BABIES BORN EXTREMELY PREMATURELY: 22^{+0}–26^{+6} WEEKS GESTATION

INTRODUCTION

- Outcomes for babies born very preterm improve with each additional week of gestational age; and have improved over time for any given gestation (see EPICure studies http://www.epicure.ac.uk
- **Make all efforts** to enable discussions between consultant-led obstetric and neonatal/paediatric teams and parents-to-be to take place **before** the birth of the baby
- See **BAPM framework for practice** https://www.bapm.org/resources/80-perinatal-management-of-extreme-preterm-birth-before-27-weeks-of-gestation-2019 to inform discussions and make an individualised clearly documented plan for the management of the baby
- Once the baby is born, further management decisions should be made in the baby's best interests, taking into account:
- prognostic factors
- previous discussions between obstetric and neonatal teams and parents-to-be
- clinical condition at birth
- response to stabilisation/resuscitative efforts
- In the event of imminent delivery before discussions have taken place (if fetal heart heard during labour), call neonatal team to attend delivery and request urgent neonatal/paediatric consultant assistance

MANAGEMENT

- Using the prognostic features from **BAPM Framework for practice**, babies will fall into one of the following groups: extremely high risk; high risk; or medium risk of dying/surviving without a good quality of life

Extremely high risk

- Babies with >90% chance of either dying/surviving with severe impairment if active care is instigated e.g.:
- babies 22^{+0}–22^{+6} weeks' gestation with unfavourable risk factors
- some babies 23^{+0}–23^{+6} weeks' gestation with unfavourable risk factors, including severe fetal growth restriction
- (rarely) babies ≥24^{+0} weeks' gestation with significant unfavourable risk factors, including severe fetal growth restriction

High risk

- Babies with 50–90% chance of either dying or surviving with severe impairment if active care instituted, e.g.:
- babies 22^{+0}–23^{+6} weeks' gestation with favourable risk factors
- some babies ≥24^{+0} weeks' gestation with unfavourable risk factors and/or co-morbidities

Moderate risk

- Babies with <50% chance of either dying/surviving with severe impairment if active care instituted e.g.:
- most babies ≥24^{+0} weeks' gestation
- some babies at 23^{+0}–23^{+6} weeks' gestation with favourable risk factors

MANAGEMENT AT BIRTH

- Consultant neonatologist/paediatrician should ideally be present at delivery of babies <27 weeks' gestation where survival-focused care may be attempted

Extremely high risk

- Palliative (comfort-focused) care would be in best interests of the baby and life-sustaining treatment should not be offered
- this should be compassionately explained to the parents by the perinatal team

- Generally neonatal team would not attend the birth (however may be helpful for individual families – offer if appropriate)

High risk

- For these babies it is uncertain whether survival-focused management is in the best interests of the baby and their family
- Counsel parents carefully; parental wishes should inform a joint decision to provide either survival-focused or comfort-focused treatment
- Senior neonatal clinician (ideally known to the parents) will attend the birth if at all possible, to lead/oversee implementation of agreed approach

Counsel parents that the plan for care may need to change based on the clinical condition of the baby before, at or after birth, or subsequently in NICU

Active (survival focused) neonatal management

- Stabilisation and support for transition to be carried out by/under direct supervision of most senior member of neonatal/paediatric team available (ideally team will be experienced in stabilisation of extremely preterm babies and led by consultant neonatologist)
- Team should be aware of parental wishes, but when the baby is born in **unexpectedly poor or unexpectedly good** condition, it is reasonable for attending neonatologist to proceed with care in the baby's best interests
- Use optimal cord management and appropriate thermoregulation
- Care should be taken not to over distend lungs when supporting respiratory transition, CPAP may be successfully used in babies from 24^{+0} weeks' gestation
- If no response to mask ventilation **and** any doubt around adequacy of ventilation, intubate and administer surfactant [see **Surfactant replacement therapy – including less invasive surfactant administration (LISA) technique** guideline]
- If the baby does not respond to stabilisation/resuscitative efforts, most senior attending professional to decide if/when attempts should stop
- absent heart rate/severe bradycardia despite effective resuscitation efforts for more than a few minutes is associated with very poor outcome in extremely preterm babies
- Stabilisation normally undertaken in same room as parents
- offer parents opportunity to see, touch, hold and photograph their baby
- Following successful stabilisation of the baby, the mother should be supported to express breast milk as early as possible (see **Breastfeeding** guideline), with ongoing facilitation of parental contact and family involvement

