Premature (less than 30 weeks) babies – information for parents

This leaflet gives information about what will happen if your baby is born prematurely, including the possible problems and procedures. If you have any questions, please speak to your midwife or obstetrician.

Before your baby is born, a member of the neonatal team will speak to you to answer any questions you might have about your baby's care if they were to be born early. You might find it helpful to read through this leaflet before then, and to write down any questions you would like to ask. You may also be able to visit the neonatal unit (NNU), where your baby will probably go for specialised care if they are born early. Please speak to your midwife to arrange an appointment with the neonatal team, or for a tour of the NNU.

A full term pregnancy usually lasts 37-42 weeks. In this leaflet we focus on those born more than 10 weeks before their due date (less than 30 weeks gestation), who need specialist support for them to live outside the womb. Some babies born early will not be able to survive, even with this help. There are many factors that influence the chance of a baby's survival, including how early they are born, their birth weight, and the reason why they are born early. A neonatal doctor (specialist in the care of new-born babies) will talk to you about your situation and what might happen if your baby is born early.

We follow national recommendations for the care of mothers and babies when a premature delivery is expected.

Babies born before 24 weeks gestation

Although some babies born before 24 weeks will survive, there is a high risk that some will die despite all efforts to help them. Of the babies that do survive, some will be left with disabilities such as those discussed later in this leaflet. Babies born this early are very small, weighing roughly 500g (about 1 pound). Their skin is thin and shiny, often with a covering of fine hair (lanugo). They can be quite bruised after labour and their eyes are likely to be closed. Some babies born this early die during labour or delivery as it can be a very stressful process for small babies.

Because there is such uncertainty for babies born this early, we aim to make a joint decision with you about how to care for your baby if they are born early with signs of life, taking into account what is important for you. We can discuss the options of active intensive support or comfort care. There is information about these different types of care below.

Comfort care

We support families to provide comfort care when we know that a baby will not survive, or we (parents and doctors) decide that more intensive treatment is not the right course of action. The aim of comfort care is to focus on making your baby as comfortable, and your time together as special, as possible. You will be encouraged to cuddle your baby, take photos and make memories, with the support of your midwife.

Babies born alive but not receiving medical intervention may continue to show signs of life, such as taking occasional breaths or gasps. This is normal and does not mean the baby is in pain or distress. You will be given as much time as you need with your baby, and staff will be there to support you.

Babies born at 24-30 weeks gestation

Babies born at 24 weeks gestation and later are more likely to respond to stabilisation and intensive support at the time of birth. We would plan to provide this for your baby, and discuss with you, before your baby's birth, what this means. The amount of support a baby needs at birth depends on their gestation, size and the circumstances leading up to their birth.

Active stabilisation

We aim to allow 'delayed cord clamping' to happen for all stable babies (who do not need immediate support). This means we allow blood to flow from mum to baby for up to a minute. The umbilical cord is then clamped and cut before the baby is brought to the neonatal team who will have equipment set up in the birthing room.

- To keep babies warm, they are kept under a heater, have a woolly hat, and they are placed in a plastic wrap, from foot to shoulders.
- Babies born early usually need some gentle help with their breathing using a mask over their mouth and/or nose and, sometimes, putting a breathing tube down into their lungs through their mouth. Through this tube, we can give a medicine, called surfactant, to help their lungs stay expanded.
- If a baby's heart rate is slower than usual, we can try to help by rhythmically pressing on their chest, or by giving medication through a small tube placed in their umbilical cord.

Once your baby is stable, they will be put into a transportable incubator and brought over to you so you can see them, take photos and be updated. Your baby will then be taken to the neonatal intensive care unit (NICU), on Level 6. Partners are encouraged to go with the baby.

Admission to the NNU

Once in NNU, your baby will be transferred to a bigger incubator and will be monitored closely. At first, their breathing will be supported by a machine. The amount of support a baby needs with their breathing can vary, and a member of the team can explain how much help your baby needs. To give your baby medication and nutrition, lines (tiny flexible tubes) will be carefully inserted into blood vessels in their hand, foot or umbilical cord.

We will introduce you to the NNU and involve you in caring for your baby as much as possible. We know it can be overwhelming at first. In the first 24 hours after your baby is born, the senior doctor caring for your baby will speak to you. We will continue to keep you up to date throughout your baby's admission, and will discuss with you any changes that need to be made to their care.

The first few hours and days in NNU can be emotional. Speak to us about your worries and fears so that we can make sure you receive the best support from the medical, nursing and psychology teams. We are here to help, and to make sure that you and you baby receive the best care possible.

What can I do for my baby?

Breast milk is best for all babies but it is particularly important for pre-term babies. We aim to start giving small amounts to new babies early as it provides protection from infection and helps to get their digestive system working. Your midwife on the birth centre and the nurse caring for your baby on the NNU will support you to start expressing your breastmilk as soon as possible (preferably within two hours of giving birth).

