

Management at the Extremes of Prematurity Guideline			
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Related documents / policies (do not include those listed as appendices)	<ul style="list-style-type: none"> • Tocolysis in preterm labour guideline • Magnesium sulphate in preterm delivery before 30 weeks guideline. • Thames Valley and Wessex Operational Delivery Networks: Policy for transfer of infants to a neonatal intensive care unit/local neonatal unit • Information for parents of babies born early around 20 to 21 weeks • Information for parents of babies born early around 22 to 24 weeks • Information for parents of babies born at around 25 weeks • Having an extremely premature baby: what it means for you and your baby 		
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Date	Consultation / Comments	Version created	Page	Key changes
July 202	Dr Kelly Brown	DRAFT		Guideline reviewed and updated

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1. Executive Summary

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

2. Introduction

Advances in perinatal care have led to steadily improving outcomes for babies admitted to UK neonatal intensive care units (NICUs), particularly at the lowest gestational ages.

Perinatal care at extremely preterm gestations will always need to be individualised and should be led by senior staff in midwifery, obstetrics and neonatology. Parents and families should be an integral part of these discussions, and their hopes and expectations explored with honesty and compassion in a realistic way.

Decisions should be based on the best available evidence about the prognosis for the individual baby, and mindful of the need to act in the baby's best interests. It is essential that such decisions reflect all relevant prognostic information and not simply gestational age.

3. Scope and Purpose

This guideline covers management of delivery and initial resuscitation of babies born extremely preterm i.e. between 22+0 and 26+6 weeks gestation.

Guideline Objectives

- To improve consistency in management and advice given to parents with extremely preterm pregnancies within the regional network.
- To promote multidisciplinary discussion between obstetricians, neonatologists, local pediatricians and midwives and plan stepwise management on an individual patient basis.
- To improve communication between parents and all health care professionals to assist decision-making prior to and/or at the time of birth relating to perinatal care and preterm delivery at 26+6 weeks gestation or less.
- To ensure in those appropriate for active management delivery is in a unit with a co-located NICU.

4. Definitions/ Abbreviations

1. **Severe impairment or disability:** likely to make a child highly dependent on care-givers e.g. cerebral palsy preventing a child from walking (GMFCS levels 3-5) (Appendix 2), severe cognitive impairment with an IQ lower than 55 (developmental quotient less than 3SDs below mean for age) profound sensorineural deafness not improved by aids, blindness.
2. **Moderate impairment or disability:** includes children with ambulant cerebral palsy (GMFCS level 2), developmental score of 2 to 3 SDs below the mean, hearing loss that can be improved by aids, functionally impaired vision.
3. **Mild impairment or disability:** abnormal neurological signs but with minimal functional implications (GMFCS level 1), developmental scores 1 or 2 SDs below the mean, hearing loss not sufficient to require aids, squints or refractive errors.
4. **Active care (survival focused):** obstetric and neonatal management that has the aim of sustaining life for the baby.
5. **Palliative care (comfort focused):** obstetric and neonatal management when the aim is not to attempt to sustain the life of the fetus/baby, but to focus on the baby's comfort.

5.0 Antenatal Management

Risk-Based Approach to Decision-Making

The BAPM framework for practice advises a stepwise approach to decision-making, involving three key stages

5.1 Assessment of the risk for the baby if delivery occurs, incorporating both gestational age and factors affecting fetal and/or maternal health.

Estimation of Gestational Age is normally made from an expected delivery dated calculated from the crown-rump length (CRL) at 10+0 and 13+6 weeks of gestation which is accurate to within 5 days in 95% of cases. From 14+0 weeks (CRL >84mm), gestation is 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.

Physical examination of the baby after delivery may lead to a revision of the original estimate of gestational age. If gestational age is unknown, as in a late booker or concealed pregnancy, an experienced paediatrician/neonatologist should be present at delivery to assess the situation regarding appropriate resuscitation.

The risk based on gestation should be modified by:

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

Clinical conditions: additional risk is posed with a prolonged pre-labour rupture of membranes before 24 weeks of gestation and clinical evidence of chorioamnionitis.

Therapeutic strategies: administration of antenatal steroid and magnesium sulphate reduce the risk even before 24 weeks of gestation.

Clinical Setting: survival is highest at these extreme preterm gestations in centres with experienced staff and higher patient numbers.

Following full history taking and risk assessment the likelihood of a poor outcome for the pregnancy can be grouped as **extremely high risk; high risk; moderate risk**.

A proposed visual tool for refinement of risk and examples are illustrated in Figure 1 and Table 1.

Figure 1 BAPM Framework for Practice 2019 Working Group Consensus: Proposed visual tool for refinement of risk

