Factors associated with improved survival and outcome include: <ul style="list-style-type: none"> ◦ Female sex^{30,34} ◦ Singleton birth ◦ Appropriate higher birth weight at a given gestational age¹³ [refer to Table 20. Birthweight percentile values (g) for live singleton females and males^{85,86}
Congenital anomaly	<ul style="list-style-type: none"> • 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
Antenatal pathology	<ul style="list-style-type: none"> • Presence and/or severity of pathology influences outcomes²⁶ with the presence of multiple risk factors for a poor prognosis likely to be associated with worse outcomes • Poor outcome associated with (but not limited to): <ul style="list-style-type: none"> ◦ Birth weight less than the 2nd centile ◦ Prolonged prelabour rupture of membranes ◦ Severely abnormal fetal Doppler ◦ Chorioamnionitis ◦ Twin to twin transfusion syndrome ◦ Multiple pregnancy

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 principles³⁷:

- 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 a similar prognosis should be treated similarly

Table 10. PAGE framework

Aspect	Consideration																
Recommendation	<ul style="list-style-type: none"> • May be useful for expert clinicians in Neonatal Intensive Care Units (NICUs) with extensive experience in the care of extremely preterm babies • 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 																
PAGE Framework^{37,38}	<ul style="list-style-type: none"> • Directs clinicians to: <ul style="list-style-type: none"> ○ Gather all relevant prognostic information [refer to Section 3 Factors affecting survivability] ○ Estimate a baby's prognosis (if resuscitation is provided) using the best available relevant data ○ Assess where a baby's prognosis sits compared with other extremely preterm babies ○ Approach counselling and decision-making for that baby in a similar way to other babies with the same outlook <table border="1" data-bbox="450 1019 1407 1518"> <thead> <tr> <th>Estimated chance of poor outcome* if intensive treatment provided</th> <th>PAGE#</th> <th>Treatment category</th> <th>Obstetric management</th> </tr> </thead> <tbody> <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> </tbody> </table> <p>*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)</p> <p>#Weeks gestation refers to the interval of the index week (e.g. 24 weeks refers to the interval 24+0 to 24+6 weeks)</p>	Estimated chance of poor outcome* if intensive treatment provided	PAGE#	Treatment category	Obstetric management	≥ 90%	20–22 weeks gestation	Not indicated Life sustaining treatment should usually not be provided	Maternal focused	50–90%	23–24 weeks gestation	Optional Life sustaining treatment should be guided by parents' wishes	Depends on parents' wishes	≤ 50%	≥ 25 weeks gestation	Usual Life sustaining treatment should usually be provided	Maternal/fetus focused
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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.³⁹ Survival of extremely preterm live-born babies has increased over time⁴⁰ and importantly, a higher survival rate was observed for babies born before 25 weeks gestation at hospitals with proactive obstetric and neonatal management.^{41,42}

Significant morbidities that occur in babies 22–25 weeks gestation who survived their initial NICU admission include³⁹:

- 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

4.1 Australia and New Zealand Neonatal Network data

Selected outcomes at 2–3 year follow-up of Australian and New Zealand Neonatal Network (ANZNN) registrants admitted to a neonatal intensive care unit during 2011–2014 across a variety of measures are reported in Table 11. Selected outcomes from ANZNN data⁴³

Table 11. Selected outcomes from ANZNN data

Outcome	*23 weeks % (n=230)	24 weeks % (n=719)	25 weeks % (n=960)
Survived to discharge	48.7	67.3	81
Follow-up rate at 2–3 years	82.5	82.2	79.5
±#No cerebral palsy	86.5	87.9	91.6
±*No cognitive delay	72.6	79.2	84.9
±^No language delay	62.1	62.3	68.4
±^No motor delay	69.5	73.8	79.0

*Includes data from two babies of 22 weeks gestation

#Denominators for each outcome vary due to missing or incomplete data

#Graded using Gross Motor Function Classification System; *Baley, Griffiths, WPPSI and Stanford-Binet assessments; ^Bayley and Griffiths assessments used

4.2 Definitions to aid parental understanding

The International Classification of Functioning, Disability and Health (ICF) is endorsed for use in Australia.⁴⁴ 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.⁴⁴ The following definitions related to disability may be helpful in discussions with the family.

