Perinatal management of extreme preterm birth before 27 weeks of gestation: a framework for practice

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INTRODUCTION

Care of the baby, mother and family around the time of an extremely preterm birth is one of the most challenging aspects of perinatal medicine, both for clinicians and families. In 2006, the Nuffield Council on Bioethics convened a working group to explore the ethical, social, economic and legal issues around clinical decisions made in fetal and neonatal medicine[1]; in response to their report, the British Association of Perinatal Medicine (BAPM), in conjunction with other professional groups, developed a Framework for Clinical Practice for the management of babies born extremely preterm at less than 26 weeks of gestation. These documents were based largely on data from the original EPICure study in 1995 of births before 26 weeks of gestation, with some additional preliminary data from EPICure 2 regarding babies born in 2006 before 27 weeks of gestation.[2 3] Subsequently, the Royal College of Obstetricians and Gynaecologists (RCOG) developed a scientific position paper about the management of delivery at the threshold of viability.[4]

The ethical principles that formed the basis for these earlier guidelines have not changed, but advances in perinatal care have led to steadily improving outcomes for babies admitted to UK neonatal intensive care units (NICUs), particularly at the lowest gestational ages. In the current era, the outcomes for babies actively managed at 22 weeks of gestation appear similar to those of babies at 23 weeks of gestation at the time of the 2008 BAPM Framework for Clinical Practice.[5–8] Reports from other countries confirm increasing survival and improving neurodevelopmental outcome for babies born before 27 weeks of gestation.[9–12] Although internationally there remain differences in practice, there is increasing willingness to consider stabilisation at birth and subsequent intensive care for the most extremely preterm babies,[13–15] accompanied by greater acknowledgement of the importance of involving parents in perinatal decision-making.[16] Reported outcomes are, of course, impacted by willingness to consider active interventions before and after birth.[17]

This updated Framework for Practice has been developed by consensus, taking into account the most recent available outcome data both from the UK and internationally, and follows wide consultation. BAPM is grateful for input from the RCOG, the British Maternal and Fetal Medicine Society, the Royal College of Paediatrics and Child Health (RCPCH), MBRRACE-UK, the Neonatal Nurses Association and parent representative organisations including Bliss and Sands. The scope has been extended to include births up to 26^{+6} weeks of gestation, better to align with national recommendations and published data, and we refer to new RCPCH and other national guidance on palliative care of babies as well as guidance on bereavement care for parents who experience loss of a baby.[18 19]

Prevention of preterm birth is now a national priority and all maternity services should ensure that measures are in place to realise this ambition. National guidance is available to enable prevention strategies; this guidance focuses on the importance of good communication between professionals and parents, strategies to ensure high-quality active and/or palliative care as appropriate and interventions to optimise outcomes for babies born too soon.[4 20–22]

Perinatal care at extremely preterm gestations will always need to be individualised and should be led by senior staff in midwifery, obstetrics and neonatology. Parents should be included in discussions about perinatal care, and their hopes and expectations explored with honesty and compassion in a realistic way. Decisions should be made together with parents, based on the best available evidence about the prognosis for the individual baby, and mindful of the need to act in the baby's best interests. It is essential that such decisions reflect all relevant prognostic information and not simply gestational age.

REMIT

The purpose of this Framework for Practice is to assist decision-making prior to and/or at the time of birth relating to perinatal care and preterm delivery at 26 weeks and 6 days of gestation or less in the UK. It does not relate to decision-making around termination of pregnancy.

For some extremely preterm babies, postnatal events may indicate that continuation of neonatal intensive care is not in the baby's best interests. While parents should be made aware of this possible outcome, this Framework does not address decisions around withdrawal or withholding of life-prolonging treatment after a baby has been admitted to a NICU.

The Framework for Practice is aimed primarily at professionals but is freely available via the BAPM website. We have included guidance designed to assist health professionals in communicating with parents about the issues and information contained within this document. It is emphasised that each case will be unique and that communication should always be tailored accordingly. We hope that the Framework will be incorporated into local and network guidelines, to ensure consistency of practice within units and networks and acknowledgement of the importance of individualised care for families.

Definitions

In the UK, a *stillbirth* is legally defined as the birth of a baby with no signs of life at, or after, 24 completed weeks of gestation.

For consistency, we have used the term '*fetus*' to describe the baby before birth, and '*baby*' after birth. Within the document, '*parents*' refers to the mother and her partner.

We have used the terms '*active care (survival focused)*' to refer to obstetric and neonatal management that has the aim of sustaining life for the baby, and'*palliative care (comfort focused)*' to refer to

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Executive summary

1. This Framework has been developed by a multidisciplinary working group in the light of evidence of improving outcomes for babies born before 27 completed weeks of gestation, and evolving national and international changes in the approach to their care.
2. Management of labour, birth and the immediate neonatal period should reflect the wishes and values of the mother and her partner, informed and supported by consultation and in partnership with obstetric and neonatal professionals.
3. Whenever possible, extreme preterm birth should be managed in a maternity facility co-located with a designated neonatal intensive care unit.
4. Neonatal stabilisation may be considered for babies born from 22^{+0} weeks of gestation following assessment of risk and multiprofessional discussion with parents. It is not appropriate to attempt to resuscitate babies born before 22^{+0} weeks of gestation.
5. Decision-making for babies born before 27 weeks of gestation should not be based on gestational age alone, but on assessment of the baby's prognosis taking into account multiple factors. Decisions should be made with input from obstetric and neonatal teams in the relevant referral centre if transfer is being contemplated.
6. Risk assessment should be performed with the aim of stratifying the risk of a poor outcome into three groups: extremely high risk, high risk and moderate risk.
7. For fetuses/babies at extremely high risk, palliative (comfort focused) care would be the usual management.
8. For fetuses/babies at high risk of poor outcome, the decision to provide either active (survival focused) management or palliative care should be based primarily on the wishes of the parents.
9. For fetuses/babies at moderate risk, active management should be planned.
10. If life-sustaining treatment for the baby is anticipated, pregnancy and delivery should be managed with the aim of optimising the baby's condition at birth and subsequently.
11. Conversations with parents should be clearly documented and care taken to ensure that the agreed management plan is communicated between professionals and staff shifts.
12. Decisions and management should be regularly reviewed before and after birth in conjunction with the parents; plans may be reconsidered if the risk for the fetus/baby changes or if parental wishes change.

obstetric and neonatal management when the aim is not to attempt to sustain the life of the fetus/baby, but to focus on the baby's comfort.

We acknowledge that these terms are imperfect: palliative care requires an active approach to the management of labour, delivery and the care of the baby, and active care may appropriately include no active interventions (eg, unassisted vaginal birth).

'*NICU*' refers to a designated neonatal intensive care unit, sometimes termed a level 3 unit.

RISK-BASED APPROACH TO DECISION-MAKING

A key ethical consideration for decisions about instituting life-sustaining treatment for an extremely preterm baby is the baby's prognosis—the risk of an acceptable (or unacceptable) outcome if active (survival focused) management is undertaken. If there is a plan to provide life-sustaining treatment for the baby, then it follows that the pregnancy and birth should be managed with the aim of optimising the baby's condition at birth and subsequently.

We advise a stepwise approach to decision-making, involving three key stages:

1. Assessment of the risk for the baby if delivery occurs, incorporating both gestational age and factors affecting fetal and/or maternal health.
2. Counselling parents, and their involvement in decision-making.
3. Agreeing and communicating a management plan.

Assessment of the risk for the baby

Gestation-based risk assessment, including mortality and survival with severe impairment

The earlier the ultrasound dating scan has been carried out, the more accurately gestational age will be known. In accordance with NICE guidelines, all pregnant women in the UK should have been offered an early ultrasound scan between 10^{+0} and 13^{+6} weeks of gestation, with crown–rump length (CRL) measurement used to determine gestation. This assessment is accurate to within 5 days in 95% of cases.[23] From 14^{+0} weeks (CRL >84 mm), gestation should be estimated from fetal head circumference; the estimated uncertainty of this gestation prediction is 6–7 days at 14 weeks, rising to 12–14 days by 26 weeks of gestation.[24]

Survival of extremely preterm infants has increased steadily since 2006 with greater willingness to offer neonatal intensive care. Recent UK data, for babies born in 2016, indicate survival to 1 year of 38% of those babies 23^{+0} to 23^{+6} weeks of gestation who received active treatment after birth[8] (online supplementary appendix 1). Similar survival rates for admitted babies at 22 weeks of gestation are reported, but the number of surviving babies at 22 weeks of gestation is small, with appreciable in-labour mortality, and thus the CIs are wider than at later gestational ages. These figures accord with international data which show a trend towards increasing survival at 22 weeks of gestation, with reported survival rates of approximately one-third in babies who receive active care at birth. Since only a small proportion of babies born at 22 weeks of gestation receive active treatment, there is the possibility of selection bias and survivors may represent a subgroup of 22-week-gestation babies with more favourable risk factors (see below).

At all gestational ages, survival rates show ongoing improvement,[6] are higher when the number of live born babies rather than all births is used as a denominator and are highest when babies who receive palliative care at birth are excluded. As survival to live birth will be influenced by management of labour and birth, and the risk of mortality is 100% when a decision is made to offer palliative care, the most relevant denominator is those babies born alive and in whom active management has been attempted. Outcomes are continually changing and management should always be based on the most recent data available; online supplementary appendix 1 presents the most up-to-date data available in September 2019.