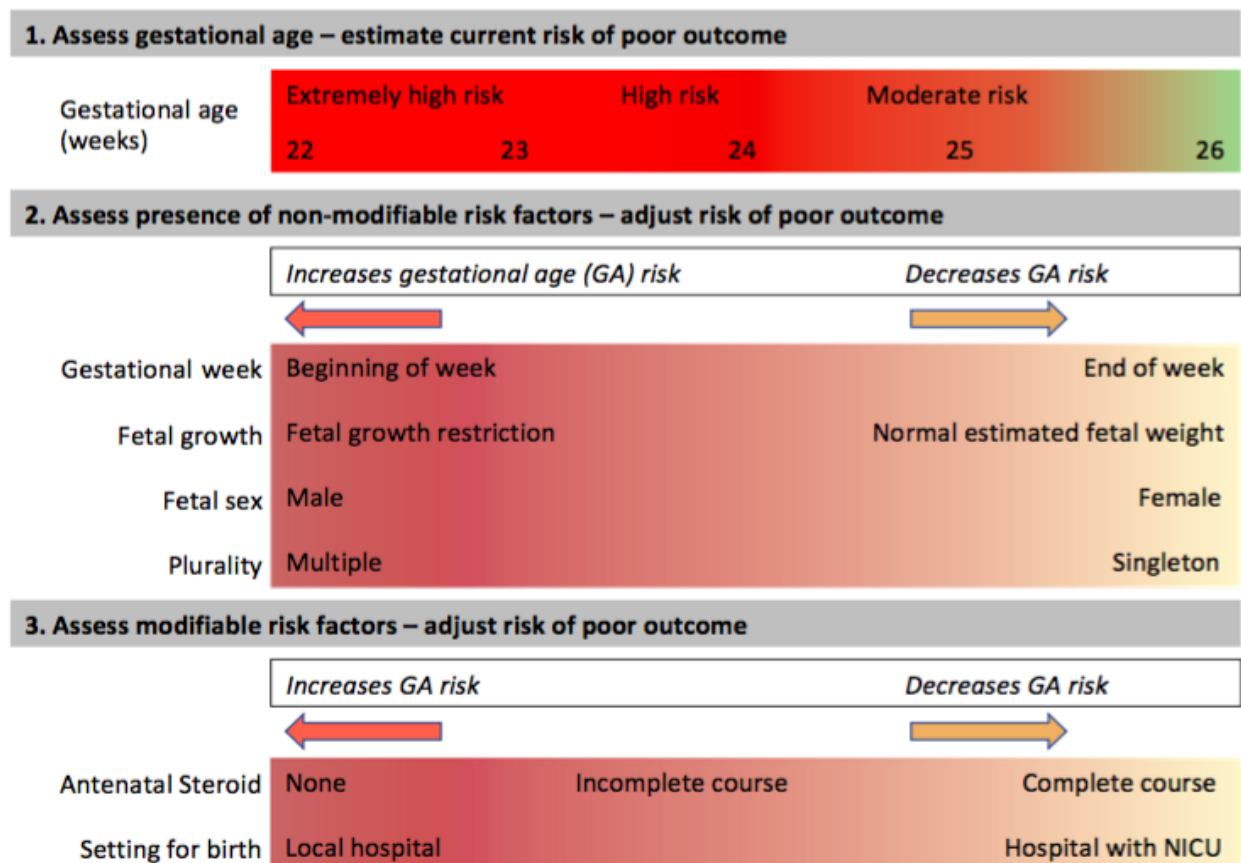


Table 1 BAPM Framework for Practice 2019 Working Group Consensus: Examples of risk categories

<p>Extremely high risk</p>	<p>Babies considered to have a > 90% chance of either dying or surviving with severe impairment if active care is instigated would fit into this category. For example, this would include:</p> <ul style="list-style-type: none"> • Babies at 22⁺⁰ - 22⁺⁶ weeks of gestation with unfavourable risk factors • Some babies at 23⁺⁰ - 23⁺⁶ weeks of gestation with unfavourable risk factors, including severe fetal growth restriction • (Rarely) babies ≥ 24⁺⁰ weeks of gestation with significant unfavourable risk factors, including severe fetal growth restriction
<p>High risk</p>	<p>Babies considered to have a 50-90% chance of either dying or surviving with severe impairment if active care is instituted would fit into this category. For example, this would include:</p> <ul style="list-style-type: none"> • Babies at 22⁺⁰ - 23⁺⁶ weeks of gestation with favorable risk factors • Some babies ≥ 24⁺⁰ weeks of gestation with unfavourable risk factors and/or co-morbidities
<p>Moderate risk</p>	<p>Babies considered to have a < 50% chance of either dying or surviving with severe impairment if active care is instituted would fit into this category. For example, this would include:</p> <p>6.0 Most babies ≥ 24⁺⁰ weeks of gestation.</p> <p>7.0 Some babies at 23⁺⁰ – 23⁺⁶ weeks of gestation with favourable risk factors</p>

5.2 Counseling parents and their involvement in decision-making

Appendix 1 and Table 2 present the most up to date outcome data available in September 2019.

Table 1 Overall Wessex region 5 year neonatal survival to discharge from NNU data 2014-19 according to gestation

Gestation (weeks)	Birth admissions to NNU	Survived to discharge	% survived	Average birth admissions per year
23	43	26	60%	8.6
24	86	73	85%	17.2
25	112	98	88%	22.4
26	127	113	89%	25.4
<27 weeks	368	310	84%	73.6

It should be explained to parents that these regional data relate to babies who have survived labour, delivery and immediate resuscitation to be admitted for neonatal care (rather than data for babies alive before or during the onset of labour). It should be noted that this does not include morbidity outcomes in survivors and national data in Appendix 1 should be used in conjunction with information leaflets in Appendix 5.

There is no objective way of defining a risk as ‘extremely high’ *versus* ‘high’ and families differ in the outcome that they regard as unacceptably poor. It is important that parents are offered choices and supported to make decisions appropriate for their individual preferences.

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

The assessed category of risk to the baby (including the inherent uncertainty around this) should be conveyed sympathetically and with clarity, and the hopes and expectations of parents explored with honesty and compassion in a realistic way. Clear, balanced information should be shared 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.

Parents should also be helped to appreciate that the baby may be born in unexpectedly poor, or unexpectedly good condition, and the implications of this for what care might be appropriate.