4.2.1 Severe impairment

The British Association of Paediatrics⁵ define severe impairment as including any of:

- Severe cognitive impairment with an IQ lower than 55
- Severe cerebral palsy: classified as Gross Motor Function Classification System (GMFCS) grade III or greater
- Blindness or profound hearing impairment

4.2.2 Gross Motor Function Classification System

The GMFCS is commonly used to describe motor skill capability.⁴⁵

Table 12. Gross Motor Function Classification System

GMFCS Level	Description at 6-12 years
Level I	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Walk indoors or outdoors on a level surface with an assistive mobility device May climb stairs holding onto a railing May propel a wheelchair manually or are transported when traveling for long distances or outdoors on uneven terrain
Level IV	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Physical impairment restricts voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited No means of independent mobility and are transported

4.2.3 Intellectual disability

Intellectual disability is characterised by significant limitations in both intellectual functioning and adaptive behaviour. Intellectual functioning (also called intelligence) refers to general mental capacity such as learning reasoning and problem solving. Adaptive behaviour is the collection of conceptual, social and practical skills that are learned and performed by people in their everyday lives.⁴⁶

Generally accepted categories of mild, moderate and severe and profound levels of intellectual disability (previously also 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 including⁴⁶:

- 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

4.2.4 General description of intellectual ability and support requirements

Table 13. Intellectual disability descriptions

Level of disability	General description of ability and support required ⁴⁶
Mild (IQ 50–70)	<ul style="list-style-type: none"> • 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)	<ul style="list-style-type: none"> • 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)	<ul style="list-style-type: none"> • 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

4.3 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.⁹ 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.¹⁵

The following questions may be useful in assessing the foreseeable quality of life²

- 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:

- Healthcare professionals are reported to underestimate survival and overestimate likely disabilities⁴
- 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^{25,47}
- Quality of life exists on a continuum and the family vary regarding where they would choose death/no resuscitation on this continuum
- 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 family⁹
- 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 after birth 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.¹⁵

- **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 healthcare team in planning and decision-making

5.1 In-utero transfer

Table 14. In-utero transfer

Aspect	Considerations
Context	<ul style="list-style-type: none"> • 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^{25,36} • Inborn babies have a better prognosis than outborn babies^{13,15,48} <ul style="list-style-type: none"> ◦ 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 <i>en route</i> • Consult with higher level clinical services as early as possible • Contact Neonatal Retrieval Emergency Service Southern Queensland (NeoRESQ) and Advanced Neonatal Transport Service North Queensland (ANTS-NQ) for advice and support re stabilisation via Retrieval Services Queensland (RSQ) (phone 1300 799 127) • If transfer required, contact RSQ <ul style="list-style-type: none"> ◦ Refer to Obstetric Retrieval Emergency Service (ObsRESQ) Obstetric interhospital transfer standard operating procedure⁴⁹ • If clinically appropriate, use tocolysis to allow in-utero transfer <ul style="list-style-type: none"> ◦ Refer to the Queensland Clinical Guideline <i>Preterm labour</i>⁶⁰ • 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	<ul style="list-style-type: none"> • 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 usually indicated if palliative care planned • 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+0 weeks) • 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 15. Antenatal corticosteroids

