South Australian Perinatal Practice Guideline

# Perinatal Care at the Threshold of Viability

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#### Note

This guideline provides advice of a general nature. This statewide guideline has been prepared to promote and facilitate standardisation and consistency of practice, using a multidisciplinary approach. The guideline is based on a review of published evidence and expert opinion.

Information in this statewide guideline is current at the time of publication.

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Health practitioners in the South Australian public health sector are expected to review specific details of each patient and professionally assess the applicability of the relevant guideline to that clinical situation.

If for good clinical reasons, a decision is made to depart from the guideline, the responsible clinician must document in the patient's medical record, the decision made, by whom, and detailed reasons for the departure from the guideline.

This statewide guideline does not address all the elements of clinical practice and assumes that the individual clinicians are responsible for discussing 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,
  - Advising consumers of their choice and ensuring informed consent is obtained,
- Providing care within scope of practice, meeting all legislative requirements and maintaining standards of professional conduct, and
- Documenting all care in accordance with mandatory and local requirements

#### Explanation of the aboriginal artwork

The aboriginal artwork used symbolises the connection to country and the circle shape shows the strong relationships amongst families and the aboriginal culture. The horse shoe shape design shown in front of the generic statement symbolises a woman and those enclosing a smaller horse shoe shape depicts a pregnant women. The smaller horse shoe shape in this instance represents the unborn child. The artwork shown before the specific statements within the document symbolises a footprint and demonstrates the need to move forward together in unison.

Australian Aboriginal Culture is the oldest living culture in the world yet Aboriginal people continue to experience the poorest health outcomes when compared to non-Aboriginal Australians. In South Australia, Aboriginal women are 2-5 times more likely to die in childbirth and their babies are 2-3 times more likely to be of low birth weight. The accumulative effects of stress, low socio economic status, exposure to violence, historical trauma, culturally unsafe and discriminatory health services and health systems are all major contributors to the disparities in Aboriginal maternal and birthing outcomes. Despite these unacceptable statistics the birth of an Aboriginal baby is a celebration of life and an important cultural event bringing family together in celebration, obligation and responsibility. The diversity between Aboriginal cultures, language and practices differ greatly and so it is imperative that perinatal services prepare to respectively manage Aboriginal protocol and provide a culturally positive health care experience for Aboriginal people to ensure the best maternal, neonatal and child health outcomes.

### Purpose and Scope of Perinatal Practice Guideline (PPG)

The guideline is designed to aid clinical decision-making in the context of anticipated or actual premature birth between 21 and 25 completed weeks' gestation. It may be used in counselling parents, in conjunction with the three PPG companion documents: *Too small. Too soon. Parent Information for Babies Born 20-22 weeks, 23-24 weeks and 25* weeks available at www.sahealth.sa.gov.au/perinatal)



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### Table 1: Schema for Neonatal Decision-making

Babies born from 22nd to 25th week: recommendations for plan of initial management according to week of gestation (X weeks +0 days - X weeks + 6 days)<sup>1,7</sup>.

Note: The percentages listed are composite outcomes based on Australian and New Zealand Neonatal Data<sup>7</sup> where there is an intention to treat. People in their counselling may wish to divide those outcomes into 'survival' (see <u>table 3</u>) and 'functional impairment' (see <u>table 4</u>), as part of their explanation to parents.