Assessment of the risk of severely disabling conditions among survivors is fraught with difficulty, not least differences in individual views about acceptable levels of disability. What for one individual or family may be an acceptable outcome may not be acceptable for another. For decisions about provision of potentially life-sustaining treatment, the ethically relevant consideration is the risk

of disabilities that could affect whether it is in the baby's best interests to survive and thus risk assessment should focus on the most severe disabilities.[25]

In the absence of regularly updated national data on the prevalence of severe disability after extremely preterm birth, we recommend that the well-established "severe impairment" category, as defined by the 2008 BAPM Working Group, be used to inform parents when discussing risk following extremely preterm birth.[26] It is acknowledged that many more extremely preterm babies will be affected by milder degrees of disability; this should also be included in information provided to parents, with clear explanation that disability is generally impossible to predict for individual babies at birth.

The severe impairment category includes any of:

- Severe cognitive impairment with an IQ lower than 55 (<−3 SD); this will usually result in the need for special educational support and require supervision in daily activities.
- Severe cerebral palsy—classified as Gross Motor Function Classification System grade 3 or greater (online supplementary appendix 1).
- Blindness or profound hearing impairment.

The risk of severe impairment increases with increasingly preterm birth and is currently approximately one in seven at 24 weeks of gestation, and 25% at 23 weeks of gestation for those babies who receive active care and survive. The number of surviving babies with long-term outcome information at 22 weeks of gestation is relatively small, and therefore CIs apply, but the risk of severe impairment is estimated to be one in three. Generally, as the risk of mortality decreases, the risk of disability among survivors also decreases (online supplementary appendix 1, figure 1).

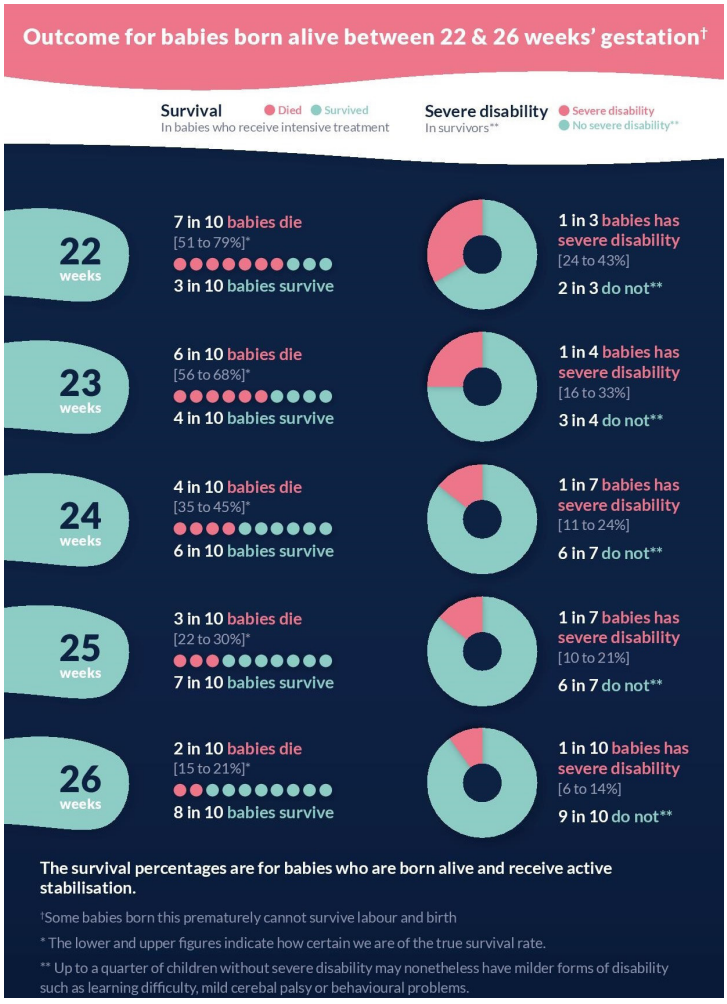

Figure 1 Infographic for parents on the outcomes of extreme preterm birth.

Modified risk assessment

Accurate information about the current pregnancy, including assessment of both fetal and maternal health should be used to refine gestation-based risk of absolute survival and survival without severe impairment.

A range of factors are associated with increased or decreased risk:

Fetal factors

Fetal factors which may increase risk include male sex, multiple pregnancy, congenital anomaly and poor fetal growth.

Clinical conditions

Clinical conditions which pose additional risk and have been associated with increased mortality and morbidity include prolonged pre-labour rupture of membranes before 24 weeks of gestation and clinical evidence of chorioamnionitis.[27 28]

Therapeutic strategies

Administration of antenatal steroid and magnesium sulfate are associated with improved survival and neonatal outcomes as well as reduced risk of childhood impairment, even before 24 weeks of gestation.[29–32]

Clinical setting

Survival is highest at these extreme preterm gestations in centres with experienced staff and higher patient numbers. A strategy of antenatal transfer below 27 weeks of gestation for birth in a maternity unit with a co-located NICU is recommended.[4 33–37]

Following full history taking and risk assessment, the risk of unacceptably poor outcome if life-sustaining care is provided for the baby will generally fall into one of the following categories: extremely high risk; high risk; moderate risk. A proposed visual tool for refinement of risk is illustrated in figure 2. See also online supplementary appendix 5 for case examples applying the risk categories.

Box 1 represents the consensus of the Working Group in regard to risk categories for the purposes of this Framework.

There is no objective way of defining a risk as 'extremely high' versus 'high' and families differ in the outcome that they regard as unacceptably poor. Thus, risk assessment may need to be modified in the light of the parents' knowledge, views and values. It is important that parents are offered choices and supported to make decisions appropriate for their individual preferences.

For women presenting to a non-tertiary maternity and neonatal centre, assessment of risk should include early discussion

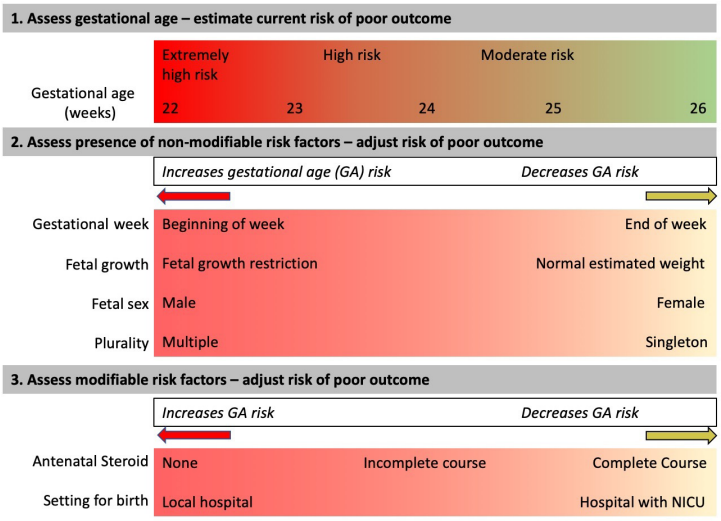

Figure 2 Visual tool for refinement of risk. NICU, neonatal intensive care unit.

with the relevant referral centre. For pregnancies from 22^{+0} weeks of gestation, decisions should not be based on gestational age alone. Within a multiple pregnancy, the risk may differ between fetuses and so each should be considered as an individual. This means that appropriate management may not be the same for each baby, even with the same gestational age. If birth occurs prior to 22^{+0} weeks of gestation, active obstetric and neonatal management is not appropriate. Situations of uncertainty (eg, uncertain gestation) or disagreement are discussed in online supplementary appendix 2.

The agreed risk for the baby has ethical and practical implications for the options that should be available.

Extremely high risk

For babies with an extremely high risk of death or of survival with unacceptably severe impairment despite treatment, palliative (comfort-focused) care would be in the best interests of the baby and life-sustaining treatment should not be offered. There is no absolute indication for paediatric attendance at the birth although for individual families this may be helpful.

High risk

For babies with a >50% risk of death or of surviving with unacceptably severe impairment despite treatment, 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. Ideally, a senior neonatal clinician who has previously met the parents will be available to attend the birth and supervise implementation of the agreed plan.

Moderate risk

For babies with a <50% risk of death or of survival with unacceptably severe impairment, active management would be in the best interests of the baby. A senior neonatal clinician should attend the birth.

Box 1 Risk categories

Extremely high risk: The Working Group considered that babies with a >90% chance of either dying or surviving with severe impairment if active care is instigated would fit into this category. For example, this would include:

- Babies at 22^{+0} to 22^{+6} weeks of gestation with unfavourable risk factors.
- Some babies at 23^{+0} to 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.

High risk: The Working Group considered that babies with a 50–90% chance of either dying or surviving with severe impairment if active care is instituted would fit into this category. For example, this would include

- Babies at 22^{+0} to 23^{+6} weeks of gestation with favourable risk factors.
- Some babies ≥24^{+0} weeks of gestation with unfavourable risk factors and/or comorbidities.