Aspect	Considerations
Context	<ul style="list-style-type: none"> • Considerations • A systematic review (observational data), reported a halving of the odds of mortality to discharge in neonates less than 24 weeks gestation who received antenatal corticosteroids compared to those who did not (OR 0.48 CI 0.38–0.61)⁵¹ • 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, respiratory distress syndrome and intraventricular haemorrhage (IVH) compared with no treatment or treatment with placebo^{52,53} • 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-exposure⁵⁴ • A single dose does not appear to be associated with significant maternal or fetal adverse effects^{52,53}
Recommendation*	<ul style="list-style-type: none"> • Informed by good quality evidence, corticosteroids are recommended where there is a high risk of preterm birth^{52,55} <ul style="list-style-type: none"> ○ From 22+0 weeks gestation ○ Where life sustaining interventions after birth are planned or may be a possibility ○ Where there is uncertainty about future decisions or appropriate counselling is delayed ○ Prior to in-utero transfer ○ Where possible, 48 hours prior to birth • Inform the family that administration does not oblige or necessarily equate to a final decision for life sustaining interventions after birth • Repeat dose <ul style="list-style-type: none"> ○ Give second dose 24 hours after initial dose, however if birth likely within 24 hours, consider repeat dose at 12 hours ○ Consider administration of additional dose if more than 7 days since initial dose⁵⁶ • Refer to Queensland Clinical Guideline: <i>Preterm labour and birth</i>⁵⁰

*Refer to Australian pharmacopoeia for complete drug information

5.3 Magnesium sulfate for neuroprotection

Table 16. Magnesium sulfate for neuroprotection

Aspect	Considerations
Context	<ul style="list-style-type: none"> • Magnesium sulfate (MgSO₄) given to mothers shortly before delivery reduces the risk of cerebral palsy and protects gross motor function in those infants born preterm⁵⁷ <ul style="list-style-type: none"> ○ Number needed to treat (NNT): 63 babies for one baby to avoid cerebral palsy (95% CI 44–155)⁵⁸ ○ NNT to benefit (NNTB): 42 babies for combined death or cerebral palsy (95% CI 24–346)⁵⁸ • The effect may be greatest at early gestational ages and is: <ul style="list-style-type: none"> ○ Not associated with adverse cardiorespiratory events⁵⁹ ○ Not associated with adverse long-term fetal or maternal outcome⁵⁷ ○ May be associated with feeding intolerance⁶⁰
Recommendation*	<ul style="list-style-type: none"> • Recommend magnesium sulfate to women at risk of preterm birth before 30+0 weeks gestation where birth is expected or planned within 24 hours⁶¹ and life sustaining interventions after birth are planned or may be a possibility <ul style="list-style-type: none"> ○ Ideally within four hours of planned birth⁶¹ ○ May be considered between 30+0 and 33+6 weeks gestation⁵⁰ • Where urgent birth is necessary, do not delay birth to administer magnesium sulfate • If birth does not occur after administration, and preterm birth (less than 30 weeks gestation) again appears imminent (planned or expected with 24 hours), a repeat dose may be considered at the discretion of the obstetrician • Refer to Queensland Clinical Guideline: <i>Preterm labour and birth</i>⁵⁰

*Refer to Australian pharmacopoeia for complete drug information

5.4 Cardiotocograph monitoring

Table 17. Cardiotocograph monitoring

Aspect	Considerations
Context	<ul style="list-style-type: none"> • 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 weeks⁶² • Compared to term infants, in extremely preterm infants FHR: <ul style="list-style-type: none"> ○ Baseline is higher (average 155 bpm at 20–24 weeks)^{62,63} ○ Baseline variability and cycling is reduced⁶² ○ Accelerations are absent⁶⁴ or significantly reduced with lower amplitude (rise of 10 beats from baseline rather than 15)⁶² ○ Decelerations in the absence of uterine contractions occur more frequently⁶³ and may represent normal development⁶² ○ Decelerations may have lower depth and duration⁶² ○ Variable decelerations occur more frequently intrapartum⁶² • Reduced FHR reactivity has been associated with early death and severe IVH (grade III or IV) in extremely low birth weight infants⁶⁵ • Poor positive predictive value of CTG in addition to variation in CTG interpretation can lead to unnecessary intervention⁶²
Recommendation	<ul style="list-style-type: none"> • 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: <ul style="list-style-type: none"> ○ Is not recommended at less than 24 weeks gestation ○ Limited usefulness between 24 weeks and 28 weeks depending on individual circumstances