WEEK	22	23	24	25
% Survival without permanent impairment	<20	20-30	30-50	>50
Recommendation	COMFORT	RESUS/ICU*	RESUS/ICU	RESUS/ICU

<sup>\*</sup> Making decisions about the baby's best interests in partnership with parents and being flexible in direction of care are particularly critical when the likelihood of survival without permanent impairment is quite low



# Table 2: Perinatal Decision Making in Extreme Prematurity: Considerations and Recommendations\*

The table originated from the Forum *"Perinatal Care of Extremely Premature Babies" held at* the Women's & Children's Hospital, 26<sup>th</sup> July 2018. It is based on consensus agreement following review of the evidence by specialist clinicians present at the Forum (Author: Dr S Scroggs, Chair, Maternal, Neonatal & Gynaecology Community of Practice)

Gestation Clinical factors	21+0 - 21+6	22+0 – 22+6	23+0 – 23+6	24+0 – 24+6	25+0 – 25+6
Transfer Mother for Neonatal reasons Depending on local service capabilities may need to transfer for maternal reasons	Not Before 22+0	Recommended	Recommended	Recommended	Recommended
Antenatal Steroids MgSO <sub>4</sub> for neuroprotection Antibiotics (GBS Prophylaxis with low threshold for broad spectrum cover)	Not Recommended	Consider	Recommended	Recommended	Recommended
CS For Fetal Indication (Malpresentation, multiple pregnancy, IUGR)	Not Recommended	Not Recommended	Consider	Recommended	Recommended
CTG in labour, otherwise intermittent auscultation	Not Recommended	Not Recommended	Not Recommended	Consider	Recommended
CS for fetal compromise in labour (possible intrapartum asphyxia): include in counselling for planned induction of labour	Not Recommended	Not Recommended	Not Recommended	Consider	Recommended
Neonatologist Present At Birth	Not Recommended	Recommended	Recommended	Recommended	Recommended
Initiation of Neonatal CPR (for bradycardia, etc.)	Not Recommended	Consider	Recommended	Recommended	Recommended

\*Note all positive ("consider"/"recommended") recommendations at periviable gestations may be modified by factors such as rapidly progressing labour or informed parental decision against interventions where estimated chance of poor outcome for the baby is high. Data is lacking on which to base recommendations in the presence of modifiers such as chorioamnionitis or estimated fetal weight <400g.



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### Summary of Practice Recommendations

### **Principles**

Infants who are born prematurely at 21 weeks gestation or earlier are not considered viable. Their extreme physical and physiological immaturity means that survival is not possible with current technology and expertise.

Infants born later, but still extremely early, for example between 22 and 24 weeks gestation, may be able to be supported with intensive care, but have a high risk of dying despite treatment or permanent impairment in survivors. This period is sometimes referred to as the "threshold of viability".

For infants born around the threshold it may be appropriate to provide only comfort measures following birth, to provide full intensive care support, or to provide a trial of treatment with management adjusted to the response to resuscitation and intensive care.

Where there is the possibility of preterm birth around the threshold, specialist obstetric and neonatal advice from any of the public metropolitan maternity hospitals should be sought, through telephone conference if necessary. Where possible and safe, early transfer of the mother should be arranged to a centre with level 6 neonatal care.

For emergency advice and/or transport, contact the Perinatal Advice Line on 137 827.

A paediatrician should be present at the birth of any infant around the threshold of viability whether or not active resuscitation is planned.

The frameworks for obstetric and neonatal decision-making below are derived from local and national consensus statements<sup>1</sup>. The following principles apply:

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

Where there is a high risk for an infant of death or survival with severe morbidity, parents should be sensitively counselled about realistic options and the risks and benefits of those options. Parents' views about resuscitation and the best interests of the child should be sought, and should be an important factor in decisions<sup>3</sup>. Written information should be provided and opportunities given for parents to reflect before decisions are made.

If there is doubt about whether or not to provide treatment, resuscitation should be provided in the first instance. If the infant responds poorly to initial treatment, or it subsequently becomes apparent resuscitation is not in the best interests of the infant, there is the option of re-directing care (palliation or comfort care).

