

Bliss Family Handbook

Information and support for
families of premature and sick babies

bliss.org.uk



Bliss

for babies born too soon,
too small, too sick

Important note to readers

This handbook has been written to give you a greater understanding of neonatal care and is intended to complement the medical advice you receive from those involved in the care of your baby. It is written principally for parents of premature or sick babies born in the UK and covers aspects of your baby's care and development – from the moment they are born until you take them home.

Though it is intended to reflect the current practices of neonatal care units throughout the UK, there will be some variation between hospitals.

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Speak to other parents of special care babies online at the Bliss messageboard **bliss.org.uk/messageboard**

Bliss is a member of **Language Line**, the telephone interpreting service, which has access to more than 170 languages.

Bliss Publications 0500 618 140 or order online at **bliss.org.uk**

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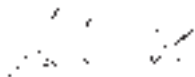
Foreword

This handbook will help you and your family take the first steps on your journey through a neonatal care unit.

Whatever the situation that you are facing, you are not alone. More than 200 babies are admitted to a special care unit every day in the UK. And Bliss, the national special care baby charity, is here to help you.

You will always be at the very heart of your baby's care. This handbook provides information about hospital care and the most common challenges that you and your baby may encounter. It also explains the many ways that you can help and comfort your baby, right from their first few moments. The handbook is informed by the experiences of thousands of families, nurses and doctors who we work with and endorsed by the leading professional organisations in neonatal care.

If anything is not clear to you, there is always help at hand. Just ask one of your baby's team of nurses and doctors. Bliss is here to help too. Our helpline, website and online messageboard offer confidential and free advice. We have more detailed information on a range of topics too and also can put you in contact with local services, support groups and other families.



Andy Cole, Chief Executive of Bliss

Caring for a premature baby is truly a team effort.

As doctors, we do everything we can to provide the necessary medical care and offer advice to families. But many parents underestimate how important their role is in ensuring that their baby gets the best possible start in life.

When a child is born early, it can be a worrying and uncertain time for parents. It is our job as health professionals to make sure that families have all the information they need to navigate through this tricky period.

That's where this handbook comes in. Produced by Bliss it is designed to give you an insight into what to expect in hospital, to explain some of the procedures and medications you may encounter and make sure you are best equipped to deal with the common challenges you're likely to face.

I hope you find this handbook useful in guiding you through your baby's hospital stay and the days and months afterwards. The more effectively we can work together as healthcare professionals and parents, the better outcomes we'll achieve for premature and sick babies.

Dr Hilary Cass, President, Royal College of Paediatrics and Child Health

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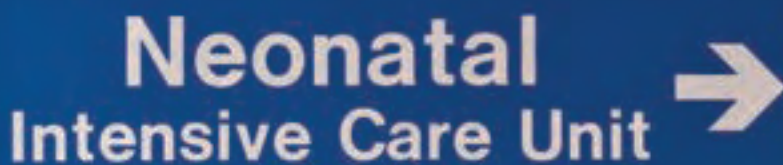
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Neonatal Intensive Care Unit



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About this handbook

All parents awaiting the birth of a child hope for a safe and straightforward pregnancy. So it comes as a shock if your baby is born too soon or needs special care.

You are not alone in this situation. One in nine babies born in the UK spends at least a few days in a neonatal unit, which adds up to around 80,000 babies a year.

This handbook provides information that will help you:

- Get a better understanding of the situation you are in.
- Seek emotional support and help with practical issues.
- Bond with your baby and help your family through this time.
- Get involved in looking after your baby day-to-day like all parents do, for example by feeding and cuddling your baby.
- Ask questions and get all the information you need from the doctors and nurses.
- Work effectively with the doctors and nurses to decide on the best care and treatment for your baby.



Many people have contributed their knowledge and first-hand experience to this handbook, including parents of babies who were born prematurely or sick and the doctors and nurses who care for these babies all the time.

How Bliss can support you

Throughout the UK, 80,000 babies are born prematurely or sick every year. The critical care that these babies receive in the first hours, days and weeks has a direct impact on their health and wellbeing for the rest of their lives.

Bliss was established in 1979 and is the only UK charity dedicated to working for special care babies and their families.

Our mission is to ensure that all babies born too soon, too small or too sick in the UK have the best possible chance of survival and of reaching their full potential.



As well as supporting research and training, and campaigning for better care, one of the ways we aim to achieve our mission is through supporting families.

Our family support services consist of:

- A helpline for families providing information and support - call **0500 618140** (Monday - Friday, 9am-9pm).
- A support service to put parents in touch with other parents who have gone through a similar experience.
- A website with information and useful contacts, as well as an interactive parent forum **bliss.org.uk**.
- A wide selection of printed books and leaflets that are available free of charge.
- Access to qualified counsellors.

Why is my baby in special care?

There are many different reasons why babies are admitted to a neonatal unit. The most common reason is premature birth (when your baby arrives many weeks before their due date).

However it isn't only premature babies, who spend time in special care. This handbook frequently refers to premature babies but the information can also help you care for your baby if they were born at term but are in hospital because of a serious illness or medical condition.

Many babies born at term, who require extra support or need an operation, will spend some time on a special care baby unit.

Some common reasons include:

- **Jaundice** Some babies need phototherapy (light treatment) for jaundice. This is common, even in otherwise healthy babies. See page 56 for more information about jaundice.
- **Breathing problems (eg respiratory distress syndrome or RDS)** This condition most commonly affects premature babies but can affect full-term babies, too. For example, maternal diabetes in pregnancy or delivery by caesarean section are two risk factors linked to RDS.



- **Problems detected on ultrasound during pregnancy** Sometimes a scan during pregnancy shows a physical problem that can be repaired with surgery after your baby is born. Two common examples are incomplete development of the gullet (oesophagus) or the windpipe (trachea).

One of your main questions is probably how soon you will be able to take your baby home. The answer depends on your baby's needs. It might be just a few days or it could be weeks, even months. Most premature babies go home around their original due date. If no one has told you how long it could be, don't hesitate to ask your baby's doctor or nurse. Remember the health care team caring for your baby will aim to get your son or daughter home as soon as they are well enough.

Questions you can ask

1. Why was my baby born early?
2. How serious is my baby's condition?
3. What kind of tests and treatment will my baby need?
4. Will my baby need to go to a specialist hospital for treatment, surgery or intensive care?
5. How soon will my baby get better?
6. Will my baby need long-term care?
7. What outcome should I expect for my baby?
8. When can my baby go home?

Why was my baby born early?

The causes of premature birth are not well understood and for the most part doctors do not know how to prevent it.

Babies can be born prematurely for many different reasons:

- Pregnancies with twins, triplets or more babies are more likely to end early.
- Pre-eclampsia (high blood pressure in the mum) occurs in about ten to 15 per cent of first-time pregnancies, and is responsible for at least 15 per cent of all premature births. It can be dangerous, particularly if it develops rapidly.
- About a third of premature births occur for no apparent reason. Often they happen with little or no warning. It may be that an infection involving the sack around the baby in the womb can trigger the delivery.
- Stressful events can start labour early. However, there is no evidence that the normal stresses of day-to-day living can bring on premature birth.
- In some cases, the waters break early, starting labour. If this happens when a baby has been in the womb for less than 35 weeks, doctors usually give the mum two sets of drugs. One is to delay the labour for a day or two, while the other is to help the baby's lungs to mature quickly so that they will function better.
- Many babies arrive in a neonatal unit because of an emergency. This can happen when the mum has bleeding, or when a problem with the umbilical cord or placenta means the baby is not getting enough oxygen.
- In a few cases, an antenatal screening test might show that a baby is not growing well in the womb, often because there is not enough blood flowing to and from the placenta. If doctors believe the baby is going to be safer outside the womb, they would advise early delivery. In this case, a caesarean section may be recommended as it puts less stress on the baby.

Medical language: prematurity and birthweight

Medical language to describe premature babies - who are sometimes referred to as preterm - are based on how long they have been in the womb and how much they weigh. The following definitions are provided by the World Health Organization (WHO):

	Medical term	Meaning
Gestation	Term	A baby that has spent at least 37 weeks in the womb
	Preterm	Born before 37 weeks
	Very preterm	Born between 28 and 32 weeks
	Extremely preterm	Born at or before 28 weeks
Weight	Birthweight	Weight
	Low birthweight	Born weighing less than 2,500g (5lbs)
	Very low birthweight	Born weighing less than 1,500g (3lbs)
	Extremely low birthweight	Born weighing less than 1,000g (2lbs)

Emergency resuscitation

Immediately after the birth, your baby may have needed help with breathing. Sometimes doctors give 'cardiac compression' (rhythmically applying pressure to the chest) to help maintain blood flow and help the baby's heart start beating properly.

Resuscitation may also be needed later when your baby is in the unit, particularly if they get a serious infection.

Moving to another hospital

Hopefully, your local hospital will be able to provide all the care your baby needs. But not every hospital has the facilities to care for the smallest or sickest babies (see page 12 to learn more about the different levels of care).

If your baby needs advanced equipment or highly specialised treatment, they may have to go to another hospital that can provide the care that's best for them. Sometimes this happens because the neonatal unit at your local hospital simply does not have enough incubators or specialist nurses.

Premature and sick babies are transported by ambulance in a specialised incubator, which maintains their temperature and oxygen levels.

A trained transfer team of doctors and/or nurses will care for your baby throughout the journey and make sure they are settled in at the new unit.

You may be allowed to travel in the ambulance during the transfer. However, in some instances this may not be the case. It is a wrench to be separated from your baby, especially if they are very ill, but there are important safety reasons behind this policy. Don't try to follow the ambulance as it may be travelling at speed – the team will give you directions to the new hospital. You will be able to see your baby before they leave and you will always be informed about where your baby is being taken. You can be confident that your baby will be safe during the transfer and that they will receive excellent care at the new unit.

Hospitals try to care for both mum and baby in the same location. However, this is not always possible for mums who are too unwell to be moved or when a bed is not available at the new hospital.

Once your baby is strong enough, every effort will be made to move them back to your local hospital.





What you can do

It's hard being separated from your baby, especially if you are recovering from the birth in one hospital while your baby is in a different one. Here are some steps you can take to feel closer to your baby and to help them:

- If you are not able to be with your baby because you are in hospital yourself, **ask your partner** or another family member to keep you updated on your baby's progress.
- **Express breast milk** for your baby. It can be frozen and used to feed your baby later. In some units, you may be able to donate your breast milk for other premature or sick babies to have. Expressing also keeps your breast milk supply flowing. Even really tiny amounts of breast milk are important, so don't be put off if it takes a little while to get going.
- **Start a journey box** for your baby, to build up memories for the future. Parents collect items like little hats, booties and photos. Some neonatal units provide these boxes for parents.
- **Keep a diary** to look back on later, or maybe to show your child when they are older.
- Some parents also use **Facebook** and **Twitter** to keep family and friends updated.

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Levels of care

Neonatal units specialise in looking after babies who are very young or very small. They are also experts in caring for babies who were born full-term but are sick. All units will be able to provide some level of care. Your baby will be moved to another unit only if they need a more specialised type of care than your hospital can offer.

Not all hospitals have the facilities and the staff to offer the full range of care for the smallest or sickest babies.

The unit your baby is in will depend on their current needs. Your baby might move between one unit and another if their condition changes. This might mean going to another hospital.

There are different levels of neonatal care. Each unit is classified according to the complexity and intensity of care it can provide for your baby.

- Neonatal intensive care unit (NICU)** This is the highest level of care and is for the smallest and sickest babies; for example, babies who need breathing support with a ventilator, weigh less than 1,000g and/or were born before 28 weeks' gestation. NICUs can offer your baby the entire range of neonatal care. If your baby has major surgery, they will spend some time recovering in the NICU after their operation. Not all NICUs can provide highly specialised services, such as neonatal surgery. These services are concentrated at just a few hospitals.
- Local neonatal unit** These units still provide sophisticated care, but the babies are not as ill as those in the NICU. Babies weighing less than 1,000g are sometimes cared for here if they are relatively strong. The local neonatal unit can provide continuous positive airways pressure (CPAP) for breathing support, and can look after babies who need their breathing to be stimulated. Your baby can also receive intravenous (IV) or tube feeding in the local neonatal unit.
- Special care baby unit (SCBU)** This level of care is sometimes referred to as 'low dependency'. The special care baby unit can offer your baby some kinds of tube feeding, oxygen and phototherapy (light treatment) for jaundice. Special care is also for babies who need to have their breathing or heartbeat monitored. The unit can provide some intensive care in an emergency but not for longer periods.



In addition to the three levels of care in neonatal units, there is a fourth level: transitional care.

- **Transitional care** This means your baby still has some needs but is almost ready to go home. Most importantly the mum becomes the main carer with support from a nursery nurse or other staff on the unit.

NHS networks and hospital transfers

Neonatal care for premature and sick babies is organised into local areas around the country. Hospitals, and other NHS services for babies and their families, work together in each of these areas, called neonatal networks. Sometimes they are also called perinatal, newborn or maternity networks.

The networks allow doctors and nurses to share knowledge and skills. They are also meant to create a smooth pathway for your baby and your family, especially if your baby needs to move between hospitals.

The networks try to provide all levels of care in a local area, from hospital nurseries through to NICUs. The idea is to ensure that all babies have the care they need, as close to home as possible.