5.5 Mode of birth

Table 18. Caesarean section for fetal indications

Aspect	Considerations
Context	<ul style="list-style-type: none"> • Considerations • The optimal mode of birth for extremely preterm babies is uncertain and controversial⁶⁶⁻⁶⁹ • There are very few randomised controlled trials⁶⁶— most studies are retrospective and are likely to be subject to selection bias and/or have other serious limitations⁶⁸ • Preterm caesarean section (CS) is usually technically more difficult to perform and is not without risk to the baby⁷⁰ as the lower segment of the uterus 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 death³⁵ <ul style="list-style-type: none"> ○ Discuss the implications of decision with the woman • Some studies suggest CS improves survival and/or morbidity of the extremely preterm vertex presentation baby⁷¹ while others have not demonstrated benefit^{67,72,73} • Similarly there are inconsistent results regarding CS for the extremely preterm breech presentation baby with some studies reporting reduced morbidity and/or mortality⁷⁴⁻⁷⁷ and others reporting no difference^{66,78} or a protective effect of vaginal birth⁷⁹
Consensus recommendation	<ul style="list-style-type: none"> • 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): <ul style="list-style-type: none"> ○ Potential for fetal and maternal risk and benefit ○ Family preferences and wishes ○ Individual clinical circumstances (e.g. fetal presentation) • Consensus recommendations of the working party regarding CS for fetal indications: <ul style="list-style-type: none"> ○ Not recommended at less than 24+0 weeks gestation ○ Not usually recommended between 24+0 and 24+6 weeks gestation ○ May be recommended from 25+0 weeks gestation depending on individual circumstances

5.6 Care at birth

Table 19. Care at birth

Criteria	Considerations
Preparation for birth	<ul style="list-style-type: none"> • Whenever resuscitation is considered an option¹⁵: <ul style="list-style-type: none"> ○ Regard the resuscitation as an emergency ○ An experienced healthcare practitioner, preferably a neonatologist, is present ○ 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^{25,80} • Refer to the Queensland Clinical Guideline <i>Neonatal resuscitation</i>³¹ • Provide palliative care to all babies for whom resuscitation is not initiated or is not successful²⁸
Delayed cord clamping	<ul style="list-style-type: none"> • Defined as waiting at least one minute after birth before clamping of the cord • Is recommended for improved maternal and infant health and nutrition outcomes while initiating simultaneous essential neonatal care⁸¹ <ul style="list-style-type: none"> ○ Improves neonatal iron status for up to 6 months after birth⁸¹ ○ May reduce the number of preterm babies who die before discharge when compared with early cord clamping⁸² ○ May reduce the number of babies who die or have neurodevelopmental impairment in early years⁸²
Condition at birth	<ul style="list-style-type: none"> • Assessment of condition at the time of birth (even by experienced practitioners) may not correlate with survival to discharge^{83,84}
Reassessment	<ul style="list-style-type: none"> • Once life sustaining interventions are initiated, continuously re-evaluate the baby's condition and reassess the prognosis • Refer to Section 3 Factors affecting survivability • Clinical assessments commonly include²⁶: <ul style="list-style-type: none"> ○ Apparent maturity ○ Extent of bruising²¹ ○ Heart rate ○ Spontaneous activity level²¹ ○ Respiratory effort and response to resuscitation²¹ ○ Birth weight [refer to Table 20. Birthweight percentile values (g) for live singleton females and males^{85,86}] ○ 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 20. Birthweight percentile values (g) for live singleton females and males^{85,86}

Gestational age (weeks)	10 th percentile		50 th percentile		90 th 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

Gestational age is only one factor impacting survival and estimation frequently includes a margin of error. Consider the entire clinical picture during decision-making. Refer to Section 3 Factors affecting survivability.