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

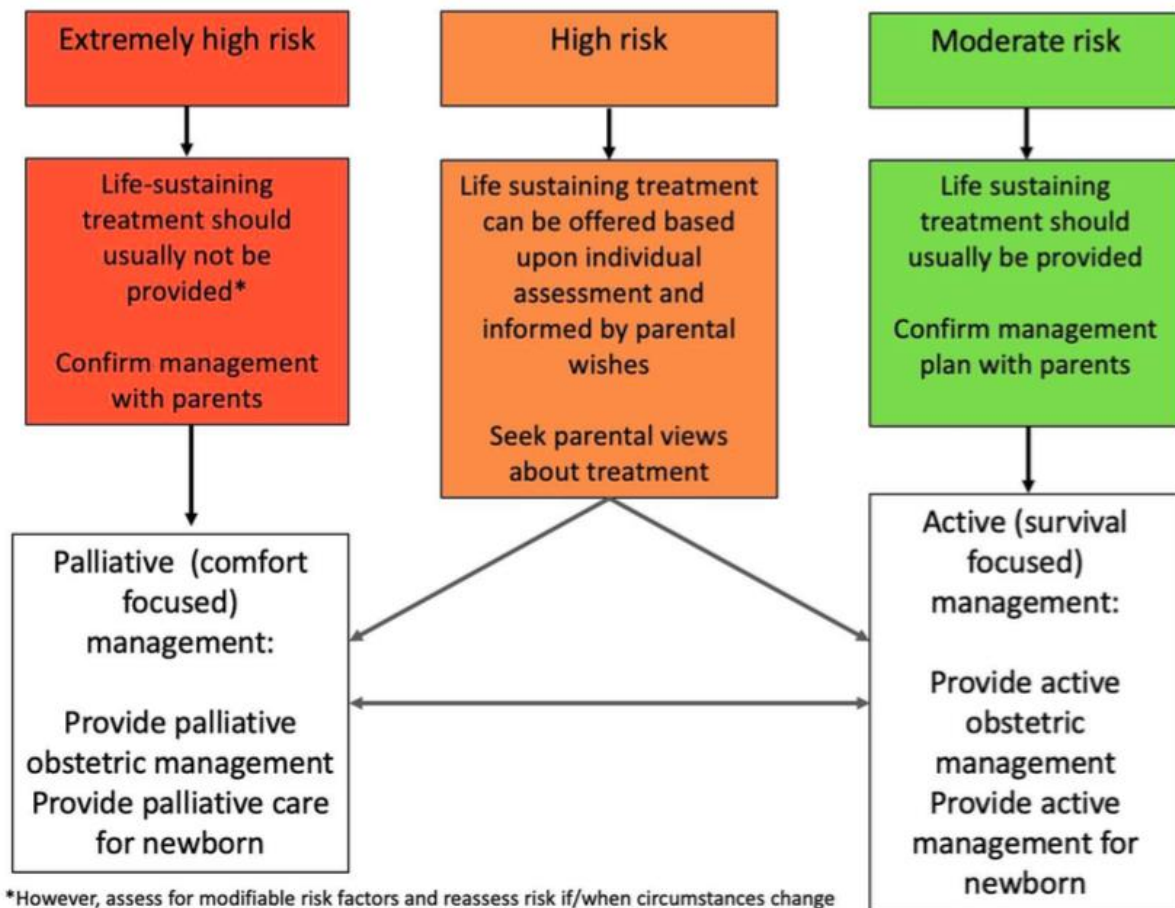
Where appropriate, the practicalities of commencing, withholding and/or withdrawing intensive care and the positive role of palliative care strategies should be described to the parents.

5.3 Agreeing and communicating a management plan.

Following consultation with parents, initial management of the birth will follow one of two pathways: **‘active (survival focused)’** or **‘palliative (comfort focused)’** (Figure 2). Consistency in obstetric and neonatal management is essential, either to ensure that the baby is born in the best possible condition or to avoid unnecessary intervention. The agreed plan should be clearly documented in the hospital notes at the time of the consultation (including completion of the proforma in Appendix 3 and 4) and communicated to all members of the obstetric and neonatal teams who may be involved in care of the family.

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

Figure 2 BAPM Framework for Practice 2019 Working Group Consensus: Decision- making around management of delivery, following risk assessment and after consultation with parents



6. Active (survival focused) obstetric management

An individualised package of obstetric intervention should be offered in all cases where a commitment to active neonatal care is in place. The potential for each component intervention to optimise the condition of the individual baby at birth should be considered, and not excluded on the basis of gestational age alone. Obstetric management should be regularly reviewed, particularly if events suggest changing prognosis for the baby. The package of obstetric care to be offered to parents may (but not necessarily) include any or all of the following:

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

Antenatal steroids

Antenatal steroids are recommended in the RCOG green-top guidelines from 24 weeks gestation in women who present at risk of preterm delivery (and where active management is planned). Although there is no conclusive evidence of a benefit before 24 weeks, their administration between 22 and 23+6 weeks should be considered if active (survival focused) management is planned. The timing of steroid administration can be a challenge with difficulty predicting when preterm delivery will occur and aiming for the maximum period of efficacy within 7 days of the last dose. A repeat rescue dose of steroids may be considered appropriate later in pregnancy if the risk of delivery is ongoing or becomes likely once more, especially if the first course was given before 26 weeks gestation. Routine repeated steroids are not currently recommended (RCOG 2014ⁱⁱ, Cochrane review 2012^{iiiiv}).

Magnesium sulphate for neuroprotection

Magnesium sulphate infusion is recommended before 30 weeks gestation to help prevent cerebral palsy. If active survival-focused management is planned due to impending preterm delivery, magnesium sulphate therapy is also recommended following discussion with senior obstetrician and paediatrician/ neonatologist (see regional magnesium sulphate guideline).

Intrapartum fetal heart rate monitoring

CTG interpretation is difficult below 26 weeks and there is no evidence that CTG improves outcomes compared to intermittent auscultation. CTG monitoring could be considered from 25+0 weeks gestation in an appropriately grown fetus following counselling by the senior obstetrician (ST6/7 or consultant) and paediatrician/neonatologist. CTG monitoring is not recommended before 25 weeks or EFW <500g. CTG monitoring should only be used when there has been a definite agreement following discussion with the parents that emergency Caesarean section may be performed for suspected fetal compromise. The limitations of continuous CTG monitoring and its interpretation at extremes

of viability should be explained. If Caesarean section is not thought appropriate, intermittent fetal heart rate auscultation for 10-15 seconds only should be used to establish fetal viability during labour, at intervals to be decided on an individual basis. A suggested frequency would be once every 1-2 hours and at the start of second stage to check the presence of a fetal heart beat.

Mode of Delivery

Caesarean sections (CS) of very preterm babies often require a classical incision, which is associated with higher maternal morbidity (bleeding, paralytic ileus) and increased risk of scar rupture/subfertility in the future. There is no clear evidence that outcome is improved by CS over vaginal delivery in these extremely preterm infants (whether singleton or twin) although appropriate trials to address this issue are not available. It is acknowledged that prognosis is partly determined by the immediate condition of the baby at birth. Unfortunately, even CS can be associated with trauma during delivery of a very preterm baby e.g. with severe oligohydramnios and transverse lie. There is a significant risk of cord prolapse with transverse lies or footling breech presentation and CS should be discussed with the parents if they opt for active management.

With flexed or extended breeches, complications may arise from inappropriate pushing before full dilatation or an entrapped head by the cervix, which occurs in 10% of cases. These complications should be anticipated, epidural considered and a senior obstetrician should be present at delivery prepared to assist delivery of the after coming head. In rare circumstances cervical incision may be required to facilitate delivery of the head but unfortunately this may well be too late to change perinatal outcome.