Moderate risk: The Working Group considered that babies with a <50% chance of either dying or surviving with severe impairment if active care is instituted would fit into this category. For example, this would include

- Most babies ≥24^{+0} weeks of gestation.
- Some babies at 23^{+0} to 23^{+6} weeks of gestation with favourable risk factors.

Counselling parents and decision-making

Whenever possible, parents should be involved in planning an extremely preterm birth. The planning consultation should include senior clinical staff from the obstetric, midwifery and neonatal teams who will be caring for the mother and her baby before, during and after the birth.

The assessed category of risk to the baby (including the inherent uncertainty around this) should be conveyed sympathetically and with clarity, and the hopes and expectations of parents explored with honesty and compassion in a realistic way. Clear, balanced information should be shared (figure 1) and management options discussed. Time should be allowed for clarification and questions, and parents offered the opportunity to revisit discussions with the perinatal team at any point, acknowledging the challenging nature of the information that they are being asked to receive and the decisions that are being made. See online supplementary appendix 3 for guidance on communication and consultation with families. Online supplementary appendix 4 provides some sample written material to complement consultations.

In utero transfer to a maternity facility co-located with a NICU should be considered at the earliest opportunity when active management is planned. All such transfers should be discussed with the receiving team, and parents should be made aware that the prognosis (and therefore management) may be revised following in utero transfer to a centre with greater experience of managing extremely preterm birth (eg, following detailed ultrasound scanning). Communication and agreed plans should be documented in full (including in the maternity handheld record) and, when relevant, clearly communicated with the receiving centre. The agreed plan of

management should be revised regularly if pregnancy continues. Parents should also be helped to appreciate that the baby may be born in unexpectedly poor, or unexpectedly good condition, and the implications of this for what care might be appropriate. Processes should be in place to ensure timely transfer.

When active care is planned and time allows, parents should be given an opportunity to visit the neonatal unit and to meet staff and should receive information and support regarding expressing breast milk.

Where appropriate, the practicalities of commencing, withholding and/or withdrawing intensive care and the positive role of palliative care strategies should be described to the parents. This will help prepare them for possible outcomes after the birth. Parents may find the advice and support of their family, friends, spiritual advisers and/or local and national support organisations to be of great value at this time and should be signposted appropriately.

Agreeing a management plan

Following consultation with parents, initial management of the birth will follow one of two pathways: 'active' (survival focused) or 'palliative' (comfort focused) (figure 3). Consistency in obstetric and neonatal management is essential, either to ensure that the baby is born in the best possible condition or to avoid unnecessary intervention. The agreed plan should be clearly documented and communicated to all members of the obstetric and neonatal teams who may be involved in care of the family.

The challenges inherent in making a binary decision from a continuum of risk should not be underestimated and categorisation of risk should always be undertaken by the most senior clinicians available. Electronic risk calculators may be of value, but care should be taken to ensure they are populated with the most recent data and include the most relevant denominator.

Parents should be counselled that the plan for management will be reviewed and may need to change based on the clinical condition of the baby before, at or after birth, or subsequently in a NICU.

Obstetric management

Active (survival focused) obstetric management

When it has been agreed that potentially life-sustaining care for the baby is appropriate, active obstetric management is important to ensure the baby is born in the best possible condition. An individualised package of obstetric intervention should be offered in all cases where a commitment to active neonatal care is in place.[4 35] The potential for each component intervention to optimise the condition of the individual baby at birth should be considered and not excluded on the basis of gestational age alone. Obstetric management should be regularly reviewed, particularly if events suggest changing prognosis for the baby.

The package of obstetric care to be offered to parents *may* (but not necessarily) include any or all of the following:

- Antenatal steroids.
- Tocolysis.
- Antenatal transfer to a tertiary obstetric centre co-located with a NICU.
- Magnesium sulfate for neuroprotection.
- Deferred cord clamping, ideally for 60 s or more.
- Intrapartum fetal heart rate monitoring.
- Caesarean section (if potential benefits are considered to outweigh risks)

Antenatal steroids, tocolytic use, magnesium sulfate and deferred cord clamping[38] have been shown to be of benefit in improving outcome in preterm infants. However, parents should be made aware that there is a paucity of data in relation to the magnitude of benefit and risks of these interventions, particularly below 24 weeks of gestation.

In utero transfer to a tertiary centre optimises outcomes for the baby, is better than ex utero transfer and is now a prioritised NHS England recommendation as well being recommended in the Scottish Maternity and Neonatal Services Review.[21 36 37] While the majority of women presenting in threatened preterm labour before 27 weeks of gestation do not deliver in the subsequent 24 hours, there is currently no proven test which accurately predicts preterm delivery. Transfer may present challenges for the family as well as obstetric and ambulance services, but the Working Group strongly recommends that this is considered at the earliest opportunity. A decision for antenatal transfer should include documented discussion with the relevant tertiary centre and careful risk assessment by a senior obstetrician, to ensure that the mother is fit for transfer and to reduce the risk of birth in transit. Both written and verbal information should be given to parents. In some cases, poor maternal health and/or advanced stage of labour may mean that in utero transfer is not the safest option.

Below 26 weeks of gestation, a senior obstetrician should be involved in decisions around intrapartum fetal heart rate monitoring as there is a lack of evidence to inform practice.[20] The family should be made aware of the rationale for either recommending or withholding fetal heart rate monitoring; for example, it may be appropriate not to monitor the fetal heart if delivery by caesarean section is not part of the agreed package of care, either because it is considered that the risks of caesarean section outweigh any potential benefits or because parents have declined caesarean section should there be a fetal heart rate abnormality. Autonomic immaturity at gestations below 26 weeks makes

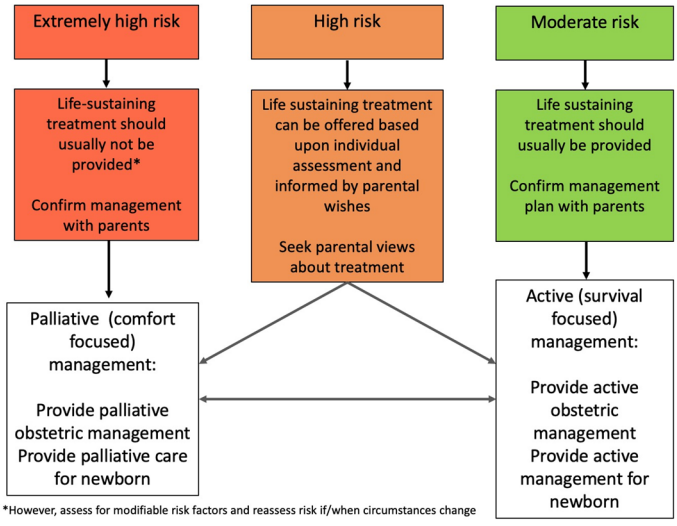

Figure 3 Decision-making around management of delivery, following risk assessment and after consultation with parents.

interpretation of continuous electronic fetal heart rate monitoring (CEFM) difficult and there is no evidence that CEFM improves outcomes compared with intermittent auscultation. From 26^{+0} weeks of gestation, when active management is planned, women in established preterm labour should be recommended CEFM.[4 20]

In the majority of extremely preterm births, the mother presents in spontaneous labour and an uncomplicated vaginal delivery may be anticipated. The risk of head entrapment following breech presentation is approximately 10%,[4] but the evidence for delivery by caesarean section for extremely preterm babies is limited and of poor quality[39 40] and prognosis is more likely to be dictated by factors other than mode of delivery. NICE guidance is that delivery by caesarean section may be considered in cases of breech presentation after 26 weeks of gestation.[20] Extremely preterm caesarean sections can be difficult, and fetal trauma including head entrapment can still occur.[4] Maternal risks and consequences including pain, haemorrhage, infection, thrombosis and injury to bowel and bladder are higher after caesarean section compared with vaginal birth, particularly at extremely preterm gestations, and should be discussed with the mother. There is an impact on future pregnancies in terms of increased risk of uterine rupture and morbidly adherent placenta, and the likelihood of classical caesarean section, with its increased risk of serious maternal complications, is greatest at the most preterm gestations.[40 41] For all these reasons, it is essential that obstetric care is individualised after full discussion between the family and a senior obstetrician along with the neonatal team. There should be clear documentation of this conversation and the mother's wishes.[42] Where delivery by caesarean section has been agreed as the optimal mode of birth, this should only occur once labour is established, unless maternal or fetal condition dictates otherwise. Established preterm labour can be difficult to determine and even at advanced cervical dilation birth may not occur for several days. There may be additional benefit to the baby of delaying delivery.

In the absence of labour and where delivery should be expedited for maternal reasons (eg, pre-eclampsia or chorioamnionitis) or, more rarely, for fetal reasons (eg, severe fetal growth restriction) delivery by caesarean section may be the only option to ensure timely delivery for mother and/or baby. Induction of labour is unlikely to be appropriate in such circumstances where there is maternal or fetal compromise and a commitment to potentially life-sustaining care for the baby has been agreed with the parents.

