

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

This leaflet is written for parents who are at risk of having an extremely premature baby (born between 22 and 26 weeks of pregnancy). We understand that this is an incredibly stressful and worrying time for you and your family, and hope that the information in this leaflet helps you to understand some of the difficult decisions that need to be made. This leaflet is designed to complement discussions you will have with the obstetricians (the doctors who look after pregnant women and oversee the delivery of their babies) and the neonatologists (the doctors who care for extremely premature babies when they've been born).

Before birth

It may be appropriate to offer you interventions to help assess your baby and optimise their condition (and survival chances) when they're born. Any appropriate interventions will be discussed with you. These include:

- **An ultrasound scan** – to look at the length of your cervix and to check on the wellbeing of your baby
- **Steroids** – If we suspect that your baby will be born soon, we will give you steroid injections (an injection into the muscle in your leg) to help mature your baby's lungs.
- **Magnesium sulphate** – If we suspect that your baby will be born soon, we will give you magnesium sulphate through your cannula (into your blood stream). Magnesium crosses the placenta quickly and helps the development of your baby's brain.
- **Place of birth** - The NICU at Liverpool Women's Hospital provides care to the sickest and most premature babies across the Northwest. You may have been transferred here despite booking your pregnancy at a more local hospital. This is so we can offer the best care and survival chances to your baby. If your baby is born prematurely, we would aim to transfer them back to your local hospital when they are big enough and strong enough for this to be safe. This transfer is done by a specialist neonatal transport team.

- **A tour of the NICU** – we understand that most families will not have visited a NICU before. Having a tour can help reduce some of the anxieties about where your baby will go after they've been born. Your midwife can help you arrange this.

The way your baby is born

If you are likely to have an extremely premature baby, then there will be discussions from the obstetricians about the best way to deliver your baby. In extremely premature babies there is no evidence to suggest that the baby's health is improved following birth by caesarean section compared to a normal vaginal delivery. A caesarean section is more difficult in early pregnancy and is associated with significant risks to the mother's health and future pregnancies.

What will happen when my baby is born?

At the time of birth, there will be a team of people to look after you (obstetricians, midwives) and a team of people to look after your baby (neonatologists, neonatal nurses). There will be more people there if you need to have a caesarean section in an operating theatre. What happens after birth depends on the gestation of your baby, any other medical problems they have, and the condition that they're born in. We will try and talk about what happens with you before you have your baby.

- **Keeping them warm** – Once your baby is born, they will be placed immediately inside a special plastic bag and then onto a heated mattress. We will do this on a specially designed trolley (called the LifeStart™ trolley) next to your bed. Premature babies lose heat very quickly and become more unwell if they get cold. We carefully monitor their temperature after birth to keep them warm.
- **Leaving them attached to your umbilical cord** – We know that there are many important benefits to leaving your baby attached to your umbilical cord for at least 60 seconds after birth. We will leave your baby attached to your umbilical cord whilst we keep them warm and assess them on the LifeStart™ trolley.
- **Assessing their breathing** – Premature babies are expected to need help with their breathing after birth due to their immature lungs. In extremely premature babies, we will need to place a breathing tube into their windpipe (trachea) and breath for them using a ventilator (breathing machine). In slightly more mature babies who show a good breathing effort after birth, we can support their breathing with a mask over their nose and mouth.
- **Cuddles** – We know that having a premature baby is scary. We also know that cuddling your baby is important and something that every mother, father or partner should be able to do after their baby is born. Once we've stabilised their breathing and their oxygen levels are acceptable, we will move them up onto your chest for cuddles (and photographs/memory making etc.) before we transfer your baby to the neonatal unit.
- **Transfer to the Neonatal Intensive Care Unit (NICU)**. Extremely premature babies need different levels of intensive care to support the different organs in their bodies as they grow. Unfortunately, they cannot stay with their parents after birth and need to be moved to NICU to stabilise them and commence intensive care. We will re-unite you with your baby as quickly as possible after birth.

What does being born prematurely mean for my baby?