#### **Decision pathway for babies**

Birth anticipated around the threshold of viability:

- 1. Seek obstetric and neonatal advice, via telephone conference if necessary.
- 2. Arrange antenatal transfer if safe and feasible.
- 3. Assess prognostic factors for infant (e.g. gestation, gender, birth weight estimate).
- 4. Sensitively counsel parents about realistic options, provide written information (see the three PPG companion documents: Too small. Too soon. Parent Information for Babies Born 20-22 weeks, 23-24 weeks and 25 weeks available at <a href="https://www.sahealth.sa.gov.au/perinatal">www.sahealth.sa.gov.au/perinatal</a>) and determine parents' wishes.
- 5. Give antenatal steroids if birth not immediate (see <u>Obstetric Decision Making Table</u>). Give magnesium sulphate for neuroprotection if birth expected within 24 hours and resuscitation/intensive care planned.
- 6. Neonatal management:

Week 22: Provide comfort care (but see Management Points in Gestation Ranges)

Weeks 23-24: Provide treatment, but shared decision-making with parents critical

Week 25: Provide resuscitation and intensive care



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#### **Abbreviations**

ANZNN	Australian and New Zealand Neonatal Network
CS	Caesarean Section
CPR	Cardio Pulmonary Resuscitation
CTG	Cardiotocography
g	Gram(s)
GMC score	
IUGR	Intrauterine Growth Restriction
MgSO <sub>4</sub>	Magnesium Sulphate
NICHD	National Institute of Child Health and Human Development
PAGE+	Prognosis for Average Gestation Equivalent infant
PI	Profound impairment
PPG	Perinatal Practice Guideline

#### **Definitions**

Threshold of viability	Time period for babies born between 22 and 24 weeks gestation, who may be able to be supported with intensive care, but have a high risk of dying despite treatment or have permanent impairment in survivors
Gestation week	In this document, reference to a particular gestation refers to the interval of the index week: e.g. 24 weeks refers to the interval 24 <sup>+0</sup> – 24 <sup>+6</sup>
Level 6 Neonatal Service	Capacity to provide multidisciplinary comprehensive management of the 'low – high risk' neonate including most conditions at any gestation

### **Obstetric Management**

See <u>Perinatal Decision Making in Extreme Prematurity: Considerations and Recommendations</u> table. In addition, the following general points can be noted:

- > Expert obstetric and neonatal advice should be sought for any woman presenting in preterm labour around the threshold of viability or with birth anticipated around this time (e.g. pre-labour rupture of membranes, evolving pre-eclampsia).
- > Transfer of the woman should be considered and arranged if safe and appropriate. This may facilitate counselling, obstetric and neonatal management. There is a significant increase in mortality and morbidity for extremely premature infants born outside centres with neonatal intensive care capability.
- Management during labour will be influenced by the estimated prognosis of the infant, and planned management after birth (see <u>Assessing Prognosis for Extremely Premature</u> <u>Infants</u>).
- > If active resuscitation of the infant after birth is planned, obstetric management should consider measures to improve fetal wellbeing and improve outcome for the infant.
- Antenatal corticosteroids should be considered in any mother where birth is anticipated soon and active resuscitation is planned. They should also be considered even if resuscitation is not currently planned (e.g. during week 22), but where birth may be delayed long enough that resuscitation would be desired/planned.
- > Neuroprotection of the fetus (with magnesium sulphate) should be considered in women with active preterm labour where birth is expected within 24 hours and active resuscitation is planned. See *Magnesium Sulphate for Neuroprotection of the Fetus in Women at Risk of Preterm Birth* PPG available at <a href="www.sahealth.sa.gov.au/perinatal">www.sahealth.sa.gov.au/perinatal</a>.



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### Assessing Prognosis for Extremely Premature Infants

Where birth around the borderline of viability is anticipated, the prognosis for the infant should be determined, taking into account *all* relevant factors. Parents should be informed of the prospects for survival and for survival without profound impairment.

