British Association of Perinatal Medicine

# Perinatal Management of Extreme Preterm Birth Before 27 Weeks of Gestation

## A BAPM Framework for Practice

February 2026

Endorsed by

Bliss for babies born premature or sick

bmfms British Maternal & Fetal Medicine Society

Neonatal Nurses Association

Developed in partnership with

sands

## Contents

Cover image kindly provided by Tahira Bilal of her son Muhammad Zayd Bilal.

# Foreword for revised 2026 Framework

The 2019 BAPM Framework on Perinatal Management of Extreme Preterm Birth before 27 weeks gestation provided a revised approach to decision-making and care for some of the smallest and most vulnerable premature babies. It was based on evidence from UK and international data on improved survival, and included consideration of survival focused care for babies as early as 22 weeks gestation, following a risk-stratified approach to counselling and decision-making. The change in guidance had wider implications beyond neonatal services, with an increase in antenatal transfers of women at 22-23 weeks gestation with threatened preterm labour. We recommend that perinatal teams across neonatal and maternity services familiarise themselves with this framework to facilitate counselling and management decisions.

Whilst the risk stratified approach was welcomed by perinatal teams, feedback indicated that this needed greater emphasis and clarity to avoid misinterpretation. Whilst this update retains the core elements of the 2019 Framework, we have made revisions to provide clearer language, support and guidance around appropriate decisions for babies assessed to be at extremely high risk of dying. It emphasises that for such babies, comfort care should be provided. This framework also includes updated survival and neurodevelopmental outcome figures and the proportion of babies liveborn. This revision emphasises the importance of joint maternity and neonatal counselling with families, which includes communication between centres when transfers antenatally or postnatally are considered.

To help support teams apply the framework in practice, we have included new example cases (Appendix 2), and situations that present uncertainty and potential conflict, for example born outside hospital or born at 22 weeks in centres without a co-located NICU (Appendix 3). We have also included signposts to available educational and training resources. We are co-developing with parents some resources to support counselling (for example an alternative to the previous infographic).

Neonatology continues to evolve as a specialty, and it is inevitable that this framework will need further updates as new evidence becomes available. The key elements, however, will remain constant: the need for perinatal teams to work collaboratively, to inform and involve parents in decision-making, and to support them at one of the most stressful times of their lives.

## Executive summary

1. Decision making for babies born 22+0 to 26+6 weeks of gestation should not be based on gestational age alone, but on assessment of the baby's risk profile and prognosis taking into account multiple factors~~.~~ Survival focused care should not be offered for babies born before $22^{+0}$ weeks gestation.

2. Decisions should be made with input from obstetric and neonatal teams, and joint counselling with families is recommended. Where transfers antenatally or postnatally are considered, communication between referring, receiving and transfer centres should take place to facilitate shared and informed decision making with families.

3. Risk assessment should be performed with the aim of stratifying into three groups:
   a) Extremely high risk.
   b) High risk.
   c) Moderate risk.

4. For babies at **extremely high risk** of poor outcome (death or survival with severe disability), comfort focused care should be provided. Survival focused care should not be offered. It includes some babies born at 22 weeks or later with extremely low chance of survival without severe impairment. A full assessment of the risks of continuation of the pregnancy to the woman's health must be considered alongside the outcome for the baby, with particular attention to preterm prelabour rupture of membranes (PPROM) and the development of infection. Antenatal multidisciplinary discussions, ideally initiated before 22 weeks, are essential to prepare and support parents around the rationale for not providing survival focused care in this setting.
5. For babies at **high risk** of poor outcome, the decision to provide either survival focused care or comfort focused care should be based on individual assessment and informed by parental wishes, and supported by consultation and in partnership with obstetric and neonatal professionals.
6. For babies at **moderate risk**, survival focused care should be provided initially. Ongoing treatment in intensive care should be reviewed regularly and discussed with parents subsequently, particularly if complications arise.

7. Conversations with parents and the multi-disciplinary team plan should be clearly documented and care taken to ensure that this is communicated between professionals and staff shifts.

8. If survival focused care for the baby is anticipated, pregnancy and birth should be managed with both the aim of ensuring maternal wellbeing and optimising the baby's condition at birth and subsequently.

9. If comfort focused care for the baby is planned, obstetric management should focus on maternal wellbeing and minimising risks for future pregnancies.

10. Whenever possible, babies born before 27 weeks (where survival focused care is planned) should be born in a maternity facility co-located with a designated neonatal intensive care unit (NICU).

11. A new section on Implications for Transport/LNU and SCU teams has been included. Most

babies born prior to 23 weeks gestation in a maternity unit without a co-located NICU (ie an LNU or SCU) will be **extremely high risk**. For such babies neonatal management focused on comfort should be provided, and it would usually **not** be appropriate to retrieve and transfer ex-utero.

12. Management should be regularly reviewed before and after birth in conjunction with the parents; plans may be reconsidered if the risk for the baby changes, or if parental wishes change.

13. Perinatal professionals involved in the counselling and care of families and babies born before 27 weeks should undertake relevant training and engage in educational opportunities.

14. While the main focus of this framework is on the care of babies once they arrive to hospital or that are born in hospital, some scenarios of babies born outside a hospital setting are covered in Appendix 3.

15. References have been updated and include signposting to previous BAPM frameworks and other national guidance.

16. A new section on recommendations for audit and research has been included. Neonatal units who care for extremely preterm babies should participate in national audit and research activities. Specifically, given the small number of babies born at 22 weeks in each unit, participation in national research initiatives focusing on this population of infants and their families is recommended.

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We acknowledge the members of the 2019 Working Group **Ms Caroline Lee-Davey** (Chief Executive Officer of Bliss), **Ms Erica Everett (**representing the Neonatal Nurses Association), **Dr Tracey Johnston (**Consultant in Maternal and Fetal Medicine, representing British Maternal and Fetal Medicine Society), **Dr Helen Mactier (Chair,** Consultant Neonatologist and Honorary Clinical Associate Professor, President of BAPM), **Prof Neil Marlow** (Professor of Neonatal Medicine, representing RCPCH), **Dr Tara Selman** (Consultant in Fetal and Maternal Medicine, representing British Maternal and Fetal Medicine Society), **Dr Meekai To (**Consultant in Obstetrics and sub specialist in fetal and maternal medicine, representing the Royal College of Obstetricians and Gynaecologists).

## Introduction

The 2019 BAPM Perinatal Management of Extreme Preterm Birth Before 27 Weeks of Gestation Framework, changed its previous guidance from 2008, and recommended consideration of survival focused care for some babies from 22 weeks of gestation using a risk-stratified approach and following multi-professional discussion with parents. This change was informed by improvement in outcomes for babies born at the lowest gestational ages admitted to neonatal intensive care units (NICUs) in the UK and other countries (Norman, 2019, Patel, 2017, Mehler, 2016, Myrhaug, 2019). 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 (Guillén, 2015, Lemyre, 2017, Wilkinson, 2018). This was accompanied by greater acknowledgement of the importance of involving parents in perinatal decision making (POPPY Steering Group 2018) and the impact of the willingness to provide survival focused interventions on outcomes (Rysavy, 2015).

Since the introduction of the BAPM 2019 framework, there has been a three-fold increase in babies born at 22 weeks of gestation given survival focused care and admitted to neonatal units (Smith, 2023). Two out of 10 babies provided with survival focused care, and 3 out of 10 babies admitted to neonatal care survived to neonatal discharge. This corresponded to 13 and 39 survivors in years 2018-19 and 2020-2021, respectively. There has been no change over time in the provision of survival focused care for babies alive at the onset of labour born at 23 and 24 weeks (80% and 90%, respectively) (Smith, 2023). There were implications on the maternity service, with an increased need for capacity to transfer women antenatally between 22 and 23 weeks gestation with threatened preterm labour, to NICUs (Griffin, 2025).

This 2026 revision includes updated survival figures using outcome data for births in years 2020-21 for babies born 22 to $26^{+6}$ gestational weeks in England and Wales; and additional guidance for specific example scenarios in the appendices. This framework emphasises and encourages perinatal teams to communicate and work together, sometimes across referring, receiving and transport services, to carefully consider risk factors (and not just gestational age) for decisions about survival focused care in the most vulnerable cohort of babies.

Prevention of preterm birth remains 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 survival focused and/or comfort focused care as appropriate and interventions to optimise outcomes for babies born too soon (NICE NG25, NHS England Saving Babies Lives Version 3).

Perinatal care at extremely preterm gestations will always need to be individualised and should be led by senior staff in midwifery, obstetrics and neonatology. Joint counselling with maternity/obstetric and neonatal teams to inform management decisions for woman and baby is recommended where possible. 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.

## 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 birth at 26 weeks and 6 days of gestation or less in the United Kingdom. Options for the pregnancy should have been discussed with the parents. Decision-making and the legal approach to termination of pregnancy including definitions of "viability" are out of the scope of this framework. However, it is essential to consider the views and circumstances of families where they have not wanted to continue the 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 neonatal unit. A separate recent BAPM framework 'Recognising uncertainty: an integrated framework for palliative care in perinatal medicine' outlines the principles of comfort focused care and support for these babies.

Whilst this framework focuses on the management of extremely preterm babies after arrival at hospital or those born in hospital, Appendix 3 also includes discussion of the care of extremely preterm babies who have been transferred after being born out of hospital. Management of extremely preterm babies by pre-hospital clinicians is found in the BAPM Framework: 'Pre-hospital management of the baby born at extreme preterm gestation'.

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 this 2026 update to the 2019 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 pregnancy.

Within the document "**parents**" refers to the mother or birthing person and their partner. BAPM is aware that the use of gendered language such as mother, can make some families feel excluded. We use the term "woman" prior to the birth of baby and "mother" postnatally. When supporting individual families, professionals should use the terms that the family identifies with, as well as their desired pronouns.

We have used the terms "**survival focused care"** to refer to obstetric and neonatal management that has the aim of sustaining life for the baby, and **"comfort focused care"** to refer to obstetric and neonatal management when the aim is not to attempt to sustain the life of the baby, but to focus on the baby's comfort.

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

**Perinatal care teams** include multi-professional healthcare staff dedicated to providing care for pregnant women, their newborns, and their families. The team includes, but is not limited to, obstetricians, midwives, neonatologists/paediatricians, nurses, and allied health professionals including dietitians, physiotherapists, occupational therapists and psychologists. Importantly, parents are also considered integral members of the team, actively involved in decision-making and care planning.