Caesarean section is not considered appropriate before 24 weeks gestation except for maternal indications e.g. bleeding placenta praevia, severe pre-eclampsia. In rare cases a Caesarean section may be performed at 24 weeks following full discussion with the parents regarding prognosis. It should be emphasised to the parents that although intrapartum death may be avoided by CS, there is an increased risk of survival with major morbidity. An objective and balanced discussion of the risks and benefits must be made with the parents.

At 25 weeks, following discussion with the parents regarding their wishes for active intervention, continuous monitoring is usually offered in labour aiming for vaginal delivery, but resorting to emergency Caesarean section for an abnormal CTG if time allows.

In view of the potentially difficult CS in these cases of extreme prematurity, it is recommended that a senior obstetrician is present at the operation.

In-Utero Transfers (IUTs)

See Thames Valley & Wessex Neonatal ODN [Policy for transfer of infants to a neonatal intensive care unit/local neonatal unit](#) for categorization of neonatal care services in Wessex and the 'Wessex In-Utero Transfer' guideline for IUT protocols within Wessex.

In utero transfer to a maternity facility co-located with a NICU should be considered at the earliest opportunity when active management is planned. All such transfers should be discussed with the receiving team, and parents should be made aware that the prognosis

(and therefore management) may be revised following *in utero* transfer to a centre with greater experience of managing extremely preterm birth (e.g. following detailed ultrasound scanning). Communication and agreed plans should be documented in full (including in the maternity handheld record) and, when relevant, clearly communicated with the receiving centre. The agreed plan of management should be revised regularly if pregnancy continues.

In-utero transfer would not normally be recommended below 22+3 weeks following discussion with the parents, given the extremely high risk of severe outcome. However each case should be individualised.

Consultant to consultant discussion is required when pregnancies at the extremes of prematurity are involved.

7.0 Palliative (comfort focused) obstetric management

When a decision is made for palliative (comfort focused) management at birth, only interventions for maternal benefit are appropriate. Intrapartum fetal heart rate monitoring is not advised, although assessing or listening for the presence of a fetal heart to check viability may be helpful in clarifying expectations around the baby's condition at birth and be preferable for parents (see 6.).

7.1 Palliative (comfort focused) neonatal management

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

The aim of palliative neonatal management is to support the parents and their baby and to avoid interventions that may cause discomfort, pain or separation of the baby from the parents. This care should be delivered in the most appropriate location for the family (which is not necessarily a neonatal unit) and should not necessitate in-utero transfer. There should be an emphasis on family centred care, with opportunities for parents to create positive memories of their baby. An Individualised Care Plan should be made in partnership with parents following guidance within the Perinatal Palliative Care Pathway from Together for Short Lives.^v

Depending on parents' wishes and service provision, a senior neonatologist or paediatrician may be present at delivery to provide a brief assessment of the baby's condition at birth and to support midwifery staff and the family.

They should have been counselled that the baby may show brief reflex movements or signs of life after birth. In the unlikely scenario of the baby being born in much better condition than expected, palliative management may need to be reconsidered. On average, babies born before 24 weeks of gestation who receive comfort care in the delivery room live for approximately 60 minutes (range from a few minutes to several hours)^{vi}.

After the baby has died a parent-led bereavement care plan (Neonatal Bereavement Care Pathway) should be put in place for the family, including communicating with parents and creating memories. Parents should understand what to expect in terms of a review into the care provided during pregnancy and birth using the Perinatal Mortality Review Tool, and the benefits of investigations such as autopsy and placental histopathology, to provide as much explanation as possible for the preterm birth and the death of their baby

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.

Parents should be offered bereavement counselling and the opportunity to meet with perinatal staff for a follow up consultation in an outpatient setting. Parents should also be offered the opportunity to participate in a multi-professional perinatal mortality review process.

8. Summary of risks and management

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

High risk: For babies with a > 50% risk of death or of surviving with unacceptably severe impairment despite treatment, it is uncertain whether active (survival focused) management is in the best interests of the baby and their family. Parents should be counselled carefully and parental wishes should inform a joint decision to provide either active or palliative treatment. Ideally, a senior neonatal clinician who has previously met the parents will be available to attend the birth and supervise implementation of the agreed plan.

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

9. Roles and Responsibilities

This guideline applies to all clinical staff employed or contracted by any Wessex Obstetric or Neonatal Unit who provide antenatal care to women. Staff have a responsibility to ensure that they are aware of this guideline and its contents. They should clearly document their rationale if they have not complied with the recommendations detailed in this guideline. It is the responsibility of department managers, consultants, team leaders and education leaders to ensure staff are aware of this guideline.

10. Communication and training

The guideline will be displayed on the Staffnet, and sent to the relevant Care Group clinical teams. The team leaders will be expected to cascade to all relevant staff groups. All medical, nursing and midwifery staff caring for women and newborns should have support and training in implementing the contents of the guideline. In addition, the guidelines will be included in local induction programmes for all new staff members.

The author is responsible for ensuring the effective dissemination of this guideline. To ensure dissemination takes place and to avoid duplication of work, do not assume others will do this based on their involvement in guideline consultation process.

Methods of dissemination may include

- Present the guideline at meetings e.g. ICC, MOST, MSG
- Discussion at mQuest
- Email correspondence e.g.

- midwiferystaff@uhs.nhs.uk,
 - O&Gjuniordoctors@uhs.nhs.uk,
 - consultantobstetricians@uhs.nhs.uk,
 - consultantneonatologists@uhs.nhs.uk,
 - W&Nanaestheticguidelineconsultationgroup@uhs.nhs.uk
- Theme of the Week (bear in mind busy schedule so may need to plan ahead)
 - Communication board in birth environments and ward areas for discussion at handover
 - Teaching sessions – involve Education team early in guideline consultation process
 - Training materials e.g. prompt cards, laminated flowchart
 - PGDs – new PGDs need to be read and signed and signature list given to Education team
 - Consider how you will audit/measure uptake of new guidance

11. Process for Monitoring Compliance

The purpose of monitoring is to provide assurance that the agreed approach is being followed. This ensures that we get things right for patients, use resources well and protect our reputation. Our monitoring will therefore be proportionate, achievable and deal with specifics that can be assessed or measured.

