

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.

Most babies born at 22 weeks are not strong enough to survive, and may even die during labour or birth. If they are born alive, and are a good weight, they may be able to survive if they receive intensive medical treatment. 23 week babies have somewhat better chances of survival. However, often these extremely premature babies sadly die despite intensive care 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 more common in those children born before 25 weeks of gestation. Health problems may include breathing difficulties, gut problems (including difficulties with feeding) and sight problems. Developmental problems may include problems with movement, learning and behaviour that can range from mild to severe; such problems are described on the following page.

In some situations, there are difficult decisions to be made around the care for you and 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'

These pictures below 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' as they grow up.

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 outcomes for your baby depend on a number of different factors. 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, whether you have received steroids antenatally and also how well you and your baby are around the time of birth.

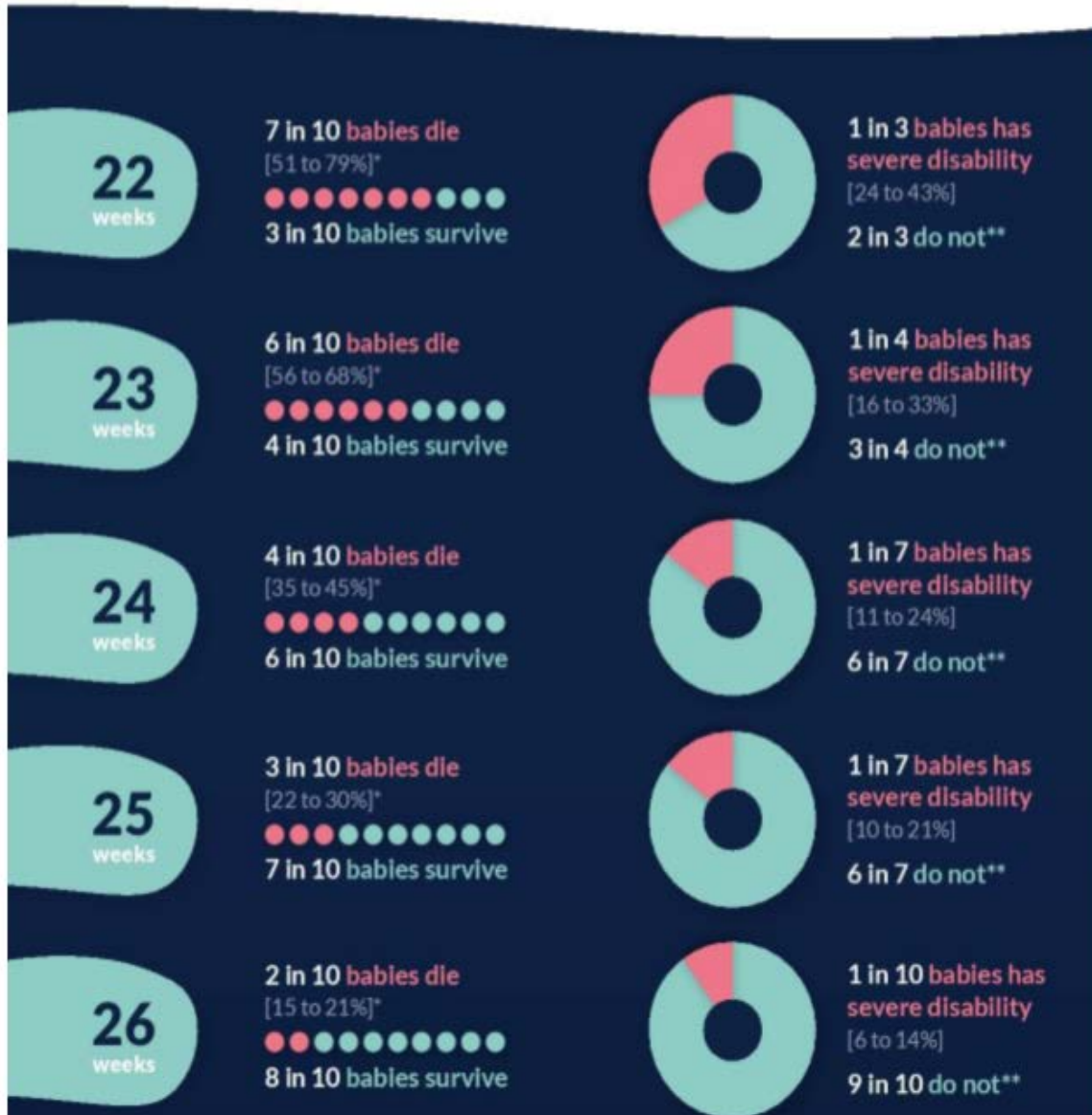
Outcome for babies born alive between 22 & 26 weeks' gestation†

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.