# 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 likelihood of an acceptable (or unacceptable) outcome for baby and parents. 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. Risk assessment should be based on the overall risk profile for the baby (ie the combination of the gestation and any positive or negative risk factors), rather than being based on gestation alone or on any single factor.

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

1. Assessment of the risk profile for the baby if birth occurs, incorporating both gestational age and factors affecting fetal and/or maternal health.
2. Counselling parents, and their involvement in decision-making. It is important that parents are offered choices and supported to make decisions appropriate for their individual preferences.
3. Agreeing and communicating a management plan.

## 1. Assessment of the risk profile for the baby

### 1a. Gestation-based risk assessment, including mortality and survival with severe impairment

**Gestation**

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 (NICE NG201). From $14^{+0}$ weeks (CRL > 84mm), 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 (Papageorghiou, 2016). Where a dating ultrasound has not taken place, gestational age assessment may not be accurate.

**Neonatal survival and morbidity**

There have been incremental increases in the survival of extremely preterm babies since 2006 with greater willingness to offer neonatal intensive care. The number of surviving babies to neonatal discharge at 22 weeks of gestation remains small, with appreciable in-labour mortality. UK figures accord with international data (Appendix 1). Survival to live birth is influenced by management of labour and birth, and survival after birth will clearly be affected by whether active survival focused care is provided. Management should be based on the most recent data available. Recent UK data for babies born 2020-2021 are included in Table 2 in Appendix 1. Survival to neonatal discharge rates differ by denominator. For babies born at 22 weeks of gestation, survival to neonatal unit discharge is around 8% of babies alive at the onset of labour, 10% of live births, 20% of babies who received survival focused care, and 30% of babies admitted to neonatal units. Survival to neonatal discharge rates are higher for babies born at greater gestation (Appendix 1). As a proportion of neonatal admissions, survival to neonatal discharge is around 50% for babies born at 23 weeks, 70% at 24 weeks, 80% at 25 weeks and 85% at 26 weeks. Denominators used should be relevant to the decision being made. For decisions about whether to provide survival-focused care at birth, the most relevant statistic is the chance of survival (or severe morbidity) for live born babies who receive survival focused care.

1 in 10 of babies born at 22 weeks gestation and 1 in 5 of those born at 23 weeks of gestation admitted to neonatal care survive to neonatal discharge without major morbidities (excluding bronchopulmonary dysplasia (BPD, defined as receiving any respiratory support at 36 weeks postmenstrual age). All surviving babies at 22 and 23 weeks of gestation have evidence of BPD (Smith, 2023).

**Longer term outcomes**

There are important differences in individual views about acceptable levels of disability. What for one individual or family may be an acceptable outcome may not be 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 (Wilkinson, 2013).

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. 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 standard deviation); 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 (GMFCS) grade 3 or greater (Appendix 1).
- Blindness or profound hearing impairment.

The risk of severe impairment increases with increasingly preterm birth (Appendix 1) and using the most recent population level two-year neurodevelopmental data from babies born 2008-2018 is approximately the following for babies who receive survival focused care and survive to two years of age (van Blankenstein, 2024).

**$22^{+0}$ - $22^{+6}$ weeks: 1-in-3 survivors has severe impairment***
**$23^{+0}$ - $23^{+6}$ weeks: 1-in-4 survivors has severe impairment**
**$24^{+0}$ - 24+6 weeks: 1-in-5 survivors has severe impairment**
**$25^{+0}$ - $25^{+6}$ weeks: 1-in-9 survivors has severe impairment.**
**$26^{+0}$- $26^{+6}$ weeks: 1-in-12 survivors has severe impairment.**

*Presently, relatively few babies born at 22 weeks of gestation have available long-term outcome data available, meaning estimates of rates of such adverse outcome are imprecise. However, it is believed that the proportion of such babies with severe impairment is at least 30%.

### 1b. 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 to neonatal discharge and survival without severe impairment.

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

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

**Multiple birth:** 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.

**Clinical conditions** which pose additional risk and have been associated with increased mortality and morbidity include the following:

> **Chorioamnionitis** increases the risk of neonatal complications including mortality and morbidity, particularly brain injury and adverse long-term neurodevelopment outcomes. Although ultimately a histological diagnosis (hence not possible to diagnose prior to birth), combinations of clinical symptoms can lead to a clinical diagnosis of chorioamnionitis in the antenatal or intrapartum periods. Symptoms include lower abdominal pain or uterine tenderness, abnormal vaginal discharge, fever, malaise, reduced fetal movements, increased baseline fetal heart rate, abnormal maternal observations, abnormal maternal biochemistry (in particular, C-reactive protein and white cell count) (RCOG GTG No.73).
>
> **Preterm prelabour rupture of membranes (PPROM):** Pregnancies with PPROM prior to 23 weeks gestation have a high risk of perinatal and maternal morbidities. Risk is highest with very early PPROM (eg <20 weeks) in association with oligo or anhydramnios (Kacerovsky, 2014, Goodfellow, 2024).

**Therapeutic strategies:** administration of antenatal steroid and magnesium sulphate are associated with improved survival and neonatal outcomes as well as reduced risk of childhood impairment, even before 24 weeks of gestation (Roberts, 2017, Travers, 2017, Ehret*,* 2018, Doyle, 2019). It would be appropriate to provide antenatal steroids if a baby is anticipated to be high (or moderate) risk if they deliver in the next 48 hours, and parents would wish for survival focused care to be provided in such a scenario. (see more in section on obstetric management)

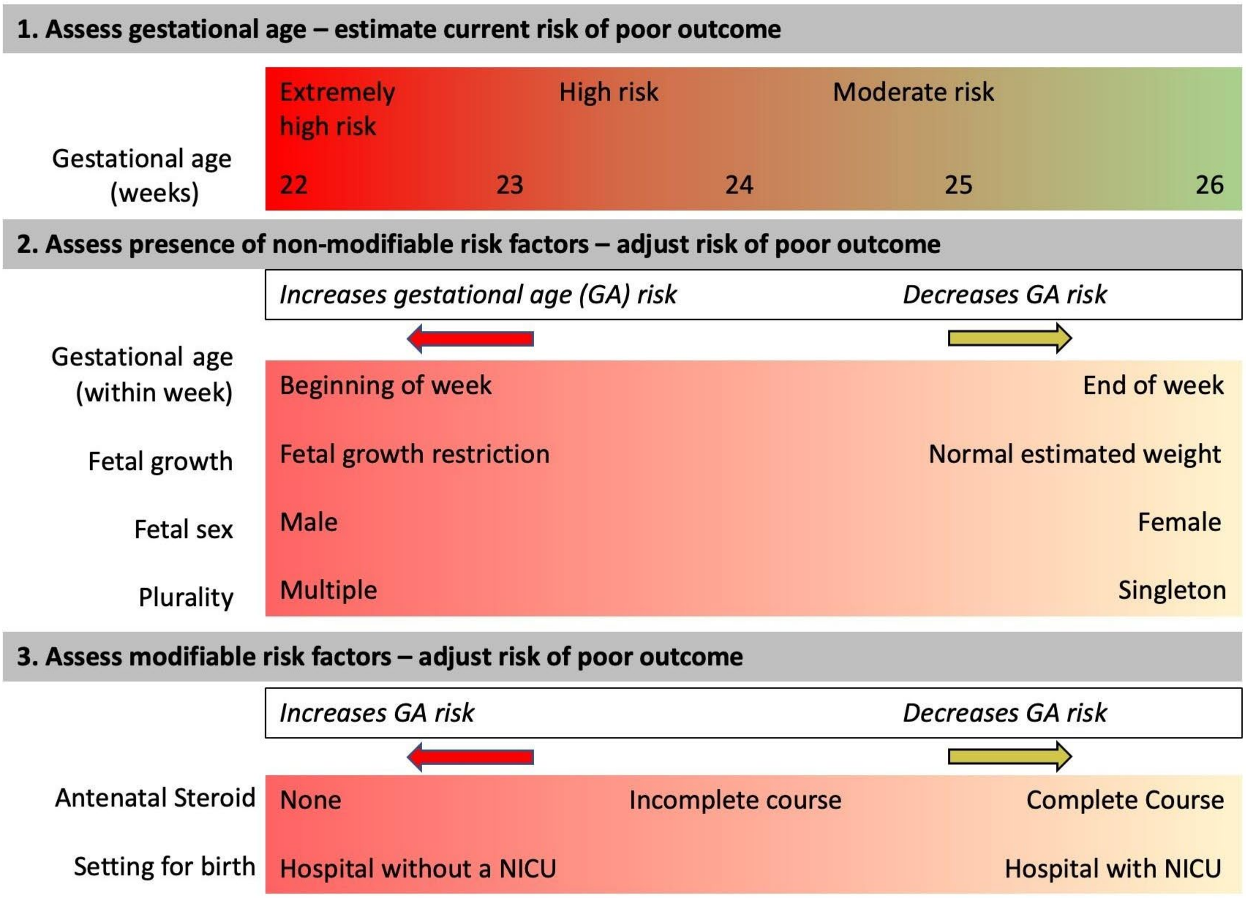
**Clinical Setting:** survival is highest at these extreme preterm gestations in centres with experienced staff and higher patient numbers. For women presenting to a maternity centre without a co-located NICU, assessment of risk should include early discussion with the relevant referral centre. A strategy of in utero transfer below 27 weeks of gestation for birth in a maternity unit with a co-located NICU is strongly recommended (where survival focused care is clinically appropriate and desired by parents) (Marlow, 2014, David*,* 2018*,* Helenius, 2019, BAPM NSQI 2017). Where extremely preterm babies are born in centres without a co-located NICU, this will increase the risk for the babies, and in some cases will mean that survival focused care is not appropriate. See Appendix 2 and 3.

**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 risk profiles:

- Extremely high risk.
- High risk.
- Moderate risk.

**A visual tool** for refinement of risk is illustrated in Figure 1. Some clinical factors (chorioamnionitis, PPROM) are not included in the visual tool because of variability in diagnosis and impact on risk. However, they would be important to include in assessment of risk profile in cases where they are present and clearly adversely affect individual risk.