Some babies born extremely prematurely will survive and be healthy. Others will survive and have a degree of disability. Some babies will very sadly die on the neonatal unit, and some may die before they're born. The chance of your baby surviving increases with each additional week of pregnancy and the risk of disability decreases.

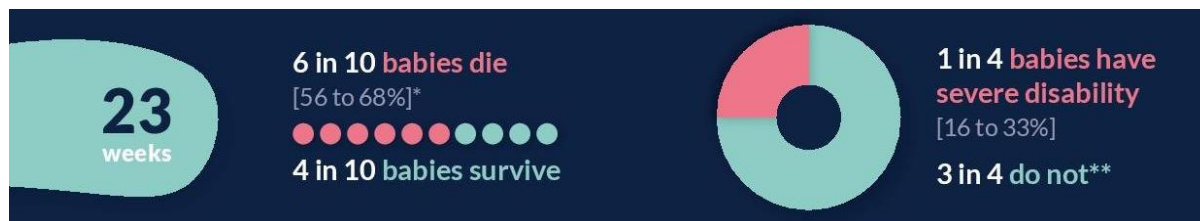
Below is a guide to what being born extremely prematurely might mean for your baby. The survival figures quoted on each graphic are for babies who are born alive and are stabilised in the delivery room.

22 weeks



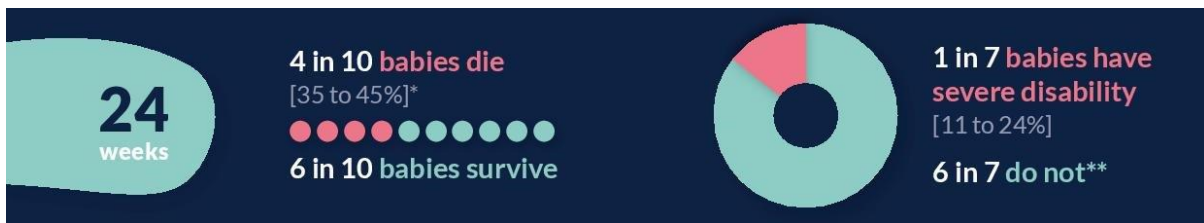
At 22 weeks, your baby is very small and unlikely to survive. Some of these babies will die whilst being born. We focus on making sure your baby is comfortable and not in any pain. We will help you make the most of your precious time together as a family. In some circumstances, offering intensive care may be considered. A Senior Neonatologist will explore the options with you that are appropriate for you and your baby and help you make a choice as a family.

23 weeks



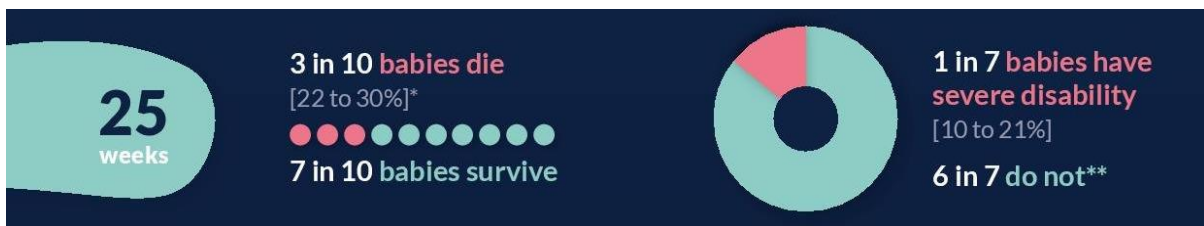
At this stage in pregnancy, the outcome remains uncertain for your baby. They are more likely to die than survive. A Senior Neonatologist will talk through the options you have with you and your family. If intensive care (with the aim of survival) is felt to be appropriate, then a team of neonatal doctors and nurses will be present at the birth of your baby and will stabilise them in the delivery room (as discussed above) and transfer them to NICU for intensive care. If we decide together that intensive care is not in the best interests of your baby, then the care provided will be focused on comfort and spending time together as a family.

