Liverpool Women's
NHS Foundation Trust

You and Your Premature Baby
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 a very premature baby (delivering between 22 and 25 weeks of pregnancy). We will help you to make some important choices about your care before and during labour if this was to happen.

This leaflet contains important information to help you decide what would be best for you, your baby and your family. We are happy to go through this leaflet with you to explain things further and give you a chance to ask questions.

The obstetricians (doctor who look after pregnant women) and neonatologist (doctor who look after sick newborn babies) will discuss with you what it may mean for your baby if he or she delivers early. Babies born very prematurely may not survive or may have long-term problems.

These problems are set out in more detail below. The chances of survival depend on many factors including how many weeks into the pregnancy you are, birth weight, any abnormalities picked up on scan, how strong they are when they are born and whether there is any infection present. You will be offered a visit to the neonatal unit, which is where your baby is likely to receive specialist care, if delivered early.

This leaflet is written for parents who are at risk of having a very premature baby (delivering between 22 and 25 weeks of pregnancy).

We will help you to make some important choices about your care before and during labour if this was to happen.

For All Women at Risk of Extremely Premature Delivery We May Consider The Following

- **Ultrasound scan:** to look at the length of your cervix and to look at your baby's growth and well-being
- **Antenatal steroids:** after 23 weeks we will give you steroid injections to help the development of your baby's immature lungs.
- **Magnesium sulphate:** after 23 weeks we will give you an infusion to help the development of your baby's immature brain
- We look after babies from other hospitals in the Northwest as 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. Also, if your baby remains well on our neonatal unit they may be transferred back to the hospital where you were initially booked so that another baby that needs intensive care with us can have it.

Problems Premature Babies May Have

Babies born extremely prematurely have very immature organs. They are at increased risk of problems in later childhood even if they survive the neonatal period. These are some of the potential problems:

- **Damage to the lungs** (chronic lung disease) causing breathing problems
- **Damage to their brain** from bleeding or cyst formation (small "holes" in the brain)
- **Damage to their bowels**
- **Damage to their eyes** (retinopathy), which may affect their vision
- **Hearing problems**

Outcomes

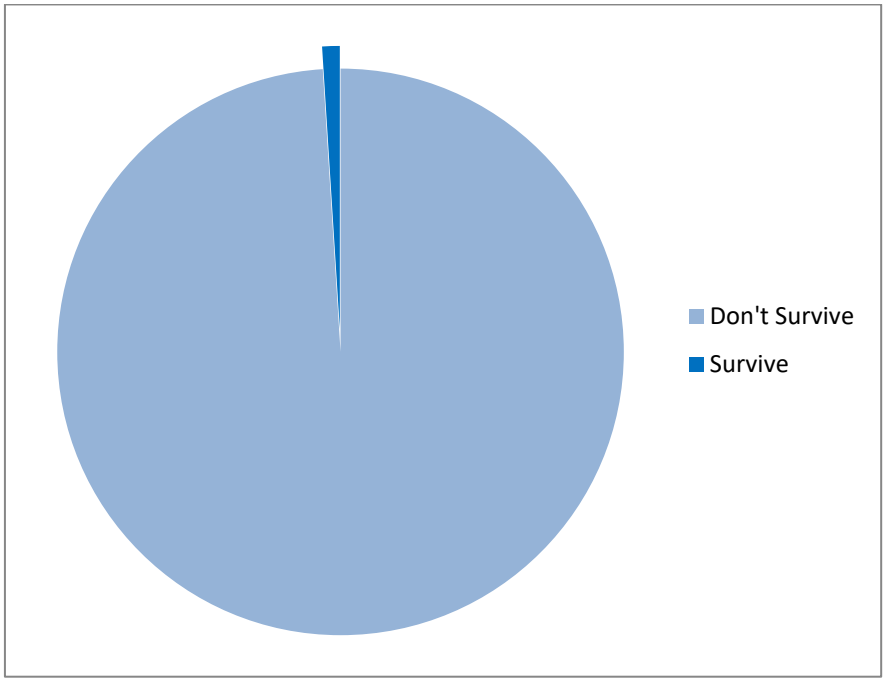
Babies born early may be stillborn, may die soon after being born alive, may survive and be healthy or may survive but have long term problems and disabilities. The chance of survival increases with each additional week of pregnancy and the risk of disabilities reduces. The charts below show what proportion of babies fall into each group for babies born at either 22, 23, 24 or 25 weeks.

The information in these charts comes from two large studies (EPICURE 1 in 1995 and EPICURE 2 in 2006), which assessed the outcome of large groups of babies that were born during these weeks of pregnancy in the U.K.

The definitions they used for different types of disability are shown below.