**Figure 1: Visual tool for refinement of risk profile (See text and appendix for suggestions for how to use this tool)**



Other conditions which have been associated with increased mortality and morbidity include Preterm Pre-labour Rupture of Membranes before 24 weeks of gestation and clinical evidence of chorioamnionitis

**Box 1 represents the consensus of the Working Group in regard to risk profiles for the purposes of this framework.**

BOX 1

***Extremely high risk:*** The Working Group considered that babies with a > 90% chance of either dying or surviving with severe impairment if liveborn and survival focused care is instituted would fit into this profile. For example, this would include:

- All babies born before 22 weeks of gestation.
- Babies born at $22^{+0}$ - $22^{+6}$ weeks of gestation with unfavourable risk factors (for example, those born in hospitals without a NICU and/or in the first half of the week, and/or in the absence of antenatal steroids).
- Some babies born at $23^{+0}$ - $23^{+6}$ weeks of gestation with unfavourable risk factors, including severe fetal growth restriction.
- (Rarely) babies born at or after $24^{+0}$ weeks of gestation with significant unfavourable risk factors, including very 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 survival focused care is instituted would fit into this profile. For example, this would include:

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

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

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

***Extremely high risk:*** For babies with >90% chance, an extremely high risk of death or of survival with unacceptably severe impairment despite treatment, comfort-focused care would be in the best interests of the baby. Survival focused care should not be offered. There is no absolute indication for paediatric/neonatal 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 survival focused care 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 survival focused or comfort focused care. 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, together with an experienced neonatal team.

***Moderate risk:*** For babies with a < 50% risk of death or of survival with unacceptably severe impairment, survival focused care would be in the best interests of the baby. A senior neonatal clinician should attend the birth, together with an experienced neonatal team.

## 2. 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 woman and her baby before, during and after the birth.

The assessed risk profile of the baby (including the inherent uncertainty around this) should be conveyed empathetically 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 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. Some parents may not wish to engage in shared decision-making, or to make an active decision. In that case, there should be a provisional plan for care at birth based on the risk assessment.

*In utero* transfer to a maternity facility co-located with a NICU should be considered at the earliest opportunity when survival focused 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 (*e.g.* following detailed ultrasound scanning). Communication and agreed plans should be documented in full (BAPM Practice Guide: In-utero Transfer) 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 the care that might be appropriate. Processes should be in place to ensure timely transfer. Both written and verbal information should be given to parents, with appropriate use of translation services. In some cases, poor maternal health and/or advanced stage of labour may mean that *in utero* transfer is not the safest option.

When survival focused 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 comfort focused care strategies should be described to the parents. This will help prepare them for possible outcomes after the birth. Parents may find the access to neonatal psychology services, support and advice from 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.

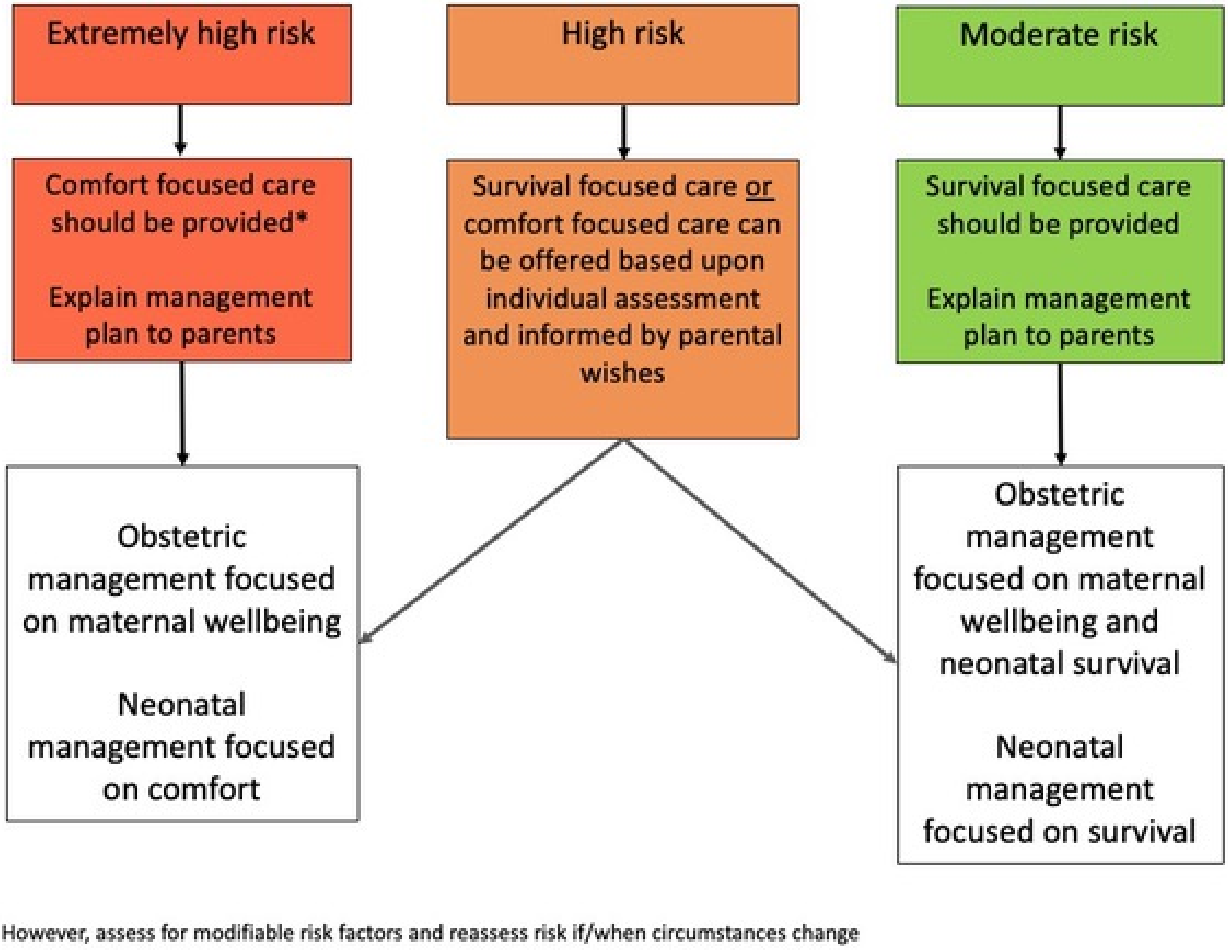
## 3. Agreeing and documenting a management plan

Following consultation with parents, initial management of the birth will follow one of two pathways: “Survival focused” or “comfort focused” (Figure 2). Parallel planning can be a useful strategy to discuss these options. This includes (where desired), providing survival focused care, but discussing the possibility of changing to comfort focused care in the event that a baby responds poorly to attempted stabilisation or develops serious complications later.

Consistency in obstetric and neonatal management is essential, both to ensure that the baby is born in the best possible condition and 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 evaluating risk should not be underestimated and categorisation and communication of risk should 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.

**Figure 2. Decision-making around management of birth, following risk assessment and after consultation with parents.**



## Obstetric management

### Obstetric management focused on maternal wellbeing and neonatal survival

- When it has been agreed that potentially life-sustaining care for the baby is appropriate, survival focused obstetric care 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 survival focused neonatal care is in place (David, 2018). This should be in line with the Saving Babies Lives Care Bundle, Version 3 and BAPM Perinatal Optimisation Pathway and should utilise all optimisation resources, including clinical and parent optimisation passports found in the pathway. 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. All discussions and decisions should be documented clearly in the clinical record.

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

- ***In utero* transfer to a tertiary maternity centre with a co located NICU** optimises outcomes for the baby, is better than *ex utero* transfer and is now a prioritised recommendation across all nations of the UK (NHS England Saving Babies Lives Care Bundle (version 3), BAPM Practice Guide: In-utero Transfer).

- While the majority of women presenting in threatened preterm labour before 27 weeks of gestation do not deliver in the subsequent 24 hours, and transfer may present challenges for the family as well as obstetric and ambulance services, the Working Group strongly recommends that this is considered at the earliest opportunity.

- **Joint obstetric and neonatal counselling** should occur where possible, or at the very minimum, a conversation between the neonatal and obstetric consultant should take place prior to a conversation with the parents. These discussions will inform the decision whether to provide neonatal survival or comfort focused care and obstetric management. If in a non-tertiary centre, this discussion will also inform whether a woman is transferred in utero for the baby to be born in a maternity unit with a co-located NICU.

- A decision for antenatal transfer should be made in a timely manner to facilitate earliest possible in-utero transfer of the woman. Some regions now offer neonatal cot and maternity bed finding services to facilitate in utero transfers. A careful risk assessment should be conducted to ensure that the woman is fit for transfer and that birth in transit is unlikely. Use of tocolysis would be appropriate in this situation. Discussions between the referring unit, transport team and receiving tertiary NICU are recommended, and can be facilitated through use of Microsoft® Teams or other conference calling modalities.

- A decision to transfer antenatally does not necessarily commit management to survival focused care and assessment of risk should be an ongoing assessment and reviewed when birth is imminent. Decisions around mode of birth should also be reviewed to ensure appropriate balance of risks and benefits for the woman and baby.

- **Optimally timed course of intrapartum antenatal steroids, tocolysis, magnesium sulphate for neuroprotection**. 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. (LeMoine, 2025). Decisions about the timing of antenatal steroids should be informed by risk assessment and knowledge of the wishes of parents.  It would not be appropriate to provide antenatal steroids (or antenatal transfer) prior to 22 weeks gestation since the risk profile of the baby, even if steroids (and transfer) are provided would be extremely high. As a general principle, It would be appropriate to provide antenatal steroids if a baby is anticipated to be high (or lower) risk if they deliver in the next 48 hours, and parents would wish for survival focused care to be provided in such a scenario.

- **Maternal Intrapartum Antibiotic Prophylaxis to reduce the risk of neonatal Group B Strep (GBS) disease** – The risk of early onset GBS disease in babies of those women who deliver preterm is estimated to be 2.3 per 1000, with a mortality rate in preterm babies 10 times that of term babies. Current national guidance advises that intrapartum antibiotic prophylaxis should be administered to any woman in established preterm labour (RCOG GTG No 36, NHS England Saving Babies Lives Care Bundle (Version 3).