24 weeks



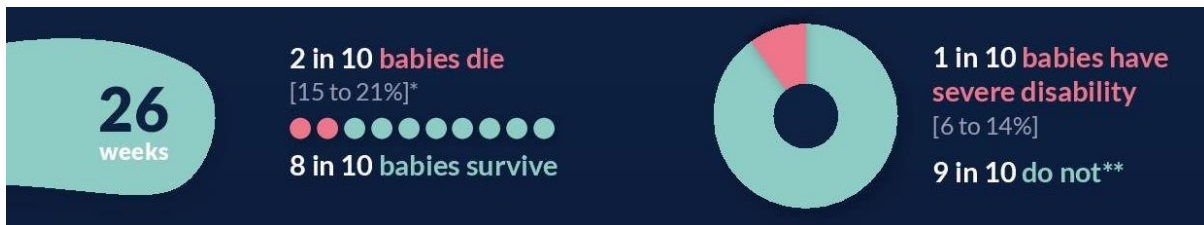
At 24 weeks, stabilisation and intensive care is usually offered and the neonatal team will attend the delivery of your baby. A Neonatologist will talk to you before birth about what to expect after your baby is born.

25 weeks



At 25 weeks, stabilisation and intensive care is usually offered and the neonatal team will attend the delivery of your baby. A Neonatologist will talk to you before birth about what to expect after your baby is born.

26 weeks



At 26 weeks, stabilisation and intensive care is usually offered and the neonatal team will attend the delivery of your baby. A Neonatologist will talk to you before birth about what to expect after your baby is born.

What can I expect when my baby is on NICU?

When a baby is born extremely prematurely, they face a long journey before they can go home. We usually tell parents to plan for discharge home around your due date. This can mean 3-4 months in hospital for your baby.

Whilst your baby is on NICU, you (their parent) and any of their siblings, can spend as much time with them as you wish. We will support you in caring for your baby (changing their nappy, feeding them, giving them medications etc.) and show you how to do this – even when they are very small.

Your baby will be looked after by a team of doctors, nurse practitioners, nurses, health care assistants, physiotherapists, and pharmacists. They will be looked after by a highly skilled team 24 hours a day, 7 days a week.

What might the future look like for my baby?

When your baby is born extremely prematurely, their organ systems (lungs, heart, brain, kidneys etc.) are incredibly immature. On the NICU, we work to support these organs as your baby grows and develops.

Sometimes, these immature organs can encounter problems which can make your baby unwell. Some of these problems can result in significant illness which might have long term implications for your baby if they survive and go home.

The graphics for each gestational age (shown in a previous section) show the chances of growing up with severe disability. This could mean not being able to walk or move independently, having a lot of health care needs with frequent visits to hospital, and needing extra educational support (or needing to attend a special school).

Up to one quarter of children without severe disability may have impairments they need support with, such as learning difficulties and behavioural problems.

Your child will be reviewed regularly as they grow up in outpatient clinic by a highly skilled team of doctors and physiotherapists. If we identify any areas in which your child needs support, we will work quickly to put this in place.

Research

Much of the care provided on NICU is based on research about medicines and other treatments. The NICU works to improve the care we give to babies and so we always have several research studies ongoing at any time.

You may be approached about one or more research studies while your baby is on the unit, or before your baby is born. We hope you will consider allowing your baby to join these studies.

We will respect your decisions about whether your baby joins any studies and it will not affect the care that your baby receives if you decide to not take part.

Advice and Recommendations

Further information

This leaflet is intended to give you information and answer some of your immediate questions. Further information is available from your obstetrician, midwife and neonatologist. Please do not hesitate to ask to speak to us. The following resources may be useful:

Bliss – www.bliss.org.uk

Tommy's – www.tommys.org

Nuffield Council for Bioethics – www.nuffieldbioethics.org

Sick Children's Trust – www.sickchildrenstrust.org

This leaflet can be made available in different formats on request. If you would like to make any suggestions or comments about the content of this leaflet, then please contact the Patient Experience Team on 0151 702 4353 or by email at pals@lwh.nhs.uk

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