

## Patient information factsheet

# 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 26 weeks of pregnancy). You will need to make some important choices about your care before and during labour if this occurs. 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 clarify any points and answer your questions.**

The obstetricians and paediatrician/neonatologist (baby doctor) will discuss with you what it may mean for your baby if he or she delivers soon. 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 stage of the pregnancy, birthweight, presence of inherited abnormalities, condition at birth and presence of infection. The potential risks in your individual situation will be explained.

You may be offered a visit to the neonatal unit, which is where your baby is likely to go for specialist care, if delivered early.

### Outcomes

Babies born early may not survive, may survive and be healthy or may survive but have disabilities. The chance of survival increases with each additional week of pregnancy and the chance of disabilities reduces. The charts below show what proportion of babies fall into each group for babies born between 22 and 23 weeks; 23 and 24 weeks; 24 and 25 weeks and 25 and 26 weeks.

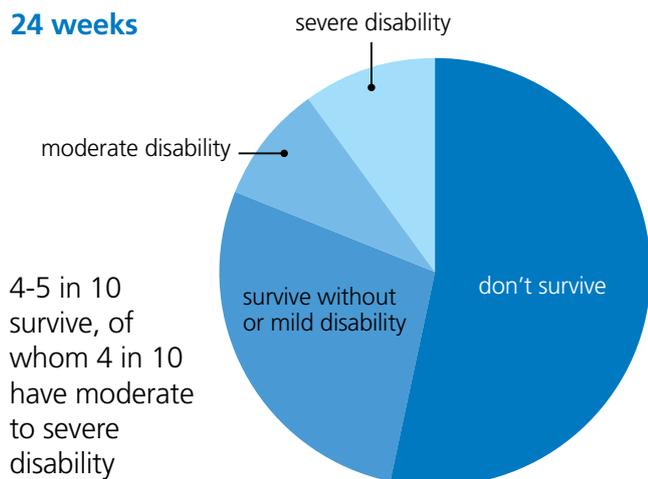
The information in these charts comes from a large study (EPICURE 2 in 2006), which assessed the outcome of large groups of babies that were born during these weeks of pregnancy. The definitions they used for different types of disability are shown below.

**Figure 1: Survival and disability up to three years in babies admitted to neonatal units under 26 weeks from EPICURE 2 study**

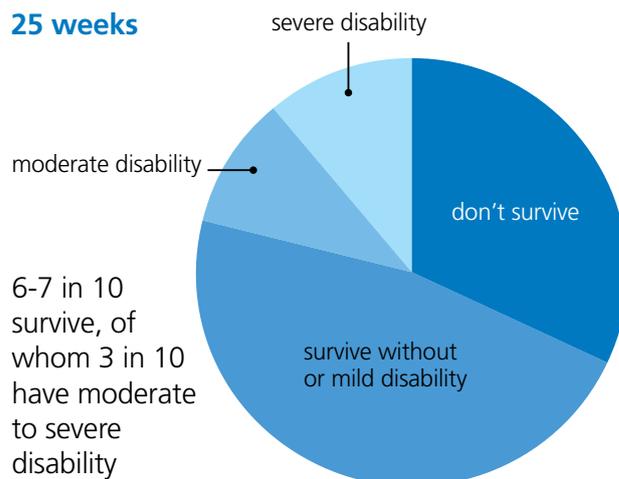


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## 24 weeks



## 25 weeks



**Severe disability** – includes disorders requiring high dependency on carers, e.g. cerebral palsy preventing a child from walking, severe learning difficulties, profound hearing problems and blindness.

**Moderate disability** – includes children with cerebral palsy who are able to walk but with some limitations, development scores below normal range, hearing loss correctable by a hearing aid, impaired vision without blindness.

**Mild disability** – includes those with mild learning problems or other impairments such as squints, which do not interfere significantly with everyday life.