- **Intrapartum fetal heart rate monitoring** Below 26 weeks of gestation, a senior obstetrician should be involved in decisions around intra-partum fetal heart rate monitoring as there is a lack of evidence to inform practice (NICE NG25). However, assessment of whether the fetal heart was present before birth by intermittent auscultation or ultrasound is helpful to the attending neonatal team, particularly where survival focused care is planned. The family should be made aware of the rationale for either recommending or withholding fetal heart rate monitoring, this should be discussed and agreed on an individual basis. For example, it may be appropriate not to monitor the fetal heart if birth 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 interpretation of continuous electronic fetal heart rate monitoring (CEFM) difficult and there is no evidence that CEFM improves outcomes compared to intermittent auscultation. From $26^{+0}$ weeks of gestation, when survival focused management is planned, CEFM should be recommended for women in established preterm labour (NICE NG25).

- **Mode of birth** The decision on mode of birth should be informed by the balance of risks and benefits to baby and woman. In the majority of extremely preterm births the woman presents in spontaneous labour and an uncomplicated vaginal birth may be anticipated. The risk of head entrapment following breech presentation is approximately 10% but the evidence for birth by caesarean section for extremely preterm babies is limited and of poor quality (Grabovac*,* 2018, Reddy, 2015) and prognosis is more likely to be dictated by factors other than mode of birth. NICE guidance is that birth by caesarean section may be considered in cases of breech presentation **after 26 weeks of gestation** (NICE NG25). Extremely preterm caesarean sections can be difficult, and fetal trauma including head entrapment can still occur. Maternal risks and consequences including pain, haemorrhage, infection, thrombosis and injury to bowel and bladder are higher after caesarean section compared to vaginal birth, particularly at extremely preterm gestations, and should be discussed with the woman. 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 (Reddy*,* 2015, Blanc, 2019). 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. If the baby is deemed extremely high risk for a poor outcome, a decision for a caesarean section should only made if there are benefits for the woman, or this is her choice following informed counselling of the above risks. There should be clear documentation of this conversation and the woman's wishes (NICE NG192, RCOG consent advice no 14). Where birth 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 birth. In the absence of labour and where birth should be expedited for maternal reasons (e.g. pre-eclampsia or chorioamnionitis) or, more rarely, for fetal reasons (e.g. severe fetal growth restriction) birth by caesarean section may be the only option to ensure timely birth for woman and/or baby. Induction of labour may not 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. Detailed discussion regarding the risk of the demise of the baby during induction versus the risks of caesarean section should be fully discussed with the parents. There are clinical situations in which the woman may already be dilated, with a low presenting part and multiparous, thus making the choice for oxytocin induction a more favourable decision.

## Obstetric management focused on maternal wellbeing

When a decision is made for comfort focused care approach of the baby at birth, only interventions for maternal benefit are appropriate. This may include a discussion of options for not continuing the pregnancy where there is a high risk of maternal and neonatal morbidity and mortality. This is particularly important in cases of PPROM and chorioamnionitis and should, where appropriate, include input from fetal medicine and preterm birth experts. 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. Assessment of signs of life after birth should be undertaken following the MBRRACE-UK guidance. (resources including videos are available MBRRACE-UK Guidance, 2020) ensuring that care following birth is respectful and that the individual needs of the baby and parents are prioritised at this difficult time. Parents should be made aware that their baby may show signs of life after birth, including visible heartbeat, gasping and/or movement of limbs but also that some babies who have died before birth may show brief reflex movements.

# Neonatal management

## Survival focused neonatal care

- This should be in line with the BAPM Perinatal Optimisation Pathway and should utilise all optimisation resources, including clinical and parent optimisation passports.
- 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 babies (Resuscitation Council UK). Ideally this multidisciplinary team will be experienced in stabilisation of extremely preterm babies, including an experienced intubator (BAPM Airway Safety Standard), experienced neonatal nurse and led by a consultant neonatologist.
- **Deferred cord clamping for at least 60 seconds** should be routine practice as deferring clamping the cord for at least one minute (Fogarty, 2018) has been shown to reduce mortality in preterm babies. Perinatal teams should work to develop ways to reliably provide this, in conjunction with thermal care and initial stabilisation, in different birth circumstances.
- **Normothermia** should be a key area of focus, 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 then be initiated. Care should be taken not to over distend the lungs.
- **Intubation:** Clinical assessment immediately following birth is not a good predictor of survival in extremely preterm babies (Manley, 2010); if there is no response to mask ventilation, and any doubt around the adequacy of ventilation, the baby should be intubated by the most experienced intubator available (BAPM Airway Safety Standard) and surfactant administered. The most important intervention is establishment of adequate lung recruitment, and the most important measure of success is heart rate. If the baby's heart rate and general condition are not improved by active stabilisation efforts such as intubation and ventilation, then it may be necessary to inform the parents of the change in clinical situation and of a need to move to a comfort care approach.
- Use of **advanced measures for resuscitation** including cardiac massage and endotracheal or intravenous adrenaline 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. Clinicians should discuss the possibility of more extensive forms of resuscitation with parents prior to extremely preterm birth and involve them in decisions. In some extremely preterm babies who are already designated to the ‘high risk’ profile, clinicians may consider that the failure to respond to initial measures (including intubation and ventilation) would indicate that the baby now has an ‘extremely high risk’ of adverse outcome, and that it would be in their best interests to move to comfort focused care (Wilkinson, 2020).
- 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 stabilisation, contact (for example cuddles), may provide positive experiences for parents and can be considered where feasible and appropriate. 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.

Where babies are born in much poorer condition than expected it may be appropriate to reconsider the planned provision of survival focused care and to move to comfort focused care (see Appendix 2 and 3). Absent heart rate or severe bradycardia persisting despite *effective* resuscitation for more than a few minutes is associated with high rates of mortality and neurodevelopmental impairment in extremely preterm babies (Wyckoff, 2012, Haines*,* 2016). The most senior experienced attending professional should decide if or when attempts to stabilise and/or resuscitate the baby should stop (McGrath, 2016, Wilkinson 2020).

Extreme preterm babies born out of hospital should have been managed according to the BAPM Framework 'Pre-hospital management of the baby born at extreme preterm gestation'. Deferred cord clamping and mask ventilation via a self-inflating bag is advised and ideally the baby should arrive in a plastic bag, swaddled in a blanket on a thermal mattress. The provision of thermal care and mask ventilation en route does not mean that the hospital team are obliged to provide ongoing survival focussed care following admission to hospital. Management subsequently should be guided by the same principles as described above. For more detail see Appendix 3.

## Comfort focused neonatal care

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

The aim of comfort focused 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. (Bliss 2024) An Individualised Care Plan should be made in partnership with parents following guidance (Larcher, 2015) within the BAPM Framework: 'Recognising uncertainty: an integrated framework for palliative care in perinatal medicine'.

Depending on parents' wishes and service provision, a senior neonatologist or paediatrician may be present at birth 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. Please refer to the MBRRACE-UK Guidance 2020 Determination of signs of life following spontaneous birth before 24+0 weeks of gestation where, following discussion with the parents, active survival-focused care is not appropriate. Parents should have been counselled that the baby may show signs of life after birth including visible heartbeat, gasping and/or movement of limbs but also that some babies who have died before birth may show brief reflex movements.

In the rare scenario of the baby being born in much better condition than expected, comfort focused management may need to be reconsidered (see Appendix 3 for further discussion).

Babies born before 24 weeks of gestation who receive comfort care following birth may live for between a few minutes to several hours (Macfarlane*,* 2003). 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, referring to the BAPM Framework: 'Recognising uncertainty: an integrated framework for palliative care in perinatal medicine'. 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, the national Child Death Review process, 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 (Together for Short Lives). In England, this will include mandatory discussion with local medical examiners (NHS England Medical Examiners System). In England and Scotland this should follow the guidance outlined in the National Bereavement Care Pathway (NBC Pathways). 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 GP, 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 (BAPM Framework 'Lactation and loss'). 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 contribute to a multi-professional perinatal mortality review process that follows the framework set out in published statutory and operational guidance (NBC Pathways in England and Scotland, 2022). At an appropriate time, the prognosis for future pregnancies should also be discussed.

## Implications of this framework for Transport/LNU and SCU teams

Babies less than 27 weeks gestation should be delivered wherever possible in a hospital with a NICU. If extremely preterm babies are born in an LNU or SCU, this will increase their risk of death and adverse outcome. Effective in utero transfer processes and adequate capacity in receiving centres are a vital part of the care for these babies.

Given the impact of place of birth on outcome, most babies born prior to 23 weeks gestation in a maternity unit without a colocated NICU (ie an LNU or SCU) will be **extremely high risk**. UK data indicates extremely low survival rates for babies transferred ex-utero at this gestation. As a consequence, for such babies neonatal management focused on comfort should be provided, and it would usually **not** be appropriate to retrieve and transfer ex-utero. Decision making in such cases should be made in a collaborative way, with LNU and /SCU teams supported by NICU and neonatal transport colleagues, ideally using conference calling.

Transport teams should ensure that teams dispatched to extreme preterm uplift transfers have an optimum composition with a suitably experienced and senior team lead.

Transfer timing will be dependent on the condition of the newborn but it is expected that transport teams dispatch promptly for extreme preterm babies born outside of a hospital with a NICU. Transfer should take place when adequate stability has been achieved.

### Implementation of this Framework for Practice

A lead team should be identified in each maternity and neonatal facility with responsibility for implementation, education, and dissemination of this updated Framework for Practice and the accompanying parent information. This is likely to be best placed within the designated Preterm Birth Lead Team (Saving Babies' Lives Care Bundle Version 3).

Links to relevant national documents are provided within this document; these should be highlighted and made easily available within each perinatal 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. Some example cases with application of the framework are offered in Appendix 2, with additional discussion of challenging scenarios in Appendix 3 and a suggested format for parental information is to be found in Appendix 4.

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. Following birth, the mother should be accommodated in a maternity facility adjacent to her baby.

## Recommendations for audit and research

There is limited research evidence to inform optimal perinatal management of extreme preterm birth, resulting in variation in care and outcomes. In particular, babies born at the lowest gestational ages (<24 weeks) are poorly represented in most research studies, and it remains unclear whether this cohort are embryologically and physiologically different, and require a different approach.

BAPM recommend that neonatal units who care for extremely preterm babies should participate in national audit and research activities, in addition to reviewing their own local outcomes. Specifically, given the small number of babies born at 22 weeks in each unit, a national perinatal approach is necessary to meaningfully build knowledge and experience, to improve care and outcomes (BAPM Nanopreterm Special Interest Group). National registries of outcomes (for example of babies receiving advanced resuscitation) may support and drive further research.