#### Survival

- > The prognosis for infants born extremely prematurely is affected by a number of factors. These include the infant's gestation, birth weight, gender, whether a singleton or multiple birth, whether or not the mother has received antenatal corticosteroids or magnesium sulphate, and the presence of acute chorioamnionitis, fetal compromise or major congenital malformations<sup>4,5</sup>.
- > Gestation at birth is strongly correlated with survival<sup>6</sup>. Survival rates at a particular gestation represent the average survival for infants born during a particular week e.g. 24 week gestation represents infants born between 24 weeks and 0 days and 24 weeks and 6 days.
- In Australian and New Zealand neonatal units over the 4 years 2011-2014, the rate of survival to hospital discharge was 82.7% for infants born at 25 weeks' gestation and admitted to intensive care, 68.2% at 24 weeks' and 54.5% at 22/23 weeks' gestation<sup>7</sup>. Survival rates at 22 weeks have not been reported separately in Australia and New Zealand Neonatal Network (ANZNN) data<sup>7</sup> because of the very small numbers of infants admitted to intensive care at this gestation. Studies in North America suggest an approximately 20% survival rate to hospital discharge for this group of infants if admitted to intensive care<sup>4,8</sup>.
- Prenatal steroid exposure, singleton versus multiple birth and appropriate birth weight all have an influence on survival rate that is equivalent to up to one weeks' additional gestation<sup>4, 8</sup>. Infants born at the same gestation may have a significantly different prognosis depending on these and other factors.

**Table 3: Survival to discharge home 2011-2014** (<u>excluding</u> neonatal deaths on labour wards, babies born in hospitals without a NICU and babies not transferred to a NICU or children's hospital)<sup>7</sup>

Gestational age (weeks)	Number of babies	Lethal congenital anomalies	Babies alive on day 7	Babies alive on day 28	Babies alive on discharge to home	Percent survival at discharge to home
<24	101	< 5	75	62	55	54.5
24	176	0	145	132	120	68.2
25	220	< 5	208	194	182	82.7
26	311	< 5	304	295	284	91.3
27	343	0	339	329	322	93.9
28	445	< 5	439	433	431	96.9

<sup>\*</sup> Adapted from ANZNN Report 2017, p 33

#### **Impairment**

- In population-based studies, approximately one quarter of surviving extremely premature infants are diagnosed with a significant neurosensory disability at follow-up including cerebral palsy, cognitive impairment and sensory deficits<sup>8</sup>. By mid-childhood two thirds of surviving children had one or more chronic health problems and increased health care needs compared to 11% of children born at term.
- > However, only a small proportion of surviving extremely premature infants have severe impairments affecting activities of daily living<sup>7,9,10</sup>. In a Victorian population based study, only 3.7% of surviving infants born between 22 and 27 weeks' gestation in 2005 had a "severe disability" (cerebral palsy unlikely to walk, severe developmental delay or blindness)<sup>11</sup>. In an earlier Victorian cohort (born in 1997) the rates of severe disability at age 8 were 22% at 23 weeks, 8.3% at 24 weeks and 12.8% at 25 weeks' gestation<sup>12</sup>.



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Table 4: Severity of functional impairment at 2-3 year follow-up by gestational age, 2011-2014 (excluding infants with congenital anomalies known to affect impairment)

Gestational Age in Weeks: Number (Percent)					
Functional impairment	< 24	24	25	26	27
None	26 (48.1%)	148 (52.7%)	278 (61.5%)	410 (67.0%)	443 (67.9%)
Mild	15 (27.8%)	65 (23.1%)	102 (22.6%)	118 (19.3%)	113 (21.1%)
Moderate	NP	46 (16.4%)	45 (10.0%)	50 (8.2%)	41 6.3%)
Severe	< 5	22 (7.8%)	27 (6.0%)	34 (5.6%)	21 (3.2%)
Incomplete	10	36	59	75	93
Different formal test	1	3	8	23	21
No formal test	10	32	52	69	87

<sup>\*</sup> Adapted from ANZNN Report 2017, p48

### **Decision-making**

### **Legal Principles**

The legal principle that underpins all decisions relating to resuscitation of newborn infants is that of the 'best interests' of the child<sup>15</sup>.

