NHS
East Midlands
Neonatal Operational Delivery Network

Understanding Extreme Preterm Birth

Parent Information

March 2022

Who is this information for?

This information has been given to you because your healthcare team think you may have your baby extremely early (prematurely). Babies are considered 'extremely early' if they are born before 27 weeks of pregnancy. It is important that you and your family understand what is likely to happen to you and your baby if this occurs. The maternity and neonatal team (specialist baby doctors and nurses) will talk to you about this in detail as well as giving you this information leaflet, and you will have the opportunity to ask any questions that you wish.

What does this mean?

We understand that you might feel sad, scared and/or nervous when reading the wide range of facts within this leaflet. It is therefore important to keep in mind that your baby is an individual, and as such, they will receive a plan of care that is tailored for your family.

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) or from your last menstrual period.

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

The longer a pregnancy continues before a baby is born, the more likely the baby is to survive. There are important factors involved when looking at survival such as where the baby is born, their gender and whether there is the opportunity to give the mother medications including steroids and magnesium sulphate which can improve the baby’s chances. Babies born between 22-27 weeks gestation can be thought of in three groups: extremely high risk, high risk and medium risk. Risk means different things to different people, but knowing the level of risk your baby carries can be helpful when planning care and next steps. You can find more information about level of risk at different gestations on pages 5 and 6.

Some babies that are born extremely early can survive with little or no disability, however many babies that do survive being born extremely early have a risk of severe disability linked to their early birth. The chances of not surviving, surviving with severe disability and surviving without severe disability are shown in charts for babies of different gestations on the next page.

The doctors and midwives will talk to you about what they expect for your baby. In some situations, there will be difficult decisions 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†

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.

‘Outcome’
These charts are based upon what we know about babies born extremely prematurely in the UK. They show how many babies survive out of those who are born alive and receive intensive care in the delivery room. Of those who do survive with intensive care, they also show how many are likely to have a ‘severe disability’ when they grow up. Some babies born at the lower gestations (22 and 23 weeks) will receive comfort care in the delivery room after discussion between parents and the medical team. They will sadly die shortly after birth, even if born alive. The outcomes for these babies are not included in this chart.

As shown in the picture, extremely preterm babies have a high chance of developing long term problems. At 22 weeks gestation, 1 in 3 babies who survive with intensive care would be expected to have a severe disability.

It is important to think about this as a family, as what happens around the time of birth can have lifelong effects for your baby.

The studies used in this guidance looked at the ‘worst’ long term problems, such as being unable to walk, unable to feed, or being blind or deaf. 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 such as Autism Spectrum Disorder (ASD) and/or Attention Deficit Hyperactivity Disorder (ADHD). The frequency with which children have these problems is greatest the earlier they are born, and are most common in children born at 22 to 24 weeks of gestation.

The chance for your baby to survive without severe disability depends on a number of different things. As well as how early they are born, it also matters how much your baby weighs when they are born, whether they are a boy or girl, whether they are a multiple birth, where they are born 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 conditions such as:

· Not being able to walk or get around independently (this includes severe cerebral palsy)
· Being unable to talk, or see or hear properly
· Difficulties with swallowing or feeding safely
· Having multiple health difficulties with frequent visits to hospital
· Needing to attend a specialist 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 what the future will be 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 and communicating your hopes, wishes, and fears for your baby can help the team support you in the best way possible.

What care options are there for your baby?
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 additional treatments before your baby is born. You will be given steroids which can help your baby's lungs and brain, and magnesium sulphate which also helps to protect your baby's brain. You may need to be transferred to a specialist hospital, ideally before you have your baby, but there may not be time to do this safely.

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 may happen with my baby?

Your baby's situation is likely to change on a daily basis as your pregnancy and/or condition progresses, therefore it is important to have regular discussions with both the neonatal and maternity teams so that you understand the most recent picture. We also know that your thoughts may change over the next day or two and so keeping discussions open is very important.

Extremely high risk

22-23 weeks gestation

The neonatal team has a duty of care to your baby, to do no harm. If your baby is born extremely early, the neonatal team together with you, must think about the possibility of causing harm when trying to help your baby immediately after delivery, and also the days/weeks/months that might follow by providing intensive care.

We know that for many babies who are born alive at an extremely early stage of pregnancy, particularly those born before 23 weeks gestation, the family and neonatal team will decide together that comfort care is the best option. For those babies whose family and neonatal team decide to start intensive care treatment, this decision can be reviewed as time moves forward. Whatever decision you and your baby's medical team make the team are there to support you.

High Risk

24-25 weeks gestation

When thinking about the best way to care for your extremely early baby, the neonatal team will talk to you about your baby's unique situation and their chances of survival and what that might look like.

Typically speaking, the majority of babies born between 24-25 weeks gestation will receive some level of intensive care in line with family wishes and discussion with medical team. This is because while babies born at this point are still at significantly increased risk of disability the chance of disability free survival is increasing with each week that passes. In some situations family wishes and discussion with medical team may still lead to a comfort care decision at this gestation.

Medium risk

26-27 weeks gestation

In most circumstances at this later stage of extreme prematurity, families and medical teams choose to provide intensive care at birth. However, survival at this gestation is not guaranteed. Research shows that an average of 8 in 10 babies born at this stage will survive and of those that survive the majority will survive without severe disability. It is key to remember to have regular conversations with your medical team in order to understand the level of risk your baby carries and how that might change on a daily basis. You are not alone in making decisions and the medical and nursing teams are there to help support and guide you.

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. You will have the opportunity to spend as much time with them as you would like and make memories. Under UK law, only babies born after 24 completed weeks of gestation can be registered as stillborn. If your baby was stillborn before 24 weeks, this is known as a miscarriage, and you will not need to register the stillbirth of your baby formally.

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, depending upon when your baby comes and other factors that affect a baby's chances of responding to treatment. 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. You will be able to discuss and change 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 look quite different from how we imagine a new born baby. Their skin is shiny and thin (so babies often look dark pink/purple due to their skin being slightly see-through) and covered with fine hair. Due to not being fully developed, their eyes may not be able to open yet. Sometimes babies can be quite bruised from the birth. If a 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 stop very quickly.

If your baby is born alive, they may take a breath and make a small cry, or they may not breathe.

Transfer to a different hospital

If you have decided with the obstetric and neonatal care teams that starting neonatal intensive care would be best for your baby, then the hospital you give birth in becomes very important. 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'). In this instance, wherever possible, you will be moved before your baby is born to a hospital which has a NICU. If a baby is born before 27 weeks of gestation in a maternity unit (or at home) where there is not a specialist NICU, then the evidence shows us that although transfer of extreme preterm infants is not without risks, the baby will generally do better if they are moved to a specialist NICU at a suitable time after birth.

For more information on transfer, please refer to the EMNODN Transfer Information leaflet.

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. 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 wants to work with you to make the best decision for your baby and your family.

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

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

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

Tommys - Pregnancy, birth and loss
https://www.tommys.org/

This information leaflet was adapted from the guidance produced by BAPM by the East Midlands Neonatal Operational Delivery Network for use across the East Midlands.

For further information on what we do, please visit our website; www.emnodn.nhs.uk