The Working Group propose the following research questions:

- What additional information or tools will help inform decision making around perinatal care (including mode of birth and neonatal management) at the time of counselling?
- Whether and how are babies born at 22-24 weeks different to babies born 25-26 weeks gestation? Should their care approaches be different?
- What are the long-term outcomes, for the baby as well as family, how are they affected by socio-economic determinants, and what additional health, educational and social care resources are needed to support families and babies born extremely preterm?
- An international research priority setting partnership identified priorities for extremely preterm babies born less than 25 weeks (Peart, 2025). The most important research question identified was ‘what can be done in the neonatal intensive care unit to improve long-term health and developmental outcomes?’. Other important areas for research included antenatal interventions and neonatal care at birth, preventing intraventricular haemorrhages, managing pain, postnatal corticosteroid treatment and supporting families.

# Appendix 1: Outcomes for extremely preterm babies

## International comparisons (Table 1: 22 to 25 weeks gestation) and UK data (Table 2: 22 to 26 weeks gestation)

### Survival/Mortality

International studies indicate incremental improvements in survival for the most premature babies over the last 1-2 decades. Since the 2019 BAPM framework, an increasing number of multi-centre, population studies and meta-analyses have reported survival figures for babies born extremely preterm including at 22 weeks gestation. Table 1 shows published UK population data (England and Wales) up until 2021 alongside international data; colour coded to indicate whether studies are population based or limited to tertiary and quarternary centres. Even more recent data from 2023 in the UK National Neonatal Audit Programme Report show unchanged survival to 44 weeks post menstrual age for babies at 22 and 23 weeks gestation, with a continued increase in the absolute number of admissions and survivors at 22 weeks gestation until 2023 (NNAP 2023).

International comparisons should be interpreted with caution, given differences in the provision of survival focused care, how survival is reported, the type of neonatal units (e.g. only including inborn babies born in tertiary centres versus all units serving a population), denominator populations, and differences in attitudes and practice. A meta-analysis published in 2024 reviewed survival figures for babies born 22-25 weeks gestation. Among high income countries, there was wide variation in survival estimates of live born babies (from 7% (95% CI 5 – 10) at 22 weeks and 49% (43-54) at 24 weeks of gestation); with higher survival among those admitted to neonatal intensive care (30% (25-36) at 22 weeks , 61% (57-64) at 24 weeks) (Table 1).

Survival in absolute numbers has increased among those born at the lowest gestational ages admitted to neonatal units. In particular, at 22 weeks of gestation, the most recent cohort studies from US, Sweden and Japan indicate that survival to discharge of livebirths range from 24% in US, 39% Sweden, to 46% in Japan. Survival figures are higher among those provided with survival focussed care in US (36%) or admitted to neonatal intensive care in Sweden (46%) and Japan (51%). (Table 1). A meta -analysis which focused on babies born at 22 weeks receiving proactive treatment found a pooled prevalence of 29.0% survival (95% CI 17.2-41.6; 31 studies, 2226 babies, 13 countries). Importantly, the studies included births 1991-2016, which reflects a time in some settings when survival focused care may not be commonly practiced, and need to be interpreted with caution (Backes, 2021).

The reported survival rates varied greatly among studies and were likely influenced by combining observational data from disparate sources, lack of individual patient level data, and bias in the component studies from which the data were drawn. There may also be differences in population characteristics, as shown by recently published UK data (Smith, 2023), which showed an increase in the proportion of babies born at 22 weeks with less favourable characteristics for survival (e.g. born in the first half of the 22nd week, weighing less than 500g, not born in a tertiary centre, no antenatal steroids).

**Table 1. Outcomes for extremely preterm babies: international comparisons. Born 22 to 25 weeks gestation**

| Country (Reference) | Unit Type | Years of Birth Included | Survival assessment timepoint | Denominator | Survival (95% CI) | | | |
|---|---|---|---|---|---|---|---|---|
| Gestation (completed weeks) | | | | | 22w | 23w | 24w | 25w |
| UK<br>(Smith, 2023) | All babies, all units | 2020-21 | Discharge from neonatal care | Live births | 12%<br>(9-16) | 40%<br>(36-44) | 69%<br>(66-72) | 78 %<br>(76-81) |
| | | | | Survival focused care | 21%<br>(15-27) | 42%<br>(38-46) | 69%<br>(66-72) | 78%<br>(76-81) |
| | | | | Neonatal unit admissions | 30%<br>(21-37) | 48%<br>(43-52) | 72%<br>(69-76) | 80%<br>(78-82) |
| | | | | | | | | |
| Sweden<br>(Farrooqi, 2023) | All babies, all units | 2017-19 | 1 year of age | Live births | 39%<br>(28-50) | 67%<br>(57-75) | Not reported | Not reported |
| | | | | Neonatal unit admissions | 46%<br>(34-59) | 70%<br>(61-78) | Not reported | Not reported |
| | | | | | | | | |
| Japan<br>(Kono, 2018) | Inborn, selected NICUs | 2008-12 | Discharge from neonatal centre | Live births | 46%<br>(40-52) | 73%<br>(71-77) | 85%<br>(82-87) | Not reported |
| | | | | NICU admissions | 51%<br>(45-58) | 75%<br>(72-78) | 85%<br>(83-88) | Not reported |
| | | | | | | | | |
| USA<br>(Edwards, 2024) | Inborn, selected NICUs | 2020-22 | Discharge from hospital | Live births | 24%<br>(23-26) | 52%<br>(51-54) | 70%<br>(69-71) | 81%<br>(80-82) |
| | | | | Postnatal life support | 36%<br>(34-38) | 55%<br>(54-56) | 72%<br>(71-73) | 82%<br>(80-82) |
| | | | | | | | | |
| Meta-analysis<br>(Li, 2024) | High income countries | 2000-20 | Pooled survival (discharge or at 1-3 years old, latest follow up assessment) | Live births | 7%<br>(5-10) | 26%<br>(22-31) | 49%<br>(43-54) | 68%<br>(63-72) |
| | | | | NICU admissions | 30%<br>(25-36) | 44%<br>(41-48) | 61%<br>(57-64) | 74%<br>(70-77) |

**Key**

| | |
|---|---|
| 🟪 | National level data |
| 🟦 | Inborn tertiary/quarternary level NICUs only |
| 🟩 | Meta-analysis data |

*** International Survival Data Search Strategy:** A search using Pubmed was conducted including English language results between 2018 and 2025 using the search terms below (in Title/Abstract). Each country/ network was then added to the search to look for national data. No limitation to the type of study was applied.

22 OR 23 OR 24 OR 25 OR 26 AND week(s) OR extreme(ly) preterm OR premature* OR periviable OR limit viability AND survival OR death OR mortality OR outcome(s) , Then AND ‘Country’ or ‘Vermont Oxford Network’ or VON or ‘National Institute of Child Health and Development’ or ‘NICHD’ or “systematic review”

Confidence intervals where not given by papers were calculated using figures using online CI calculator. Kohn MA, Senyak J. Sample Size Calculators [website]. UCSF CTSI. 28 September 2024. Available at https://www.sample-size.net/ [Accessed 01 October 2024]

**UK figures survival for babies born extremely preterm 22-26 weeks gestation (Table 2)**
The latest survival and outcomes data from births in England and Wales for years 2020-2021 are presented in Table 2. Survival has increased steadily and survival focused care has also increased and is provided to 94% (CI 93-96) of babies at 23 weeks and 42% (CI 37-47) of live births at 22 weeks of gestation. (Smith, 2023). 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.

**Table 2. England and Wales births and outcomes born 22 to 26 weeks gestation**

| | Births in 2020-2021 | | | | |
|---|---|---|---|---|---|
| Gestational Week | 22 weeks | 23 weeks | 24 weeks | 25 weeks | 26 weeks |
| **All births** | 727 | 892 | 993 | 1081 | 1403 |
| **Alive at onset of labour** | 477 | 655 | 751 | 833 | 1169 |
| **Live births** | 319 | 559 | 700 | 802 | 1144 |
| As a % of births alive at onset of labour (95% CI) | 66.9%<br>(64.1 to 69.8) | 85.3%<br>(83 to 87.6) | 93%<br>(91.3 to 94.7) | 96.3%<br>(95.1 to 97.5) | 97.9%<br>(97.1 to 98.7) |
| **Receiving active care/ survival focused care** | 183 | 528 | 700 | 800* | 1139** |
| As a % of births alive at onset of labour | 38.4%<br>(34 to 42.7) | 80.6%<br>(77.6 to 83.6) | 93.2%<br>(91.4 to 95) | 96%<br>(94.7 to 97.3) | 97.4%<br>(96.5 to 98.3) |
| As a % of live births | 57.4<br>(51.9 to 62.8) | 94.4<br>(92.6 to 96.4) | 100.0<br>(100.0 to 100.0) | 99.4<br>(98.9 to 99.9) | 99.5<br>(99.1 to 99.9) |
| **Admitted for neonatal care** | 134 | 467 | 669 | 785 | 1121 |
| As a % of births alive at onset of labour | 28.1%<br>(24.1 to 32.1) | 71.3%<br>(67.8 to 74.8) | 89.1%<br>(86.9 to 91.3) | 94.2%<br>(92.7 to 95.7) | 95.9%<br>(94.8 to 97) |
| As a % of live births | 42%<br>(36.6 to 47.4) | 83.5%<br>(80.5 to 86.6) | 95.6%<br>(94 to 97.1) | 97.9%<br>(96.9 to 98.9) | 98%<br>(97.2 to 98.8) |
| As a % of babies receiving survival focused care | 73.2%<br>(66.8 to 79.6) | 88.4%<br>(85.7 to 91.2) | 95.6%<br>(94 to 97.1) | 98.1%<br>(97.2 to 99) | 98.4%<br>(97.7 to 99.1) |
| **Survival to discharge** | 39 | 222 | 483 | 626 | 966 |
| As a % of births alive at onset of labour | 8.2%<br>(5.7 to 10.6) | 33.9%<br>(30.3 to 37.5) | 64.3%<br>(60.9 to 67.7) | 75.2%<br>(73 to 77.4) | 82.6%<br>(80.8 to 84.4) |
| As a % of live births | 12.2%<br>(8.6 to 15.8) | 39.7%<br>(35.7 to 43.8) | 69.0%<br>(65.6 to 72.4) | 78.1%<br>(75.9 to 80.4) | 84.4%<br>(82.6 to 86.2) |
| As a % of babies receiving survival focused care | 21.3%<br>(15.4 to 27.2) | 42.0%<br>(37.8 to 46.3) | 69.0%<br>(65.6 to 72.4) | 78.3%<br>(76.1 to 80.6) | 84.8%<br>(83.1 to 86.6) |
| As a % of those admitted to neonatal units | 33.3%<br>(18.5 to 48.1) | 47.5%<br>(43.0 to 52.1) | 72.2%<br>(68.8 to 75.6) | 79.7%<br>(77.5 to 82) | 86.2%<br>(84.5 to 88) |

*Including 3 intrapartum stillbirths **Including 1 intrapartum stillbirth

Source: Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries (MBRRACE-UK) and the National Neonatal Research Database (NNRD)
Adapted table (Smith, 2023) with additional data on births at 25,26 weeks from NNRD and MBRRACE-UK.