Palliative (comfort focused) obstetric management

When a decision is made for palliative (comfort focused) management of the baby at birth, only interventions for maternal benefit are appropriate. Intrapartum fetal heart rate monitoring is not advised, although assessing or listening for the presence of a fetal heart to check viability may be helpful in clarifying expectations around the baby's condition at birth and be preferable for parents. Parents should be made aware that their baby may show signs of life after birth, including visible heartbeat, gasping and/or movement of limbs.

Neonatal management

Active (survival focused) neonatal management

Stabilisation and support for transition should be carried out by, or under the direct supervision of, the most senior member of the neonatal/paediatric team available at the time of birth, and in accordance with Resuscitation Council UK guidance, noting specific recommendations for preterm infants.[43] Ideally, this team will be experienced in stabilisation of extremely preterm babies and led by a consultant neonatologist. The team should be aware of parental wishes, but when the baby is born in unexpectedly poor, or unexpectedly good condition, it is reasonable for the attending neonatologist to proceed with care in the baby's best interests (see online supplementary appendix 2).

Deferred cord clamping for at least 60 s should be routine practice (unless contraindicated), and particular attention should be paid to the maintenance of normothermia, with the use of a plastic bag and/or other methods of delivering thermal care, and skin protection. Stabilisation and supported transition with lung inflation, using an appropriately sized facemask, should be initiated. Care should be taken not to over-distend the lungs.

Clinical assessment in the delivery room is not a good predictor of survival in extremely preterm babies[44]; if there is no response to mask ventilation, and any doubt around the adequacy of ventilation, the baby should be intubated and surfactant administered. The most important intervention is establishment of adequate lung recruitment, and the most important measure of success is heart rate. Use of advanced measures for resuscitation including cardiac massage and endotracheal or intravenous epinephrine are rarely required following extreme preterm birth. In the absence of sufficient evidence to justify a different approach in extremely preterm babies, if advanced resuscitation is considered appropriate, the Working Group recommends applying newborn resuscitation algorithms as used in more mature babies.

Where babies are born in much poorer condition than expected, it may be appropriate to reconsider the planned provision of active management and to move to palliative care (see online supplementary appendix 2). Absent heart rate or severe bradycardia persisting despite *effective* cardiopulmonary resuscitation for more than a few minutes is associated with high rates of mortality and neurodevelopmental impairment in extremely preterm babies.[45 46] The most senior experienced attending professional should decide if or when attempts to stabilise and/or resuscitate the baby should stop.[47]

Stabilisation should normally be undertaken in the same room as the parents, who should be offered the opportunity to see, touch and photograph their baby. Following successful stabilisation of the baby, the mother should be supported to express breast milk as early as possible, with ongoing facilitation of parental contact and family involvement as partners in care.

Palliative (comfort focused) neonatal management

Where there is an extremely high risk of a poor outcome for the baby, it would be considered in the best interests of the baby, and standard practice, not to offer active neonatal management.

The aim of palliative neonatal management is to support the parents and their baby and to avoid interventions that may cause discomfort, pain or separation of the baby from the parents. This care should be delivered in the most appropriate location for the family (which is not necessarily a neonatal unit) and should not necessitate in utero transfer. There should be an emphasis on family-centred care, with opportunities for parents to create positive memories of their baby. An Individualised Care Plan should be made in partnership with parents following guidance within the Perinatal Palliative Care Pathway from Together for Short Lives.[18] Further recommendations may be found in a RCPCH monograph on making decisions to limit treatment in life-limiting and life-threatening conditions.[19]

Depending on parents' wishes and service provision, a senior neonatologist or paediatrician may be present at delivery to provide a brief assessment of the baby's condition at birth and to support midwifery staff and the family. Respiratory support (including provision of positive pressure ventilation) should not be provided. Parents should be offered the opportunity to hold and to spend as much time as they wish with their baby in a quiet and private location; they should have been counselled that the baby may show brief reflex movements or signs of life after birth. In the unlikely scenario of the baby being born in much better condition than expected, palliative management may need to be reconsidered (see online supplementary appendix 2 for further discussion).

On average, babies born before 24 weeks of gestation who receive comfort care in the delivery room live for approximately 60 min (range from a few minutes to several hours).[48] Supplemental oxygen is not necessary but could be provided if parents desire.

After the baby has died, a parent-led bereavement care plan should be put in place for the family, including communicating with parents and creating memories. Parents should understand what to expect in terms of a review into the care provided during pregnancy and birth using the Perinatal Mortality Review Tool, and the benefits of investigations such as autopsy and placental histopathology, to provide as much explanation as possible for the preterm birth and the death of their baby.[18] In England and Scotland, this should follow the guidance outlined in the National Bereavement Care Pathway[49]; in Wales and Northern Ireland, there are locally developed bereavement pathways. Parents should be facilitated to make informed choices and signposted to support available after they go home. Follow-up pathways for all women who have undergone an extremely preterm birth should be in place and include planning care for future pregnancies. Placental histology, undertaken by a perinatal pathologist, should be routine.

After discharge home, optimal communication with all professionals involved (and in particular the general practitioner, health visitor and community midwife) is essential. The mother will continue to require postnatal care and should also receive information and advice about milk suppression or donation. Parents should be offered bereavement counselling and the opportunity to meet with perinatal staff for a follow-up consultation in an outpatient setting. Where possible, this meeting should be conducted by the same staff that counselled the family in the peripartum period. Parents should also be offered the opportunity to participate in a multiprofessional perinatal mortality review process that follows the framework set out in published statutory and operational guidance.[49] At an appropriate time, the prognosis for future pregnancies should also be discussed.

IMPLEMENTATION OF THIS FRAMEWORK FOR PRACTICE

A lead person should be identified in each maternity facility with responsibility for implementation, education, and dissemination of this new Framework for Practice and the accompanying parent information.

Links to relevant national documents are provided within this document; these should be highlighted and made easily available within each maternity facility.

Management of extreme preterm birth and the conversations around this can be exceptionally challenging for staff, so it is recommended that implementation of this Framework into individual units is accompanied by education and training in specific consultation skills.

Networks need to ensure sufficient resource to cope with the predicted number of extreme preterm deliveries, both actual and threatened, and pathways should be in place to ensure appropriate prioritisation and assessment of women likely to deliver extremely preterm. A newly delivered mother should be accommodated in a maternity facility adjacent to her baby.

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British Association of Perinatal Medicine

Perinatal Management of Extreme Preterm Birth before 27 weeks of gestation

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October 2019

in collaboration with

Bliss for babies born premature or sick

British Maternal & Fetal Medicine Society

MBRRACE-UK Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK

Royal College of Obstetricians & Gynaecologists

Sands Stillbirth & neonatal death charity

Neonatal Nurses Association

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Appendix 1: Outcomes for extremely preterm babies

Survival/Mortality

International studies indicate incremental improvements in survival for the most premature babies over the last 1-2 decades. There is wide variation in survival estimates of live born babies (for example, from 3 – 22% at 22 weeks and 39 - 70% at 24 weeks of gestation), influenced by cohort selection, place of birth and variation in provision of active obstetric and neonatal treatment [(12)]. The largest changes in outcome appear to be at the lowest gestational ages. In particular, at 22 weeks of gestation, recent cohort studies from US, Sweden and Germany [(9-12)] indicate that approximately 30% of live born babies who receive active treatment survive to discharge.

The latest data on outcome for extremely premature babies in the UK are presented in Table 1 (source: MBRRACE-UK) [(8)]. Survival has increased steadily since 2006 and currently active respiratory care is offered to 88% of babies at 23 weeks and 23% of births at 22 weeks of gestation. Survival at 22 weeks of gestation is based on small numbers of babies and thus the confidence limits are wider than at other gestational weeks. It is probable that selection of babies for active treatment is biased towards those with best outlook, and so expected survival following active (survival focused) management for all infants born at 22 weeks of gestation is likely to be lower than the reported survival figures. Figure 3 displays graphically the estimated survival rates at different gestations for babies who are provided with active care in the UK compared to 3 recent publications; recent MBRRACE-UK findings are consistent with those in other settings.