Key aspects of this policy will be monitored:

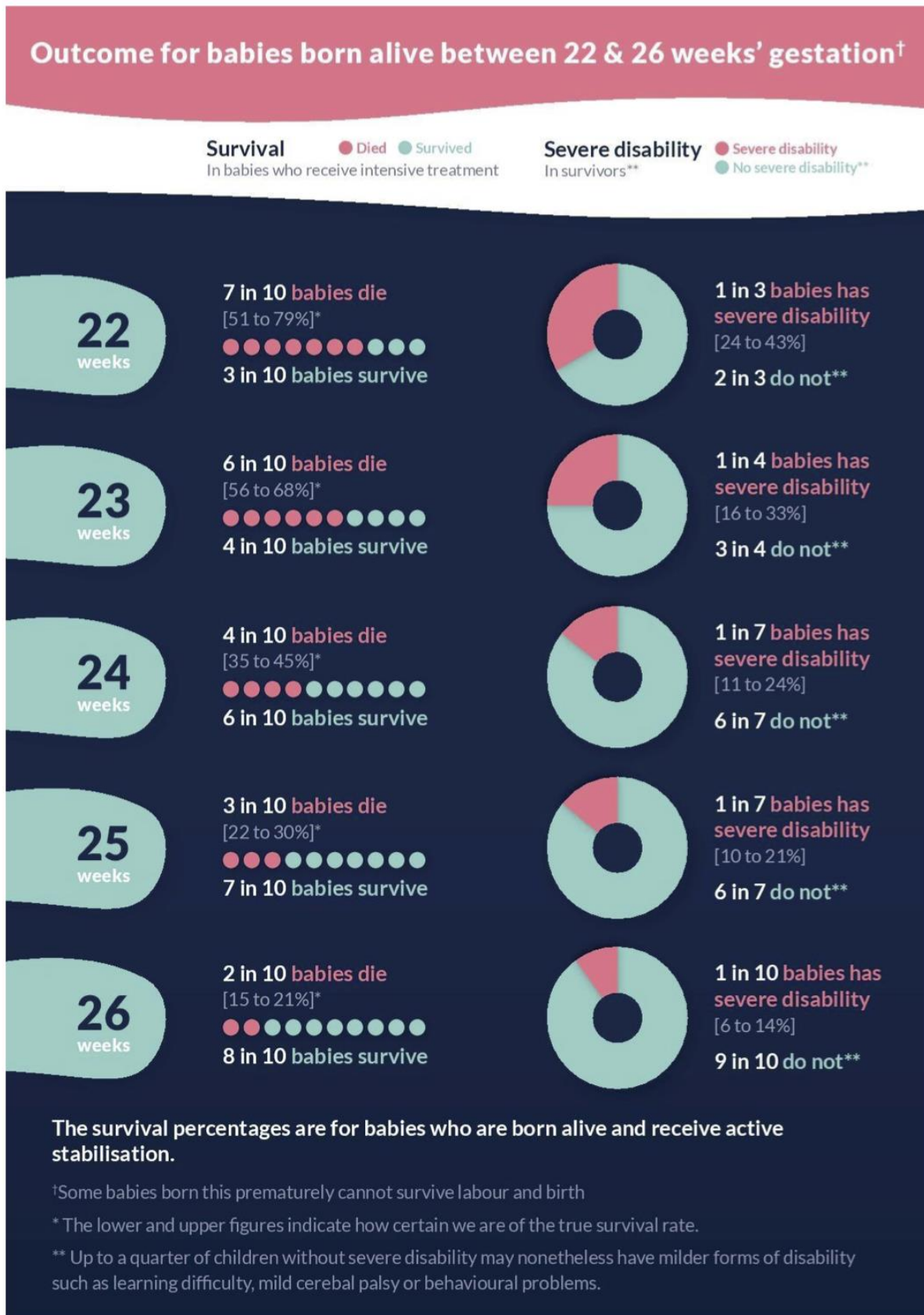
Element to be monitored	Use and evaluation of the extreme prematurity proforma
Lead (name/job title)	Tara Selman - Consultant Obstetrician
Tool	Review of maternity records (electronic and paper)
Frequency	As required
Reporting arrangements	Audit Meeting

Where monitoring identifies deficiencies actions plans will be developed to address them.

12. Document review

This guideline to be reviewed after three years or sooner as a result of audit findings or as any changes to practice occurs.

Appendix 1: BAPM 2019 National mortality and morbidity data



Appendix 2: GMFCS Grades 1-5 description:

Level I	Children walk at home, school, outdoors and in the community. Children are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Children perform gross motor skills such as running and jumping but speed, balance, and co-ordination are limited. Children can participate in physical activities and sports depending on personal choices and environmental factors.
Level II	Children walk in most settings. At school, children may walk using a hand held mobility device for safety. Outdoors and in the community, children may use wheeled mobility when travelling long distances. Children walk up and down the stairs holding a railing or with physical assistance if there is no railing. Limitations in performance in gross motor skills may necessitate adaptations to enable participation in physical activities and sports.
Level III	Children walk using a hand-held mobility device in most indoor settings. When seated, children may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface. When travelling long distances, children use some form of wheeled mobility. Children may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.
Level IV	Children use methods of mobility that require physical assistance or powered mobility in most settings. Children require adaptive seating for trunk and pelvic control and physical assistance for most transfers. At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility. When positioned, children may use a body support walker at home or school. At school, outdoors and in the community, children are transported in a manual wheelchair or use powered mobility. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.
Level V	Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and to control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and/or mobility but limitations are not fully compensated by equipment. Transfers require complete physical assistance of an adult. At home, children may move short distances on the floor or may be carried by an adult. Children may achieve self- mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

Appendix 3: Extreme Premature Birth- Risk Assessment

Extreme Premature Birth – risk assessment

Referral Details

Patient name/MRN _____

Presentation (eg Preterm labour, PET) _____

EDD (specify source – eg US at 12/40) _____

Progress of labour (eg Cx dilation) _____

Referral hospital (location, and type eg level 2/3) _____

Risk Factors

Gestation today (note if any discrepancy in dates) _____

Estimated fetal weight _____ Severe growth restriction Y/N _____

Fetal Sex _____ Singleton/multiple _____

Antenatal steroids (complete/incomplete)? _____

Other factors affecting fetal prognosis (eg major congenital malformation/hydrops) _____