## Severe impairment

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 (Gallagher, 2001, Gallagher, 2016). What for one individual or family may be an acceptable outcome may not be so for another.

The severe impairment category defined by 2008 BAPM Working Group includes any of:

- Severe cognitive impairment with an IQ lower than 55 (< -3 standard deviation); 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 (GMFCS) grade 3 or greater. GMFCS grade 3 is walks with assistive mobility devices indoors and outdoors on level surfaces, May be able to climb stairs using a railing, may propel a manual wheelchair; may require assistance for long distances or uneven surfaces.
- Blindness or profound hearing impairment.

## Two-year neurodevelopmental outcome data for recent cohorts

The previous BAPM 2019 framework presented prevalence of severe neurodevelopmental impairment assessed using standardised Bayleys assessment for the EPICure2 cohort born in 2006. However, more recent national data show that only 40% of babies born less than 30 weeks in England and Wales have a standardised e.g. Bayleys or Griffiths neurodevelopmental assessment conducted (van Blankenstein*,* 2024). National data show that of 41 505 babies born less than 30 weeks gestation over the 11-year period 2008-2018 in England and Wales, 24 125 (58%) had a 2-year neurodevelopmental assessment recorded. Completeness improved from 32% in 2008 to 71% in 2018; completeness was around 70% in 2014-2018. The majority (>=87%) of babies were assessed using functional versus standardised neurodevelopmental assessments. Whilst there are recognised limitations to non-standardised neurodevelopmental assessments, they provide meaningful functional outcomes of babies receiving contemporary neonatal care.

Functional assessments comprised parent reported outcome measures and health professional assessment in the following neurodevelopmental domains: visual, auditory, communication and neuromotor, each graded as 'impairment' or 'no impairment'. In addition, health professionals provide an overall developmental outcome; 'normal' (<3 months delay), 'mild' (3–6 months delay), 'moderate' (6–12 months delay) and 'severe' (>12 months delay).

Table 3 reports the incidence of 'severe impairment' based on the definition "unable to walk without assistance or blind or hearing impairment not correctable" following a re-analysis of data from a published study that maps to this definition (van Blankenstein*,* 2024). The risk of severe impairment increases with increasingly preterm birth and is around one in seven at 24 weeks of gestation, and one in four at 23 weeks of gestation for those babies born who receive survival focused care and survive. Rates of impairment were higher for the earlier gestation group across all domains, and there was no improvement over time. Relatively few babies born at 22 weeks of gestation have available long term outcome data, which means estimates of rates of outcomes are imprecise. However, evidence from other studies show that the proportion of babies born at 22 weeks with severe impairment is at least 30%.

## UK data informed revised estimates of survival outcomes (Table 3 2008-2018 birth cohort)

**$22^{+0}$ - $22^{+6}$ weeks:** **1-in-3 survivors has severe impairment**
**$23^{+0}$ - $23^{+6}$ weeks:** **1-in-4 survivors has severe impairment**
**$24^{+0}$ – 24+6 weeks:** **1-in-5 survivors has severe impairment**
**$25^{+0}$ - $25^{+6}$ weeks:** **1-in-9 survivors has severe impairment.**
**$26^{+0}$- $26^{+6}$ weeks:** **1-in-12 survivors has severe impairment.**

Where '**severe impairment'** is defined as being unable to walk without assistance and/or blind, and/or hearing impairment which is not correctable at two years old.

**Table 3. Incidence of 'severe impairment': England and Wales births 2008-2018 (Adapted from van Blankenstein, 2024)**

| Gestation (completed weeks) | Severe developmental delay (over 12 months)<br>n<br>% (95% CI) | | Unable to walk without assistance<br>n<br>% (95% CI) | | Less than 5 words<br>n<br>% (95% CI) | | Blind or only sees light<br>n<br>% (95% CI) | | Hearing impairment not correctable<br>n<br>% (95% CI) | | Severe impairment<br>n<br>% (95% CI) | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | N with data | Impairment | N with data | Impairment | N with data | Impairment | N with data | Impairment | N with data | Impairment | N with data** | Impairment |
| 23 | 527 | 120<br>22.8%<br>(19.4 to 26.5) | 576 | 104<br>18.1%<br>(15.1 to 21.4) | 554 | 175<br>31.6%<br>(27.9 to 35.6) | 552 | 7<br>1.27%<br>(0.62 to 2.59) | 549 | 16<br>2.91%<br>(1.80 to 4.68) | 547 | 114<br>20.8%<br>(17.7 to 24.4) |
| 24 | 1404 | 198<br>14%<br>(12 to 16) | 1542 | 216<br>14%<br>(12 to 16) | 1492 | 366<br>25%<br>(22 to 27) | 1471 | 11<br>0.7% (0.4 to 1.3) | 1452 | 26<br>1.8%<br>(1.2 to 2.6) | 1438 | 234<br>16.3%<br>(14.5 to 18.3) |
| 25 | 2007 | 186<br>9.3%<br>(8.1 to 11) | 2241 | 240<br>11%<br>(9.9 to 12) | 2189 | 408<br>19%<br>(17 to 20) | 2140 | 14<br>0.7%<br>(0.4 to 1.1) | 2132 | 21<br>1.0%<br>(0.6 to 1.5) | 2101 | 263<br>12.5%<br>(11.2 to 14.0) |
| 26 | 2873 | 215<br>7.5%<br>(6.6 to 8.5) | 3255 | 267<br>8.2%<br>(7.3 to 9.2) | 3177 | 456<br>14%<br>(13 to 16) | 3146 | 16<br>0.5%<br>(0.3 to 0.8) | 3125 | 33<br>1.1%<br>(0.7 to 1.5) | 3078 | 292<br>9.49%<br>(8.5 to 10.6) |

*Only 20 children born at 22 weeks were followed up at 2 years, hence not included in the table
**Adapted table from van Blankenstein*,* 2024, CI calculated by the study authors

## International neurodevelopmental outcomes in preterm born babies

A search using Pubmed was conducted including English language results between 2018 and 2025. Each country was then added to search for national data. No limitation to the type of study was applied. We did not include single centre or regional studies. Definitions of 'severe NDI' can vary between assessments and reports so care should be taken when interpreting these figures, especially where there are small numbers of patients assessed.

Severe neurodevelopmental impairment at 22 weeks ranged from 36% to 52% among babies born at 22 weeks, and 21% to 42% for babies born at 23 weeks.

### Table 4. International neurodevelopmental outcomes in preterm born babies

| Country | Unit types | Method of assessment | Years | Assessment timepoint | Level of NDI Reported | NDI in Assessed Survivors (95% Confidence Interval) | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | 22w | 23w | 24w | 25w | 26w |
| Sweden§ (Serenius 2013) | All babies, all units | BSID III | 2004-2007 | 30 months | Severe | N = 5<br>**40%**<br>(5-85) | N = 47<br>**21%**<br>(11-36) | N = 86<br>**13%**<br>(7-22) | N = 151<br>**10%**<br>(5-16) | N = 167<br>**7%**<br>(4-12) |
| Japan¶ (Kono 2018) | Inborn, selected NICUs | GMFCS and KSPD | 2008-2012 | 36-42 months | NDI* | N= 77<br>**52%**<br>(40-63) | N = 308<br>**42%**<br>(36-48) | N = 447<br>**34%**<br>(30-39) | - | - |
| US* (Bell 2022) | Selected academic NICUs (NICHD) | BSID III | 2013-2016 | 22-26 months | Severe | N = 29<br>**31%**<br>(15-51) | N = 278<br>**34%**<br>(28-40) | N = 539<br>**29%**<br>(25-33) | N = 695<br>**18%**<br>(15-21) | N = 878<br>**15%**<br>(12-17) |
| Meta-analysis (Myrhaug, 2019) | High income countries | BSIDII or III | 1994-2017 | 18-36 months | Severe | N = 44<br>**36%**<br>(24-51) | N = 316<br>**22%**<br>(12-38) | N = 968<br>**19%**<br>(11-31) | N = 1441<br>**14%**<br>(10-19) | N = 1683<br>**8%**<br>(4-18) |

**Key**

🟪 National level data

🟦 Inborn tertiary/quarternary level NICUs only

🟩 Meta-analysis data

**Footnotes on neurodevelopmental impairment (NDI) Categorisation**
§Reporting severe NDI, defined as any of BSID III composite cognitive, language or motor score <55 (<3SD), severe cerebral palsy unable to walk even with an aid, bilateral blindness or deafness.
¶Grouped neurodevelopmental impairment (not 'severe' NDI). NDI defined as cerebral palsy with ability to walk using aids or more severe (GMFCS >2), visual impairment, hearing impairment, DQ <70 on KSPD (= BSIDIII <85/ <1SD) or delay assessed by physicians where child not fully evaluated.
*Severe NDI, defined as BSID III cognitive composite or motor composite score <70 (<2SD), limited walking even with an aid (GMFCS >3), bilateral blindness or bilateral severe functional hearing impairment.

N is number of children evaluated (not including those lost to follow up). NDI Neurodevelopmental Impairment, BSID Bayley Scales of Infant Development, GMFCS Gross Motor Function Classification System, KSPD Kyoto Scale of Psychological Development, DQ Developmental Quotient. CIs calculated by framework authors where not provided in individual publication(s). CIs were calculated using Online CI calculator. Kohn MA, Senyak J.

