Information for parents of extremely premature babies
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Photographs were kindly provided by Dr. Angela Huertas-Ceballos, University College London Hospital, and are used with permission.

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What is a premature baby?
Most babies are born between 37 and 42 weeks, but some babies are born early. These babies are called *premature* or *preterm*. The earlier that a baby is born, the less developed his or her organs are.

Who is this leaflet for?
This leaflet is for parents or parents-to-be of extremely premature babies. It explains the risks of extremely premature birth, and answers questions commonly asked by parents and relatives. Please be aware that this leaflet only explains the risks and complications for babies born below 27 weeks gestation. These risks are less common in babies born at 27 weeks and above.

If you have any specific concerns or questions, you should ask your midwife or doctor.

Why are babies born early?
We don't always know why babies are born early. Sometimes a baby needs to be delivered early because of concerns about growth and the blood flow from the mother to the baby; or because of concerns about the mother, for example, if she has high blood pressure. Another cause of preterm delivery is infection, which may cause
premature rupture of membranes (when the “waters” break early), or spontaneous (no cause) onset of labour. Also, twins or triplets are more likely to be born early.

**Where is the best place for my baby to be delivered?**

Extremely premature babies – babies born below 27 weeks - have a better chance of survival if they are born in a hospital with a neonatal (newborn) intensive care unit (NICU). In England, all neonatal units work together in “Newborn Networks”. Not every unit in a Network will have all the facilities to care for extremely premature babies. The units which can care for babies below 27 weeks are called “NICUs” (neonatal intensive care units). There are usually only 1 or 2 NICUs in each Newborn Network. The other units can either provide short term intensive care – called “local neonatal units” (LNUs) – or special care, and are called “special care baby units” (SCBUs).

You and your baby may need to be transferred to another hospital in your network with a NICU if your
nearest hospital does not have one. If this happens, your baby will be transferred back to your nearest hospital for further care once she or he is well enough.

What can be done to help my baby before birth?
Depending on the cause of the early birth, special treatments can be given to help protect your baby from complications. Some medications can slow or stop contractions and delay labour for a short period to allow for treatment or transfer to hospital.

An injection of a medication called a “steroid” can be given to you to help your baby’s lungs to develop and to protect against a bleed in your baby’s brain. Steroids work best if given between 48 hours and 7 days before a baby is born.

What are the chances my baby will survive?
If your baby is likely to be born early, your doctor will discuss the specific risks and potential treatments with you and together you can decide what will be best for you, your baby and your family.

Babies born below 27 weeks are more likely to survive if they are cared for in a NICU. Every extra week that the baby stays in the mother’s
womb increases the chances of survival, and the risk of complications decrease. After the age of 27 weeks, greater than 90% of babies are expected to survive.

The EPICure 2 study was a big study that followed all babies who were born between 22 and 26 weeks in England in 2006. (This followed on from the first EPICure study which looked at a similar group of babies born in 1995). The information in the graph shows the most recent data on survival of babies from this study.

![Percentage survival of babies from the onset of labour (22-26 weeks)](chart)

**Source:** EPICure2 study, 2006. The numbers on top of the columns indicate how many babies survived for every 100 births at that gestational age.

Survival is rare before 23 weeks, but by 26 weeks, 3 out of 4 babies are expected to survive.
As a result, babies born at 23 weeks are always treated compassionately, but are not always resuscitated, as the chances of survival are very low. The decision to resuscitate depends upon each baby's individual situation.

**Why do some premature babies die?**

The organs of babies born very early are not fully developed yet, and are therefore very fragile. The main problems in babies of less than 27 weeks are:

- **Lungs and breathing**
  Most premature babies need help to breathe, to make sure they are getting enough oxygen around their body, until they are able to breathe well on their own. Breathing may be supported by a breathing machine called a “ventilator”, and needs the baby to have a breathing tube called an “endotracheal tube”, or “ETT”. Some babies manage well with “CPAP” (continuous positive airways pressure), given by a little mask over the baby’s nose. We can improve their breathing by giving the mother steroids before birth, as already mentioned, and by giving the baby a treatment called “surfactant” to help their lungs open up and become air-filled. However, in some cases these treatments will not be
enough to keep the baby alive.

- **Bleeding in the brain**
  While the brain is still developing, the small blood vessels are very delicate and fragile. Even small changes in the baby’s condition may result in vessels bleeding into the fluid channels of the brain (called “ventricles”), or into the brain tissue itself. These bleeds may be small and cause no problems, however bigger bleeds can lead to significant brain damage.

- **Infection**
  Being born early means that the baby’s immune defences are not fully developed. This means that they are more likely to get infections. These infections can usually be treated with antibiotics, but occasionally this will not be enough to keep the baby alive. One of the best ways to reduce the risk of infection in your baby is to give the baby your breast milk as soon as possible after they are born.

- **Gut problems and nutrition**
  The gut of the preterm baby is immature and is not able to support the baby's nutritional needs in the first week or two. For this reason nutrition called “parenteral nutrition” or “PN”
is given to your baby from the start. In addition, it is desirable to give mother’s own breast milk to a baby to help the gut and immune system develop. Good growth improves nerve and brain development.