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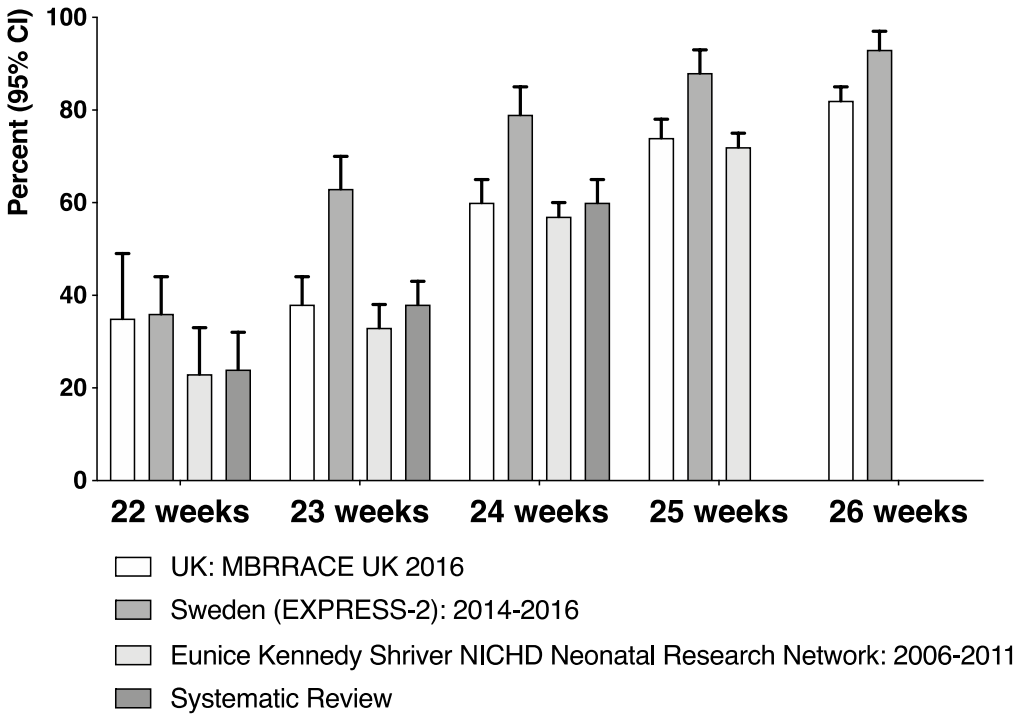

Figure 3: Estimated survival if active (survival focused) care is provided, comparing UK with recent international studies [8,9,11,12]

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Table 1: Number and percentage of births, including births where the fetus was alive at onset of labour, live births, births receiving active care, admissions for neonatal care and survival to 1 year of age for births in 2016 in the UK. Recording of active care on the MBRRACE-UK database commenced during 2016 and thus rates are inferred from recording of a total of only 292 deaths [8].

Gestational Week	**22 weeks**	**23 weeks**	**24 weeks**	**25 weeks**	**26 weeks**
All births	486	510	656	664	832
Births alive at onset of labour	290	362	497	508	674
Live births	183	301	456	486	662
% live births (of those alive at onset of labour)	**63%** **57 to 69**	**83%** **79 to 87**	**92%** **90 to 94**	**96%** **94 to 98**	**98%** **97 to 99**
Delivery room deaths	155	78	26	19	16
% deaths before admission	**85%** **80 to 90**	**26%** **21 to 31**	**6%** **4 to 8**	**4%** **2 to 6**	**2%** **1 to 3**
Live births receiving active care	43	264	449	486	662
% receiving active care (of all live births)	**23%**	**88%**	**98%**	**100%**	**100%**
Admitted for neonatal care	28	223	430	467	646
% admitted for neonatal care (of births receiving active care)	**65%** **51 to 79**	**85%** **81 to 89**	**96%** **94 to 98**	**96%** **94 to 98**	**98%** **97 to 99**
Deaths < 1 year	13	122	160	108	106
Survivors to 1 year	15	101	270	359	540
Survival					
Of those alive in labour	**5%** **2 to 8**	**28%** **23 to 33**	**54%** **50 to 58**	**71%** **67 to 75**	**80%** **77 to 83**

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Of live births receiving active care	**35%** **21 to 49**	**38%** **32 to 44**	**60%** **55 to 65**	**74%** **70 to 78**	**82%** **79 to 85**
Of those admitted to intensive care	**54%** **36 to 72**	**45%** **38 to 52**	**63%** **58 to 68**	**77%** **73 to 81**	**84%** **81 to 87**

Severe impairment

The impact of a particular impairment has ramifications for functioning in many areas and is captured in the WHO International Classification of Functioning, Disability and Health (ICF) [(50)]. Individual perception of the impact of impairment on functioning in society (i.e. disability) is highly personal and varies from family to family, dependent on their experience, knowledge and attitudes, and the support available to them. Indeed, it also varies between neonatal health professionals [(51,52)]. What for one individual or family may be an acceptable outcome may not be so for another.

The criteria for categorisation of impairments in neonatal studies also vary. In 1992, a working party sponsored by the National Perinatal Epidemiology Unit and Oxford Health Authority defined health status at 2 years into severe disability, likely to result in high levels of dependency on others with reduced chances of independent living or other or no disability. This was refined in the BAPM working group document published in 2008 [(26)]. Other authorities have used a profound category, a subgroup of severe disability, on which to base counselling [(53)]. In the absence of regularly updated national data on the prevalence of profound impairments after extremely preterm birth, the working group recommended that the well-established "severe impairment" category as defined by the BAPM Working group be used to inform parents when discussing risk following extremely preterm birth. This has been used in several large population-based studies and gives a reliable estimate of risk not available from local data, where the small number of survivors introduces significant uncertainty into estimates. Generally, for extremely preterm babies, as mortality risk decreases, the risk of severe disability among survivors also decreases.

The severe impairment category includes any of:

- severe cognitive impairment with an IQ lower than 55 (<-3 standard deviation); this will usually result in the need for educational support and require supervision in daily activities
- severe cerebral palsy – classified as Gross Motor Function Classification System (GMFCS) grade 3 or greater (see Box 2)

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- blindness or profound hearing impairment

Estimated prevalence rates of severe impairment in four major studies are shown in Figure 4, which may be summarised as:

22^{+0} - 22^{+6} weeks: **1-in-3 survivors has severe impairment**

23^{+0} - 23^{+6} weeks: **1-in-4 survivors has severe impairment**

24^{+0} - 25^{+6} weeks: **1-in-7 survivors has severe impairment**

26^{+0} - 26^{+6} weeks: **1-in-10 survivors has severe impairment**

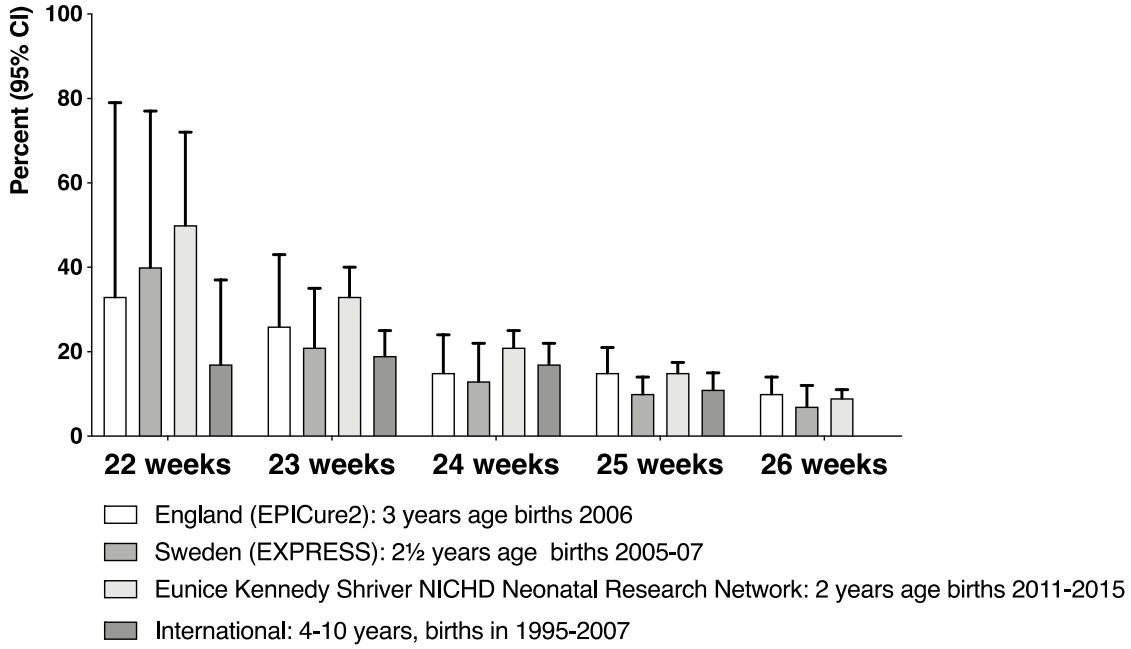

Figure 4 – Prevalence of severe neurodevelopmental impairment in England (2006) compared with rates reported in recent international publications using similar classifications [7,54-56]; note that data from reference 55 were kindly reanalysed by the NICHD NRN to match the UK classification.

Level III: Children walk using a hand-held mobility device in most indoor settings. When seated, children may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface. When travelling long distances, children use some form of wheeled mobility. Children may walk up and

down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Children use methods of mobility that require physical assistance or powered mobility in most settings. Children require adaptive seating for trunk and pelvic control and physical assistance for most transfers. At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility. When positioned, children may use a body support walker at home or school. At school, outdoors and in the community, children are transported in a manual wheelchair or use powered mobility. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and to control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and/or mobility but limitations are not fully compensated by equipment. Transfers require complete physical assistance of an adult. At home, children may move short distances on the floor or may be carried by an adult. Children may achieve self- mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

Box 2: GMFCS Grades 3-5 description:

Appendix 2: Situations of uncertainty and potential conflict

Uncertain gestational age

If gestational age is uncertain, (*i.e.* no dating ultrasound scan) but thought to be $\geq 22^{+0}$ weeks, an ultrasound scan by an experienced sonographer should be carried out if time permits. If the fetal heart is heard during labour, a professional experienced in stabilisation of extremely preterm babies should attend the birth. The baby should be delivered into a plastic bag and an estimate made of gestation. Unless the baby is clearly $< 22^{+0}$ weeks of gestation, and/or estimated (or weighed) at < 350 g, stabilisation and supported transition with lung inflation, using an appropriately sized facemask, should begin, usually after one minute of deferred cord clamping. Subsequent management will be dictated by the clinical condition of the baby, the response to stabilisation manoeuvres and parental wishes and expectations. In this scenario, it is likely that the parents will have had little, if any, time to consider the situation and so it may be appropriate to proceed with initiating active (survival focused) neonatal management and to reassess the situation in the ensuing minutes, hours and days. It is noted that assessment of either gestation or risk of poor outcome based on condition at birth is not reliable [(44)].