- There is no statutory definition of viability, nor any legal definition as to when resuscitation should or should not be provided. It is a clinical judgement.
- > The South Australian Consent to Medical Treatment and Palliative Care Act (1995) indicates that medical practitioners are not required to provide life-sustaining treatment to children in the "terminal phase of a terminal illness" if that would merely prolong life in a moribund state (section 18[2]), in the absence of an express direction to the contrary.
- There is no relevant case law in Australia relating to resuscitation of extremely premature infants. In the case of Baby D, the Australian Family Court affirmed that a decision to withdraw life-sustaining treatment could be in the interests of a newborn infant, and that parents were authorised to consent to such decisions (Re:Baby D [No.2] [2011] FamCA 176 [16 March 2011]. Other legal cases and ethical analyses have found no legal or ethical difference between decisions to withhold life-sustaining treatment and decisions to withdraw the same treatment <sup>16</sup>.
- Withholding resuscitation from a newborn infant where this treatment is reasonably judged to be not in the best interests of the infant is therefore consistent with existing law.

#### **Ethical and Practical Framework**

Resuscitation of infants born around the borderline of viability has been called into question because of the relatively high risk of death despite resuscitation and intensive care, the high burden of treatment for infants (prolonged hospitalisation, repeated invasive and painful procedures), and the poor long-term outcome for some survivors.

There are three general principles relating to these decisions:

- Decisions should be based on the best available evidence about the prognosis for infants born in situations similar to that currently present. They should reflect all relevant prognostic factors.
- 2. Where there is a high risk for an infant of death or survival with severe morbidity, parents' wishes about resuscitation should be sought. The views and values of parents are an important factor in determining whether intensive treatment or comfort care is in the infant's best interests.
- 3. If there is doubt about whether or not to provide treatment, for example, where gestation is uncertain or there is little or no time to discuss options and ascertain the parents' views, a paediatrician should be present at birth and resuscitation provided in the first instance. If the infant responds poorly to initial treatment, or it subsequently becomes apparent that parents do not feel that resuscitation is in the best interests of the infant, there is the option of withdrawing life-sustaining measures and providing comfort care.



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The framework for appropriate decision-making is based on the following statements, for which there is broad agreement internationally (see <u>Table 1</u>):

- > Fetuses and infants with similar estimated outcome should be treated similarly.
- In general, at 23 weeks' gestation, parents' views about the intention to provide resuscitation and intensive care should be sought and decision-making in partnership is critical.
- > From the 24th week onwards, all else being equal, resuscitation and intensive care should normally be provided.
- > Decisions should not be based on gestational age alone.

### Management points in gestation ranges

#### Week 22

- In some situations, even if full resuscitation and intensive care is provided after birth, the chance of survival without profound impairment is estimated to be less than 10%. In this situation, it is often judged not to be in the infant's best interests to provide resuscitation and intensive care. This would be the case for an average infant born in the 22nd week. It may also be the case for some more mature infants with very severe adverse prognostic features (such as birth weight <400g) or combinations of features.</p>
- In these situations, it is appropriate only to offer comfort care, though parents should be as far as possible involved in the decision-making process. If comfort care of the infant is planned, obstetric interventions should usually be limited to those focused on maternal wellbeing. If it is possible that birth will be delayed to a point at which resuscitation would be appropriate, antenatal corticosteroids should be given, since these have been shown to reduce mortality if given prior to delivery in the 23rd week<sup>17</sup>. Under these circumstances, transfer of the mother to a maternity facility with Level 6 neonatal services should be undertaken.
- In some situations (e.g. birth late in the 22nd week), it may be appropriate to consider resuscitation as 'investigational' or as a 'trial of life'<sup>3</sup>. Despite the apparently low chance of survival without profound impairment, resuscitation and intensive care may be undertaken on a provisional basis. In practical terms, this means that full resuscitation and intensive care is offered and continued for as long as it takes to ascertain how the infant will respond to active treatment. Ideally an agreement with parents should be in place that, if the infant responds poorly (death or survival with profound impairment seem inevitable), then care will be redirected to provision of comfort only.