Search terms: Extreme(ly) preterm OR extreme prematurity OR extremely premature OR limit viability OR periviable
OR 22 week* OR 23 week* OR 24 week* or 25 week* or 26 week* AND neurodevelopment* OR developmental disability* OR mortality OR survival OR child development OR cerebral palsy OR Bayley scale OR gross motor function classification OR gmfcs OR cognition Or hearing loss Or vision disorders

## Appendix 2: Example case scenarios

### C1. Counselling at 22+6 weeks, unfavourable risk factors, maternity unit with co-located NICU

A woman presents to a maternity unit co-located with a NICU at 22+6 weeks gestation in imminent labour. She had ruptured her membranes three weeks earlier at 19 weeks gestation, with subsequently oligo/anhydramnios. There is maternal pyrexia, with suspected chorioamnionitis and there has been insufficient time to give antenatal steroids before the baby is born. She has a singleton male baby with an estimated weight of 490g.

*Recommended considerations and actions:* Whilst this baby is anticipated to be born towards the end of week 22, added unfavourable risk factors place this baby at extremely high risk of death or severe impairment if born today. The rationale for comfort care should be explained. Maternal focused obstetric care should be provided (it should be noted that there is high maternal morbidity in this scenario.)

*Outcome:* The baby is born later that day (birth weight 530g). Paediatricians are not present at the birth. Only brief reflex movements are observed in the first minute, and consequently this is not registered as a live birth (MBRRACE-UK Guidance 2020 Determination of signs of life following spontaneous birth before $24^{+0}$ weeks of gestation where, following discussion with the parents, active survival-focused care is not appropriate). His family is supported by bereavement midwives.

### C2. Counselling at 23+6 weeks, favourable risk factors, maternity unit with co-located NICU

A woman is transferred to a maternity centre with a co-located NICU 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 baby 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 birth, the woman expresses that she is very concerned about the possibility of the baby surviving with severe disability. She requests no survival focused obstetric management, and comfort focused care of the baby at birth.

*Recommended considerations and actions:* The neonatal team should explore the woman and her partners’ concerns and provide information about the nature and risks of severe disability for her baby. They should advise the couple that, taking all factors into account, her baby would have a moderate risk of dying or of severe disability. It would be recommended to provide survival focused care 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. She should also be advised that until 24 weeks gestation the option of termination of pregnancy would be legal and could be discussed with the obstetric team

*Outcome*: The woman agrees to the plan for survival focused care and the baby is born a few hours later, receives stabilisation in the birth room and is transferred to the neonatal intensive care unit.

### C3. Counselling at 24 weeks, fetal growth restriction, local neonatal unit

A woman has been admitted to a local maternity unit (LNU) in preterm labour at $24^{+3}$ weeks of gestation. The singleton male baby is very small with an estimated weight of 450 grams. The woman has not yet received antenatal steroids. The on-call paediatric team is asked to provide counselling and attend the birth.

*Recommended considerations and actions:* As per the Framework, the first step is to assess the risk for the baby if birth occurs. At a gestation of $24^{+3}$ weeks, the average survival rate for liveborn babies in the UK (if survival focused 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 baby 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 profile. Given the risk for the baby, 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 survival focused obstetric and neonatal management if that were desired by the parents. However, it would also be appropriate to provide comfort focused care, if that was felt by the parents to be in the baby's best interests.

*Outcome:* In this case, the parents decide after consultation that they wish the baby to receive comfort focused care. Labour progresses and a baby is born showing signs of life and 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 comfort focused care. The baby is wrapped and given to his parents to hold. He dies at approximately 30 minutes of age. The family are supported by bereavement midwives and neonatal palliative/bereavement care team.

## C4. Counselling at 22+0 weeks, SCBU and comfort care

A woman 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 baby is 510g.

*Recommended considerations and actions*: In this situation, there is an extremely high risk of poor outcome for this baby if birth occurs within a short period of time. The woman and her partner should be informed of the likely outcome, and advised that if baby is born in the near future (as appears likely) intensive medical treatments would not help baby. If birth occurs in the next day or two, baby will be provided with comfort focused care.

The woman's partner asks if there isn't anything the neonatal team could do to save the baby.

The neonatal team should sensitively explain that if their baby arrives today, the baby would be too immature and fragile to save them. However, if birth does not occur imminently, and the baby stays in utero for even a few days, antenatal steroids and transfer to a hospital with a NICU can be considered. In that situation, the risk for the baby would still be very high, but survival focused neonatal care may be an option.

The option and timing of in utero transfer and steroids should be discussed with the local maternity centre with co-located NICU. Transfer and steroids should be considered at the point where active survival focused care would be appropriate if delivered in the maternity centre with co-located NICU.

*Outcome:* Labour progress in the next 24 hours. The woman is supported with obstetric management focused on maternal wellbeing, and the baby is born with no signs of life.

## C5. Counselling at 22+3 weeks, labour without chorioamnionitis, in utero transfer from LNU to NICU

A woman presents in preterm labour to a maternity centre without a co-located NICU (eg a Local

Neonatal Unit or Special Care Unit setting) at $22^{+3}$ weeks of gestation. The baby was conceived by IVF and gestation is certain. The baby is female and has an estimated fetal weight of 480 grams. The woman has not yet received antenatal steroids. The paediatric team is asked to provide counselling and attend the birth.

*Recommended considerations and actions:* 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 recommended to provide comfort focused care at birth. The neonatal team may attend the birth to provide support for comfort focused 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 temporarily with tocolysis and so, if the parents desire, a survival focused approach to management, antenatal transfer and corticosteroids could be provided. If desired by parents, this should be expedited, as the baby would likely remain extremely high risk if they are born in the LNU prior to 23 weeks.

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" profile. Accordingly, after further consultation with parents, it would be appropriate to support survival focused management if this is what parents wish.

*Outcome:* In this case, the parents decide that they wish the baby to receive survival focused neonatal care, magnesium sulphate is given, and a baby is born showing signs of life and weighing 490 grams. The baby is intubated, receives surfactant and is transferred to neonatal intensive care.

## C6. Counselling 25+2 and declines in utero transfer to NICU

A woman presents to her local maternity unit (SCBU) at $25^{+2}$ weeks of gestation in early labour. She has a well grown female baby. 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 considerations and actions*: 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 woman does not wish to be transferred and to address all of her concerns. If the woman still refuses transfer she cannot be moved, but she should be offered magnesium sulphate and counselled that the baby will be moved after birth. 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 woman 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 birth.

*Outcome:* The baby is born 24 hours later in the SCBU. The local team provide survival focused care, including thermal management and non-invasive respiratory support. The local transport team are called, and transport the baby to the closest NICU.

# Appendix 3: Situations of uncertainty and potential conflict: recommended considerations and actions

## S1. 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 transferred 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 management. 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 survival focused neonatal care and to reassess the situation in the ensuing minutes, hours and days. It is noted that using condition at birth to assess either gestation or risk of poor outcome is not reliable (Manley, 2010).

## S2. 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 birth, but redirecting to comfort focused care if the baby appears very immature or responds poorly to stabilisation (for example remains severely bradycardic despite intubation and intermittent positive pressure ventilation). Some extremely preterm babies will present to hospital after having been born in the out-of-hospital setting and having been managed according to the relevant BAPM pre-hospital framework. (See also Appendix 3 S8)

## S3 Baby born in unexpectedly good condition

In the rare circumstance where 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 comfort focused approach is still appropriate. (NB The presence of a heart rate/breathing do not automatically indicate a better prognosis). Stabilisation should not be delayed if deemed in the baby's best interests.

## S4. Baby born in unexpectedly poor condition

When survival focused neonatal care 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 empathetically but unambiguously to parents, and comfort focused care recommended.

## S5. Parents requesting survival focused care in settings of extremely high risk.

Where preterm birth has been assessed to be at extremely high risk of poor outcome, comfort focused care would be appropriate and the rationale for not providing survival focused care should be explained. For example, this would apply to an baby being born at the start of the 22nd week of gestation, in a centre without a co-located NICU and without antenatal steroids.

In such situations, if parents request or insist on survival focused care, attending neonatologists should sensitively explain that sadly it appears that baby is arriving too early. If birth is able to be delayed for even a few days, other options can be revisited. (see Appendix 2, C3, C4).

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, RCPCH guidance around dealing with conflict may be helpful (RCPCH 2019).

### S6. Parents requesting comfort focused care in settings of moderate risk.

Where preterm birth is anticipated and has been assessed to be at *moderate* risk of poor outcome, survival focused care would be appropriate, and the rationale for providing this should be explained. Rarely, parents may request or insist that comfort focused care be provided notwithstanding the clinical recommendation (see Appendix 2, Case 2).

In such situations, identifying and addressing parents' concerns will usually enable agreement to be reached. Parents should be reassured that after birth, if baby's outlook worsens (for example if he or she responds poorly to treatment or develops severe complications), that there will be further discussions and potentially the option of withdrawing or withholding treatment.
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, RCPCH guidance around dealing with conflict may be helpful (RCPCH 2019).

### S7. Threatened birth before $22^{+0}$ weeks of gestation

Where gestational age is certain and is below $22^{+0}$ weeks, it would not be considered in the best interests of the baby, to offer survival focused care. If birth is imminent, there would be no benefit (to the baby) in arranging transfer of the woman to a centre with a co-located NICU. If it is possible that the birth may be delayed to a point where survival focused care of the baby would be planned, transfer of the woman to a maternity unit adjacent to a neonatal intensive care unit should be considered. In individual cases, it may be helpful for parents to speak with neonatal teams to understand options if delivery does not occur imminently, and/or to discuss comfort care.

### S8. Born outside of hospital

If a maternity unit receives a call regarding a woman in preterm labour who is imminently delivering or if a preterm baby has been born prior to arrival at hospital the caller should be recommended to call an ambulance.

The ambulance clinicians will follow JRCALC (Joint Royal Colleges Ambulance Liaison Committee) guidelines to provide care to the woman and baby. These guidelines are aligned to the BAPM Framework: "Pre-hospital management of the baby born at extreme preterm gestation". Where gestation is uncertain, ambulance clinicians should begin to provide survival focused care (see S1). The prehospital guidelines closely reflect the content of this document, but interventions will likely be limited to facemask ventilation with a self-inflating bag and thermal care with a plastic bag, thermal mattress, swaddling and foil blanket. A pre-alert should be placed to the receiving hospital, as directed by their local policies.