- If resuscitation is intended, refer to:
 - Queensland Clinical Guideline *Neonatal resuscitation*³¹
 - Australian and New Zealand Committee on Resuscitation (ANZCOR) for specific considerations for preterm babies⁸⁷
- If palliative care is intended, refer to Section 6 Palliative care.

Table 21. Resuscitation at birth

Gestational age	Recommendation
Less than 23+0 weeks	<ul style="list-style-type: none"> • Life sustaining interventions are not usually recommended for babies born at less than 23+0 weeks gestation • Palliative care is usually recommended • Recommend counselling by practitioners experienced in the care of extremely premature babies (e.g. by telehealth)
23+0–23+6 weeks	<ul style="list-style-type: none"> • Consider individual circumstances when making recommendations about initiation of life sustaining interventions for babies born at 23+0–23+6 weeks gestation • Recommend counselling by practitioners experienced in the care of extremely premature babies • 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: <ul style="list-style-type: none"> ◦ Consider the individual circumstances of the case ◦ It may be appropriate to initiate life sustaining interventions and reassess the baby's condition when parental wishes can be ascertained
24+0–24+6 weeks	<ul style="list-style-type: none"> • Life sustaining interventions are usually recommended • Recommend counselling by practitioners experienced in the care of extremely premature babies • If after appropriate counselling, the family make an informed decision for palliative care, support the family's wishes
25+0–25+6 weeks	<ul style="list-style-type: none"> • Life sustaining interventions are recommended <ul style="list-style-type: none"> ◦ It is unusual not to provide resuscitative interventions to babies born alive at 25 weeks gestation • Recommend counselling by practitioners experienced in the care of extremely premature babies • 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, support the family's wishes • Where there is conflict in the decision-making process between parents and members of the healthcare team take all possible steps to resolve the conflict <ul style="list-style-type: none"> ◦ Refer to Table 6. 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.²¹

- 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*³¹
- 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.²¹

Table 22. Palliative care

Aspect	Considerations
Planning care	<ul style="list-style-type: none"> • Conduct a thorough assessment of the baby's clinical condition • Develop an agreed care plan with the family, including as appropriate to the circumstances^{11,21}: <ul style="list-style-type: none"> ○ Resuscitation ○ Postnatal care ○ After death care²¹ ○ Discuss the advantages of post-mortem examination in confirming specific pathology and for informing future pregnancies^{11,25,88} • 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 met⁸⁹ • Include social worker/psychological supports in care planning • Involve the paediatric palliative care team (1800 249 648) as appropriate/required⁸⁹ • Document decisions in detail to ensure a clear and unambiguous understanding by the healthcare team and the family⁸ <ul style="list-style-type: none"> ○ Consider use of specific palliative care plans • Inform the healthcare team caring for the mother of the plan⁸ including the general practitioner (GP)
Newborn care	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Insertion of a gastric tube for feeding is not usually recommended at extremely preterm gestations, 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	<ul style="list-style-type: none"> • 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) <ul style="list-style-type: none"> ○ Consider individual circumstances and parental wishes in timing these decisions ○ Prepare the family for the likely/possible clinical sequelae that may follow withdrawal of technological supports²¹ (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 baby⁸ • Stop all unnecessary interventions and observations and actively consider interventions that increase comfort⁸ • Provide sensitive emotional support and reassurance to parents throughout the dying process and afterwards