If your baby needs to be moved to another hospital, they will travel by ambulance with a specially trained nurse and/or doctor. These hospital transfer services for premature or sick babies are also part of the neonatal network. You can read more about transfers on page 8.

“The first transfer was by far the worst; Joe was only a few hours old and I hadn’t had much time by his incubator when it was time for him to go. But the transport team were wonderful. They talked us through the mobile rig and the route they would take and told us how experienced they were. Still, nothing prepares you for the sight of your tiny little baby being wheeled off in this huge NASA-type pod.”

Vicky, mum to Joseph, born at 30 weeks

Staff: who’s who

Doctors, nurses and other professionals work as a team on the neonatal unit. This is ideal for your baby and it means your family has a lot of help and support. But at first it can be confusing to know who’s who, what everyone does, and who to turn to for help and answers. This summary explains who you will meet on the unit.



Staff you will see day-to-day

Nurses:

- The nurses provide most of the day-to-day care for your baby.
- They can answer a lot of your questions, show you how to feed and take care of your baby, and arrange for you to speak to the doctors.
- Some nurses with further training are advanced neonatal nurse practitioners (ANNPs) or nurse consultants. These nurses often perform similar duties to the doctors.
- The matron or charge nurse coordinates your baby's care. They are a good person to ask if you have questions or concerns about your baby's progress, treatment and care, or if your family needs extra help.
- Ask for their help right away if you're ever worried your baby is in pain or distress.
- If you need advice or practical help with breastfeeding, the nurse can help. You can also ask the nurses whether there is a breastfeeding specialist who can help you.

Doctors:

- The doctors coordinate the treatment of your baby's care.
- You can ask the doctors about your baby's treatment, condition and progress.
- You can also ask them for a second opinion, especially if you are feeling unsure about an important medical decision.
- Doctors who specialise in the medical care of children and/or babies work in a team that is led by a consultant paediatrician or neonatologist.
- Surgeons work in a separate team of doctors, which is also led by a consultant. If your baby needs an operation, the surgical team will work closely with your baby's other doctors.

Nursery nurses:

- In some neonatal units, nursery nurses provide care for sick babies under the supervision of the midwife or nurse in charge. They also carry out non-clinical tasks/duties which contribute towards the smooth running of the clinical area. They use family-centred care as a way of communicating and listening to babies.
- Nursery nurses work with members of the neonatal teams.
- They also often work with the community discharge team to help parents and babies prepare for going home.

Staff you may meet

Pharmacists

- Pharmacists will look after your baby's medicines.
- They can tell you what medicines your baby is taking and provide information about the benefits and possible side effects.

Therapists

- There are different types of therapists that specialise in different aspects of your baby's development.
- Physiotherapists and occupational therapists are trained to help with your baby's physical and social development.
- Speech and language therapists are trained to assess your baby's ability to feed and swallow.

Dietitians

- Dietitians make sure that your baby gets the best nutrition possible.
- They can explain your baby's nutritional needs.

Psychotherapists and counsellors

- Some units may have counsellors or psychotherapists for parents to talk to during difficult times.

Other team members

An ophthalmologist may check your baby's eyes and audiology technicians will check your baby's hearing.

If your baby needs x-rays, these may be taken by radiology technicians. Ultrasound scans are carried out by a consultant specialising either in radiology (x-rays and scans) or neonatology (care of newborn babies).

Students and trainees

You may also meet foundation doctors who have just finished medical school, medical students, or nursing and midwifery students. You should always be asked beforehand whether you're happy for students to observe or examine your baby

Family-centred care

Your baby is part of your family. Your baby is precious to you, their brothers and sisters, their grandparents and the rest of the family. Everything that happens to your baby affects their family, too.



Family-centred care places the baby firmly in the context of the family, acknowledging that the family is the most constant influence on a baby's development. Adjusting to parenthood while your baby is receiving special care can be difficult. Listening to and learning from your baby is all part of this care.

Doctors and nurses will work with the whole family when they are caring for your baby. They understand that you know your baby best, and they will support you in caring for your baby and making informed decisions.

Family-centred care means:

- Responding to your family's emotional and social needs.
- Giving you clear information.
- Making sure you understand your baby's treatment and getting your consent for it.
- Showing you how to care for your baby and, over time, encouraging you to become your baby's main carer.

Family-centred care can help you bond with your baby. It can reduce the length of your baby's stay in hospital and improve their chances of having a healthier future.

Making sure you have enough time with your baby, and talking to the nurses and doctors, is really important. It also helps if you have a chance to talk to other parents in the same situation.

“One very kind midwife took the time to sit with us and explain what would happen when the baby arrived. She took us on a tour of the special care baby unit, which was comforting.”

Carrie, mum to Samuel, born at 30 weeks

Support in an emotional time

Having a baby admitted into neonatal care is a difficult time for many parents, and it is normal to find yourself needing to talk to someone besides your friends, family and the medical staff.

Ask if your unit has a counsellor or psychologist you can speak to. Don't hesitate to ask the nurse if you do want to speak to somebody. The nurse should be able to provide you with some information.

All hospitals also have a chaplain's office or multi-faith prayer room. People from various religious groups staff this centre. Ask the nurses on the unit or hospital reception if you would like to speak to a chaplain.

The chaplaincy or prayer room also has contact details for members of different faith groups who live near to the hospital and have volunteered to visit anyone who would like to see them. Nurses on the unit should be able to help you to get in touch with them.

Questions you can ask

1. Can you show us around the unit?
2. Can you help me understand my baby's responses? What do they mean?
3. Can we organise my baby's day so we are not disturbing their sleep?
4. How can I support and comfort my baby during and after difficult procedures?
5. Can you show me the best way to comfort my baby with touch?
6. What are the visiting arrangements? Is there somewhere for my other children to play?
7. Is there a place where I can rest or talk to other parents?
8. If I am struggling, can I see a counsellor? Is there any other kind of support?

Bliss is here to help

Call the Bliss Helpline on 0500 618 140, or go to bliss.org.uk for information, support and advice.

“Not only was I a first-time mum, I felt isolated and had no idea what to expect. My initial reassurance came from the Bliss booklets. About two weeks after Olivia was born, I began to look on the Bliss website and messageboard. I couldn’t say what I felt and this was the only place that made what I felt seem normal. When I read other stories I could relate to them. The messageboard kept me sane, it was my outlet. Whenever I needed a question answered I used the messageboard.”
Caroline, mum to Olivia, born at 32 weeks

Routines on the unit

When your baby is admitted to the neonatal unit, one of the nurses should offer to show you around and explain the routines. It can really help if you know what to expect. Each unit works differently, but there are standard policies that apply in most hospitals.

Hand cleaning

Everyone entering neonatal units must wash their hands and forearms with a special disinfectant and, after drying, apply the hand gel provided. These steps reduce the risk of babies catching infections that could be brought in from outside the unit.

Peace and quiet

It is now seen as good practice to keep light and sound levels low at all times, to minimise stress to babies. Many units now try hard to provide a peaceful atmosphere for babies and families.

Doctors’ rounds

The doctors’ rounds usually happen twice a day, morning and evening. During the morning round, the doctors and nurses plan your baby’s care. The evening round is more of a handover and allows the day and night staff to share information and agree overnight plans.

You can stay when your baby’s case is being discussed. Feel free to ask the doctors questions or share any concerns you have about your baby’s condition or treatment. Rounds are an important opportunity for you to stay informed and become involved in decisions about your baby’s care.

You may be asked to leave when other babies are being discussed, to protect the privacy of other families.

Checking on your baby

The nurse caring for your baby can update you on their progress when you visit or when you telephone the unit. You can also ask to see a doctor for an update on the condition of your baby or to talk about their treatment. If you want to see your baby's consultant just ask the nurse and they will arrange an appointment.

You can ring the unit any time, day or night. The nurse or ward clerk should be able to provide you with the unit's direct telephone number.

Information about your baby's daily nursing care will be recorded in their bedside notes. You are free to read these at all times.

Your baby's medical notes, which give details of their condition and treatment, are kept securely at the nurse's desk. These records are safeguarded by the Data Protection Act, which states that only people involved in the care of your baby can see them. You can request a copy of your baby's medical notes.

Shifts and staff changes

Doctors and nurses are on duty at the hospital 24 hours a day. They work in shifts, coming in to work and going home at set times. The handover between shifts can be a busy time on the unit. The exact shift pattern will vary from unit to unit.



How you can help your baby

As a parent, your natural instinct is to nurture and protect your new baby. When your baby is in hospital, it can feel like this relationship is impossible.

Research supported by Bliss has shown that parents can feel pushed out or sidelined when their baby is in the neonatal unit. It might feel like you are separated from your baby, even if you can be right next to their incubator.

One of your biggest responsibilities as a parent is making decisions about your baby's treatment and care. It's best for your baby if you can work as part of a team with the doctors and nurses. Stay informed and don't be afraid to ask questions, seek a second opinion and say what you think.



What you can do

You can do a lot to build a bond with your baby and encourage their development.

- When your baby has a medical procedure or just needs to be calmed down, you can **soothe them with Comfort holding** (see page 30). Ask the nurse or the physiotherapist or occupational therapist to show you how.
- **Try Kangaroo Care.** This means holding your baby against your chest, skin-to-skin (see page 32). Ask the nurse to show you the best way to do this.
- **Talk or sing** to your baby in a quiet voice.
- Learn to **read your baby's responses** and how to put them in a comfortable position.
- Let your baby **get to know their brothers and sisters** by having them visit (see page 37).
- **Ask the nurses** when you can change your baby's nappies, and when you can wash and dress your baby (see page 34).
- Also ask how you can help **care for your baby's eyes and mouth.**
- **Become involved** with feeding your baby as soon as possible (see page 35). You'll find more details in the following sections of this handbook.

You, your family and your baby

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Dealing with emotions

Different people react in different ways when they first enter the neonatal unit. It is quite possible that you felt shocked; the room was full of high-tech equipment and alarms seemed to be going off all the time.

Many babies in the neonatal unit are extremely small and immature. The equipment is designed to keep them warm, help them breathe and alert the nurses if there is a problem.

On top of all this, it is likely you have just been through a frightening and unexpected episode in your life. The nurses and doctors know you are under stress, and they are there to help you and your whole family, as well as your baby.

Despite the stress, you are still parents with a new baby. This situation might not be what you had in mind, but it is good to be congratulated and welcome your new baby into your family.

In some ways you have just suffered a loss. People may say that you're lucky and you might feel this is so. But you may also feel you missed out on a normal pregnancy, or worry that you can't go straight home with your baby, as you had hoped. In many ways, parents of premature and sick babies can find this to be a very emotional time.

“The nurses were so lovely and very encouraging on the first few days when I kept bursting into tears. They encouraged us to give her a name so that she would have an identity. One of the nurses suggested that I start to keep a diary, which I did the whole time I was in there – it was super advice.”

Liz, mum of Lara, born at 24 weeks

Over the weeks and months ahead, you are likely to have some stressful days so it is good to know who can help.

Some people find it easier to talk about their feelings and worries with someone who doesn't already know them. Some units have counsellors or psychologists who offer a confidential service for parents and families. You can ask the nurse or your GP if you're not sure how to arrange an appointment. Bliss can also help you find a counsellor.

You can also talk to the hospital chaplain or they can put you in touch with people from local faith groups who have volunteered to come and talk to families at the hospital.

Discussing your feelings with other parents can help. Many units run groups where parents meet to share their experiences or simply have a coffee and a chat. Parents who have been to such groups often say that it helped them to feel less alone.

How Bliss can help

Supporting parents through emotional times is an important part of our work.

- For free information, advice and support, talk to our trained advisers by calling the Bliss helpline.
- We can put you in touch with qualified counsellors.
- We also have a network of trained parent volunteers whose babies have been in neonatal units.
- You can contact a local Bliss Champion. Champions are parents who have had a baby in special care. They regularly visit the unit and share their experiences.
- You can visit bliss.org.uk and have a look at our interactive parent message board.
- We provide free booklets and factsheets on many issues affecting premature babies, parents and families.

Call the Bliss helpline on 0500 618 140 for more information about any of these services.

“*Thanks so much for our chat this morning. My shoulders feel a lot lighter! I will take a look at the Bliss website in more depth and possibly even post something on the messageboard. Thanks for all the information you sent to me as well, it's time I stopped being so stubborn and talked more to people that are in similar situations.***”**

An email to the Bliss Family Support Team

Not what we expected

Depending on how early your baby was born or how unwell they are, you may be shocked when you see them for the first time.



Premature babies may appear thin, with very little body fat. They look quite different from most full-term newborn babies you may have seen before. This is simply because your baby is at an earlier stage of development, as they were born early. The difference is that you can see a premature baby at an age when they would normally still be in the womb.

Normal appearance

If your baby is very premature, they may only be the length of your hand.

Many premature babies have a fine covering of dark hair, called 'lanugo'. This hair growth is normal and has been stimulated by maternal hormones while your baby was in the womb. It soon goes away.

Your baby's skin could seem waxy at first. It may also be transparent because there is little or no fat beneath it. This means that you can see a fine network of blood vessels.

Very premature babies are sometimes born with their eyes temporarily fused shut.

The skull bones of premature babies are quite soft. If your baby's head is flat on the incubator for long, it can develop a flattened shape. The team caring for your baby will turn and position your baby to ensure this doesn't happen.