Rapid birth without time for counselling

Preterm labour often progresses rapidly, and there may be insufficient time for detailed discussion with the parents before the baby is born. In such a scenario, a decision about management at birth will need to be made based on the available clinical information and informed by the most recent management plan, if any. When risk is unclear (for example gestation is uncertain), and particularly if there has not been time for full discussion with parents, it would usually be reasonable to embark on a provisional plan of stabilisation +/- resuscitation – providing potentially life-sustaining treatment at delivery, but redirecting to palliative care if the baby appears very immature or responds poorly to stabilisation (for example remains severely bradycardic despite intubation and intermittent positive pressure ventilation).

Baby born in unexpectedly good condition

In the rare circumstance where palliative (comfort focused) care has been agreed, but a baby is born in unexpectedly good condition, attending midwifery and/paediatric medical staff should discuss with parents whether the estimated gestation and prognosis were accurate and whether the planned palliative approach is still appropriate. Stabilisation should not be delayed if deemed in the baby's best interests.

Baby born in unexpectedly poor condition

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When active neonatal management has been agreed, but the baby is born in unexpectedly poor condition, it is the responsibility of the most senior attending neonatal professional to decide if ongoing attempts at stabilisation and/or resuscitation are in the baby's best interests. This should be conveyed sympathetically but unambiguously to parents, and palliative care offered.

Parents request a second opinion

If the parents wish, they should have the opportunity to discuss outcomes with a second senior member of the perinatal team. When parents do not agree with the perinatal team, recently published RCPCH guidance around dealing with conflict may be helpful [57].

Threatened birth before 22^{+0} weeks of gestation

Where gestational age is certain and is below 22^{+0} weeks, it would be considered in the best interests of the baby, and standard practice, not to offer neonatal intensive care. If it is possible that the birth may be delayed to a point where active care of the baby would be planned, transfer of the mother to a maternity unit adjacent to a neonatal intensive care unit should be considered.

Appendix 3: Communication: Guidance for professionals consulting with families at risk of extreme preterm delivery.

This Appendix is designed for use by all staff caring for families at risk of extreme preterm birth, to facilitate the sharing of consistent and accurate information. It should be used to support conversations about decision making with parents, in conjunction with written information such as the suggested *Template Parental Information - Helping parents to understand extreme preterm birth* (Appendix 4). Written information should *never* be used as a stand-alone information sharing tool.

In order properly to involve parents as equal partners in care and decision-making for their babies, all parents facing potential extreme preterm birth need to understand the risks associated with their baby's birth, and possible treatment options.

In the context of the different risk scenarios outlined in this Framework, health professionals need to consider how their approach to consulting with parents may differ, depending on the individual circumstances:

- In **extremely high risk** cases, parents should be provided with relevant information about the risk to their baby, and the recommendation that it would be best for their baby to provide palliative (comfort focused) obstetric and neonatal management. Parents should be told about the role they can play in caring for their baby and memory making after birth, and should be fully involved in decisions about how and where palliative management takes place.
- In **high risk** cases, the role of the consultation is critical in supporting parents together with professionals to decide on the right pathway for their baby. Parents should be provided with as much information as is available and should have as much time as possible, ideally over a number of discussions, to work through the different options available in order to agree with professionals what the right option is for their family.
- In **moderate risk** cases, parents should be provided with relevant information about the risk to their baby, and the recommendation that it will be best for their baby to provide active management both antenatally and after birth. Parents should be told about likely interventions and what may happen next, and be fully involved in decisions about how active treatment is managed.

Thus, consultation is most critical where delivery would be associated with a high risk of unacceptably poor outcome (see main text). In such situations, parents need support to make an informed choice about the provision of either active or palliative management; such situations demand the greatest care and sensitivity. Consultation should not be directive, but professionals

should seek to determine when gentle guidance around what is likely to be in the baby's best interests would be helpful for the family.

When is the right time?

Evidence suggests that parents find that, where time allows, consultation is most useful at the earliest opportunity, both to allow time for information processing, discussion, and decision making, and to minimise the effects of labour and medications on cognition. Follow up consultations allowing ongoing dialogue are highly valued by families [58,59] and should be offered at any point, acknowledging the challenging nature of the information that parents are being asked to receive, the time this may take to process and the decisions that need to be made.

Who should be involved?

Consultation with parents should ideally be provided by the most experienced members of the perinatal team involved in care of the mother and her baby. Continuity of care is essential and, whenever possible, consultation should be delivered as a joint obstetric, neonatal and midwifery approach, ensuring transparency and consistent, clear communication. The presence of members of the multidisciplinary team (particularly nurses and midwives) during such conversations is highly valued by families, and may provide opportunity for clarification and ongoing conversation outside the formality of such settings [59,60]. Parents may also find the advice and support of their family, friends, spiritual advisers and/or voluntary organisations to be of great value at this time.

Structuring the Consultation

1. ***Exploring the parents' prior knowledge and understanding*** can be a useful way to open the consultation. Establishing parents' own understanding about the risks of their situation, their prior experience and knowledge, as well as their expectations of the conversation is important, both to generate trust and to ensure that the consultation meets their individual needs. Parents' hopes, priorities and expectations of the care that they and their baby will receive should be explored with sensitivity, honesty and compassion in a realistic way.
2. ***Balanced Information*** - Studies suggest that conveying solely negative information to parents is not well received. Providing balanced information with honesty seems to be most useful to parents. Respecting parents' perspectives and the importance of hope, even in the most difficult of situations, is highly valued. Exploring parental hopes, wishes and fears in each scenario can help to do this, and to build trust and rapport

with the clinical team. Where survival is not possible, or is extremely unlikely, parental hopes relating to spending time with their baby, involving family members, and memory making should be explored.

3. ***Conveying Risk*** - Categorisation of risk to the baby of death or survival (with or without impairment) in a given scenario should be conveyed sympathetically and with clarity. Parents may find it useful to see this displayed graphically (see Appendix 4). Gestation-based risk should be explained within the context of other risk modifiers (such as birth weight, gender, multiplicity, *etc.*). It is important to convey information accurately, in the appropriate context. While the most relevant statistic for parents is usually the chance of survival if active stabilisation and neonatal intensive care is attempted, parents should be helped to understand that not all babies survive labour, and so outcome data depend upon the stage at which parents are being counselled. Outcome data are, of course, also highly influenced by intention to treat at delivery and it is likely that current published outcomes are skewed towards those fetuses/babies in the best condition at birth. Not all parents find percentage figures easy to understand. It can be helpful to explain in terms of odds *e.g.* 1 in 4, or 1 in 10. To avoid framing bias, we suggest interpreting risk neutrally. For example, *"Given what we know about the situation for your baby, there is a 30% chance of your baby surviving. This means that for every 10 babies treated actively (with intensive care) in situations like this, three would survive while sadly seven would not".*

4. ***Discussing Poor Outcomes*** - There is not a simple definition of a 'poor' outcome – the interpretation of this is likely to vary greatly between clinicians, parents, and families. Published data generally refer to scoring systems and classification of motor and cognitive dysfunction, but also often include children with profound vision or hearing loss. Some of these terms may not be meaningful to families, and families' views may differ on the outcome that they would regard as unacceptably poor. Therefore, discussions should always include exploration of the parents' views and values relating to an acceptable outcome.

Conveying the concept of severe disability in childhood, and the possible implications for future quality of life, is difficult. Some helpful phrases may include:

- Not being able to walk or move independently
- The possibility of being unable to speak
- Difficulties with swallowing or feeding safely
- The possibility of not being able to understand the world around them in a meaningful way

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- Not being able to see or hear properly
- Not being able to live independently
- Having a lot of health care needs with frequent visits to hospital
- Needing extra educational support (or needing to attend a special school)

It is important also to highlight the potential for longer term health issues, including chronic lung disease and consequences of necrotising enterocolitis as well as milder neurodisability, behavioural problems and issues with educational achievement.

5. ***Discussing Palliative Care*** **–** Where appropriate, the practicalities of commencing, withholding and withdrawing intensive care and the positive role of palliative care should be described to the parents. This will help prepare them for possible outcomes after the birth. It can be useful to speak about memory making, exploring parents' hopes and wishes. We suggest referring to guidance from Together for Short Lives and the National Bereavement Care Pathway.

https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/ProRes-Perinatal-Pathway-for-Babies-With-Palliative-Care-Needs.pdf

http://www.nbcpathway.org.uk/file/aw_5844_nbcp_neonatal_death_pathway.pdf

6. ***Decision making*** **–** A shared decision making process is vital, especially in situations of moderate to high risk of unacceptably poor outcome. Support and guidance should be tailored to the needs of each family. Parents should be helped to understand that, even taking all available information into account, babies may be born in unexpectedly poor or unexpectedly good condition, and that this may impact upon what care at birth would be best for their baby.