Breast milk also protects against a disorder of the gut called “necrotising enterocolitis” or “NEC”. NEC is a very serious illness in which the intestine (gut) becomes inflamed and may get permanently damaged. This can lead to a perforation (hole) developing in the gut, which allows the contents of the intestine to leak into the abdomen (tummy).

**How long will my baby be in hospital for?**
The length of time your baby stays in hospital depends how early the baby is born and how sick he or she is. Most babies are usually in hospital until the date they were due to be born (aged 40 weeks). However, some babies stay longer than this, and others will leave hospital sooner.

**Will my baby have other medical problems long-term?**
There is a risk of developmental disability with extremely early birth which may lead to problems with seeing, hearing, understanding and movement.
The key developmental areas which may be affected are:

- **Overall movement (also called “gross motor development”)**
  Sitting, standing, crawling, walking, running, balancing. Some babies may be very floppy or very stiff (due to decreased or increased muscle tone). This can lead to problems with development. These problems may disappear as the babies get older. If it is permanent it is called cerebral palsy.

- **Fine movement**
  Gripping small objects, drawing, writing.

- **Seeing, hearing, speech and language**
  Premature babies are at risk of visual impairment called “retinopathy of prematurity” or “ROP” and for which all babies are routinely screened. Some babies may need to wear hearing aids. Talking and reading to your baby can help them to develop their language.
• **Social development and behaviour, and learning and understanding**

Smiling, laughing, socialising, feeding and dressing. Some children who were born extremely preterm have difficulties learning at school. This may cause problems with spelling or mathematics, or may be an overall learning problem that requires extra teaching support.

A **mild** disability means that children are slower to reach certain milestones, for example learning to walk, but once this ability is developed, there is little functional impact on the child's everyday life.

A **moderate** disability means that children are slower to reach certain milestones, for example learning to walk; once they develop this ability they still need some support, for example using walking sticks.

A **severe** disability means that children never reach certain milestones, for example learning to walk, and will need lifelong support in this area, such as using a wheelchair.
This graph shows how many premature babies that were followed in the EPICure 2 study had a disability at age 3. The blue bars show that many extremely premature babies have no disability at all. This increases from one in three babies born at 22 weeks, to over 3 out of 4 babies born at 26 weeks having no disability. However, only three babies born at 22 weeks survived to the age of 3, so data for babies born at 22 weeks is not very reliable.
How can I support my baby?
Breast milk is extremely important for all babies, but especially so for preterm babies. By expressing breast milk while your baby is too small to breastfeed, you can give your baby the best nutrition possible, and help improve his or her outcome. It is best to start expressing milk within 4-6 hours of giving birth, if at all possible.

How you may feel
Having a premature baby can be very difficult. It is natural to feel a mixture of emotions, some negative, some positive. Many families of premature babies feel some or all of the following: overwhelmed, shocked, traumatised, worried, powerless, full of grief, angry, guilty, hopeful, intense love for your baby, longing to be with your baby, a sense of loss.

The first step is to recognise and accept your feelings – try to talk to someone about how you feel: your partner, a friend, your midwife or doctor. Consider writing down your emotions and experiences, as things can happen very quickly and it may be difficult to take everything in at once.

You may find that seeing a counsellor – to talk things through – is helpful. You can also join a support group to meet other parents of...
premature babies.

Spend time with your baby – ask the neonatal staff how to get involved in your baby's care. When your child is more stable, holding them close to you against your skin will help them to grow and develop better; this is called kangaroo care. You will also be able to help feed your baby and to look after them like changing their nappy or cleaning them.

Where can I get more support?
The doctors, nurses, midwives and social workers will be there to help support you and your family while you are in hospital and when you go home.

What happens when I go home?
You will continue to get support at home and you will receive follow-up appointments with your doctor and other health care professionals according to your baby's needs.

Where can I get more information?
If you have any concerns or questions ask your midwife, or the doctors and nurses looking after your baby. You can also contact the organisations on the following page for more information or to request other leaflets.
**Bliss**  
2nd Floor, Chapter House,  
18-20 Crucifix Lane,  
London, SE1 3JW

Bliss is the UK charity working to provide the best possible care and support for all premature and sick babies and their families. Bliss is active across England, Scotland, Wales and Northern Ireland, delivering a range of nationally available services.

Free help and advice line: 0500 618 140  
(Open from 9am to 9pm, Monday to Friday)  
Email: hello@bliss.org.uk  
Website: www.bliss.org.uk

**Contact a family**  
209-211 City Road  
London, EC1 1JN

Contact a family is the only national charity that exists to support the families of disabled children whatever their condition or disability. They can offer support, advice and information.

Freephone Helpline: 0808 808 3555  
Email: helpline@cafamily.org.uk  
Website: www.cafamily.org.uk
Contact a family also run a service called 'making contact' through which they may be able to put you in touch with other families who are affected by the same disability/medical condition as your child.

Website: www.makingcontact.org

The authors of this leaflet take no responsibility for the content of the above websites.

This leaflet has been produced by the EPICure study team. More information about the EPICure studies is available online at: www.epicure.ac.uk