By the time your baby is mature enough to go home, the skull bones will have hardened up.

When your baby reaches the date on which they were expected to be born, they will probably look pretty much like most full-term babies of the same weight.

“She was so fragile...I couldn't hold her properly for two weeks. I do remember lifting her up in her incubator for the nurse to change her sheet, and I was overwhelmed by the feelings I had for her. When I did eventually hold her for the first time, it was amazing.”

Liz, mum of Lara, born at 24 weeks

Privacy, peace and quiet

Your baby needs peace and quiet so they can rest and catch up on their growth. A calm atmosphere also helps your baby relax and feel less frightened.

Unfortunately, hospitals are not naturally very quiet places. Staff and visitors come and go, there are tests, scans and medical procedures, bleeps and alarms are sounding all the time. Some neonatal units can be crowded, with the incubators close together and not much room for parents.

Neonatal units can keep the environment calm for babies by:

- Turning lights low at night and shielding the babies from bright lights as much as possible. Many units place fabric covers on top of the incubators to shield the babies from light. These are always placed in a way that allows the nurses to keep a safe watch on your baby.
- Protecting them from loud or continuous noise from equipment.
- Keeping conversations and telephones at a quiet level.
- Scheduling quiet times for babies and parents.

It is important that all parents respect these guidelines.

Units can also respect the needs of babies and their families by:

- Ensuring privacy for feeding, cuddling and medical procedures. A private room or screens are ideal if your baby does not need to be monitored all the time.
- Asking visitors not to approach other babies' incubators when their parents are not there, and not to read their notes.
- Providing a private spot for discussions about your baby's condition and treatment.

There should be a sitting room nearby for parents to relax and a simple kitchen for making tea and snacks. The hospital should also offer a safe, child-friendly area close at hand for your baby's brothers and sisters. Some units offer overnight accommodation so you can stay overnight near your baby. This is usually free of charge for at least one parent and includes bathroom facilities. Priority is usually given to parents who have far to travel.

Bonding with your baby: comfort and daily care

No parent expects to be separated from their baby straight after the birth. But it's quite possible this is what happened, for example, if your baby was delivered by emergency caesarian section or rushed to another hospital right away.

If you are not able to see your baby for now, you could ask your partner to go and visit in your place. Many neonatal units have digital cameras so you can take a photo of your baby.

Your baby should receive the level of care they need as close to home as possible. Every effort should be made to move your baby near to you and your family as soon as your baby is ready to be transferred.

However, separations do happen and this situation can be quite distressing for parents. Sometimes it takes longer to bond with your baby because of the shock and because you've been apart, but that is perfectly normal. You





should be together soon and there are many ways to build a strong bond with your baby, and feel more in control as a parent.

Tuning in to your baby

It is important that your baby gets to know you through all their senses: your smell, voice and loving touch. It reassures your baby to know you are there.

There could be days when your baby is so tired that it's best to keep contact to a minimum. This should happen less often as your baby makes progress. There will rarely be a day when you can't at least hold your baby's hand. Your baby can also be comforted by your smell. Try keeping a soft toy or cloth next to your skin for a while and then ask the nurse if you can put it in your baby's incubator. You'll have a chance to sit and talk to your baby, too. Before your baby goes home, they should meet their brothers and sisters.

All of the equipment around can be distracting. But try not to be overwhelmed by the machinery. Keep focused on your baby as much as possible. Remember that the nurses constantly check the monitors. Leaving you free to devote your time to caring for your baby and getting to know them. This way, you can learn to pick up on your baby's responses and to tell when they are contented, uncomfortable or distressed.

See our free *Skin-to-skin* booklet for further information.

Comfort holding

Even if your baby is very ill or fragile, you can still provide loving comfort. Ask the nurse or therapist to help you recognise the signs that tell whether your baby is relaxed and comfortable, or feeling tense, highly sensitive or uncomfortable.

Comfort holding is one of many ways for you and your baby to get to know each other. It allows you and your baby to experience loving touch, even when your baby is not ready to be held.

There may be times when it is safer for your baby to stay in the incubator. In this case the nurses may suggest that you try Comfort holding, if they think your baby is well enough.

Comfort holding is 'still touch'. Cradling your baby with still, resting hands can be more comforting than stroking or massage, which are more stimulating.

Comfort holding can:

- Soothe your baby during uncomfortable procedures.
- Settle your baby when they are restless.
- Help your baby to get back to sleep after feeds, washing or nappy changes.

You should always speak to the nurse before you try comfort holding, as they can show you how to do it:

- Before you start, remove watches and jewellery, pull your sleeves up to the elbows, and wash your hands and lower arms. This reduces the risk of infection inside the incubator.
- Always make sure that your hands are warm before touching your baby. If your baby has difficulty keeping warm, make sure there is a layer of fabric (a hat, vest or blanket) between you.
- Speak to your baby before touching them, so that they are aware of your presence before you start.
- Cradle one or both of your hands around your baby's feet, head or body. Keep your hands still.
- Your baby might like to grasp one of your fingers.
- You can continue for as long as you are both comfortable. Watch your baby for signs that they are tired or want you to stop.
- When you finish comfort holding, move your hands away from your baby slowly so they aren't startled.

Premature and sick babies undergo many medical procedures that can cause them discomfort. As your baby's parents, you are the best people to balance this with a positive, reassuring touch – when you feel confident and ready to do this.

'Positive touch' is a way of communicating your love and reassurance to your baby and hearing your baby's needs in return. Babies do communicate. By watching and listening to your baby, you can learn what kind of touch to use and how to make sure it is safe, soothing and pleasant.

It's harder for your baby to communicate when they are exposed to lots of noise or light, when they feel chilly, or when they are in an uncomfortable position. See if the environment can be calmed down first. In time, you will get to know your baby's individual ways and you may find your baby responding more often and for longer periods.



Kangaroo Care

If your baby is well enough you can try Kangaroo Care. This is a way of holding your baby skin-to-skin on your chest.

Kangaroo Care has many physical and emotional benefits for your baby. It helps establish breastfeeding, improves their weight gain and encourages deeper sleep, which promotes your baby's health and development.

This also helps you feel closer to your baby and more confident about caring for them.

“The first time I got to hold Samuel was quite scary, I was really nervous of knocking his tubes and wires. My husband is a big man and he was too nervous to hold him for about a week. I was fortunate enough to be able to express milk for him. For me this really helped me feel like I was contributing to his care.”

Carrie, mum to Samuel, born at 30 weeks

Kangaroo Care is something that both parents can do and is a really good way for dads and babies to bond.

Before you try skin-to-skin, talk to the nurses and ask if your baby is well enough. Together with the nurses, plan a good time and a comfortable place to try it.

Even if your baby still needs help with breathing, they might be able to have Kangaroo Care with careful planning and extra help from the nurses to make sure it is safe. If it's possible, they will help you manage any wires and tubes while you hold your baby.

Here are the basic steps:

- Kangaroo Care is based on direct skin-to-skin contact but removing your baby's clothes is not vital if this is upsetting for them. A hat and a blanket for extra warmth might be necessary for very small babies.
- Hold your baby and tuck them inside your clothes, enclosing them to keep their temperature stable.
- Check your baby's head is well supported and if you can't see your baby easily, try using a hand mirror.
- Explore what you both like to enjoy together. Some babies like to have their eyes shielded, others like to be sung to softly.

- Your baby can be tube fed while enjoying Kangaroo Care. Linking this closeness with a full tummy can help your baby get ready for breastfeeding, too.
- Allow time for your baby to settle so they can get the full benefit.



If your baby is happy, you can continue with Kangaroo Care for as long as you are both comfortable. Lie back, relax and enjoy.

Daily baby care

As soon as your baby is well enough, it's ideal for you to start looking after their daily needs, just like any parent with a new baby. This helps you and your baby get to know each other and it builds your confidence.

The nurses will show you how to manage everyday tasks, which they might refer to as your baby's 'cares'. You may feel all fingers and thumbs to start with but don't worry – practice makes perfect.

“It was also hard being scared to touch him. I didn't really feel like his mum as all the nurses and doctors were doing a better job caring for him than I could. The only thing I clung to was that I could give him my milk. At first I thought I wouldn't be able to cuddle him but Kangaroo Care helped a lot. As I became more capable at giving Henry his medications it got easier, and he felt more like my son.”

Liz, mum to Henry, born at 24 weeks

See our free *Skin-to-skin* booklet for further information.

Mouth care

Cleaning your baby's face and mouth can help you get involved in your baby's care very early on. Try to do this when your baby appears to be awake and comfortable.

If you have some expressed breast milk, dip a cotton bud into the milk and clean your baby's mouth very slowly, with a gentle press-and-scoop action to the lips. If your baby looks interested in the taste, let them suck on the cotton bud. You can use sterile water for your baby's mouth care, too.



Nappy changing

At first you may want to watch the nurse change your baby's nappy, and then gradually master it yourself, one step at a time.

When you are ready to get involved, ask the nurse if you can take a first step by finishing off the nappy change, just fixing the clean nappy in place and settling your baby afterwards. Then as you feel more confident, take the process further each time.

Nappy changing can be quite tiring for your baby, especially if they are very small or sick. Your baby might find it easier if they are placed on their side. Do not raise your baby's legs – by holding the feet together, sole-to-sole, you can clean your baby properly without distressing them.

Bathing

To start with, the nurses may advise against washing your baby. The concern is that washing could cool your baby down, which is something to avoid. The little flakes of dried-on blood and waxy 'vernix' (the white substance that coats the skin of newborn babies) will do no harm and are best left where they are.

Some very small babies find a first bath less stressful if they are wrapped up (swaddled). Ask the nurse if this is something they do on your baby's unit. You should be able to give your baby their first bath, with help from the nurse. It can feel daunting at first, but it won't take long before you are confident.



For a short time, the hospital will provide everything your baby needs. However, soon the nurses will ask you to bring in some of your own baby care supplies, including premature baby nappies, cotton wool and clothes.

Feeding

Of course, feeding is an essential part of looking after your baby. As a bonus, this is the time when your baby is awake, making it an excellent chance for you to get to know one another. You can learn more about feeding on page 66 of this handbook.

“ I did find doing Amy's cares (changing her nappies, keeping her mouth and eyes clean, washing her) very intimidating at first, but later on, especially when she came out of the incubator, it became a great way to bond. ”

Karen, mum of Amy, born at 31 weeks

Caring for babies, parents and families

Family-centred care means looking after parents, brothers and sisters, and other family members who are close to your baby. It's stressful having a baby in hospital and parents have a lot of other responsibilities, such as looking after other children, running the home and paying the bills.

This section of the guide takes a look at family life, including:

- The importance of dads.
- You and your partner.
- Brothers and sisters.

Keeping the family strong is important for everyone and it will also benefit your baby in the long run.

The importance of dads

Mums and babies are often the centre of attention, especially in hospital. But this is a tough time for dads, too, both physically and emotionally. You are probably holding the family and the household together on your own. It's even tougher if you have to go to work as well.

Family and friends may also be worried about the baby, and are often anxious to know how they can help without getting in the way. People around you can be a big help. Give them specific things to do. It can really ease the pressure when friends bring a meal around or pick up the children from school.

This will give you more time to spend with your baby, your partner and your other children. The love and care you provide as a dad can make a huge difference to your baby's health and development.

Most new parents put their own needs second. It is hard to juggle running your home, work and visits to the hospital. But it is really important to look after yourself so that you can keep going. Look after the basics, like eating well and getting



enough sleep. Try to talk about how you are feeling to someone who understands.

You and your partner

Mums and dads both go through an emotional rollercoaster when a baby is born early or sick, but they may react in very different ways. It's important to try to keep tuned in and back each other up.

Here are a few ideas to keep your relationship strong:

- Don't keep problems to yourself. Talk to your partner, friends and family, or the advisors on the Bliss freephone Helpline. You could also talk to a counsellor, or the nurses on the unit.
- Agree with your partner how you will take turns with the baby, caring for other children and running the household.
- Be kind to yourself and your partner. No one is at their best when they are stressed or exhausted. It's really important to eat regular, healthy meals and get enough sleep.
- Take time to just be together. Try to have a break from the baby to have some time as a couple, if you can.

The usual rules of relationships still apply – doing small favours for one another always makes life nicer and easier.

Brothers and sisters

If you have other children, a new baby's arrival is a huge event in their lives. It is a time they will always remember.

Having a brother or sister in neonatal care can be very hard on older children in the family. They can see their parents are struggling, but they may not understand everything that is going on. They probably want to help but may not see how they can. Take time to explain what is happening. Use words that are right for your child's age and don't make it too complicated.

Children may secretly blame themselves and feel guilty when things go wrong, so make sure they understand it is not their fault that this has happened. They may also have a lot of worries that they keep to themselves. Give your child a chance to talk about their anxieties and do what you can to reassure them in an honest way.

The arrival of a new brother or sister can trigger jealousy, particularly when a new baby is demanding so much of both parents' time and attention. During this time, your other children need to be reminded that you still love them and they are still as important as ever.

Involve your baby's brothers and sisters as much as possible. Try to help them have some positive experiences with the baby.

Some hospitals allow brothers and sisters to visit, but others do not because they could bring childhood illnesses onto the unit. If you can, it's important to bring your older children to see the baby in hospital.