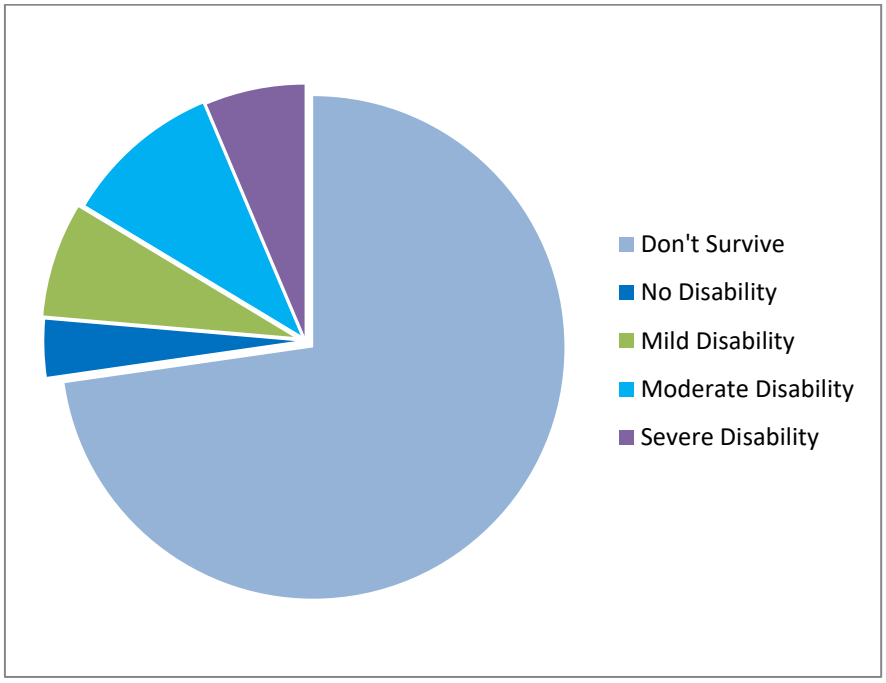
22 Weeks

Only 1 in 100 babies survive with likely severe disability:



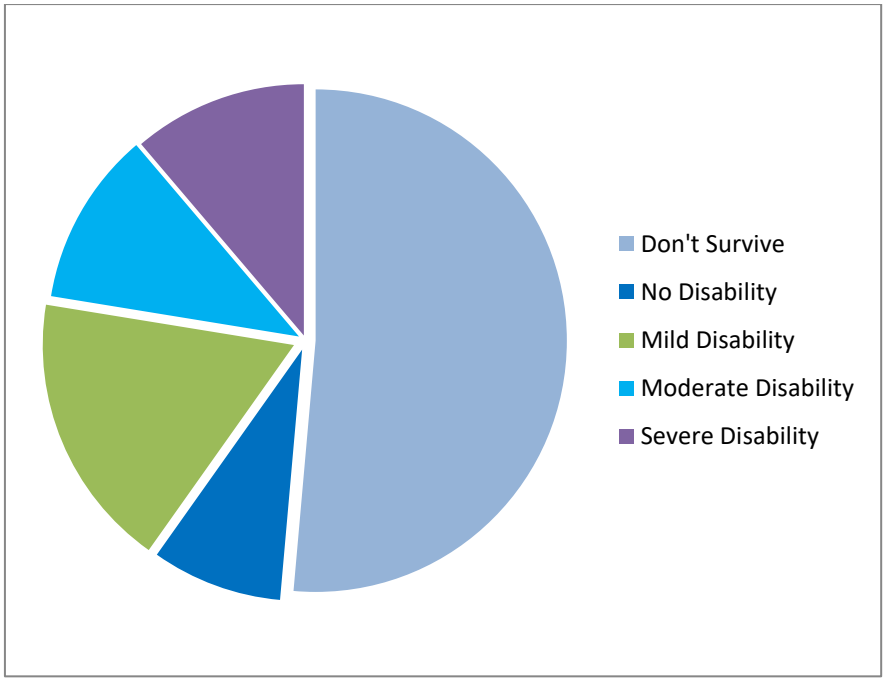
23 Weeks

2-3 in 10 babies survive of whom two thirds have moderate to severe disability:



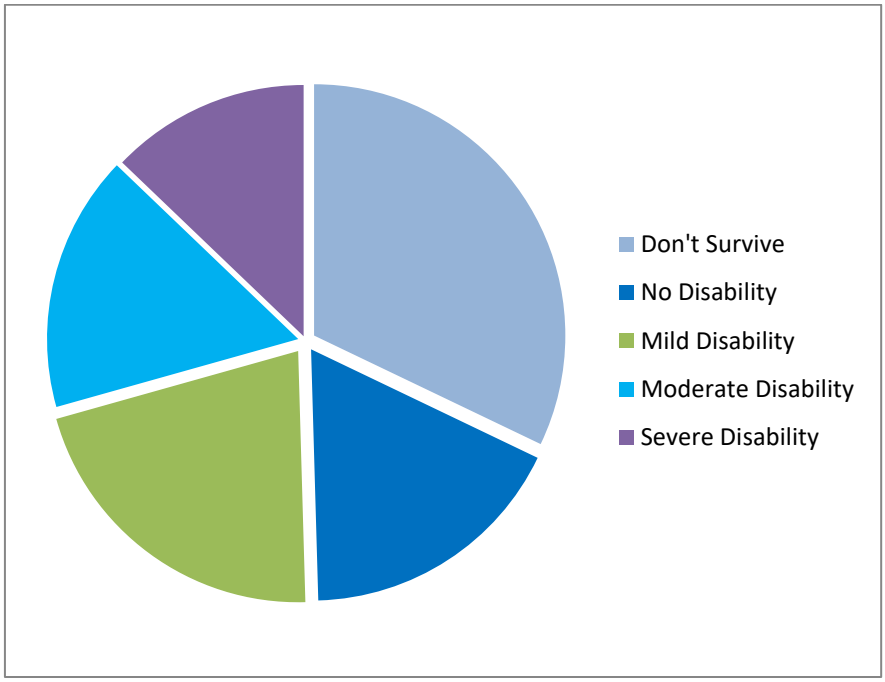
24 Weeks

4-5 in 10 babies survive of whom half have moderate to severe disability:



25 Weeks

6-7 in 10 babies survive of whom 4 in 10 moderate to severe disability:



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

Moderate Disability - Children who have reached a reasonable level of independence, e.g. cerebral palsy but still able to walk, lower than average IQ, hearing loss correctable by a hearing aid, impaired vision without blindness

Severe Disability - Children with problems that require dependency on carer's, e.g. cerebral palsy preventing a child from walking, inability to feed them, profound hearing problems and blindness.

Choices

There are some important choices that we need to make together.

The Way Your Baby Is Born

In extremely preterm babies there is no evidence that the baby's health is improved by Caesarean section over a normal vaginal birth. The operation is more difficult very early in pregnancy and when the baby is very small. The two main reasons for not opting for a Caesarean section are that it doesn't improve how you baby does and it is associated with serious risks to the mother's health and future pregnancies.

Our usual advice is that Caesarean section is not appropriate before 24 weeks of pregnancy unless the mother's life is at risk. A Caesarean section may be considered after 24 weeks of pregnancy in specific situations, such as transverse lie (baby lying across in mum's womb instead of in head down position) because of the associated risks to the baby.

After 26 weeks we would normally offer Caesarean section 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 Caesarean section if there was evidence of the baby becoming unwell during labour, but some might choose to allow the baby to deliver naturally. We will discuss your particular circumstances with you and help you with this decision

Heart Rate Monitoring For Your Baby in Labour

This is usually advised from 26 weeks of pregnancy a small, safe and noninvasive 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 Caesarean section in labour if the trace showed the baby was developing problems.

What Will Happen When My Baby Is Born?

Preterm babies have all parts of their bodies formed but are very small and thin. Their skin is much darker than a baby born nearer their due date. They can cry when first born but they can also be stillborn. Unfortunately, the earlier the baby is born, the less chance there is of it surviving and being healthy. We are here to help you make the decision about what we should do for your baby when they are born:

22 weeks – Your baby is sadly highly unlikely to survive at this gestation and intensive care is not usually offered. When intensive care is not offered you will have the opportunity to hold them. They may be stillborn or there can be signs of life like breathing or a heartbeat that lasts for several hours sometimes. We will make sure they are not suffering. We understand this is a very difficult time and a senior neonatologist will speak to you, if you request, to discuss your specific circumstances and whether resuscitation and intensive care could be considered.

23 weeks – At this stage of pregnancy, there is greatest uncertainty about the outcome for a baby. Intensive care support will be offered if parents specifically request it and the senior neonatologist present feels it to be appropriate based on your specific circumstances. Otherwise we will wrap your baby up and you can hold them if you wish.

24 weeks – Resuscitation and intensive care support is usually offered unless parents and doctors agree that there is little hope of survival due to other things that have happened in your pregnancy or that have been found on scan.

25 weeks and over – Your baby will be given full intensive care support. They will be helped with their breathing, kept warm, and transferred to the neonatal intensive care unit for ongoing care.

A neonatal team of doctors and nurses (about 4 people) will be present at the birth of your baby. More people will be present if you are having more than one baby. They will involve you in decisions about the amount of medical support that is in your baby's best interests and will keep you fully informed of your baby's progress after delivery. If your baby is strong enough they will be transferred to the neonatal unit very soon after birth.

You will be able to see them before they go and will be able to see them on the neonatal unit once they are stabilized. They will not be weighed until they get to the neonatal unit. Fathers sometimes feel excluded from the birth of a preterm baby experience and are often also worried about their partner who can be very ill. The neonatal team will include you throughout the process – please feel free to become involved and ask lots of questions.

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Research

Much of the care provided on the unit is based on research about medicines and other treatments.

The unit works to improve the care received by the babies and so we always have a number of research studies open on the unit.

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.

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Advice and Recommendations

Further information

This leaflet is intended to give you information and answer some of your immediate questions. Please feel free to discuss any further questions and concerns with your midwife or doctor. The following resources may be useful:

Bliss – www.bliss.org.uk
Tommy's – www.tommys.org
EPICURE – www.epicure.ac.uk
Nuffield Council for Bioethics – www.nuffieldbioethics.org

This leaflet can be made available in difference 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

Liverpool Women's NHS Foundation Trust
Crown Street
Liverpool
L8 7SS
Tel: 0151 708 9988
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