#### Week 23

- > The probability of survival without permanent impairment in different gestation ranges apply to the average infant born at those gestations. In the 23rd week, of the approximately 50% that survive, almost 50% will have some level of functional impairment. Therefore the probability of intact survival is relatively low (20-30%) and may be modified downwards by adverse prognostic factors (e.g. major congenital malformations, severe growth restriction, or prelabour preterm rupture of the membranes with anhydramnios). Nevertheless, the default position should be that provision of resuscitation and intensive care should be available to these infants if it is practicable. Decisions about their care should be made in partnership with families
- If, following discussion, it is judged that it is not in the best interests of the infant to provide resuscitation and intensive care, comfort care should be provided. It may be appropriate for that care to be provided locally in the case of imminent birth at a distance from Level 6 resources. If active treatment is judged to be in the infant's best interests, efforts should be directed towards providing resuscitation and intensive care for the infant at a Level 6 neonatal centre, with antenatal or postnatal transfers according to safety considerations. As with infants born late in the 22nd week, a 'trial of life' approach may be appropriate if practicable.
- If birth is likely and the decision for comfort care only for the infant has been made, obstetric management should focus on maternal wellbeing. However, if birth may be delayed such that the decision tips in favour of resuscitation and intensive care, antenatal steroids and transfer are indicated. For parents who are unsure about decisions, transfer may also facilitate counselling and support.



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If birth is likely and active resuscitation and intensive care for the infant is planned, obstetric management should be guided by both maternal and fetal considerations. This includes antenatal transfer, fetal neuroprotection with magnesium sulphate, electronic fetal monitoring and expedited birth in the presence of fetal compromise. There is a high morbidity for extremely preterm infants who require transfer after birth and consequently antenatal transfer to a maternity facility with level 6 neonatal services should be undertaken if this is practicable and safe. Options for mode of birth should be discussed with the mother. At present there is insufficient evidence to determine whether planned caesarean section offers any benefit for the baby over vaginal birth. Caesarean section around the threshold of viability is associated with increased maternal complications.

#### Week 24

Similar considerations apply to birth in the 24th week as to birth in the 23rd week. However, because the probability of survival without permanent impairment is significantly greater (30-50%), there is likely to be a greater degree of disagreement about the acceptability of an elective comfort care approach (no intention to provide resuscitation) and intensive care. This is a "grey area" in decision-making at the border of viability. However, it would be reasonable to argue that, if provision of resuscitation and intensive care is the default position for infants born in the 23rd week, then they should normally be provided in the 24th week and, in the absence of adverse factors (e.g. severe fetal growth restriction or major congenital anomaly), elective comfort care is probably not appropriate.

#### ≥25 weeks

- > Where the chance of a good outcome with resuscitation and intensive care is relatively high (>50%), resuscitation and intensive care is clearly indicated. This would be the situation for the average infant born in the 25th week or later.
- Obstetric management should be guided by both maternal and fetal considerations. This includes antenatal transfer, fetal neuroprotection with magnesium sulphate, electronic fetal monitoring, and expedited birth in the presence of fetal compromise. Options for mode of birth should be discussed with the mother. There is a high morbidity for extremely preterm infants who require transfer after birth and consequently antenatal transfer to a Level 6 neonatal centre should be undertaken if this is feasible and safe.
- Although resuscitation and intensive care will normally be provided, as in infants born from late in the 22nd week, through the 24th week, this may be modified by the infant's response to treatment. For example, prolonged cardiopulmonary resuscitation (>5 minutes) of extremely premature infants in the birthing room has been associated with high rates of mortality and neurodevelopmental impairment<sup>22</sup>.