Palliative (comfort focused) neonatal management

- Aim is to support the parents and their dying baby, and to avoid interventions that may cause discomfort, pain or separation of the baby from the parents
- Care to be delivered in most appropriate location for the family (may not be NNU, and does not require in utero transfer of mother)
- For some families the presence of a senior neonatologist/paediatrician at delivery may be helpful
- all involved should understand that respiratory support will not be provided
- Give opportunities and support parents in creating positive memories of their baby
- Offer parents the opportunity to hold and spend as much time as they wish with their baby in a quiet and private location
- In the unlikely scenario of the baby being born in much better condition than expected, palliative management may need to be reconsidered

PARENT INFORMATION

- See https://www.bapm.org/resources/80-perinatal-management-of-extreme-preterm-birth-before-27-weeks-of-gestation-2019 **Appendix 4: Helping parents to understand extreme preterm birth**

Perinatal management of extreme preterm birth before 27 weeks of gestation
A BAPM Framework for Practice

Helping parents to understand extreme preterm birth.

Who is this information for?

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

What does this mean?

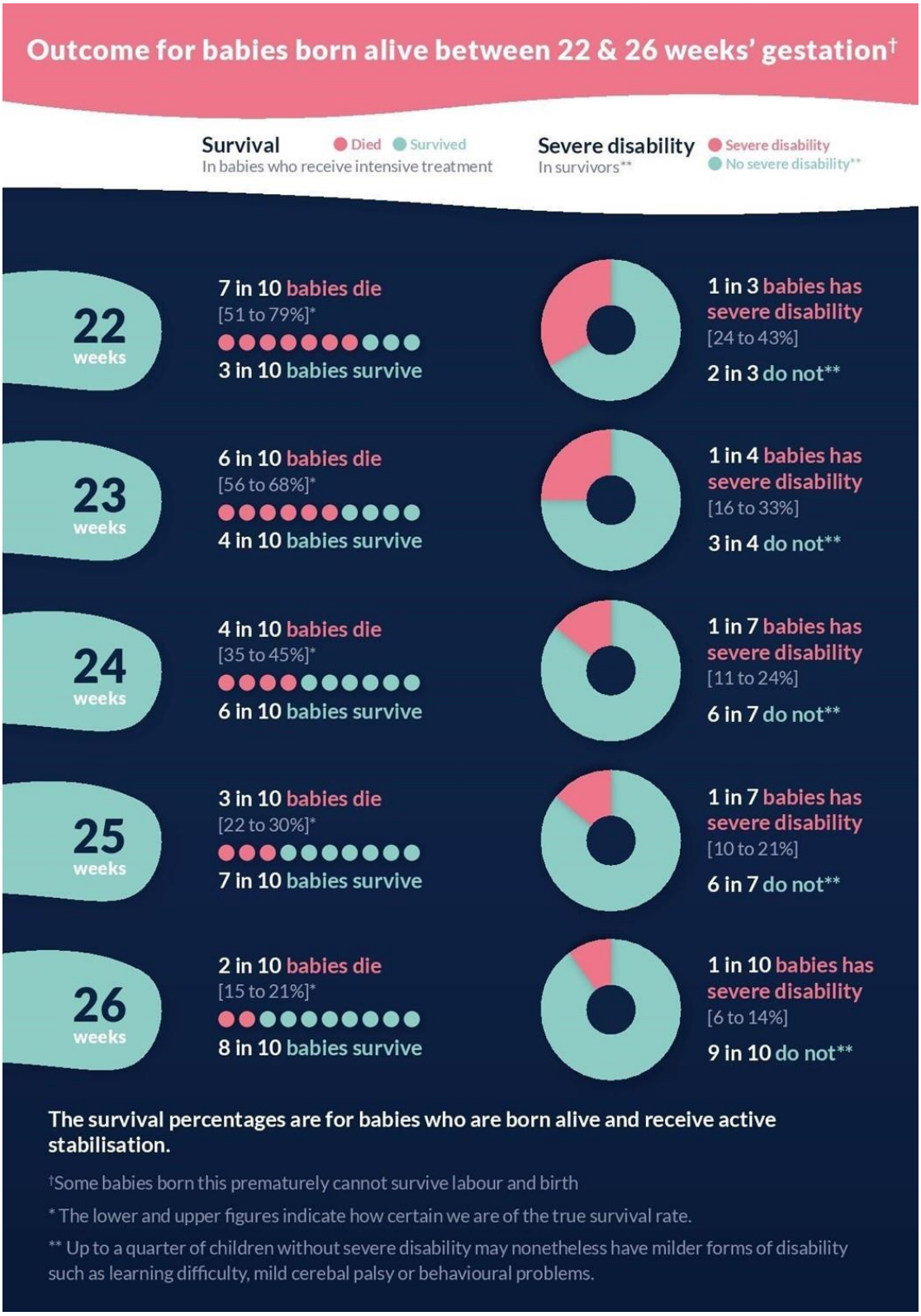
A pregnancy usually lasts for about 40 weeks. How many weeks you are along in your pregnancy (gestation) is usually worked out from an ultrasound scan at around 12 weeks (your dating scan).