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 could include 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
- Needing assistance to care for themselves or difficulties living independently as they grow up

What does this mean for your baby?

It is difficult to predict the outcomes for your baby. Every baby is different and there will be specific information about your own and your baby's condition that you, as parents will need to consider

What can parents do?

What is right for your baby and your family is very individual to you. Your doctors will discuss with you about your situation and seek to understand what is important for you and your family. They will help you to make decisions about treatment for your baby. Discussing 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 may 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. Occasionally, where babies have died very close to being born, they may make brief reflex movements that disappear very quickly.

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 or by accessing the NW Neonatal Network website at <https://www.neonatalnetwork.co.uk/nwnodn/palliative-care/>

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 medication before your baby is born. You will be given steroids to help your baby's lungs and brain and magnesium which may also help 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 any treatment. The neonatal team will be present at the delivery and their focus will be to stabilise baby prior to transferring to neonatal unit. If you and the team decide that intensive care is an option 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 early expression of colostrum and continued milk expression has many benefits for both mother and baby, which can make such a big difference for premature babies.

What if my baby isn't born yet?

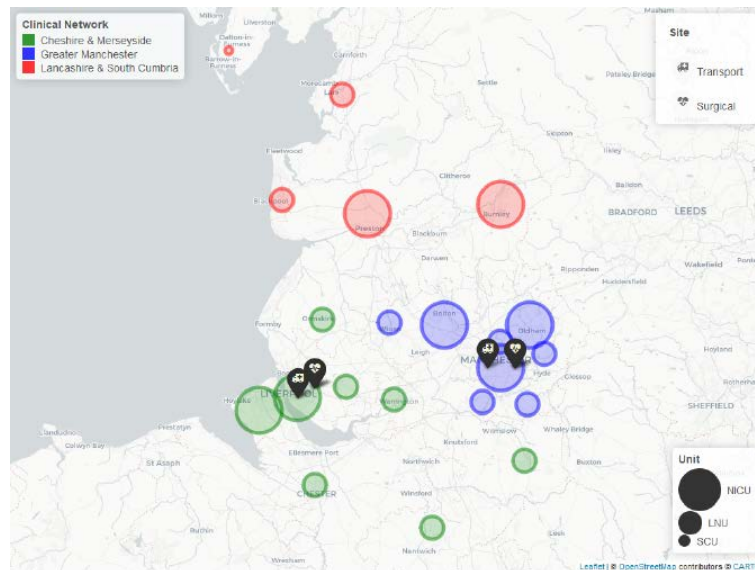
If your baby isn't born in the next few days their outcomes may improve. Ideally, they will stay in the womb for as long as possible (depending on the health of you and your baby). If that happens there may be different options for you and your baby around the time of birth. That will depend on when your baby is born and on other things that affect your baby's response 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 new-born baby. Their skin is shiny and thin and covered with fine hair. Sometimes babies can be quite bruised from the birth. So your baby's colour may not be as expected initially. If your baby is born alive, they may take a breath and make a small cry, although it is also common for a very premature baby not to cry or make any noise at delivery, or they may not breathe. Their eyes may not be able to open yet.

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. Details of all the neonatal units within the North West can be found on the NWNODN website: <https://www.neonatalnetwork.co.uk/nwnodn/>



Information on the hospitals within the three localities across the North West (Lancashire & South Cumbria, Greater Manchester and Cheshire & Merseyside) can be found at: <https://www.neonatalnetwork.co.uk/nwnodn/publications-and-downloads/>

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 but transferring is in the best interests of the baby. 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. It is recognised that partners may have to make the difficult decision of whether to stay at the local maternity unit with the mother, travel to the NICU where the baby transfers to or care for other children at home. This is something you may wish to discuss and agree on as a family, remembering all choices are appropriate.

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

What if I have more questions?

This information has been provided to you as part of the conversation that your healthcare team will have with you about your baby. If you have any other questions do make sure you ask your doctors and nurses to answer them, so you have all the information you need about your situation and the options available to you. Your healthcare team want to work with you make the best decision for your baby and for your family. This space is for the health care team who are discussing this with you to write extra details about your baby or babies.

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.

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

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

Taken from the BAPM Perinatal Management of Extreme Preterm Birth Framework for Practice (©BAPM 2019)

For local support near to where you live please visit the North West Neonatal Operational Delivery website at:

<https://www.neonatalnetwork.co.uk/nwnodn/cheshire-and-merseyside/family-peer-support/>

For local parent stories visit:

<https://www.neonatalnetwork.co.uk/nwnodn/parent-stories/>

For further information on palliative and end of life care visit:

<https://www.neonatalnetwork.co.uk/nwnodn/palliative-care/#1501245355602-079c34b5-024e>