**More recent local and regional data suggest further improvement in the survival rates of babies born very preterm, which will be discussed with you, although information on long term outcomes is not yet available.**

Babies born extremely prematurely have very immature organs and 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 their brain, such as cerebral parenchymal cysts (small “holes” in the brain) and hydrocephalus (too much fluid in the brain). These changes can cause cerebral palsy and/or learning difficulties.
- Damage to their eyes (retinopathy), which may affect their vision
- Hearing problems
- Damage to the lungs (chronic lung disease) causing breathing problems or asthma
- Problems with feeding and longer term growth

**For all mothers at risk of very premature delivery we may consider the following:**

- Examination of the neck of your womb for signs of labour and fetal fibronectin testing (similar to cervical smear) to predict your chances of naturally delivering in the next two weeks.
- Ultrasound scan: this may be carried out to assess your baby's growth and well-being and to tell if the baby is head or bottom-first.
- Antenatal steroids: after 24 weeks we will give you steroid injections to help the development of the baby's immature lungs.
- Magnesium sulphate infusion before delivery to help reduce the risks of cerebral palsy in your baby.
- Transfer to another hospital: 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.

## There are two important choices we would like to involve you in:

### 1. The way your baby is born:

There is no clear evidence that the baby's health is improved by Caesarean section (CS) over vaginal birth in extremely preterm babies (whether single or twins). The operation is more difficult when the baby is very small and the pregnancy very early, and it may not improve the outlook for the baby, especially if there is a high chance of it not surviving. Alternatively, the baby may be delivered and survive but with the long-term problems that affect very premature babies. Compared to vaginal birth, a CS is associated with increased risks to the mother's health and future pregnancies.

Our usual advice is that CS is not appropriate before 24 weeks of pregnancy unless the mother is very unwell and urgent delivery is required for her health (e.g. very high blood pressure) rather than awaiting induction of labour and vaginal birth. This is because these babies have a high risk of dying or suffering from major disability. A CS **may** be considered after 24 weeks of pregnancy in specific situations, such as transverse lie (baby lying across in mum's womb instead of the accepted head down position) or footling breech (baby lying in bottom down position with foot presenting first) because of the associated risks to baby. However any potential benefits are still unclear and many parents would not want to consider CS until after at least 25 weeks.

After 26 weeks we would normally offer CS 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 CS if there was evidence of the baby becoming unwell during labour, but some might choose to allow the baby to labour naturally.

### 2. CTG or heart rate monitoring:

This is usually advised from 26 weeks of pregnancy (a small, safe and non-invasive 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 CS in labour if the trace showed the baby was developing problems.

## Management of preterm baby after delivery

The earlier the baby is born, the less chance there is of it surviving and being healthy (see figure 1), so the national recommendations for care of babies born very early are as follows:

- **25 weeks and over** – The baby will be actively cared for to support breathing and keep it warm, and transferred to the neonatal intensive care unit for ongoing care.
- **24 weeks** – Resuscitation and intensive support is usually offered unless parents and doctors agree that there is little hope of survival or baby's level of suffering would outweigh the baby's interest in continuing to live.
- **23 weeks** – At this stage of pregnancy, there is greatest uncertainty about the outcome for an individual baby. Intensive support will be offered if parents specifically request it and the senior paediatrician/neonatologist (baby doctor) present feels it to be appropriate. Otherwise comfort care only will be given to your baby with no active intervention to support life.
- **22 weeks** – At this very early gestation the chances of survival without severe long term problems are so low that active intervention to support life is not recommended and comfort care is given to a baby. An experienced neonatologist will be close at hand if appropriate, though the baby would not usually be given active support because the chances of survival are so low.

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Please be reassured that the neonatologists will keep you fully informed of your baby's progress after delivery and involve you in decisions regarding appropriate care that is in your child's best interests.

## 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](http://www.bliss.org.uk)

Tommy's – [www.tommys.org](http://www.tommys.org)

EPICURE – [www.epicure.ac.uk](http://www.epicure.ac.uk)

Lisa Leppard, family liaison sister, neonatal unit, Princess Anne Hospital  
Telephone: **023 80 77 7222** ext. **8112** or bleep **1458**

Birth Afterthoughts, Princess Anne Hospital  
Telephone: **023 8120 6834**  
Princess Anne Hospital  
Coxford Road  
Southampton  
Hampshire  
SO16 5YA

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