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

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

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

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


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**
22 weeks
7 in 10 babies die
[51 to 79%]*
3 in 10 babies survive
1 in 3 babies has severe disability
[24 to 43%]
2 in 3 do not**
23 weeks
6 in 10 babies die
[56 to 68%]*
4 in 10 babies survive
1 in 4 babies has severe disability
[16 to 33%]
3 in 4 do not**
24 weeks
4 in 10 babies die
[35 to 45%]*
6 in 10 babies survive
1 in 7 babies has severe disability
[11 to 24%]
6 in 7 do not**
25 weeks
3 in 10 babies die
[22 to 30%]*
7 in 10 babies survive
1 in 7 babies has severe disability
[10 to 21%]
6 in 7 do not**
26 weeks
2 in 10 babies die
[15 to 21%]*
8 in 10 babies survive
1 in 10 babies has severe disability
[6 to 14%]
9 in 10 do not**
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 cerebal palsy or behavioural problems.

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

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

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

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

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

What does this mean for your baby?

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

What can parents do?
What is right for your baby and your family is very individual to you. Your doctors will talk with you about your situation and seek to understand what is important for you and your family. They will support and guide you and involve you in making decisions about treatment for your baby. Thinking about your hopes, your wishes, and your fears about your baby can help the team to support you in the best way possible.

What may happen with my baby?

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

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

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

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

What if my baby doesn't come now?
If your baby does not come in the next few days their chances may improve. Ideally, they will stay in the womb for as long as possible (depending on the health of you and your baby).
If that happens there may be different options for you and your baby around the time of birth. That will depend on when your baby comes and on other things that affect the baby's chances of responding to treatment. If this is the case, your healthcare team will continue the conversation with you about what has changed and what different options may be available depending on when your baby is likely to be born, and you will be able to discuss and revise your agreed plans accordingly.

What might my baby look like?
Babies born this early can weigh less than half a kilogram (1 small packet of sugar) and can look quite different to how we imagine a newborn baby. Their skin is shiny and thin and covered with fine hair. Sometimes babies can be quite bruised from the birth. If the baby has died before being born, they will usually be still. Occasionally, where babies have died very close to being born, they may make brief reflex movements that disappear very quickly.
If your baby is born alive, they may take a breath and make a small cry or they may not breathe. Their eyes may not be able to open yet. The baby's colour is often purple or blue to start with.

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

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

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

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

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

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

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 8088100

Sands – Stillbirth and neonatal death charity
https://www.uk-sands.org
Helpline 0808 164 3332
Email helpline@sands.org.uk

This space is for the healthcare team who are discussing this with you to write extra details about your baby or babies. You may want to use this space to write down some questions to discuss with the team.