Hospital staff receiving babies from the ambulance service should be prepared to greet the ambulance crew immediately and assess the baby on arrival. Further management should be in accordance with the principles in this framework based on a full assessment of the situation and the baby's condition on handover. The provision of thermal care and mask ventilation en route does not mean that the hospital team is obliged to provide ongoing survival focussed care following admission to hospital. Birth outside hospital will often be associated with significantly increased risk of mortality and morbidity. Where it is clear following assessment that the baby is at extremely high risk of poor outcome, this should be sensitively communicated to parents and the baby should be provided with comfort focused care. Should the woman be travelling separately to her baby, care should be continued if possible pending her arrival.

On occasion, a prehospital critical care team may be involved, and in these cases interventions may include intubation. Networks should liaise with teams providing this care to establish pathways for providing remote support and guidance.

It should be recognised by hospital staff that for ambulance personnel this will be an extremely rare occurrence and a situation with which they are unfamiliar. As such it will be a profoundly stressful situation for them and care should be taken to ensure that communication is respectful and sensitive. Ambulance clinicians and emergency department staff should not be expected to counsel parents regarding likely outcomes and options regarding ongoing management; this would be the role of the neonatal, obstetric and midwifery teams. Pre hospital clinicians should be encouraged and supported to attend the Out of Hospital NLS (OHNLS) courses available through the Resuscitation Council UK to gain further expertise in this area. A rapid ‘hot’ debrief of the clinicians involved may be helpful.

## S9. Live birth following termination of pregnancy in obstetric setting

Rarely, neonatal teams may be called by the maternity teams to attend an extremely preterm baby (for example at 22 or 23 weeks gestation) who is liveborn following a termination of pregnancy. It is important to clarify the reason for requesting attendance of the neonatal team. This may be in order to confirm the presence of signs of life. In that case, it is preferable for the baby to be seen by a member of the obstetric team, rather than the neonatal team to avoid confusion and to support notification to the coroner (required for all live births following termination of pregnancy) (RCOG Position Statement 2023). A National Bereavement Care Pathway for Termination of Pregnancy for Fetal Anomaly (also referred to as ‘medical reasons’) is also available for reference (NCBP ToPFA, 2022).

If a neonatal team does attend the birth, the same principles for care of the baby apply as to any extremely preterm birth. Because of the gestation of such births (almost all will fall into the Extremely High Risk profile) and the nature of parental wishes, comfort-focused care should be provided.

## Appendix 4: Communication: Guidance for professionals consulting with families at risk of extreme preterm birth.

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 where possible. Written information should *never* be used as a stand-alone information sharing tool, but can be helpful given the difficulty in retaining information in medical consultations.

It is the role of professionals to ensure that parents facing potential preterm birth can be equal partners in care and decision-making for their babies. This will involve providing parents with information about the risks associated with their baby's birth, and possible treatment options. You should be led by parents as to the level of detail of information they wish to hear.

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:

- **Extremely high risk** profile: 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 obstetric care focused on maternal wellbeing and comfort focused neonatal care. 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 comfort focused care takes place.
- **High risk** profile: 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 the information they need to be part of the decision making process and should have as much time as possible, and where possible, 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.
- **Moderate risk** profile: 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 survival focused care 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 survival focused treatment is managed.

Thus, consultation is most critical where birth would be associated with a high risk of a poor outcome (see main text). In such situations, parents need support to make an informed choice about the provision of either survival focused or comfort focused 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 (Young, 2012, Kharrat, 2018) 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 woman 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 (Kharrat, 2018, Kaempf, 2009). Parents may also find the advice from psychology professionals, 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 with compassion and with clarity. 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 survival focused 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. 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 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, can be difficult.
5. ***Discussing Comfort focused Care –*** Where appropriate, the practicalities of commencing, withholding and withdrawing intensive care and the positive role of comfort focused care should be described to the parents. This will help prepare them for possible outcomes after the birth. Signs of life may or may not be present after birth. If present, the length of time

that the baby may show signs of life will vary (MBRRACE-UK). It can be useful to speak about memory making, exploring parents' hopes and wishes. We suggest referring to the BAPM Framework: 'Recognising uncertainty: an integrated framework for palliative care in perinatal medicine' and the learning module 'Managing uncertainty in Perinatal Medicine and Palliative Care' which is free to access https://www.futurelearn.com/courses/managing-uncertainty-in-perinatal-medicine-palliative-care

6. ***Decision making –*** A shared decision making process is vital, especially in situations of 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. It should also be explained that if survival focused care is provided, but the baby develops serious complications or responds poorly to treatment, that they will be supported to discuss further treatment, including the option of comfort focused care.
7. ***Parental involvement in care* -** Evidence suggests parents find it very useful to hear how they can be involved in care for their baby. Neonatal care in the UK now typically implements Family Integrated Care (FICare), a model and philosophy of care within which families are enabled to be primary caregivers to their babies in partnership with clinical teams. This is proven to be of benefit to babies and parents, including in cases of extremely premature birth. Units can support families in this model of care by 'listening to them, building on their strengths, and encouraging their participation in experiences and decision-making to enhance control and independence.' (BAPM FICare Framework for Practice; Bliss Baby Charter) or to view a video tour of the unit if one is available.
8. ***Visit to neonatal unit*** - Where it is planned to offer survival focused care to the baby, and time allows, parents should be given an opportunity to visit the neonatal unit and to meet staff or view a video tour of the unit if one is available. Parents should receive information and support regarding expressing breast milk (including being shown the facilities for expressing breastmilk, introduced to the infant feeding team) 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.
9. ***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. BAPM are currently discussing the development of further supporting materials with parents/carers. If needed this section of the framework may be revised in line with recommendations from the group.

# Appendix 5: Lay Summary

## Making Decisions About Care for Babies Born Very Early

When a baby may be born extremely early (between **22 and 26 weeks of pregnancy**), parents and doctors have to make very difficult decisions together. These decisions are about whether to focus on **survival-focused care** (intensive medical care to try to help the baby live) or **comfort-focused care** (keeping the baby comfortable without intensive treatments in the knowledge that baby will sadly not survive). There is **no single "right" decision**. What matters most is the risks and outlook for baby, based on medical information and parents' wishes and values.

## How decisions are made nationally in the UK

Doctors do **not** make decisions based on gestational age (how many weeks of pregnancy the baby is born) alone.

Instead, they look at:

- **Gestational age.**
- **Baby's individual risk factors.**
- **How likely baby is to survive.**
- **How likely baby is to survive with serious long-term disability.**
- **Parents' wishes.**

**Risk profiles for a poor outcome (death or survival with severe disability)**
Babies are usually described as being at:

- **Extremely high risk.**
- **High risk.**
- **Moderate risk.**

These risk profiles help guide discussions.

## What do "survival-focused" and "comfort-focused" care mean?

**Survival-focused care**
The goal is to help the baby live. This may include breathing support, medicines, and admission to a neonatal intensive care unit (NICU).

**Comfort-focused care**
The goal is to ensure the baby is comfortable, without treatments that may cause pain or distress, with an understanding that the baby will not survive. Parents are supported to spend time with their baby.

## What do the national survival figures show?

These numbers are **UK population averages**. Every baby is different.
**Babies born at 22 weeks**

- Out of **10 babies born alive**:
    - About **2** will survive to leave hospital **if intensive care is given**
    - About **3** will survive to leave hospital if **admitted to a neonatal unit**
- Among survivors:
    - About **1 in 3** has **severe long-term disability**
- Many babies at 22 weeks are considered **extremely high risk**, especially if there are additional risk factors.

**Babies born at 23 weeks**

- Out of **10 babies born alive**:
    - About **4** will survive to leave hospital **with intensive care**
- Among survivors:
    - About **1 in 4** has **severe long-term disability**
- Decisions are often **shared with parents**, depending on individual risks.
- Most babies at 23 weeks are considered **high risk**.

**Babies born at 24 weeks**

- Out of **10 babies born alive**:
    - About **7** will survive to leave hospital
- Among survivors:
    - About **1 in 5** has **severe long-term disability**
- Many babies are in the **moderate-risk** group.

**Babies born at 25 weeks**

- Out of **10 babies born alive**:
    - About **8** will survive to leave hospital
- Among survivors:
    - About **1 in 9** has **severe long-term disability**
- Most babies are in a **moderate-risk** group

**Babies born at 26 weeks**

- Out of **10 babies born alive**:
    - About **8–9** will survive to leave hospital
- Among survivors:
    - About **1 in 12** has **severe long-term disability**
- Most babies are in a **moderate-risk** group

## What does ‘severe disability’ mean?

In national UK guidance, **severe disability** means **one or more** of the following:

- **Severe learning difficulties**, needing lifelong support
- **Severe cerebral palsy**, meaning a child cannot walk without help
- **Blindness** or **profound hearing loss**

Many babies may have **milder difficulties**, which are **not predictable at birth**.

## Factors that can increase or reduce risk

- Whether the baby is **growing well**
- **Infection** during pregnancy
- **Early waters breaking**
- Whether the baby is **one of twins or triplets**
- Whether **steroids** were given before birth
- Whether birth happens in a hospital with a **specialist neonatal intensive care unit**

These factors can change the outlook **positively or negatively**, even at the same gestational age.

## What role do parents have?

**Parents are central to decision-making.**

- Doctors should explain risks **clearly and honestly**
- Parents’ values, hopes and concerns should be explored and listened to
- Plans can be **reviewed and changed** if circumstances change

## Parents can ask for:

- More time to decide (though sometimes that may not be possible)
- A second discussion
- Written information
- Support from specialist nurses, psychologists or chaplaincy services

## Key message

Decisions about extremely early birth are made **together**, using the **best national evidence**, the **specific situation for baby**, and **what matters most to parents**.
Parents are not expected to make these decisions alone.

## Useful contact details to direct parents and staff to:

**Bliss -** Premature and sick baby charity
www.bliss.org.uk

**Together for Short Lives -** Charity for babies and children with life-limiting conditions
www.togetherforshortlives.org.uk
Helpline: 0808 8088 100

**Sands -** Stillbirth and neonatal death charity
www.uk-sands.org
Helpline: 0808 1643332
Email helpline@sands.org.uk

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