### Counselling

Birth around the threshold of viability may occur suddenly, without the opportunity for counselling or consideration of treatment options. However there is often time for some counselling to occur.

Careful counselling is most critical in situations where the risk of adverse outcomes for the infant is high, and obstetric and neonatal decisions should be guided by the outcome of discussions with parents.

Parents should be given the opportunity to speak to staff experienced in obstetric and neonatal care and should be as fully informed as possible about the risks and benefits of available treatment options, including place and mode of birth and the relevant normal approaches to care of the newborn infant (comfort only, trial of therapy, active resuscitation and intensive care as appropriate).

Studies of parents who have been involved in prenatal decision-making suggest that parents wish to be involved in the process<sup>23, 24</sup> but that their understanding and recall of information conveyed during counselling varies. The values that parents find most important may not be the same as those of clinicians<sup>23</sup>.



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Clinicians should be sensitive to the needs of individual families and adapt counselling accordingly<sup>25</sup>. Counselling should avoid overwhelming parents with facts and statistics. Clinicians should assess parents' understanding and recall of the information conveyed, and repeated consultations may be required<sup>26</sup>.

Counsellors should be sensitive to the potential vulnerabilities of parents, and aware that the way information is presented to parents may influence their decision-making. For example, in one study participants were more likely to choose resuscitation when mortality statistics were presented as the chance of survival, rather than the chance of death<sup>27</sup>.

Where possible, parents should be provided with printed information about treatment options, and the risks and benefits of these for extremely premature infants. Provision of information in printed form as part of counselling has been demonstrated to improve recall of factual information and reduce parental anxiety<sup>28</sup>.

Too small. Too soon. Parent Information for Babies Born 20-22 weeks, 23-24 weeks and 25 weeks pamphlets are available at <a href="www.sahealth.sa.gov.au/perinatal">www.sahealth.sa.gov.au/perinatal</a>. It may be necessary to explain to parents how certain factors may modify the prognosis for their infant.

Clinicians should be sensitive to the needs of parents from different cultural or religious traditions. It may be necessary to obtain an interpreter (if available) for parents whose first language is not English. Discussions should be conducted in a way that respects parents' particular cultural values and practices. For example, it may be important for Aboriginal women to include members of their extended family or community in discussions and decision-making. Aboriginal women and families should be offered support from Aboriginal Liaison Officers or other agencies such as Aboriginal Maternal Infant Care (AMIC) workers where available.

Where death of the newborn infant is anticipated, counselling should include sensitive discussion of such issues as the appearance of the infant and the different care options such as holding, dressing, bathing, creating mementos and going home with the baby. Autopsy should be discussed and encouraged, except in circumstances where the cause of preterm birth is known and is not fetal in origin. The range of autopsy options (e.g. full, organ-limited, MRI) should be discussed in most cases with appropriate sensitivity to families' psychological and cultural circumstances. If a Palliative Care service is available, it may be able to provide support for the family in this context. For further information about bereavement support, see the *Perinatal Loss* PPG available at www.sahealth.sa.gov.au/perinatal.

#### Disagreement

If there is disagreement within the medical team or between the medical team and parents about what would be best for the infant, a second opinion should be sought. This usually allows reinforcement of prognosis and appropriate treatment options. Where disagreement persists, a staged approach to resolution may be employed. It may be helpful to obtain the assistance of an independent third party, agreed upon by those involved. The person should be transparently independent of the treating team and in a position of seniority which commands the respect of all parties. Alternatively or additionally, a hospital clinical ethics committee may provide a mechanism for resolving disagreement. As a last resort, legal advice should be sought with a view to resolution by adjudication in the courts.