Ideally, the hospital should have a play area for children not far from the neonatal unit. Sometimes these play areas are supervised by hospital staff. As children can get bored quickly, it's a good idea to come prepared and bring along some books, colouring or quiet games to keep them busy.

Even when they can't visit, your children can stay in touch with the new baby. Give your child a picture of the baby and put one up at home. You can also encourage your child to give the baby a present or make cards and paintings to hang near the baby's incubator. You might want to make a journey box; see page 10 for more details.



► Family focus

"She was like a doll"

When Rosie Joy was born early at 27 weeks, her two older brothers Niall and Archie were 11 and four years old. Their mum was in the hospital with the new baby. Sometimes dad looked after them and sometimes they stayed with their grandparents.

"I remember the first night mum was away, when Rosie was born," says Niall, who is now 14. "I was really anxious about mum and the baby being OK. Archie was really little. He didn't really understand what was going on. He was very sad the first night, so I tried to tell him it was going to be alright."

"I tried to look after Archie. At school, I used to try and put it all at the back of my mind. But I could see Archie was a lot quieter and didn't talk to his friends so much."

Niall and Archie didn't get to see their baby sister until she was two and a half weeks old, because a local outbreak of chickenpox made it too dangerous for children to visit the unit. "When I first saw her, I was shocked. I didn't realise she'd be that small – sort of like a doll," says Niall.



Mum Suzanne says: "The boys reacted very differently to the situation. Niall seemed to grow up overnight, looking after his younger brother, while Archie went back to baby mode as soon as I got home."

For Rosie's first birthday, the family held a party raising funds for the unit that had looked after her. Niall donated his pocket money.

Rosie is now three years old and thriving, while Archie and Niall are back to squabbling like they used to.

Family finances

Having a baby in hospital can put a strain on family finances: you may lose income just at a time when your expenses go up. Many parents feel pressured to work even when the family is going through difficulties. It's especially hard when your baby becomes ill suddenly or arrives before you had planned to take time off.

The first thing to do is talk to your employer and let them know what is happening. The Bliss helpline can advise you on your rights to time off from work.

In addition to paid maternity or paternity leave, you may be entitled to time off to care for children and deal with family emergencies. Over the longer term, you can ask your employer about more flexible working arrangements if this will help your family.

Claiming benefits

Benefits can be a helpful source of additional income so they're worth looking into. Even if you are in work, you may be able to claim at least some benefits. If you are already receiving benefits, you may be able to claim additional money because your family's circumstances have changed.

It is important to make any claims as soon as you can, as it is difficult to get benefits backdated.

You can get advice on benefits from:

- Your local Citizens Advice Bureau.
- The Department for Work and Pensions (DWP).
- Your local jobcentre.
- Your trade union or staff association.
- A social worker at the hospital.
- Charities like Turn2us (see page 91 for contact details).

The benefits system is subject to change. You can get up-to-date information on the government website **gov.uk**

The Bliss helpline can also tell you where to get expert help with employment rights, debts and financial emergencies.

See our free guide, *Financial advice - a guide for families of premature and sick babies*, for more information.



Your baby's medical care

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Staying informed and making decisions

Looking after the best interests of your baby is a fundamental part of parenthood. That responsibility includes making choices about your baby's medical treatment. Doctors and nurses want the best for your baby, too, and that means keeping you informed and respecting your views.

They have a professional duty to:

- Explain everything that is happening to your baby.
- Make sure you understand the options.
- Work with you to make decisions together about your baby's care.

Following these steps and seeking your approval is called 'informed consent'. You will be asked to sign consent forms for major procedures like an operation.

Many procedures, such as routine blood tests, are considered low risk for your baby. You may not be asked for formal consent for every test like this. If your baby develops a serious and unexpected problem when you are not in the hospital, it may be necessary to begin tests and treatment urgently, before there is a chance to speak to you. In this situation, the doctors or nurses should explain what has been done and why, as soon as they can.

Shared decision-making, with doctors and nurses working together with you and your partner, is best for your baby. You should always feel free to ask about any test or procedure – and don't be afraid to make it clear if you are not happy to consent. If you're not sure or it's a big decision, you can ask for a second opinion. And if something has gone wrong, it's best to bring it up right away and try to have the problem set right (see page 62 at the end of this section).

Questions you can ask

1. How quickly do we need to decide?
2. What are the benefits for my baby?
3. What will the tests tell us and how will that help?
4. What are the risks of the test or treatment?
5. Will my baby feel pain? How can any pain be controlled?
6. What might happen if we do nothing, or wait and see?
7. Where can I find more information and details?

Pain relief

As a parent, you do not want to see your child suffer in any way. It's probably at the top of your list of worries. That's why this section explains the many ways to control pain and keep your baby's distress to a minimum.

During their time in special care, babies may need various medical tests and procedures. These are only undertaken if absolutely necessary.

Very simple steps can help a lot. For example, research has shown that familiar smells like breast milk or a parent's skin can have a calming effect on babies when blood samples are being taken. This works for full-term and premature babies.

Other things you can do to help control your baby's pain or anxiety include:

- Breastfeeding your baby during the test or treatment.
- Putting a little bit of expressed milk on your baby's tongue.
- Comfort holding and Kangaroo Care (see pages 30 - 33).
- Watching your baby for signs of distress and alerting the nurses and doctors that your baby might need more pain relief.

Every medicine has risks as well as benefits, so painkillers are not used needlessly. If your baby has a medical procedure that could be more than mildly painful or uncomfortable, they will be given pain medication. The dose is calculated based on your baby's weight. If your baby needs an operation, they will sleep through it under a general anaesthetic.

Your neonatal unit should have a written policy on providing pain relief. Don't hesitate to ask your baby's nurse or doctor if you want to know more about the policy. Always speak up if you think your baby is in pain and needs more help to cope.

Equipment on the unit

Neonatal units are full of equipment, which can be intimidating until you get used to it. But it's reassuring, too, when you think about how this equipment is all there to help your baby.

This section of the guide explains some of the most common equipment on the neonatal unit, including:

- Incubators
- Breathing machines
- Monitors
- Tubes.

Understanding the equipment can make you feel more confident and help you make good decisions about your baby's care.

Incubators

An incubator keeps your baby warm. It's an important basic need as premature babies struggle to stay warm on their own. Some incubators are closed boxes with hand-sized holes on the side. The enclosed box not only keeps the heat in, but also helps to control the humidity by circulating moist air around your baby. This prevents your baby from losing too much moisture by evaporation from their fine skin.

Other incubators have open tops and an overhead heater. This style makes it easier for you, the doctors and the nurses to reach your baby.

The temperature is regulated in two ways: with hand-operated controls or automatically in response to a sensor placed on your baby's skin. If the sensor falls off or does not work an alarm is triggered, telling the nurse to check and make sure the incubator is not too warm.

Breathing machines

There are different machines to help with breathing. The type your baby has will depend on their needs. Your baby may be switched from one type of breathing machine to another if their condition changes.

In the womb, a baby receives all the oxygen they need from the mum. The oxygen in the mum's blood moves across the placenta and into the umbilical cord. Once they are born, babies must get oxygen through their lungs by breathing. This can be a particular problem for very premature babies. There are two main reasons. First of all, their lungs may not be fully developed. The second problem is that the baby may be unwell and very weak. Machines can help babies breathe until they are strong enough to do it on their own. Full-term babies can also become unwell for a variety of reasons and might also need help with breathing. Please see page 54 for common lung conditions in premature babies.



Ventilators

The strongest machine that helps babies breathe is a ventilator. It drives air through a tube that has been placed in your baby's windpipe (the trachea). This procedure is called intubation.

There are two basic types of ventilator:

- **Positive pressure ventilators** (the most common) blow oxygen-enriched air gently into your baby's lungs through a tube that is passed through their mouth or nose. These ventilators inflate the lungs. The rate of breathing will be regularly adjusted to meet your baby's needs.

- **High frequency ventilators** blow small amounts of air into the lungs very rapidly, at hundreds of times per minute. Your baby's chest will appear to vibrate. Though this may look alarming, this type of ventilation works extremely well for some lung conditions.

The doctor will recommend the type of ventilator that is best for your baby's condition.

The breathing tube may need to be replaced quickly if it becomes blocked with mucus, or if it falls out. Problems like this are usually detected when your baby's blood oxygen level drops and their chest does not move in time with the ventilator. The doctors may wait and give your baby a chance to breathe on their own before replacing the tube.

The first time your baby is taken off the ventilator, they may breathe well for a short period but then become very tired. In this case, doctors will replace the ventilator and try again later. Your baby may be weaned off the ventilator, with the rate and pressure used being slowly reduced.

If your baby develops an infection, they may have difficulty breathing and might need to go back on a ventilator until the infection is cleared.

Continuous positive airway pressure (CPAP)

Some babies need a little help with their breathing, but they do not need the strength of a ventilator. They can be helped with continuous positive airway pressure (CPAP). Air flows through two fine tubes placed in your baby's nose, or through a small mask over their nose. CPAP slightly raises the air pressure and helps to keep your baby's lungs inflated.

If CPAP is used for a long time, the pressure of the nosepiece on the tip of your baby's nose can give a snub-nose appearance. This goes away on its own after CPAP is stopped, but the nurses will watch out for this.

There is more information about common lung problems and treatments later on in this section of the handbook, on page 54.

High flow oxygen

This is a new technique that some units use to provide similar support to CPAP.

“The team worked on Tabitha for 17 minutes before she was stable but still critical. During this time she was intubated twice. She was linked to lots of machines to monitor breathing, blood pressure, temperature and she was covered in bubble wrap to keep her warm. Tabitha was always lively and forever using her feet to move the bubble wrap.”

John, brother of Tabitha, born at 24 weeks



Monitors

It seems like alarms and beeps are always sounding in the neonatal unit. This is because the nurses use various monitors to keep track of your baby's condition, minute by minute.

Vital signs monitors

These machines pick up the electrical signals given out by your baby's heart and constantly check that it is beating properly. They can also detect changes in your baby's breathing. Pauses in your baby's breathing may trigger an alarm. These monitors pick up the information through small pads placed on your baby's chest. Wires run from the pads to the monitoring machine.

Oxygen saturation monitors

These monitors check the amount of oxygen in your baby's blood, by shining a light through their skin. The sensors are strapped gently to your baby's foot or hand.

Tubes

It might seem like your baby has tubes everywhere. It's less frightening when you know the purpose of all these tubes, and how they work.

Intravenous (IV) drips

Your baby may have fine tubes (called drips or cannulae) inserted into a tiny blood vessel. The IV is usually placed in a hand, foot, arm or leg. Occasionally it is necessary to use one of the tiny veins on the surface of the baby's head. These tubes are there to give fluids or medication, such as antibiotics. Sometimes, a baby's delicate blood vessels can break or become blocked. In some cases, fluids can leak into the surrounding tissues and cause swelling for a short period of time.

Umbilical catheters

These long, soft tubes are inserted into the blood vessels in your baby's belly button. Umbilical catheters are mostly used in the first few days after birth. There are two types of umbilical catheter. One type goes into an artery and is used mainly to measure your baby's blood pressure and to take samples for blood gas testing. The other kind goes into a vein and this is used to give your baby nutrition or medicines. Most umbilical catheters have only one tube but some have a second or third, meaning different fluids and medications can be given through the one entry point. This means your baby can have several procedures at once without being disturbed or distressed.



Long lines

These are very fine tubes passed into one of your baby's larger veins. This is a more complex procedure than inserting drips, and can involve surgery. Long lines are regularly used for giving nutrition and certain drugs that need to go into a large vein. It isn't always easy to position the line in exactly the right place. If a long line is not correctly placed, it may get blocked or leak. The nurses and doctors always watch long lines carefully. The line will be removed if there are any concerns.

Endotracheal tube

This is placed down your baby's windpipe if they are on a ventilator. Sometimes these tubes become blocked or fall out, meaning they must be replaced. (See page 45 in this section of the handbook for more information about machines that help with breathing.)

Feeding tube

If your baby can't feed normally yet, they might receive breast milk or formula through a tube that goes down their mouth or nose and into their stomach. This is called enteral feeding. If your baby is not strong enough to take milk yet, they can receive nourishment through a long line that goes into a blood vessel as described above (this is called parenteral feeding). Please see the Feeding section (page 65) of this handbook for information.

Medical tests

Your baby will need medical tests while they are on the unit so the doctors can understand their condition and see how well treatments are working.

This section tells you about common medical tests, including:

- Blood tests
- Scans
- Lumbar puncture
- Screening for inherited conditions or infections
- Vision and hearing tests.

Tests are only done when necessary and the doctors, nurses and other staff will do their best to keep any discomfort to your baby to a minimum. You can learn about ways to help your baby cope by looking at page 43 in this section of the handbook.

Blood tests

Blood acts as the body's transport system, moving oxygen, nutrients, waste products and chemical messages to all the right places. Your baby's blood is full of living cells with different functions, including fighting infection. For these reasons, blood tests can give the doctors vital clues about your baby's health.

Most blood samples are taken by pricking the skin to get blood from the back of your baby's hand or heel.

Doctors or scientists test your baby's blood sample in the laboratory. Some of the most common blood tests are explained here.