Establishing a milk supply can take time, particularly if your baby is born early. This is normal. If this happens, we will talk to you and ask your permission to use donor milk (donated by other expressing mothers) from the milk bank at Evelina London Children's Hospital. This would be used in addition to any milk you produce, to make sure your baby gets the benefits of breast milk. Please ask a neonatal nurse for more information, and/or visit, **w:** www.ukamb.org.uk.

We aim for parents to get as involved as possible in the care of their baby. Some of the ways we do this are through 'kangaroo care' (skin-to-skin cuddles), nappy changing, feeding and other aspects of your baby's daily routine. It may not look like babies notice you much, but just being there for them has a calming effect and enhances their wellbeing and growth.

What is the long-term outlook for babies born before 30 weeks?

The outcome is very variable because every baby is different. Most babies born at about 30 weeks survive and do well. Factors that affect a pre-term baby's survival, and the possibility of longer-term problems, include how early they are born, how small they are and the particular circumstances surrounding the pregnancy and birth. Potential problems during their time in the NNU and afterwards can involve different systems in the body, including:

Lungs

The amount of breathing support babies need varies. Some babies' lungs are so underdeveloped at very early gestations that they may not survive. If babies make it through their initial breathing difficulties, they can require breathing support and oxygen for a long time. This lung condition is called chronic lung disease (CLD). Babies with CLD can still need oxygen when they are discharged home. They can be prone to wheezy episodes and chest infections as a child. Most children grow out of these problems.

Heart

All babies have a duct (small blood vessel) in their heart. This is important for their blood flow when they are in the womb. After birth this duct usually closes on its own. When the duct doesn't close it is called a patent ductus arteriosus (PDA). PDAs are more common in premature babies and they sometimes need treatment to close this duct either with medicine or an operation. There is almost always full recovery.

Digestive system (gut)

Pre-term babies are at risk of developing an infection of the gut called necrotising enterocolitis (NEC), which can be very serious and may even cause death. Giving breast milk and increasing feeds slowly helps reduce this risk. Some babies who develop NEC may need surgery to remove part of their bowel. Some need special or intravenous feeds until they are older, and others will need further operations.

Brain
Premature babies have an increased risk of learning, behavioural, visual and/or hearing problems, problems with movement (cerebral palsy) and, rarely, seizures (fits). We routinely perform ultrasound scans to look for obvious bleeding within the brain (intraventricular haemorrhage, IVH). These scans are done at the baby's cot-side. Even with these scans, it is difficult to predict which babies will develop problems and how severe these will be. All premature babies have follow-up appointments in outpatient clinics for the first few years of life in order to pick up any issues quickly and provide early intervention and support.

Eyes
Premature babies have their eyes checked by a specialist from a few weeks of age, to identify early signs of a problem called retinopathy of prematurity (ROP) so they can be treated, if necessary. Some babies require long-term follow-up, but most have full vision.

It is important to remember that most babies have no problems, or only mild problems, at the time of discharge. If you would like to know more, please speak to a doctor or nurse.

Getting closer to home
Transfer of stable babies to local hospitals is essential as it allows us to care for the region's most premature and unwell babies in this specialist NNU.

If you do not live in Lambeth or Southwark, we will plan to transfer your baby back to your local NNU as soon as they are stable and well enough, even if you booked to deliver your baby here. This is a positive step towards getting home. It is also important as it allows your local team of paediatricians and nurses to get to know your baby before discharge, as they will support you and your baby after you go home and be involved in your baby's care as they grow up.

Most pre-term babies are discharged home before their due date. You and your baby will be supported by a discharge team regardless of which hospital you are discharged from.

Research
We are constantly trying to improve the care we give to babies. At Evelina London we lead and carry out research studies that look at improving care. We will talk to you about any research projects you or your baby could take part in. Taking part in research is always a voluntary process and is only done with your consent. If you don't want to take part in research it will not affect your treatment in any way.

It is thanks to cooperation from parents and babies in the past that we are able to give the quality of care we provide today. Thank you for considering helping us to shape the future of neonatal care.

More information
During your pregnancy, you can talk to your obstetrician or midwife at any time if you have questions. You can ask them to arrange a meeting with the neonatal doctors or nurses.

Useful sources of information
BLISS, Premature baby charity **w:** www.bliss.org.uk/ **e:** hello@bliss.org.uk
Sands, Stillbirth & neonatal death charity **w:** www.sands.org.uk/ **t:** 0808 164 3332

Contact us

If you have any questions, please contact your midwife or obstetrician.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** www.evelinalondon.nhs.uk/leaflets

Evelina London Medicines Helpline
If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.
t: 020 7188 3003, Monday to Friday, 10am to 5pm **e:** letstalkmedicines@gstt.nhs.uk

Your comments and concerns
For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.
t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services
If you need an interpreter or information about your care in a different language or format, please get in touch.
t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111
Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.
t: 111

NHS website
Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.
w: www.nhs.uk

Get involved and have your say: become a member of the Trust
Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.
t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:**

Was this leaflet useful?
We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, **w:** www.guysandstthomas.nhs.uk/leaflets, or **e:** patientinformationteam@gstt.nhs.uk

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