1. Assess gestational age – estimate current risk of poor outcome

	Extremely high risk	High risk	Moderate risk		
Gestational age (weeks)	22	23	24	25	26

2. Assess presence of non-modifiable risk factors – adjust risk of poor outcome

	Increases gestational age (GA) risk		Decreases GA risk	
Gestational week	Beginning of week		End of week	
Fetal growth	Fetal growth restriction		Normal estimated weight	
Fetal sex	Male		Female	
Plurality	Multiple		Singleton	

3. Assess modifiable risk factors – adjust risk of poor outcome

	Increases GA risk		Decreases GA risk	
Antenatal Steroid	None		Complete Course	
Setting for birth	Hospital without a NICU		Hospital with NICU	

Categorisation

Risk Category (circle)	Extremely High High Moderate
Name of person doing assessment	_____
Signature	_____
Date and time of assessment	_____

Appendix 4: Proforma for Management Decisions at the Extremes of Viability



PATIENT DETAILS/STICKER

Form completed by:.....
NB Must be agreed by a named consultant obstetrician:.....

Date	Gestation by USS	EDD
Current antenatal problem		
Counseled by neonatologists	YES/NO	
Steroids	YES/NO Given at:	
Magnesium sulphate	YES/NO	
CTG monitoring	YES/NO	
Aim vaginal delivery	YES/NO	
Caesarean section for fetal reasons	YES/NO	
Pediatrician to be present at delivery	YES/NO	

Date and Time signed.....

Review date due at.....weeks on.....

Appendix 5: Patient Information Leaflet

Having an extremely premature baby: what it means for you and your baby

You have been given this information because your healthcare team think you might be having your baby extremely early. You will need to make some important choices about your care before and during labour if this occurs. This leaflet contains important information to help you decide what would be best for you, your baby and your family. The maternity and neonatal team (specialist baby doctors and nurses) will talk to you about this in details and you will have the opportunity to ask any questions you wish.

What does this mean?

A full pregnancy usually lasts for about 40 weeks. How far along in your pregnancy you are (the gestation) is usually worked out from an early scan around 12 weeks (your dating scan).

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

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

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

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

You may be offered a visit to the neonatal unit, which is where your baby is may be likely to go for specialist care, if delivered early.

Outcomes

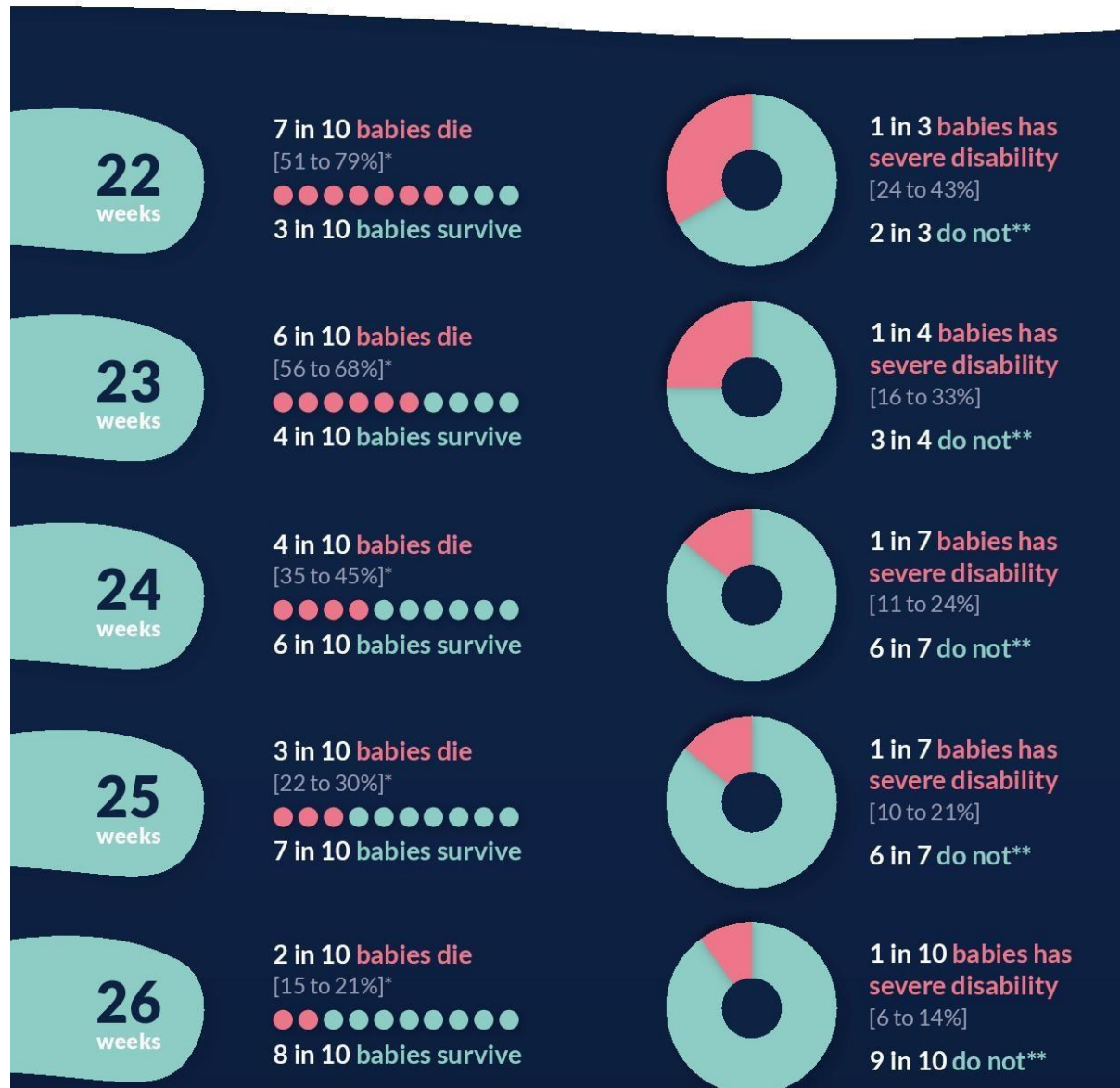
Outcome for babies born alive between 22 & 26 weeks' gestation[†]

Survival
In babies who receive intensive treatment

● Died ● Survived

Severe disability
In survivors^{**}

● Severe disability ● No severe disability^{**}



The survival percentages are for babies who are born alive and receive active stabilisation.