7. ***Parental involvement in care*** **-** Evidence suggests parents find it very useful to hear how they can be involved in care for their baby. "Family-centred care means supporting parents to be involved in their baby's care" [61,62] – this should start before birth.

   Where it is planned to offer active care to the baby, and time allows, parents should be given an opportunity to visit the neonatal unit and to meet staff, and should receive information and support regarding expressing breast milk and the other ways that they could be involved in the hands-on care of their baby if s/he is admitted to the neonatal unit.

8. **Documentation and follow up -** Communication and agreed plans should be documented in full in the clinical record and plans revised regularly if pregnancy continues and/or depending upon the condition of the baby at birth and in the early days after birth. If *in utero* transfer is undertaken, the content and results of previous conversations should be clearly communicated (verbally, and in writing) with the receiving centre. Evidence suggests that parents find it very useful to receive supplemental information such as written information, visual aids and links to other resources. We include a suggested template for this information below.

Appendix 4: Helping parents to understand extreme preterm birth.

Who is this information for?

You have been given this information because your healthcare team think that you may have your baby extremely early (prematurely). You and your family need to know what is likely to happen for you and your baby if this occurs. The maternity team and neonatal (specialist baby doctors and nurses) team will talk to you about this in detail as well as giving you this information and you will have the opportunity to ask any questions that you wish.

What does this mean?

A pregnancy usually lasts for about 40 weeks. How many weeks you are along in your pregnancy (gestation) is usually worked out from an ultrasound scan at around 12 weeks (your dating scan).

Babies born before 22 weeks are so small and fragile that they do not survive. Their lungs and other organs are not ready for them to live outside the womb. Such tiny babies may show signs of life for a short time after birth but even with the very best neonatal care they cannot survive for more than a few minutes or hours.

Babies born from 22 weeks sometimes are not strong enough to survive labour and either vaginal (normal) or caesarean birth. If they are born alive, they may be able to survive if they receive intensive medical treatment. However, some extremely premature babies sadly die despite this treatment. The earlier the baby is born, the less likely it is that they will be able to survive.

Babies who are born extremely early are also at increased risk of problems with health and development as they grow up. These risks get higher the earlier (more prematurely) a baby is born, and are especially common in those children born before 25 weeks of gestation. Health problems may include breathing difficulties, gut problems (including difficulties with feeding) and eye problems. Developmental problems may include problems with movement, learning and behaviour that can range from mild to very severe; such problems are described on the following page.

The doctors and midwives will talk to you about what they expect for your baby. In some situations, there are difficult decisions to be made about how to care for your baby before and after birth. The right thing to do can be different for different families. That is why it is important that you are fully informed and feel able to let the doctors and midwives know your wishes for your baby.

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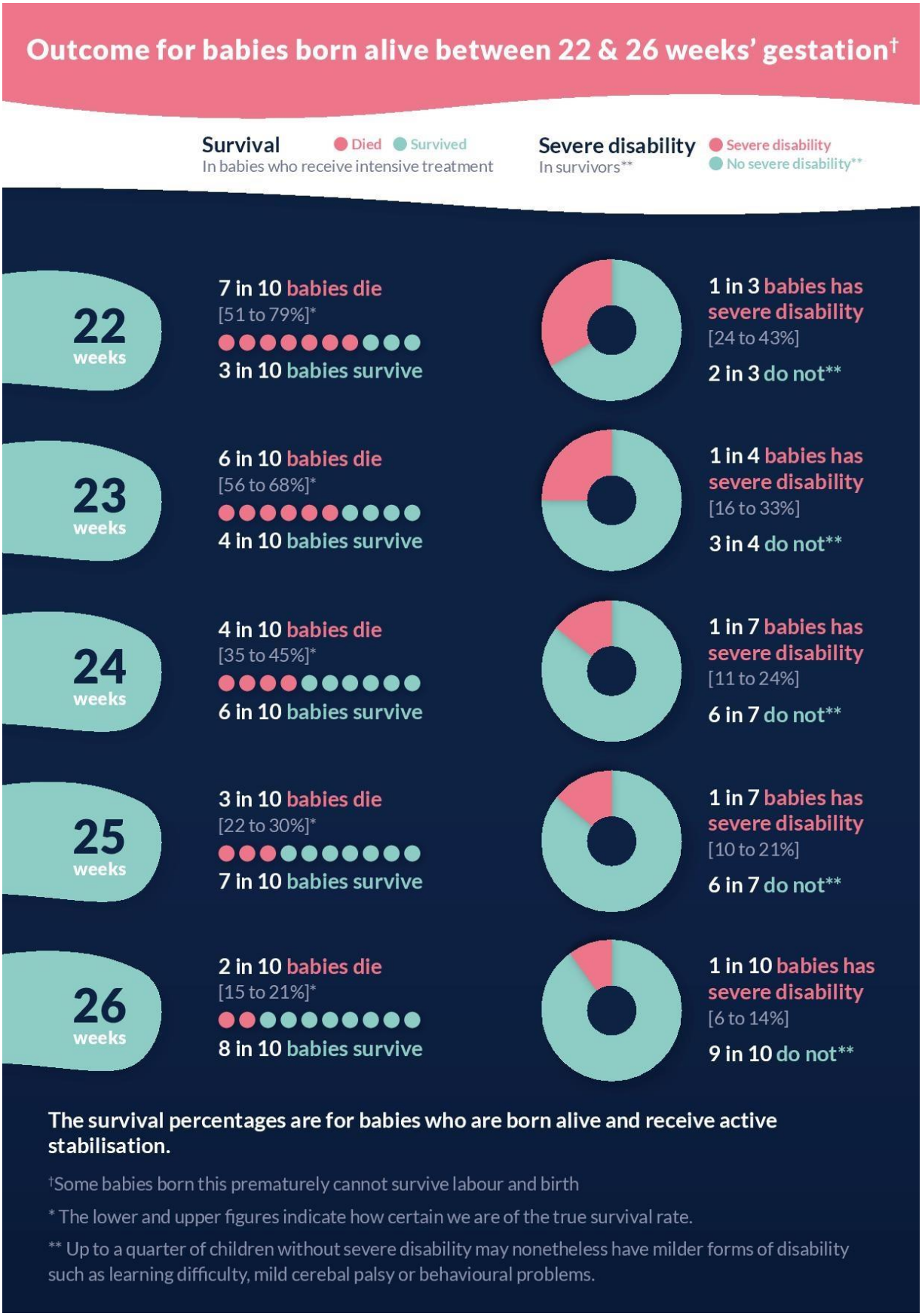

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'Outcome'

These pictures are based on what we know about the small number of babies born extremely prematurely in the UK. They show how many babies survive out of every 10 babies born alive this early, and of those who do survive, how many are likely to have a 'severe disability' when they grow up.

The majority of babies grow up without severe disability. A proportion of these children will develop other problems as they grow up which may mean, for example, that they need extra help in school or have problems with walking or moving around. Some may have social and emotional problems. The frequency with which children have these problems is greatest the earlier they are born, and problems are most common in children born at 22 to 24 weeks of gestation.

The chance for your baby depends on a number of different things. As well as how early they are born, it also matters how much your baby weighs when it is born, whether it is a boy or girl, whether it is a multiple birth and also how well you and your baby are around the time of birth.

What does 'severe disability' mean?

Disability can mean different things to different people. When talking about babies who have been born extremely prematurely, the term severe disability includes problems such as:

- Not being able to walk or even get around independently (this includes conditions such as severe cerebral palsy)
- Being unable to talk, or see or hear properly
- Difficulties with swallowing or feeding safely
- Having multiple health problems with frequent visits to hospital
- Needing to attend separate school for children with special educational needs
- Being unable to care for themselves or live independently as they grow up

What does this mean for your baby?

We don't know exactly the future for your baby. Every baby is different and it is important to talk with your doctors and midwife. They will give you specific information about your own and your baby's condition.

What can parents do?

What is right for your baby and your family is very individual to you. Your doctors will talk with you about your situation and

seek to understand what is important for you and your family. They will support and guide you and involve you in making decisions about treatment for your baby. Thinking about your hopes, your wishes, and your fears about your baby can help the team to support you in the best way possible.

What may happen with my baby?

Stillbirth: Some babies who are born this early do not survive labour and delivery. If this happens your baby will be given to you to hold for as long as you would like. You will have the opportunity to spend as much time with them as you would like and to make memories with them. Under UK law only babies born after 24 completed weeks of gestation can be registered as stillborn.

***Neonatal Intensive Care*:** You and the team may decide that starting neonatal intensive care would be best for your baby. This will mean you will need some extra treatments before your baby is born. You will be given steroids to help the baby's lungs and brain and magnesium which also helps to protect your baby's brain. You may need to be transferred to a specialist centre, ideally before you have your baby, but there may not be time to do this safely. The team will also talk to you about the treatment that will be given to your baby immediately after birth and what may happen next depending on how your baby reacts to this treatment.