Sugar levels

Blood distributes energy to all the body's organs by carrying sugar. This level test tells doctors whether your baby's blood sugar levels are properly controlled. Babies born to diabetic mums or very low birthweight babies may have problems maintaining blood sugar levels and so need extra monitoring.

Blood gases

As well as carrying oxygen from the lungs to the rest of the body, blood transports the waste gas, carbon dioxide, back to your baby's lungs so they can breathe it out. Measuring the amount of carbon dioxide, along with some of the waste chemicals the blood collects, can give clues about how well your baby is breathing. This test also helps the doctors see how well your baby's other organs, such as the kidneys, are working.

Platelets

These cells in your baby's blood are important to control bleeding. In premature babies, the platelet count is often too low. If this happens to your baby, they may need a platelet transfusion.

Haemoglobin

The blood's ability to transport oxygen depends on this naturally-occurring chemical. In blood, haemoglobin is carried by red blood cells. When your baby does not have enough red blood cells, the rest of the body may not get enough oxygen. This is called anaemia. If your baby is anaemic, they may need to have blood transfusions. (See page 59 for more information on transfusions).

White blood cells

These cells play a big role in fighting infections. Checking the number of white blood cells helps the doctors know how well your baby is overcoming infection and provides clues about new infections that might be forming.

Scans

Doctors can tell a lot from scans that give them a look inside your baby's body. They should always explain the results of any scans to you.

Ultrasound

The most common scan uses ultrasound waves, which create a picture of what is happening inside your baby's body. Ultrasound does not use harmful radiation. One common use for ultrasound is to look at the structure of your baby's brain and show whether there is bleeding or other problems. You might be able to stay with your baby while they are having an ultrasound scan.

Magnetic resonance imaging (MRI)

Many neonatal units have access to magnetic resonance imaging (MRI) scanners. These scanners use a magnetic field to give very useful pictures of your baby's internal organs. An MRI scan is painless and does not use harmful radiation. If your baby has an MRI scan, they will be moved to the scanner in a special incubator that keeps them safe and warm. In most hospitals, the MRI scanner is located far away from the neonatal unit. Your baby may need to wait for this test, until they are strong enough to make the journey. Your baby may be sedated before having the scan, to help them stay still enough for the MRI to be completed.



X-rays

X-rays are commonly used to look at a baby's chest, especially when they are on respiratory support. Another common reason for x-rays is to look at a baby's abdomen when feeds are not tolerated and a serious disorder or infection of the gut is suspected. As x-rays use ionising radiation, they are used only when absolutely necessary. You may need to leave the room while your baby is having an x-ray.

Lumbar puncture

If the doctors think your baby could have a severe infection, they may want to check whether the brain and spinal cord are affected (meningitis). In a lumbar puncture, the doctor takes a sample of fluid that surrounds the spinal cord. This fluid also surrounds the brain and flows down from there. Therefore, this test can also tell doctors if there is an infection affecting the brain.

A nurse will hold your baby in a curled position on their side so that the space between the bones of the spine is increased. The nurse will watch the baby closely while the doctor inserts a small needle between two bones low in your baby's back. As far as we know, babies only experience slight discomfort from this procedure. Simple pain relief measures, such as giving a taste of sugar or breast milk, are usually all that is needed.



Screening for inherited conditions or infections

The doctors might want to test your baby for viral infections acquired during pregnancy or genetic (inherited) conditions, which may have serious health

implications not only for the baby but also for you and your family. Doctors will discuss these tests with you before they are carried out.

Vision and hearing tests

Premature babies are at increased risk of eye problems. If your baby weighed less than 1,500g at birth or was born before 32 weeks, an eye specialist (an ophthalmologist) should check your baby for retinopathy of prematurity (ROP). This can be a serious condition and occasionally needs laser treatment. Routine checks start once the baby reaches a certain level of maturity, which can be a few weeks after birth.

Premature babies are also at higher risk of other eye problems, such as squints and long- or short-sightedness. It is important to make sure your child has regular eye checks as they get older because these problems can be helped with glasses or other treatment.

Similarly, premature babies have a higher risk of hearing problems. As part of a national programme, all newborn babies should be offered a hearing test before leaving hospital.

Complications and medical conditions

Premature and sick babies in special care often have medical problems. The risks are higher for babies who were born the earliest. This section of the handbook tells you about some medical conditions that occur most often in premature babies, including:

- Infections
- Lung problems
- Meconium aspiration syndrome (MAS)
- Jaundice
- Brain haemorrhage
- Heart, kidney or liver conditions
- Necrotising enterocolitis (NEC)
- Blood transfusions

Some of these conditions can affect premature or older babies, too. There is also information about blood transfusions, which your baby may need for various reasons.

Infections

This happens when the body's normal reaction to inflammation or a bacterial infection goes into overdrive. The bacteria create a toxin that causes widespread inflammation and rapid changes in the baby's body temperature, blood pressure, and lungs and other organs. Premature babies are especially vulnerable to infection because their immune systems are less developed. Babies in the NICU can also get infections through catheters, ventilation tubes and long-term intravenous lines. If the doctors suspect an infection, your baby may receive intravenous antibiotics before the diagnosis has been confirmed by laboratory tests. Antibiotics are commonly used to treat infections.

Lung problems

Breathing problems are common in premature babies, especially if they were born before the lungs had a chance to develop fully in the womb. Helping babies to breathe is often an important part of their care in the neonatal unit.

Surfactant

If your baby is premature and their lungs aren't fully developed, they are likely to receive surfactant. This is a natural substance produced in the lungs to make breathing easier. It makes lung tissue stretchy and elastic, which prevents the lungs from collapsing. Surfactant is produced by the body from about 20 weeks' gestation and premature babies often don't have enough. This shortage can lead to low oxygen levels in the blood and breathing problems. Surfactant can be produced artificially. It is given to your baby by placing a tube into the throat and slowly easing the surfactant into the lungs.

Apnoea of prematurity

Premature babies often display a pattern of breathing that has short pauses. Occasionally, these pauses can be long and the baby needs to be 'reminded' to breathe with gentle stimulation.

Drugs, like caffeine, might be used to help stabilise your baby's breathing.

Sometimes these pauses can be severe enough for your baby to need some short-term assistance with their breathing. In most cases, this problem will get better.

If your baby is coming off a ventilator, they will be fitted with a monitor that sets off an alarm if they pause for too long between breaths.

See our free *Retinopathy of preterm (ROP) screening* factsheet for more information.

“Joseph had countless blood transfusions and medications. He had a PDA which was treated with medication. He had laser treatment on his eyes and a hernia operation. He is still on oxygen and still small but despite this he is a very happy little boy with lots of smiles.”

Becky, mum to Joseph, born at 23 weeks

Collapsed lung (pneumothorax)

Air can sometimes leak from damaged air sacs in the lungs, particularly if your baby is on a ventilator. Bubbles of air may form in the lung tissues or around the lungs, forming a ‘collapsed lung’ (pneumothorax).

Large pockets of air can compress the lungs and make breathing more difficult. In this case, the doctor may have to pass a small tube (chest drain) through your baby’s chest wall to let the air escape. A local anaesthetic is given for this procedure. Often a chest drain has to be inserted as an emergency so it is likely the doctors and nurses will not be able to discuss this with you until afterwards.

Chronic Lung Disease

Babies who are ventilated for long periods of time may get chronic lung disease (CLD) (also known as Bronchopulmonary dysplasia or BPD).

Babies are said to have CLD if they are continuously on oxygen when they reach 36 weeks’ gestation (four weeks before their due date) and their chest x-ray confirms changes in the lung that are typically seen with this condition.

If your baby has CLD, their lungs will be stiffer than normal and they will have to work harder to get air into their lungs. When your baby is taken off breathing support, they may easily become tired, especially during feeds (which may need to be given by a tube for longer than a baby who has never been ventilated). They may continue to need oxygen for a while, possibly even when they go home.

Because the lungs are growing fast at this stage, most babies progressively get better. Many babies with CLD who go home on oxygen are off their oxygen by the time they are six to nine months past their due date.

Meconium aspiration syndrome (MAS)

One reason that babies sometimes require breathing support is that they're suffering from meconium aspiration syndrome (MAS). This happens most often in babies born at or near full term. During delivery, a newborn baby sometimes inhales a mixture of amniotic fluid and meconium. Meconium is the baby's first faeces (or poo), which is sticky, thick and dark green. If your baby has MAS, they might show signs at first, such as being floppy, limp or very still, or having a slow heart rate. The baby's windpipe is cleared as much as possible to clean up the meconium. This is done by putting in an endotracheal tube (a plastic tube that's placed into the baby's windpipe through the mouth or nose) and applying suction as the tube is slowly removed. The doctor will continue trying to clear the airway until there's no meconium in the suctioned fluids.

This condition can be serious, requiring complex intensive care treatments. However, most babies with MAS improve within a few days or weeks, depending on how much they have inhaled. There's usually no permanent lung damage.

Jaundice

Your baby might need light therapy (also called phototherapy) for jaundice – this is quite common.

Jaundice in newborns is usually caused by a build-up of breakdown products in the blood. A chemical called bilirubin is released when old red blood cells break down. This is a natural process that happens as the body constantly renews its supply of red blood cells.



Sometimes levels of bilirubin build up in the blood of newborn babies because the liver can't remove it fast enough. This is often the case for premature babies and those with liver problems. This build-up causes your baby's skin to look yellow and that is what is meant by the term jaundice. Other liver problems can also cause jaundice but this is less common.

If bilirubin builds up to very high levels in the blood it can be serious, so this is monitored closely with blood tests.

Bilirubin can be broken down by blue light. This is why babies are often placed under a special light or laid on top of a biliblanket, which gives out similar light. This is called phototherapy.

If bilirubin levels get very high, doctors may perform an exchange transfusion, replacing the baby's blood with fresh, bilirubin-free blood.

Brain haemorrhage

A baby's developing brain has an abundance of tiny blood vessels. Sometimes these blood vessels tear, causing bleeding in the brain. Small episodes of bleeding (haemorrhage) appear to cause no long-term problems.

Bleeding in the brain is classified according to how serious it is: grade 1 is mild bleeding; grade 2 is moderate; while grades 3 and 4 are the most severe. These larger bleeds are more serious and may limit blood flow to areas of the brain. This means that some parts of your baby's brain might not receive enough oxygen. If your baby has a larger area of bleeding in the brain, the doctors will monitor this with regular ultrasound scans.

Sometimes, when the amount of bleeding is larger, the flow of fluid from the brain to the spinal cord becomes blocked by blood clots.

Sometimes scans show signs that parts of the brain have not had enough oxygen. If the cells in the oxygen-deprived area die, a fluid-filled pocket called a cyst forms in place of the brain tissue. Exactly how this may affect your baby will depend on where the cyst is located.

Your baby's doctor should tell you what they see on the scans. The terminology can be confusing so don't hesitate to ask the doctor to describe it in simpler language.

Heart, kidney or liver conditions

Some babies with heart problems need surgery, but some do not.

If your baby has a heart condition, they might need to move to another hospital with cardiac specialists. In other cases, your baby might stay in your local neonatal unit until they are stable enough for further treatment.

For less serious heart problems, your baby might stay in your local hospital until they are well enough to go home, and then have follow-up care in a routine cardiac clinic.

Patent ductus or patent ductus arteriosus (PDA)

Patent ductus arteriosus (PDA) is a common heart condition in babies. The ductus arteriosus is a small blood vessel that is normally present just outside a baby's heart when they are in the womb. The ductus (duct) connects the two main blood vessels leaving the heart (called the aorta and pulmonary artery). The duct allows the blood to 'bypass' the lungs, as they are not needed when the baby is in the womb.

Normally, after birth, the lungs fill with air, and blood flows to the lungs. The duct is then not needed, and usually closes over the first few days of life. In some babies, the duct does not close properly. If the duct remains open it is called a patent ductus arteriosus or PDA.

This problem is normally spotted when doctors hear a heart murmur (noise) through a stethoscope. It is usually confirmed with an ultrasound scan of the heart. This is also known as an echocardiogram or 'echo'.



If the scan shows that the duct is large, or if it is causing problems for your baby, treatment may be started to encourage the duct to close. Starting treatment for a large duct in the first few days of life may help prevent problems later. Your baby's doctor will talk to you about this.

There are different treatment options:

- **Medication** The medications commonly used for PDA are called indometacin and ibuprofen. They work best if given before two weeks of age. Usually, they are given into a vein. Doctors normally scan the baby's heart again during the treatment to see if the medication is working.
- **Surgery** If the ductus arteriosus remains open, and is causing your baby problems, the doctors may recommend a small operation to close the duct. Not all PDAs need surgery. Some will close on their own, given time, and your baby's doctor will talk to you about whether your baby would benefit from an operation.

Necrotising enterocolitis (NEC)

This is a serious illness where tissues in the intestine become inflamed and begin to die. This can cause a serious infection as a hole may develop, allowing the contents of the intestine to leak into the abdomen. NEC is one of the most common reasons for surgery in newborn babies. It can be difficult to diagnose but the doctors and nurses may suspect it if your baby shows general signs of illness, has problems feeding and has a swollen or tender tummy. Most of the time, NEC can be treated without surgery simply by resting the intestine and feeding your baby through a drip for a while. Antibiotics are used to treat infection. Your baby will also have a nasogastric (NG) tube passed through their nose to drain off the contents of the stomach. If your baby develops a perforation (hole) in the intestine or does not respond to treatment, they will need an operation. The surgeon will remove any parts of the intestine where the tissue has died. While your baby recovers from surgery, they will continue to be fed through a vein. The drip will gradually be replaced by breast milk or formula, given through the NG tube, as your baby recovers. Breast milk is known to reduce the risk of NEC so this is a good reason to give it to your baby if you can.