[†]Some babies born this prematurely cannot survive labour and birth

* The lower and upper figures indicate how certain we are of the true survival rate.

** Up to a quarter of children without severe disability may nonetheless have milder forms of disability such as learning difficulty, mild cerebral palsy or behavioural problems.

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

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

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

What does 'severe disability' mean?

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

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

Moderate disability

Children with cerebral palsy who are able to walk but with some limitations
development scores below normal range
hearing loss correctable by a hearing aid
impaired vision without blindness

Mild disability

Children with mild learning problems or other impairments such as squints, which do not interfere significantly with everyday life.

What does this mean for your baby?

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

What may happen with my baby?

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

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

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

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

More information about comfort care or 'palliative care' for babies is available from [Together for Short Lives](#).

For all mothers at risk of very premature delivery we may consider the following:

Examination of the neck of your womb for signs of labour and fetal fibronectin testing (similar to cervical smear) to predict your chances of naturally delivering in the next two weeks

Ultrasound scan: this may be carried out to assess your baby's growth and well-being and to tell if the baby is head or bottom-first.

Antenatal steroids: after 24 weeks we will give you steroid injections to help the development of the baby's immature lungs.

Magnesium sulphate infusion before delivery to help reduce the risks of cerebral palsy in your baby.

Transfer to another hospital: not all maternity units have a neonatal intensive care unit able to look after a very premature baby for a long period. Even those that do may have their cots full when they are very busy. You may be transferred while the baby is still in the womb to another neonatal unit for a suitable cot, if this is considered better for your baby.

There are two important choices we would like to involve you in:

1. The way your baby is born:

There is no clear evidence that the baby's health is improved by Caesarean section (CS) over vaginal birth in extremely preterm babies (whether single or twins). The operation is more difficult when the baby is very small and the pregnancy very early, and it may not improve the outlook for the baby if there is a high chance of it not surviving. Alternatively, the baby may be delivered and survive but with the long-term problems that affect very premature babies. Compared to vaginal birth, a CS is associated with increased risks to the mother's health and future pregnancies.

Our usual advice is that CS is not appropriate before 24 weeks of pregnancy unless the mother is very unwell and urgent delivery is required for her health (e.g. very high blood pressure) rather than awaiting induction of labour and vaginal birth. This is because these babies have a high risk of dying or suffering from major disability. A CS **may** be considered after 24 weeks of pregnancy in specific situations, such as transverse lie (baby lying across in mum's womb instead of the accepted head down position) or footling breech (baby lying in bottom down position with foot presenting first) because of the associated risks to baby, although the potential benefits are still unclear and many parents would not want to consider CS until after at least 25 weeks.

After 26 weeks we would normally offer CS for all the usual reasons that it would be considered in later pregnancy. Between 25 and 26 weeks some parents may wish the baby to be delivered by CS if there was evidence of the baby becoming unwell during labour, but some might choose to allow the baby to labour naturally.

2. CTG or heart rate monitoring:

This is usually advised from 26 weeks of pregnancy (a small, safe and non-invasive device is strapped to mum's belly to pick up baby's heartbeat in the form of a trace on a piece of paper). This form of monitoring may be used at 25 weeks following careful discussion with the parents.

Before 26 weeks, we would not normally monitor the baby with heart rate traces unless a plan had been agreed with the parents to consider CS in labour if the trace showed the baby was developing problems.

What if my baby doesn't come now?

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

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

Further information

Useful contact details:

Bliss - Premature and sick baby charity

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

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

Sands - Stillbirth and neonatal death charity

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

Helpline: 0808 1643332

Email helpline@sands.org.uk

Appendix 6: Communication: Guidance for professionals consulting with families at risk of extreme preterm delivery.

This Appendix is designed for use by all staff caring for families at risk of extreme preterm birth, to facilitate the sharing of consistent and accurate information. It should be used to support conversations about decision making with parents, in conjunction with written information such as the patient information leaflet *Having an Extremely Premature Baby: What it Means for You and Your Baby*. Written information should *never* be used as a stand-alone information sharing tool.

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

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

In **extremely high risk** cases, parents should be provided with relevant information about the risk to their baby, and the recommendation that it would be best for their baby to provide palliative (comfort focused) obstetric and neonatal management. Parents should be told about the role they can play in caring for their baby and memory making after birth, and should be fully involved in decisions about how and where palliative management takes place.

In **high risk** cases, the role of the consultation is critical in supporting parents together with professionals to decide on the right pathway for their baby. Parents should be provided with as much information as is available and should have as much time as possible, ideally over a number of discussions, to work through the different options available in order to agree with professionals what the right option is for their family.

In **moderate risk** cases, parents should be provided with relevant information about the risk to their baby, and the recommendation that it will be best for their baby to provide active management both antenatally and after birth. Parents should be told about likely interventions and what may happen next, and be fully involved in decisions about how active treatment is managed.

Thus, consultation is most critical where delivery would be associated with a high risk of unacceptably poor outcome. In such situations, parents need support to make an informed choice about the provision of either active or palliative management; such situations demand the greatest care and sensitivity. Consultation should not be directive, but professionals should seek to determine when gentle guidance around what is likely to be in the baby's best interests would be helpful for the family.

When is the right time?

Evidence suggests that parents find that, where time allows, consultation is most useful at the earliest opportunity, both to allow time for information processing, discussion, and decision making, and to minimise the effects of labour and medications on cognition. Follow

up consultations allowing ongoing dialogue are highly valued by families and should be offered at any point, acknowledging the challenging nature of the information that parents are being asked to receive, the time this may take to process and the decisions that need to be made.

Who should be involved?

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

Structuring the Consultation

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.

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.