If you and the team decide that intensive care is best for your baby, you should be offered the opportunity to be shown around the neonatal unit (if there is time for this) as it may help to see the neonatal unit and meet the people that work there before your baby is born. You can also talk to staff about expressing breast milk, as this makes such a big difference for premature babies.

***Comfort Care*:** You and the team may decide that it will be best to provide comfort care to your baby, either because there is an extremely high risk that your baby will not survive or he/she is likely to suffer from life-long disability even with the very best treatment. Comfort care is also known as palliative care and is special care for babies whose time is precious but short. It means providing treatments that will make their time as comfortable as possible. We will help you to be part of this care if you would like. Holding your baby close to you and talking to your baby may be very comforting.

More information about comfort care or 'palliative care' for babies is available from Together for Short Lives.

What if my baby doesn't come now?

If your baby does not come in the next few days their chances may improve. Ideally, they will stay in the womb for as long as possible (depending on the health of you and your baby).

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If that happens there may be different options for you and your baby around the time of birth. That will depend on when your baby comes and on other things that affect the baby's chances of responding to treatment. If this is the case, your healthcare team will continue the conversation with you about what has changed and what different options may be available depending on when your baby is likely to be born, and you will be able to discuss and revise your agreed plans accordingly.

What might my baby look like?

Babies born this early can weigh less than half a kilogram (1 small packet of sugar) and can look quite different to how we imagine a newborn baby. Their skin is shiny and thin and covered with fine hair. Sometimes babies can be quite bruised from the birth. If the baby has died before being born, they will usually be still. Occasionally, where babies have died very close to being born, they may make brief reflex movements that disappear very quickly.

If your baby is born alive, they may take a breath and make a small cry or they may not breathe. Their eyes may not be able to open yet. The baby's colour is often purple or blue to start with.

Transfer to a different hospital

When you have decided with the obstetric and neonatal care teams that starting neonatal intensive care would be best for your baby, research shows that for babies born before 27 weeks of gestation it is best, whenever possible, to be born in a specialist maternity unit with a specialist Neonatal Intensive Care Unit (sometimes called a 'Level 3 NICU'). If a baby born before 27 weeks of gestation is born in a maternity unit (or at home) where there is not a specialist NICU, then we know that the baby will generally do better if moved to a specialist NICU after birth.

If your hospital does not have a specialist NICU, this may mean that you will be offered transfer to one of these centres before your baby is born. We understand that this can be a very anxious time and that you may be moved quite some distance from home. It can be very difficult to predict which mothers will deliver early and so some mothers may be moved to another hospital and their baby not born early.

It may also be the case that you are considered too unwell or too far on in labour to be safely moved to another hospital before your baby is born. When it is not possible to transfer you before the baby has been born your baby may be transferred by a specialist Neonatal Transport Team after the birth. Your own health needs may mean you will be unable to travel immediately with your baby but your local maternity team will do everything they can to move you to the same unit as your baby as soon as it

is safe to do so.

We appreciate that moving to another hospital can be distressing for you and your family, especially if you are separated from your baby for a while. We will talk to you about this in more detail if it is decided that this is the best option for your family.

What if I have more questions?

This information has been provided to you as part of the conversation that your healthcare team will have with you about your baby. If you have any other questions do make sure you ask your doctors and nurses to answer them, so you have all the information you need about your situation and the options available to you. Your healthcare team want to work with you make the best decision for your baby and for your family.

This space is for the health care team who are discussing this with you to write extra details about your baby or babies.

You may want to use this space to write down some questions to discuss with the team.

Many families find it useful to have follow-up discussions, so please ask to speak to the neonatal and maternity team again at any point.

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Useful contact details:

Bliss - Premature and sick baby charity

http://www.bliss.org.uk/

Together for Short Lives - Charity for babies and children with life-limiting conditions

https://www.togetherforshortlives.org.uk/

Helpline: 0808 8088 100

Sands - Stillbirth and neonatal death charity

https://www.uk-sands.org/

Helpline: 0808 1643332

Email helpline@sands.org.uk

Appendix 5: Example scenarios

Case 1.

A mother has been admitted to a local maternity unit in preterm labour at 24^{+3} weeks of gestation. The singleton male fetus is very small with an estimated weight of 450 grams. The mother has not yet received antenatal steroids. The on-call paediatric team is asked to provide counselling and attend the birth. As per the Framework, the first step is to assess the risk for the baby if delivery occurs. At a gestation of 24^{+3} weeks, the average survival rate for liveborn babies in the UK (if active treatment is provided) would be approximately 60%, with a 1 in 7 risk of severe impairment among survivors. However, in this case, the very low birth weight for the gestational age in a male fetus increases the risk. It is difficult to quantify this risk, but the baby's prognosis is worse than average for 24 weeks of gestation, and within the "high" risk category. Given the risk for the infant, counselling should, if possible, be provided by an experienced senior trainee or consultant neonatologist in conjunction with the obstetric team. If possible, this counselling should take place after the local team has discussed the case with the nearest NICU. It would be appropriate to provide active obstetric and neonatal management if that were desired by the parents. However, it would also be appropriate to provide palliative care, if that was felt by the parents to be in the baby's best interests.

In this case, the parents decide after consultation that they wish the baby to receive palliative (comfort focused) care. Labour progresses and a live-born baby is delivered weighing 460 grams. He is bruised and floppy with a heart rate of 50 beats per minute. The paediatric team attend to support provision of palliative care. The baby is wrapped and given to his parents to hold. He dies at approximately 30 minutes of age.

Case 2.

A mother presents to her local maternity unit (SCBU) at 22^{+0} weeks of gestation with bulging membranes and active preterm labour. No antenatal steroids have been given, and the estimated weight of the male fetus is 510g. There is an extremely high risk of poor outcome for this fetus if delivery occurs within a short period of time. The mother and her partner are informed of the likely outcome, and advised that active (survival focused) management is not considered to be appropriate. The mother receives palliative obstetric management, and the infant is stillborn.

Case 3.

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A mother presents in preterm labour to a level 2 centre at 22^{+3} weeks of gestation. The fetus was conceived by IVF and gestation is certain. The fetus is female and has an estimated fetal weight of 480 grams. The mother has not yet received antenatal steroids. The paediatric team is asked to provide counselling and attend the birth. Risk assessment in this case indicates that if birth occurs imminently, there would be an extremely high risk of the baby dying or of surviving with severe impairment. If labour progresses, it would be usual to provide palliative care at birth. The neonatal team may attend the birth to provide support for palliative care, but not to provide resuscitation. However, there are potentially modifiable risk factors in this case. In the absence of evidence of chorioamnionitis, it may be possible to delay preterm birth with tocolysis and so, if the parents desire, an active approach to management, antenatal transfer and corticosteroids could be provided.

Two days later, at 22^{+5} weeks, following transfer to a maternity unit co-located with NICU and administration of steroids, labour progresses. Given the advance in gestation, availability of specialised neonatal intensive care, and anticipated effect of corticosteroids, the baby's risk is now judged to fall in the "high" category. Accordingly, after further consultation with parents, it would be appropriate to provide active management if this is what parents wish.

In this case, the parents decide that they wish the baby to receive active neonatal care, magnesium sulphate is given, and a live baby is born weighing 490 grams. The baby is intubated, receives surfactant and is transferred to neonatal intensive care.

Case 4.

A mother presents to her local maternity unit at 25^{+2} weeks of gestation in early labour. She has a well grown female fetus. She is offered, and accepts, antenatal steroids, but declines transfer to the nearest NICU (1 hour's journey away) where a cot is available. Her partner asks the obstetric team what would be best for the baby, and it is clear to the midwife that parents disagree about transfer.

Recommended action: as part of the consultation with parents, the reasons why transfer is being recommended should be clearly explained. Data show that for the most preterm babies, prognosis (both survival and neurodevelopmental outcome) is better if they are delivered in a maternity unit adjacent to a NICU. It can be difficult to predict preterm labour, and so early transfer is preferred. It would be important to explore reasons why the mother does not wish to be transferred and to address all of her concerns. If the mother still refuses transfer she cannot be moved, but she should be offered magnesium sulphate and counselled that the baby will be moved after delivery. In this instance, the best interests of the child would be served by early care in a NICU. It would be prudent to alert both the NICU and the local transport team, as well as to think about who will be

available to stabilise the baby after birth. The mother should also be informed that, while every effort will be made to move her to a maternity facility adjacent to the NICU, her transfer may need to be delayed if she is unwell after delivery.

Case 5.

A woman is transferred to a level 3 centre at 23^{+6} weeks of gestation in preterm labour following premature rupture of membranes two days earlier. She had received steroids prior to transfer. The female fetus appears well grown and there are no signs of fetal compromise. After discussion with the neonatal team, and being informed about the outcomes of preterm delivery, the mother expresses that she is very concerned about the possibility of the baby surviving with severe disability. She requests no active obstetric management, and palliative care of the baby at delivery.

The neonatal team advises the mother that, taking all factors into account, her baby would have a moderate risk of dying or of severe disability. It would be usual to provide active management of the baby in this situation, with the knowledge that if complications develop in the neonatal intensive care unit, there would be the option of later withdrawal of life-prolonging treatment. The mother agrees to this plan and the baby is born a few hours later, receives stabilisation in the delivery room and is transferred to the neonatal intensive care unit.

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