6.1 Symptom management

Table 23. Symptom management

Aspect	Considerations
Context	<ul style="list-style-type: none"> • Considerations • Babies less than 800 g have been shown to receive less comfort medication than larger infants⁸ • Assess all babies for pain and symptom management • Avoid invasive procedures • Incorporate non-pharmacological interventions (e.g. minimal noise/light, stimuli, non-nutritive sucking with a dummy (pacifier), flexed position of arms and legs,)⁹⁰ • Refer to Section 2.3 Ethical and legal considerations
Assessment of pain and discomfort	<ul style="list-style-type: none"> • Limited evidence and no validated tools for assessment of pain in the extremely preterm baby receiving palliative care⁹¹ • In conjunction with assessment of clinical signs (e.g. heart rate, dyspnoea, air hunger) and parental wishes, established pain scales (e.g. PIPP-R⁹²) may be a useful adjunct
Pharmacological	<ul style="list-style-type: none"> • Administer analgesics/sedation as indicated • Select the route of administration that is best tolerated by the baby • Refer to Queensland Children's Hospital: <i>A practical guide to palliative care in paediatrics</i>⁸⁹ • Refer to Queensland Clinical Guideline <i>NeoMedQ neonatal medicines</i> at https://www.health.qld.gov.au/qcg/neonatal-medicines for dosages of: <ul style="list-style-type: none"> ○ Paracetamol ○ Morphine (sulfate and hydrochloride) ○ Midazolam

6.2 Bereavement support

The birth and death of an extremely preterm baby is a stressful experience for the family. What comprises best practice in relation to psychosocial care in these circumstances is uncertain.⁹³ 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.⁸⁸

Table 24. Bereavement care

Aspect	Considerations
Communication	<ul style="list-style-type: none"> 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: <ul style="list-style-type: none"> ‘Stable’ when referring to a dying baby Euphemisms such as ‘passing away’ Terms such as ‘There is nothing more we can do’ Refer to Sections on counselling, sharing information
Maternity care	<ul style="list-style-type: none"> If birth has occurred recently, ensure the postnatal care needs of the mother are met Liaise with maternity clinicians for care provision <ul style="list-style-type: none"> Support and facilitate continuity of care/carer
Psychosocial/ spiritual	<ul style="list-style-type: none"> Maintain a family centred approach to care^{11,88} Advise the family that the duration of the dying process is variable²¹ Provide an environment conducive to family interaction⁸⁸ (e.g. room with recliners/beds, lighting that can be dimmed, outlets where music can be played, access to a kitchenette and bathroom, away from other new parents and their babies) Facilitate unrestricted visiting⁸⁸ Involve the family prior to and beyond the death as appropriate to the circumstances⁸⁹ Facilitate spiritual/religious/cultural rituals, services and support important for the family^{88,89} (e.g. baptism, naming ceremony) Involve social worker/psychological supports
Memory creation	<ul style="list-style-type: none"> Facilitate memory creation/gathering before and after death consistent with the family’s wishes and following consent^{4,88} (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, videoconferencing if available) Offer option to take baby home if feasible¹¹ Refer to Queensland Clinical Guideline Stillbirth care⁹⁴
Follow-up	<ul style="list-style-type: none"> Offer assistance with certification and registration of death¹¹ Provide information on burial and cremation¹¹ (written or verbal as appropriate) Consider facility-initiated telephone contact after discharge Offer a future appointment to discuss the death^{11,21} with the healthcare team, particularly the lead healthcare professional Provide contact information for psychological support (e.g. professional counselling or support groups/organisations¹¹) Consider care needs for subsequent pregnancies Inform the regional referring centre/private midwife if applicable Inform the GP by telephone and in writing

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Appendix A: Summary for initiation of treatment