Conveying Risk - Categorisation of risk to the baby of death or survival (with or without impairment) in a given scenario should be conveyed sympathetically and with clarity. Parents may find it useful to see this displayed graphically. Gestation-based risk should be explained within the context of other risk modifiers (such as birth weight, gender, multiplicity, etc.). It is important to convey information accurately, in the appropriate context. While the most relevant statistic for parents is usually the chance of survival if active stabilisation and neonatal intensive care is attempted, parents should be helped to understand that not all babies survive labour, and so outcome data depend upon the stage at which parents are being counselled. Outcome data are, of course, also highly influenced by intention to treat at delivery and it is likely that current published outcomes are skewed towards those fetuses/babies in the best condition at birth. Not all parents find percentage figures easy to understand. It can be helpful to explain in terms of odds e.g. 1 in 4, or 1 in

10. To avoid framing bias, we suggest interpreting risk neutrally. For example, “Given what we know about the situation for your baby, there is a 30% chance of your baby surviving. This means that for every 10 babies treated actively (with intensive care) in situations like this, three would survive while sadly seven would not”.

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

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

- Not being able to walk or move independently
- The possibility of being unable to speak
- Difficulties with swallowing or feeding safely
- The possibility of not being able to understand the world around them in a meaningful way
- Not being able to see or hear properly
- Not being able to live independently
- Having a lot of health care needs with frequent visits to hospital
- Needing extra educational support (or needing to attend a special school)

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

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

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

http://www.nbcpathway.org.uk/file/aw_5844_nbcpathway_neonatal_death_pathway.pdf

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

upon what care at birth would be best for their baby.

Parental involvement in care - Evidence suggests parents find it very useful to hear how they can be involved in care for their baby. “Family-centred care means supporting parents to be involved in their baby's care” – this should start before birth. Where it is planned to offer active care to the baby, and time allows, parents should be given an opportunity to visit the neonatal unit and to meet staff, and should receive information and support regarding expressing breast milk and the other ways that they could be involved in the hands-on care of their baby if s/he is admitted to the neonatal unit.

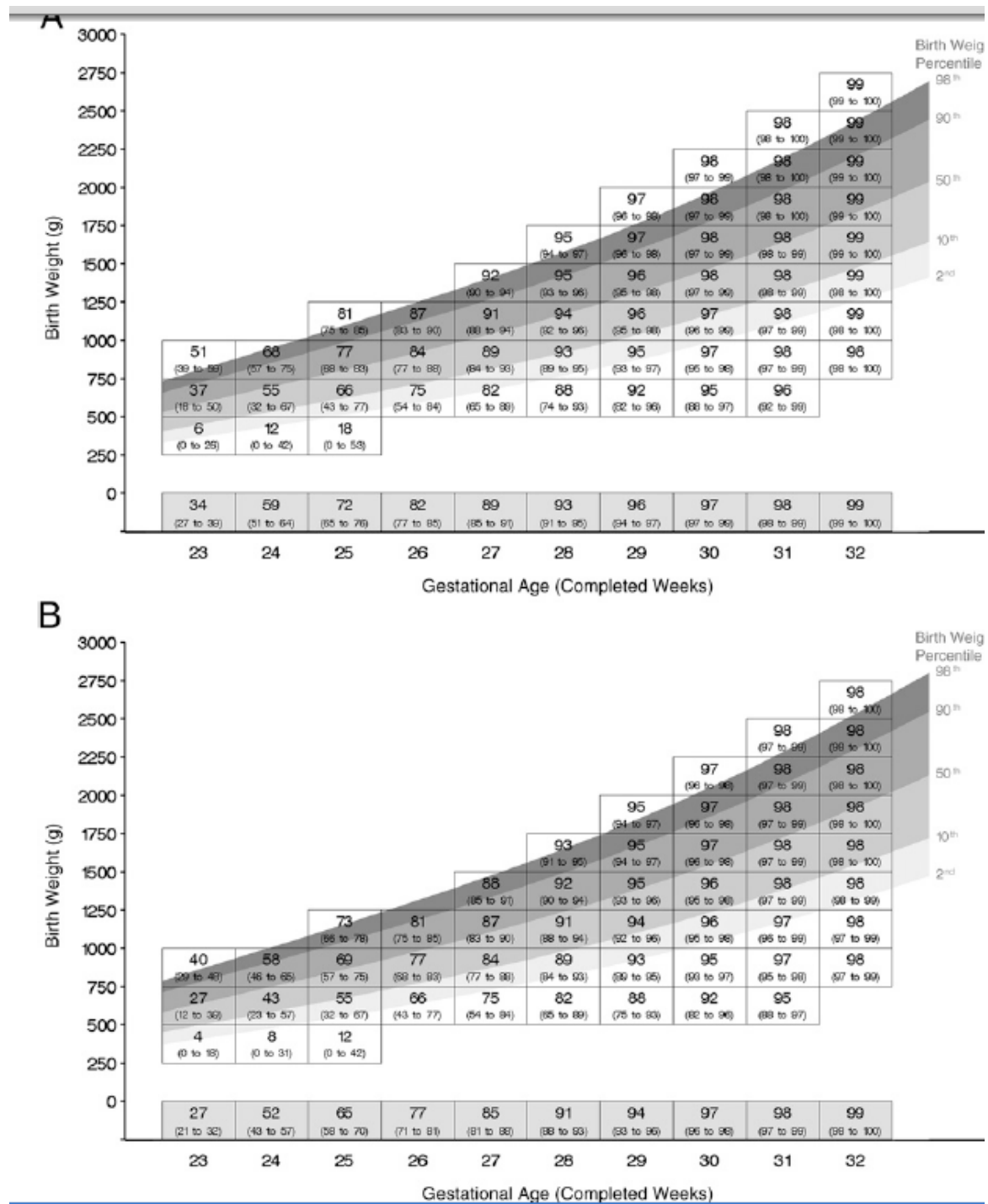
Documentation and follow up- Communication and agreed plans should be documented in full in the clinical record and plans revised regularly if pregnancy continues and/or depending upon the condition of the baby at birth and in the early days after birth. If *in utero* transfer is undertaken, the content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

Appendix 7: Grid of Predicted Survival from NNU admission (Manktelow 2013 charts)^{vii}

A: female babies

B: male babies

The main number in each cell is the predicted survival at the midpoint of the cell (week of gestational age plus 4 days and birth weight midpoint). The numbers in parentheses are the lowest and highest predicted survival within that cell.



References

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