Blood transfusions

Your baby might need a blood transfusion – there are various reasons why this could happen. During a transfusion, your baby receives donated blood through a tube into a vein.

Your consent is needed before your baby receives a blood transfusion, although in an emergency the doctors may have to start this without your permission. In this case, your baby's doctor will explain the reasons to you as soon as possible.

Blood is a very complex substance that is made up of lots of different cells plus a fluid called plasma. Sometimes doctors give a transfusion of just one part of the blood, rather than whole blood. One example is a platelet transfusion. Platelets are tiny cells that stick together and help our blood to clot. They are important because they are our body's natural defence against bleeding. All cells in the body break down and regenerate over time. Sometimes when babies are very small or very sick their platelets are used up or break down at a faster rate than new ones are formed.

A blood test shows if the platelet count is low and in this case, your baby can have a platelet transfusion to build up their levels.



Immunisations

It is standard practice to start giving routine immunisations to most babies eight weeks after birth, to protect them from common diseases. This is true even if your baby is still in hospital. You will have an opportunity to talk to the nurses and doctors first and they will ask for your consent before giving your baby any vaccinations.

Helping with medical research

Parents like you

Your baby is receiving advanced medical care thanks, in part, to the years of research that have gone before. This is why more babies, who may not have lived without such advances, are now surviving. Research has also led to dramatic improvements in the quality of life for babies and children born prematurely.

This research continues to be vitally important and you may meet people on the unit who are doing new studies. You may be asked if your baby could become involved.



At first, this can seem like a frightening idea. However, you might be reassured to know that all research is checked out thoroughly beforehand by a Research Ethics Committee. This check ensures the studies are reasonable, and that the study is unlikely to pose any increased risk for babies compared to standard treatment.

If you agree, the hospital must give you a consent form to sign. By signing this, you are confirming that you have agreed to involve your baby in the research.

You can ask for your baby to leave a study at any point if you change your mind. Again, this will never affect the quality of care given to your baby.

Solving disagreements and complaints

It's always best for your baby when you can work together with the doctors and nurses as a team. However, there are times when everyone does not see eye-to-eye, or problems occur. If you are unhappy with your baby's care, or disagree with their treatment, don't be afraid to speak up. After all, looking out for your baby's best interests is part of your job as a parent.

Often, the main problem is just poor communication. Research supported by Bliss shows that parents experience a lot of kindness on the unit and they really appreciate it. However, some parents also said they were distressed by insensitive attitudes or felt shut out from medical decisions.

Second opinion

You can ask for a second opinion from another doctor if you are worried about treatment that is suggested for your baby. This is not a legal right but it is considered good medical practice for doctors to agree to your request. In fact, doctors commonly ask each other for advice so there is no need to worry about asking for a second opinion. This will not affect your baby's care in any way. Do speak to the team looking after your baby and they can arrange for this to take place.

Complaints

Every hospital has a complaints procedure. If you want to make a complaint, the first step is to talk to the nurse or doctor concerned. Try to do this as soon as you can. Keep a clear idea of what change you want to see and focus on that. It might not be easy when emotions are running high but a solution is more likely if everyone can remain calm and polite.

If you are not confident about doing this on your own, you can get confidential help from the Patient Advice and Liaison Service (PALS) at your hospital. You can go to the PALS office for information, advice and support if you are unhappy with any aspect of your baby's treatment. They should also be able to help if you are confused about how the system works, or want to know how to get support after your baby goes home. You can also get free support from the Independent Complaints Advocacy Service (ICAS). Your PALS office can give you the contact details for your local ICAS.



► Family focus

"Against the odds"

Becky knew something wasn't bright when, at 18 weeks pregnant, she felt a heaviness and pressure in her lower abdomen.

By the time Becky reached 22 weeks and four days she had started bleeding and experienced strong contractions.

A couple of days later Becky was moved to a regional hospital with the facilities to care for the most preterm babies.

When she arrived there, Becky was given a scan and told that the baby was in breech and stuck in her pelvis. The consultant couldn't detect a heartbeat and said it could be due to his position in the womb but it was unlikely that he was still alive.

Becky and Sean were in a state of disbelief when, minutes after having a discussion about funeral arrangements, a leg popped out kicking. Joseph was born at 23 weeks weighing only 555 grams and was immediately taken to an awaiting incubator. Becky was allowed to touch his cheek before he was taken away to be stabilised.

Becky says: "The staff were happy to explain everything to us and answer our questions, despite them being quite short staffed at times. We soon got into a routine of going to the neonatal unit twice



a day. On bad days we would spend the whole day there."

On Christmas Eve, six weeks and two days after Joseph was born, he was lifted out of the incubator and the couple held him for the first time. It was the best Christmas present Becky and Sean could have asked for.

At the beginning of February Joseph was transferred from intensive care to special care.

Joseph was allowed home on 15 March, just six days after his due date, weighing 5lb 8oz.

Becky says: "He is obviously still very small for his age but he will catch up in time. He is a very happy, cheeky boy who is forever smiling."

Feeding your baby

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Nutritional needs of premature babies

It is every parent's priority to make sure their baby is well nourished. In research supported by Bliss, parents said they really valued practical guidance and encouragement in feeding their baby.

Breast milk is the ideal nutrition for any baby and this is especially true for premature babies. When you give birth prematurely, your breast milk is extra rich in antibodies. One of the best ways to help your baby is to give them breast milk, which has many advantages over formula milk. It is also the one unique thing a mum can do for her baby.

For example, it:

- Provides antibodies that protect your baby against bacteria and viruses
- Boosts your baby's immune system.
- Reduces the risk of serious gut infections, such as necrotising enterocolitis (NEC), and protects against other infections.
- Provides nutrients, growth factors and hormones that help your baby grow and develop.
- Is very easy to digest and is absorbed more easily than formula milk.

Premature babies have different nutritional needs than full-term babies. The digestive system is less mature and they may need some time to develop their sucking ability.

So if your baby is not ready for full breastfeeding yet, there will be some extra steps along the way. For a while, your baby might need to receive a nutritional solution through a vein, or receive expressed breast milk through a stomach tube.

It might take a while to get breastfeeding established, but don't give up. There are many benefits for babies and mums. Breastfeeding can also help to build a strong bond of affection with your baby.

This section of the handbook gives you the basics and you'll find lots of detailed information in our booklet about breastfeeding (see below).

See our free guide, *The best start: A guide to expressing and breastfeeding your premature baby*.

“Breastfeeding was very positive. I expressed from the first day and, although my milk threatened to dry up a number of times, I was adamant I would breastfeed like I did my first son. Kwame had a nasogastric tube, which was put in to make feeding him my expressed breast milk easier. I used to breastfeed once a day, and other times he was tube fed. He didn’t feed from the breast until he was about four months old. I was constantly encouraged by the nurses. They were amazing!”

Hyacinth, mum of Kwame, born at 23 weeks



Feeding through a tube

In the womb, your baby received nutrients and fluids through the placenta and umbilical cord. Now that your baby has been born, they need nutrition but they may not be ready for full breastfeeding yet. In the meantime, there are other ways to make sure your baby is well-nourished. They can receive nutrition through a tube in their vein or have breast milk through a tube into the stomach. The method will depend on your baby’s stage of development and their overall health.

Parenteral nutrition (PN)

If your baby is not strong or mature enough to take breast milk, they will need to receive nutrition through a vein. This is known as intravenous or parenteral nutrition.

A long, fine tube is inserted into a vein in your baby’s arm or leg. This is called an intravenous or long line (see page 49 for more information about long lines).

Through this tube, a mixture of nutrients can be delivered directly into your baby’s bloodstream. Initially, the mixture may contain glucose (sugar), salts and water. Very soon, other nutrients can be added, including amino acids (the building blocks for protein), fats, vitamins and minerals.

Parenteral nutrition is particularly useful for babies who are very poorly or for whom the stomach and gut are not developed enough to digest breast milk.

Enteral nutrition (EN)

When babies are stronger and older, they can start to take breast milk into the stomach.

But even if your baby's gut is ready for digestion, very premature babies can't coordinate all of the muscles needed for sucking, swallowing and breathing. In this case, your baby can be fed breast milk or formula through a tube that goes into their stomach. This is called enteral feeding (EN) or tube feeding.

The feeding tube is passed through your baby's nose (a nasogastric tube), or their mouth (an oral-gastric tube), into their stomach.

The milk is placed in a syringe, which is attached to the outside end of the tube. The syringe gets a slight push to get it started and is then held up above your baby's head. Gravity gradually pulls the milk down into your baby's stomach. As a parent you can get involved by holding your baby's feeding tube.

Questions you can ask

1. Can you explain how my baby is being fed at the moment?
2. What nutrition is my baby getting?
3. Is there a way I could help with my baby's feeding at the moment?
4. As my baby gets stronger, what is the next step for feeding?
5. When will my baby be able to breastfeed?
6. What can we do now to make sure breastfeeding gets off to a good start when my baby is ready?
7. Who can give us practical help with breastfeeding?

It's ideal if you can hold your baby while they have a feed. It is also important for your baby to practise sucking at the same time that they are having a tube feed. This way, your baby learns to associate sucking with the reward of a full tummy. You can express some milk so that your breast is not full and then let your baby lick and suck at the breast while they are having a tube feed.

Another method is to let your baby suck a dummy during the feed. Policies on your unit may discourage the routine use of dummies until your baby is able to begin breastfeeding. This is so your baby can focus their energy and concentration on learning how to breastfeed.

When you feel ready, you may be able to help tube feed your baby if you wish.

Advantages of breast milk

Babies get many benefits from breast milk, and these are twice as important for premature babies. Breastfeeding also allows you to have skin-to-skin contact with your baby. Research has shown this is very beneficial, especially for premature babies.

Giving your baby breast milk can help you feel more in control and involved in caring for your baby. This applies to dads, too. Research shows that encouragement and support from dads increases the chances of successful breastfeeding. If you are a dad, you can also give your baby tube feeds if they are having these.

Practical help with breastfeeding

Breastfeeding is so important for babies and mums that it is part of the *Bliss Baby Charter Standards*, which set standards of care for neonatal units across the country. The *Charter* says that breastfeeding should be actively encouraged and that mums should have all the support they need to provide breast milk for their babies.



Once you get the knack, breastfeeding your baby is the most natural thing in the world. Most new mums need some help to get breastfeeding off to a good start. There are extra problems to overcome if, for example, your baby is too premature or sick to go onto the breast yet, if their condition is unstable, or if they are on a ventilator. It is useful to practise how to hold your baby for breastfeeding long before they are actually ready to begin to breastfeed.

You can learn to pump milk from your breasts, and this is called 'expressing'. You can hand express or buy hand-operated, battery or electric pumps (battery pumps are not recommended for long-term expressing). The hospital will have an electric pump you can use. In the early days it is normal to express small amounts of a sticky clear or yellow fluid called colostrum. Colostrum is concentrated goodness for your baby and provides them with additional protection at this crucial time. It is important to express breast milk as soon as possible after the birth and then to continue to express eight to ten times every 24-hours including at night. Although your baby may be only taking tiny amounts of milk, frequent and effective expression, particularly in the first two weeks, is crucial in establishing a long term milk supply.

What you can do



- Ask the nurses on the unit for **advice on breastfeeding**. You can also ask if there is a breastfeeding specialist to support you.
- **Give your baby Kangaroo Care**. This means holding your baby against your chest, skin-to-skin. Kangaroo Care can make breastfeeding more successful. See page 32 for more details.
- If your baby is not ready to take the breast yet, you should **express (pump) breast milk**. Hand expressing is best for the first few days and then you can move on to using a pump. Your baby can have this milk if they are getting tube feeds. Expressing also keeps your milk flow going and can be frozen for later use.
- While your baby is having a tube feed, put your **baby to the breast** or give them a dummy. This helps your baby learn that sucking leads to a full tummy.
- Stress can reduce your flow of breast milk so when you are a breastfeeding mum, **looking after yourself helps your baby too**.

Some mums find pumping each breast in turn easier and more effective at increasing milk supply. Expressing milk can get your flow established so that you have a good supply going when your baby is ready to take the breast. Your breast milk will also be the best nutrition for your baby if they are being fed through a feeding tube. Breast milk can be stored in the refrigerator for a short time between (24 to 48 hours only) or frozen for future use. Ideally, breast feeding needs to be well established before bottle feeds of expressed milk are introduced, if you decide to do mixed feeding.

First feeds

It is important that your baby's first feeds are breast milk. If for any reason you are unable to express your milk, you can use donor breast milk that has been donated to one of the UK's milk banks by a mum who has been carefully screened in line with national guidelines. The donor breast milk is tested and heat treated for safety. Although breast milk banks are not available at all neonatal units, many units obtain supplies from other unit's banks or from a regional service.

Breast milk fortification

Because of the high nutritional needs of very premature babies, many will need extra protein, minerals and vitamins over and above what they get in breast milk. In most units it is routine to add a fortifier around day 10, when a baby is on full enteral feeds. This is then added to each feed until breastfeeding is fully established. Some units also send babies home with fortifier supplements.