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### **Birthing Room Management**

#### **Resuscitation and Intensive Care**

The use of advanced measures for resuscitation including cardiac massage and endotracheal or intravenous adrenaline is controversial in infants around the borderline of viability. There is concern about the lack of evidence of benefit of cardiopulmonary resuscitation (CPR) in this population and possible adverse consequences<sup>30, 31</sup>. However, the outcome in extremely preterm infants who receive CPR is not necessarily poor. Single-centre studies have reported intact survival in some extremely preterm infants who have received CPR<sup>32</sup>. Larger studies suggest that approximately 50% of extremely low birth weight infants who receive CPR in the birthing room survive without severe intraventricular haemorrhage<sup>34</sup>. On the other hand, a failure to respond to CPR may indicate a poor prognosis. In another study, only 14% of extremely low birth weight infants who received prolonged resuscitation (indicated by need for CPR and 5 minute Apgar score <2) survived without neurodevelopmental impairment<sup>22</sup>.

#### **Comfort Care**

Where comfort care has been planned on the basis of the baby's apparent prognosis, the aim should be to support both the mother and the infant and to avoid interventions that may cause discomfort, pain or separation of the baby from the mother.

Ideally, a neonatologist or paediatrician should be present at birth even if comfort measures have been planned, to provide a brief assessment of the infant's condition at birth, and to support the family and midwifery staff.

If the infant is born in unexpectedly good condition, paediatric staff should consider whether the estimated gestation and prognosis were accurate and whether the planned palliative approach is still appropriate.

Simple measures to support the infant include drying, wrapping, radiant heat and skin-to-skin contact. Supplemental oxygen is not necessary, but can be provided if the parents wish.

Parents should be counselled that the infant may breathe after birth and may develop gasping respiration. On average, newborn infants receiving comfort care in the birthing room live for approximately 60 minutes<sup>33</sup>.

#### **Trial of Treatment**

One approach to decision-making around the threshold of viability is to provide a trial of therapy. This may be an attractive option for families who find it difficult to make decisions in the face of uncertainty. Intensive care is provided initially with the expectation that care will be re-directed if the infant fails to respond or develops severe complications.

Treatment may be limited in the birthing room if the infant is born in particularly poor condition. However, it is important to recognise that prediction of death or severe impairment in the birthing room may not be accurate. In one study, heart rate and Apgar scores at 1 and 5 minutes were neither sensitive nor specific for prediction of subsequent death or severe impairment<sup>34</sup>.

Alternatively, intensive care may be re-directed after the infant has been admitted to the Neonatal Unit. One study suggests that a combination of corroborated clinical intuition (that the infant will die before discharge) and severe abnormalities on cranial ultrasound are highly predictive of poor outcome for the infant <sup>35</sup>.

There is no ethical or legal difference between decisions to withhold (not start) a treatment and decisions to redirect (stop) a treatment. Decisions to limit treatment in intensive care should be made on the same basis as those made to limit treatment at birth. However, caregivers and parents may find it more difficult to stop treatment that has already been commenced than not to embark on it. It is worth discussing this issue in advance if a trial of treatment is planned.



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### Acknowledgements

The South Australian Perinatal Practice Guidelines gratefully acknowledge the contribution of clinicians and other stakeholders who participated throughout the guideline development process particularly:

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### Document Ownership & History

**Developed by:** SA Maternal, Neonatal & Gynaecology Community of Practice

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Endorsed by: SA Health Safety and Quality Strategic Governance Committee

**Next review due**: 20/12/2024

**ISBN number:** 978-1-76083-166-0

PDS reference: CG330

Policy history: Is this a new policy (V1)? N

Does this policy amend or update and existing policy? Y

If so, which version? 1.0

Does this policy replace another policy with a different title?  ${\bf N}$ 

If so, which policy (title)?

Approval Date	Version	Who approved New/Revised Version	Reason for Change
20/12/2019	V2	SA Health Commissioning & Performance Unit	Formally reviewed in line with 5 year scheduled timeline for review.
30/09/2013	V1	SA Maternal and Neonatal Clinical Network	Original SA Maternal and Neonatal Clinical Network approved version.



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