Source	Summary of position																															
NSW and ACT Consensus Statement (2006)	<ul style="list-style-type: none"> 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. 																															
South Australia (2019)	<ul style="list-style-type: none"> Initiation of neonatal CPR (modifiable by risk factors, parental preferences, estimated chance of poor outcome) <ul style="list-style-type: none"> 21+0–21+6: not recommended 22+0–22+6: consider 23+0–23+6: recommended 24+0–24+6: recommended 																															
Royal Australian College of Physicians (2008)	<ul style="list-style-type: none"> 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 (2019)	<ul style="list-style-type: none"> For extremely high-risk babies (> 90% chance of either dying or surviving with severe impairment if active care instigated) palliative (comfort-focused) care would be in the best interests of the baby and life-sustaining treatment should not be offered. Includes for example <ul style="list-style-type: none"> Babies at 22+0–22+6 weeks of gestation with unfavourable risk factors Some babies at 23+0–23+6 weeks of gestation with unfavourable risk factors, including severe fetal growth restriction (Rarely) babies ≥ 24+0 weeks of gestation with significant unfavourable risk factors, including severe fetal growth restriction For high risk babies (50-90% chance of either dying or surviving with severe impairment if active care is instituted), it is uncertain whether active (survival focused) management is in the best interests of the baby and their family. Parents should be counselled carefully, and parental wishes should inform a joint decision to provide either active or palliative treatment. Includes for example <ul style="list-style-type: none"> Babies at 22+0–23+6 weeks of gestation with favourable risk factors Some babies ≥ 24+0 weeks of gestation with unfavourable risk factors and/or co-morbidities For moderate risk babies (< 50% chance of either dying or surviving with severe impairment if active care is instituted) active management would be in the best interests of the baby. Includes for example: <ul style="list-style-type: none"> Most babies ≥ 24+0 weeks of gestation Some babies at 23+0–23+6 weeks of gestation with favourable risk factors 																															
American College of Obstetricians and Gynaecologists (2017)	<ul style="list-style-type: none"> Over the past three decades there has been a progressive increase in the rate of survival for infants born at 22–25 weeks of gestation <table border="1" data-bbox="411 1608 1353 2020"> <thead> <tr> <th rowspan="2">Obstetric intervention</th> <th colspan="3">Gestation in weeks</th> </tr> <tr> <th>22+0–22+6</th> <th>23+0–23+6</th> <th>24+0–24+6</th> </tr> </thead> <tbody> <tr> <td>Neonatal assessment for resuscitation</td> <td>C</td> <td>C</td> <td>R</td> </tr> <tr> <td>Antenatal corticosteroids</td> <td>NR</td> <td>C</td> <td>R</td> </tr> <tr> <td>Magnesium sulfate for neuroprotection</td> <td>NR</td> <td>C</td> <td>R</td> </tr> <tr> <td>Antibiotics to prolong latency during PPRM</td> <td>C</td> <td>C</td> <td>R</td> </tr> <tr> <td>Intrapartum antibiotics for GBS prophylaxis</td> <td>NR</td> <td>C</td> <td>R</td> </tr> <tr> <td>CS for fetal indication</td> <td>NR</td> <td>C</td> <td>C</td> </tr> </tbody> </table> <p>NR: not recommended; C: consider; R: recommended</p>	Obstetric intervention	Gestation in weeks			22+0–22+6	23+0–23+6	24+0–24+6	Neonatal assessment for resuscitation	C	C	R	Antenatal corticosteroids	NR	C	R	Magnesium sulfate for neuroprotection	NR	C	R	Antibiotics to prolong latency during PPRM	C	C	R	Intrapartum antibiotics for GBS prophylaxis	NR	C	R	CS for fetal indication	NR	C	C
Obstetric intervention	Gestation in weeks																															
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Magnesium sulfate for neuroprotection	NR	C	R																													
Antibiotics to prolong latency during PPRM	C	C	R																													
Intrapartum antibiotics for GBS prophylaxis	NR	C	R																													
CS for fetal indication	NR	C	C																													

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
Thanh	2019	30,529	22 to < 37 weeks	Positive
Jarde	2019	129,475	< 1500 g or < 28 weeks	Positive for composite < 28 weeks Positive for 500–700 g, 1000–1250 g Negative for < 1250–1500
Barzilay	2016	16,435	< 1500 g	Negative
Alfrevic	2013	116	< 37 weeks	Negative for all
Reddy	2012	2138	24–31 weeks	Negative for all
Durie	2011	937	< 1500 g	Negative
Ghi	2010	109	25+0–32+6 weeks	Negative for all

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

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