For mums

Breastfeeding is really good for a mum's health. It helps you regain your figure because extra fat stored in your body during pregnancy is used to produce breast milk. There is also good evidence that breastfeeding reduces your risk of breast and ovarian cancer.

Breastfeeding may not be the choice for everyone and you may decide that long-term breastfeeding may not be for you. However, providing breast milk in the early weeks after birth gives your baby a unique boost. Get support from the nurses on your unit or from some of the organisations listed on page 87. And remember, even a small amount of breast milk is very beneficial for your baby. Even if you can only manage a little bit of milk or decide you can't continue, you will get your baby off to a good start by giving it a try. Every extra day of breastmilk provides your baby with extra protection against infection and is the best source of nutrition.

Please note: you may find the unit very hot and become hungry or dehydrated. This will affect your milk, so make sure you eat and drink regularly.

Passing on infections

If you have health problems of your own, it might mean that breastfeeding is not actually good for your baby. Some viruses, like HIV, pass through breast milk to infect the baby. Breastfeeding is not advised if you have these viruses. If you know that you have one of these infections, or if you're worried you might, you can talk to the nurses in confidence and they will help you in a caring way.

Bliss is here to help

If you would like to discuss any of these issues with someone outside of the neonatal unit, confidentially and anonymously, call the Bliss helpline on 0500 618 140.

Prescribed medicines

You might be taking medicines prescribed by your doctor, and these often pass through the breast milk to your baby. The same is true for medicines you can buy at the supermarket or pharmacy without a prescription. Tell a nurse or doctor on the unit about the medicines you are taking, and they will help you work out whether breastfeeding is safe for your baby. There are very few prescribed drugs that can't be used and often a safe alternative can be found. If you have to stop breastfeeding temporarily, you can keep your milk flow going by expressing.

Other drugs

When you are taking illegal or recreational drugs, these can pass through the breast milk to your baby and may cause them harm. It might be hard but think about telling one of the doctors or nurses so they can help you with confidential advice and treatment.

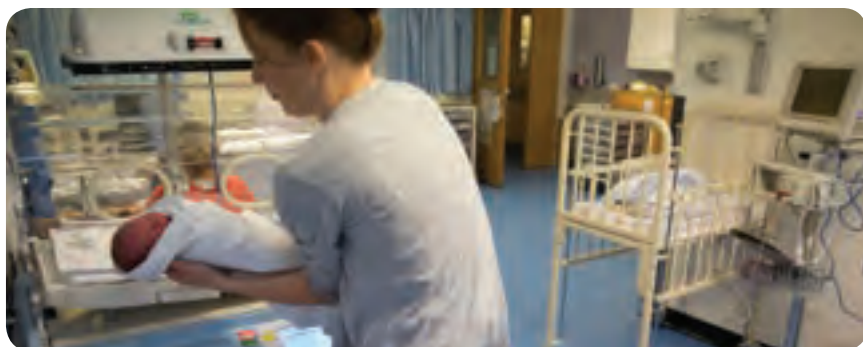
Bottle feeding

If you or your baby are unable to breastfeed you may choose to use formula milk. Your baby will have to be mature enough to coordinate sucking with swallowing and breathing before they can feed effectively from the bottle. If your baby is having trouble with bottle feeding, it might help to try different positions, teats and bottles. Nurses on the unit will advise you on what kind of formula to use, as well as how to prepare feeds and sterilise equipment. They can also show you how to feed your baby with a bottle and how to pace feeding for your baby.

Home time

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Building your confidence



It's the day you've been waiting for – taking your baby home. But you might be nervous, too, especially if your baby has been on the unit for a long time. It can also be daunting if your baby will need continued medical support at home, like oxygen or tube feeding. The answer is to build up your confidence gradually before your baby leaves the unit.

“After weeks on the unit, we were itching to get our twins home. Everything was ready for them. We would wait every morning for the doctor's round to ask if that day would be the day. Eventually, we took them home. It was so exciting. I had watched so many mums let through the doors of the maternity unit with their baby. Now it was our turn. We were so happy.”

Louisa, mum of Isobel and Imogen, born at 28 weeks

The *Bliss Baby Charter Standards*, which set standards for care in neonatal units, highlight the importance of giving your family a smooth journey home. Important steps in this process include:

- Agreeing a clear plan with you for your baby's discharge from hospital.
- Providing a chance to 'room in' with your baby before they go home.
- Making sure you have the information and professional support you need to care for your baby at home.

The nurses should give you training in basic resuscitation. This is a really useful skill for all parents. They will also give you advice about safe sleeping conditions for your baby.

Rooming in

All neonatal units should have facilities where you can 'room in' for one or two nights and practise caring for your baby on your own, but with the nurses nearby if you need them. Rooming in can help you build up confidence and realise that you really can care for your baby.

It helps to remember that your baby is only coming home because the nurses and doctors believe they are well enough – and you are absolutely up to the job.

Before you leave

Before you take your baby home, make sure you are clear about:

- Medicines your baby needs and how to get refills.
- How to measure out the dose and when to give the medicines.
- The name and contact details for your baby's GP, including how to get help at nights and weekends.
- How to contact and get to your nearest hospital A&E department, ideally one with a special A&E section for children.
- How to sterilise feeding equipment.
- How to make up formula if your baby is having it.
- How to add breast milk fortifiers if your baby needs them.
- How to give your child oxygen at home if they need it, how to get supplies and who to contact with any problems.

Check that you have contact phone numbers for the neonatal unit in case you need advice. You can contact the unit at any time if you have questions while you are getting settled in at home.

Travelling home

For your baby's safety, you must always use a suitable car seat, even on the shortest journey.

Even if you do not own a car, you still need a car seat so your baby can travel home in a taxi, or in the car of a friend or relative.

Never hold any baby on your lap in the car. It's too dangerous. You can contact the Bliss helpline for advice.



Breathing and oxygen

Although your baby is ready to go home, they may still need oxygen to support their breathing. This is very common for babies leaving the neonatal unit. Your baby may need oxygen for several months or longer.

If your baby needs oxygen at home, the doctors and nurses on the neonatal unit will teach you how to give the oxygen and look after the equipment. Don't hesitate to ask questions and keep asking until you feel sure about the answers.

The company assigned to provide your baby's home oxygen will contact you before your baby goes home from hospital. They will set up equipment and offer help and advice, including via a 24-hour helpline. You will also be assigned a community health professional to help you settle in and check your baby is doing well on home oxygen.

See our free *Going home on oxygen* booklet for more information.

Respiratory syncytial virus (RSV)

This virus commonly affects all babies and causes cold-like symptoms. It can cause breathing difficulties if it reaches your baby's lungs. If your baby was born premature, is prone to getting lung infections or was born with a heart problem, an RSV infection could be more serious for them.

Good hygiene is very important to prevent RSV. Always wash your hands and keep surfaces, toys and bedding clean. Reduce your baby's exposure to busy public areas and people who may have a cough or cold. The RSV season peaks between October and March.

See our free *Common winter illnesses* booklet for more information.

Warmth and overheating

By the time your baby comes home, they should be able to maintain a normal body temperature just as well as any full-term baby. However, if your baby is very small, they may still need a warmer environment. Ask the nurses on the neonatal unit if you are not sure.

The best room temperature for your baby is around 18°C (65°F). Too hot or too cold could be dangerous. Don't worry if your home feels cooler than the hospital, where the babies are more fragile and need much warmer surroundings. It is helpful to have a room thermometer at home, as well as a digital thermometer to check your baby's temperature, if you are concerned.



In winter you may keep your baby's room a little warmer than the rest of the house. However, take care not to let the room get too hot.

If the baby seems hot or sweaty, remove a layer of clothing or a blanket. If your baby has a fever, contact your GP and get advice (see next page for more information on what to do if your baby is unwell).

Bliss and the Lullaby Trust have produced an advice card on safe sleeping, especially for parents of premature babies. You can order a copy, ask your neonatal unit or download it from the Lullaby Trust website. For contact details, please see page 85. The Trust's advice is to always place your baby on their back – not their front or their side. This reduces the risk of cot death, even if your baby is on home oxygen.

If your baby is unwell

Many new parents are worried if their baby seems unwell. The advice for any parent is the same – if you are worried, have your baby checked out. When babies are ill, their condition can sometimes get worse quite quickly. Don't worry that you are bothering the doctor, because they would always agree that with a baby it is better to be safe than sorry.

Take your baby to the GP the same day if they:

- Lose interest in feeding or refuse to feed.
- Vomit, if this is unusual for your baby .
- Have diarrhoea.
- Are unresponsive and do not react to you.
- Are a lot sleepier than usual.
- Seem 'floppy' like a rag doll, with no strength in their muscles.
- Start to breathe rapidly, noisily or with long pauses between breaths.
- Seem pale and colder than usual.
- Get a rash.
- Have a high temperature.

If your GP is not available, don't hesitate to take your baby to your hospital's accident and emergency department.

Who can help at home

After you take your baby home it can feel like you are all alone, without the hospital nurses and doctors there around the clock. You can rely on your:

- Baby's GP
- Health visitor
- Local pharmacist
- Local children's centre.

Some areas have specialised neonatal outreach teams or community-based paediatric homecare teams, who can also provide specialist care for your baby and family. Make sure you know about all the services that are available in your area before you leave the hospital.



Your baby will have follow-up checks with the unit. How often your baby has these checks will suit their individual needs, depending on their condition, overall health and progress.

Other parents can give you common-sense advice and lift your spirits, too. Bliss can put you in contact with other parents who have had premature or sick babies.

Some babies may have problems that continue for months or years. Babies who have spent a long time on a ventilator or breathing support can often become wheezy when they

get a cold or virus that affects their chests. Others may experience learning or movement difficulties later in life. Make sure childminders, teachers and health professionals are fully aware that your child had a premature birth or health problems after birth. This information will help them understand and meet your child's needs.

Help from Bliss

At Bliss, there is something for everyone, whether it's an online chat with other parents, information from our website, activities run by your local family groups or telephone advice from the Bliss helpline. We are here to support you and your family, for as long as you need us.

How Bliss can help

Supporting parents through emotional times is an important part of our work.

- For free information, advice and support, talk to our trained advisers by calling the Bliss helpline.
- We can put you in touch with qualified counsellors.
- We also have a network of trained parent volunteers whose babies have been in neonatal units.
- You can contact a local Bliss Champion. Champions are parents who have had a baby in special care. They regularly visit the unit and share their experiences.
- You can visit bliss.org.uk and have a look at our interactive parent message board.
- We provide free booklets and factsheets on many issues affecting premature babies, parents and families.

Call the Bliss helpline on 0500 618 140 for more information about any of these services.

Bereavement

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Palliative care

Medical care for premature and sick babies has made huge advances. But some babies are so unwell that they are not likely to make a straightforward recovery. It's a terrible situation for parents when they hear their baby might not survive. The fact that it can all happen very quickly makes it even harder.

At a time like this, you may have to make some difficult choices. You and your family should receive care that helps you find the right information and support at the right time to make these decisions for your baby.

Along with the doctors and nurses, you might decide to start or continue intensive care for your baby. This means a ventilator to breathe for your baby and other life support and drug treatments. You may decide that it is time to stop all or some of the active medical treatment for your baby, or not to start any new treatment should your baby's condition change.

Whatever you choose, keeping your baby pain-free and comfortable will be a priority for all the doctors and nurses. This is often referred to as palliative care. This care is for babies and their families when the baby is recognised as having a life-threatening or life-limiting condition. It does not necessarily mean that your baby won't survive. Palliative care focuses on improving quality of life, reducing pain, and supporting you and your family, helping you make practical arrangements and cope with your emotions.

It should be possible to have the care you want for your baby in the place you want it – at home, in hospital, or in a children's hospice. The hospital team should also offer you and your family emotional, spiritual, psychological and practical support.

Whatever happens, lots of people are there to support you and your family. The doctors and nurses will talk it all through with you so that together, you can make decisions that are in your baby's best interests. For emotional support, you can also ask to see a counsellor or the hospital chaplain.

Facing hard decisions

Hearing that it would be best to limit or stop your baby's intensive care is devastating, and very few parents feel emotionally prepared to deal with this. You may disagree with the medical staff or even with your partner about it. You may feel that you are just not ready to make that decision.



Take your time and talk to the nurses and doctors. With their experience and knowledge, they can be invaluable allies at such a crucial time. When they give you information and advice, be reassured that they will always have your baby's best interests at heart. Your unit might have a psychotherapist or counsellor and there should also be spiritual support available, should you wish.

Caring from the start

Watching your baby fight for life can be very traumatic and all parents worry that their baby may not win the battle.

Some parents who have been through this experience say they did not want to get too attached because they were afraid their baby would not survive. Some parents who did get involved in their baby's care, even though their baby eventually died, said that knowing they had done all they could while their baby was alive helped them to come to terms with their loss. In the long term, it will probably help to know you did everything possible to care for your baby and show them your love.

If your baby dies

The neonatal unit will probably have a room where you can be alone with your baby. Staff may ask if you wish to wash and dress your baby. Parents choose to keep reminders of their baby's life in different ways. Most units will take a photo of your baby, if you give permission. You can take this photo home with you on the day or at a later time. You might also receive a memento card with a footprint or handprint and a lock of your baby's hair. Some parents keep the baby's nametag and hat. Keepsakes like this affirm that this baby was part of your family and always will be.

Making arrangements

It varies in each hospital, but in most units you should be able to stay with your baby for as long as you like. Many hospitals have multi-faith prayer rooms and chaplains to offer their support if or when you need it.

Sometimes, a post-mortem examination (autopsy) may be required by law. Your baby's doctor will explain everything if this happens. In this case,

you will not be able to take your baby's body away from the hospital until this is completed. Normally, you can take your baby home after the death certificate has been issued. You can also arrange for your baby to go to a funeral home. Some children's hospices offer a place where your baby can rest for a time. The nurses or the hospital's bereavement counsellor can give you any guidance you need, or put you in touch with members of any local faith community, should you wish to involve them in preparing a funeral. The hospital may also help you with the funeral.

“I got an early morning call telling me to come in quickly because baby Shaka had taken a turn for the worse and they were trying to resuscitate him as we spoke. I was there within half an hour but it was too late. He had already died. Nothing can ever prepare a parent for that news but the weekend that followed was quite beautiful. The nurses had let me stay with him and moved his brother in there with a nurse for that day so family and friends could come and say their goodbyes. We bathed him and held him for hours. It was very sad for me as I had never held him and unfortunately my first cuddle was after he had died.”

Hyacinth, mum to Kwame and Shaka, born at 23 weeks

Mourning for your baby

Mourning for your baby is a long process, which does not stop at their funeral. Some neonatal units have a bereavement counsellor who will follow up with you, especially in the early days and on important anniversaries like the date of your baby's birth and death. Hospices do this routinely. Many hospitals have an annual remembrance service and you may receive an invitation.

This is a deeply personal experience and you will find your own way to deal with what has happened. You should be offered a follow-up appointment with your baby's doctor within two months in case you have questions that you didn't think of at the time. At this very difficult time, it may be helpful to talk to your GP, a bereavement counsellor or other professional supporter. If you want to talk to a Bliss counsellor or to an adviser on our freephone Helpline, we are always here for you at Bliss.

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About Bliss

Throughout the UK, 80,000 babies are born prematurely or sick every year. The critical care that these babies receive in the first hours, days and weeks has a direct impact on their health and wellbeing for the rest of their lives.

Bliss was established in 1979 and is the only UK charity dedicated to working for special care babies and their families.

Our mission is to ensure that all babies born too soon, too small or too sick in the UK have the best possible chance of survival and of reaching their full potential.

As well as funding research and training, and campaigning for better care, one of the ways we aim to achieve our mission is through supporting families.

Supporting families

Having a premature or sick baby is often a frightening and overwhelming experience. Bliss provides a range of free advice, support and information to families, helping them to understand what is happening to their baby and offering a way for parents to talk to others who know what they are going through.

Our Family Support Team offers:

- A helpline for families providing information and support
- A service to put people in touch with other parents who have gone through a similar experience
- A comprehensive website containing information and useful contacts, as well as an interactive parent messageboard
- A wide selection of free information, both in print and online
- A network of local support groups
- Access to qualified counsellors.

How you can help

Without the support of our donors and volunteers, we would not be able to make a difference to the lives of babies born too soon, too small or too sick.

There are many ways that you could help, such as setting up a regular donation, being a volunteer on our helpline, becoming a case study for Bliss by telling your story in the media, or by campaigning for better neonatal care in your local area.

Useful organisations

Antenatal information

Action on Pre-eclampsia (APEC)

Information and support services.

† 020 8427 4217

e info@aptec.org.uk

aptec.org.uk

Antenatal Results and Choices (ARC)

Information and support during and after antenatal testing.

† 0845 077 22 90

arc-uk.org

National Childbirth Trust (NCT)

Antenatal support and breastfeeding advice.

† 0300 330 0770

nct.org.uk

Bereavement

4 Louis

Offers support and advice to families that have suffered the trauma of stillbirth or neonatal death.

† 0191 385 8066

e mail@4louis.co.uk

4louis.co.uk

Child Bereavement Charity

Leaflets, books and videos for the bereaved.

† 01494 568 900

e support@childbereavementuk.org

childbereavement.org.uk

Cruse Bereavement Care

Promotes the wellbeing of bereaved people.

† 0844 477 9400

e helpline@cruse.org.uk

cruse.org.uk

Sands (Stillbirth and Neonatal Death Charity)

Telephone support and groups for bereaved families.

† 020 7436 5881

e helpline@uk-sands.org

uk-sands.org

Lullaby Trust

The Lullaby Trust provides specialist support for bereaved families and anyone affected by a sudden infant death.

† 0808 802 6868

lullabytrust.org.uk

SIMBA Simpsons Memory Box Appeal

The Simpsons Memory Box Appeal is a fundraising site that supports families who have suffered the loss of a baby.

simba.workwithus.org

Breastfeeding equipment and support, and other practical items

Ameda

For Ameda personal breastpumps and accessories.

† 0845 009 1789

e helpline@ameda.co.uk

ameda.co.uk

Angelcare

Produces a range of sound and movement monitors as well as nappy disposal systems.

† 0845 009 1789

e helpline@babyhelpline.co.uk
angelcare-uk.co.uk

La Leche League

Breastfeeding help and information.

Helpline 0845 120 2918

laleche.org.uk

Mothercare

Produces a range of baby products including premature clothing. Available in store and online.

† 0844 875 5111

mothercare.com

Pampers

Produces specialist micro and premature nappies.

† 0800 328 3281

pampers.co.uk

Tesco tiny baby nappies

Produces a specialist range of nappies for premature babies.

† 0800 50 5555

tesco.com

UKAMB UK Association for Milk Banks

Offers informations on your nearest milk bank and also how to become a milk doner.

† 0208 383 3559

e info@ukamb.org
ukamb.org

UNICEF UK Baby Friendly Initiative

Leaflets, information and research about breastfeeding.

† 0207 375 6052

e bfi@unicef.org
unicef.org.uk

Counselling, support and advice

The Association for Postnatal Illness Helpline

The Association for Postnatal Illness Helpline offers information and support to mothers that may be struggling with postnatal depression

† 020 7386 0868

apni.org

Birth Trauma Association

Offers support to all women who have had a traumatic birth experience.
birthtraumaassociation.org.uk

Bliss Counselling Service

Aims to help you find a counsellor trained in the issue surrounding prematurity.

† 0500 618 140

bliss.org.uk

British Association of Counselling and Psychotherapy (BACP)

Provides a search facility to help you find a local counsellor or therapist.

† 01455 883 300

e bacp@bacp.co.uk
bacp.co.uk

Cry-sis

Support for families with excessively crying, sleepless and demanding babies.

† 08451 228 669

cry-sis.org.uk

Gingerbread

Information and support to lone parents through a network of local groups.

† 0808 802 0925

gingerbread.org.uk

Home-Start

Support for families with young children.

† 0800 068 6368

home-start.org.uk

NHS Pregnancy Smoking Helpline

Provides support to pregnant women who are struggling with Nicotine addiction

† 0800 022 4332

smokefree.nhs.uk

Parentline Plus

Offers support to anyone parenting a child.

† 0808 800 2222

familylives.org.uk

Patients Association

Campaigns to improve healthcare services and provides advice on dealing with problems or complaints.

† 0845 608 4455

helpline@patients-association.com
patients-association.org.uk

Relate

Offers advice, relationship counselling, and support face to face, by phone and online.

relate.org

Samaritans

Confidential counselling service.

† 0845 790 9090

jo@samaritans.org
samaritans.org.uk

Tiny Life

Northern Ireland's premature and vulnerable baby charity.

† 028 9081 5050

info@tinylife.co.uk
tinylife.org.uk

Disability and medical problems

Brain and Spine Foundation

Information on neurological disorders.

† 0808 808 1000

helpline@brainandspine.org.uk
brainandspine.org.uk

British Heart Foundation

† 0300 330 3311

heartmatters@bhf.org.uk
bhf.org.uk

British Lung Foundation

Support and advice as well as a network of Breathe Easy support groups.

† 03000 030 555

blf.org.uk

Cerebra

Foundation for brain-injured children and young people.

† 0800 328 1159

info@cerebra.org.uk
cerebra.org.uk

Cleft Lip and Palate Association

Information and support.

† 020 7833 4883

e info@clapa.com
clapa.com

Contact a Family

A charity for families of disabled children.

† 0808 808 3555

e info@cafamilly.org.uk
cafamilly.org.uk

Down's Heart Group

Support and information relating to heart conditions associated with Down's Syndrome.

† 0844 288 4800

e info@dhg.org.uk
dhg.org.uk

Down's Syndrome Association

Provides information and support to help people with Down's syndrome, their families and carers.

† 0333 1212 300

e info@downs-syndrome.org.uk
downs-syndrome.org.uk

NDCS

A national charity that is dedicated to creating a world without barriers for deaf children and young people.

† 0808 800 8880

e helpline@ndcs.org.uk
ndcs.org.uk

NHS Direct

Health information and self care advice.

† 0845 4647

nhsdirect.nhs.uk

RNIB

Offers support and advice to blind and partially sighted people in the UK.

† 0303 123 9999

e helpline@rnib.org.uk
rnib.org.uk

SCOPE

Support for cerebral palsy and related disabilities.

† 0808 800 3333

e response@scope.org.uk
scope.org.uk

Steps

Provides support for anyone affected by clubfoot, hip dysplasia and other lower limb deficiencies.

† 01925 750 271

e tim@steps-charity.org.uk
steps-charity.org.uk

Whizz Kidz

Offers a range of support and advice services for disabled children.

† 020 7233 6600

whizz-kidz.org.uk

Benefits and financial advice

Citizens Advice

Provides advice, information and details of your local bureau.

citizensadvice.org.uk

GOV.UK

Information and factsheets about benefits and other money topics.
gov.uk

Family Fund

Financial help for families of disabled and seriously ill children under the age of 16.

† 08449 744 099

e info@familyfund.org.uk
familyfund.org.uk

National Debtline

Free, confidential and independent advice about debt problems.

† 0808 808 4000

nationaldebtline.co.uk

Tax Credits Helpline

Provides advice to families on tax credits.

† 0345 300 3900

hmrc.gov.uk

Turn2us

Charity that helps people in financial need.

† 0808 802 2000

turn2us.org.uk

Working Families

Information and details on employment rights, childcare and flexible working.

† 0300 012 0312

workingfamilies.org.uk

Oxygen

Air Liquide (Homecare) Ltd

Regional oxygen suppliers

† 0800 637 737

uk.airliquide.com

BOC Medical/Vitalair

Information about where to get oxygen supplies.

† 0800 111 333

e bochealthcare-uk@boc.com
bochealthcare.co.uk

Travel and car safety

British Insurance Brokers Association

Insurance advice and products.

† 0870 950 1790

e enquiries@biba.org.uk
biba.org.uk

Child Accident Prevention Trust (CAPT)

The UK's leading charity working to reduce the number of children and young people killed, disabled or seriously injured in accidents.

† 020 7608 3828

e safe@capt.org.uk
capt.org.uk

Royal Society for the Prevention of Accidents (RoSPA)

Gives advice on purchasing, fitting and using car seats for children.

† 0121 248 2000

e help@rospa.com
rospa.com

Multiple births

Multiple Births Foundation

For information and support surrounding multiple births.

† 020 3313 3519

e mbf@imperial.nhs.uk
multiplebirths.org.uk

Twins and Multiple Births Association (TAMBA)

Helping parents to meet the challenges that multiple-birth families face.

† 0800 138 0509

e asktwinline@tamba.org.uk
tamba.org.uk

Further reading

Preemies: The essential guide for parents of premature babies

D Wechsler Linden, E Trenti, Paroli, M Wechsler Doron, 2010

Everything you need to know about premature birth, presented in easy-to-understand language for parents of premature babies.

ISBN 0-671-03491

An infant massage guidebook: For well, premature and special needs babies

M Ady, 2008

A guide to providing infant massage to your premature baby, with helpful instructions and diagrams

ISBN 978-1434340603

Your premature baby: The first five years

N Bradford, J Hellmann, S Lousada, 2003

A basic but informative book that provides new parents of premature babies with the essential information for the first weeks, months and years of their baby's life.

ISBN 978-1552976555

My baby sister is a preemie:

Helping kids heal

D M Amadeo, 2005

A lovely picture book for children who have a preemie sibling in the NICU.

ISBN 978-0310708674

No bigger than my teddy bear

V Pankow, 2004

From the view of a young boy, this book looks at circumstances children who have a premature-born sibling might encounter.

ISBN 978-0972846004

Sent before my time

M Cohen, 2003

A child psychotherapist's view of life on a neonatal intensive care unit.

ISBN 1-85575-910-1

Multiple births - A parents' guide to neonatal care

TAMBA and Bliss, 2011

A guide to special care from the Twins and Multiple Births Association.

Your premature baby and child

A Tracy and D Maroney, 1999

A tool for parents to guide them as they cope with the complex medical issues and long-term problems associated with prematurity.

ISBN 0-4251-6506-X

The premature baby book:

M Sears, R Sears and J Sears, 2004

Everything you need to know about your premature baby from birth to age one Offers easy-to-digest information and advice for parents coping with a premature baby.

ISBN 0-3167-3822-0

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