

# Your special care baby

A guide for families

[bliss.org.uk](http://bliss.org.uk)



**Bliss**

for babies born too soon,  
too small, too sick

## Important note to readers

This guide has been written to give you a greater understanding of special care and is intended to complement the medical and practical advice you receive from those involved in the care of your baby. It is written for parents of babies born moderate to late preterm and for babies born full term, who need a little extra care. It covers aspects of your baby's care and development – from the moment they are born until you take them home.

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

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# Introduction

Congratulations on the birth of your new baby - this is one of the most exciting things that can happen in a family. However, finding out that your baby is going to be born early or spend time in hospital can be a difficult and stressful experience.

Bliss, the special care baby charity, has put together this guide to help you, if you are in that position. The charity works closely with parents who know what it's like, and with doctors and nurses who look after babies in hospital, to give you accurate and reliable information.

The guide is written especially for parents and families of babies born a few weeks before their due date and babies born around their due date who may need to spend a little time in hospital.

It explains some of the common problems that might affect your baby, and the care and treatments that can help them get home safely and as soon as possible. Some parents have more than one baby and this guide also talks about looking after twins or more.

Your baby will most likely be cared for on a special care baby unit during their time in hospital. It's a new experience for most parents so you may not know what to expect, and this guide is a great introduction to all the important points. It offers a wealth of information about all the stages: the time before your baby is born, while they are in hospital, and when they go home.

Sometimes, even the most basic parenting tasks like feeding are a bit different if a baby is sick, so this guide also explains how you can look after your baby's everyday needs.

I am confident this guide will help you take your first steps on your journey through special care with your baby. If you'd like more support, Bliss has a helpline, a website and an online messageboard. They can provide confidential and free advice on any subject.

## **Dr Elaine Boyle**

Consultant Neonatologist, University Hospitals, Leicester NHS Trust

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## Finding your way

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## About this book

All parents awaiting the birth of a child hope for a safe and straightforward pregnancy. So it might come 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 will spend some time in a neonatal unit.

This guide 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 as all parents do, for example, 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 guide, including parents of babies who were born early 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 exists to ensure that all babies born too soon, too small or too sick in the UK have the best possible chance of survival and reaching their full potential.

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

**Our family support services offer:**

- A helpline for families providing information and support - call **0500 618140** (Monday - Friday 9am - 9pm).
- A support service that puts 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.



Every baby's situation is different. This section of the guide can provide a starting point if your baby is expected to arrive early, has been born prematurely, or is sick in hospital.

## If your baby is coming early

You might have been told there's a chance that your baby could arrive early.

Many times when a baby is born too early, the reason is never known. However, some things can increase the risk of this happening:

- Twins and triplets are more likely to be born early.
- High blood pressure in the mum (called pre-eclampsia or PET) accounts for around one in ten premature births. Sometimes the baby has to be delivered early if the mum's blood pressure stays dangerously high.
- About a third of premature births occur for no apparent reason. Often they happen with little or no warning. One cause might be an infection in the sack that surrounds the baby in the womb.
- Sometimes the waters break early, starting labour.
- In a few cases, an antenatal screening test might show that the baby is not growing well in the womb. Sometimes this is because there is not enough blood flowing to and from the placenta.
- 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.

If the midwives and doctors believe you are likely to give birth before 35 weeks, they will offer you a drug that will help your baby's lungs mature more quickly, and work better after the birth. If you are in labour they may also give you a drug to delay the birth for a day or two. Sometimes if they are concerned your baby is stressed they may also recommend a caesarean section.

When their baby is born early, parents often feel guilty, and wonder if they should have done something differently. But most of the time, it can't be prevented. Try not to blame yourself, and instead focus your energy on taking good care of your baby.



“ Our two children were both born at 34 weeks. With our first we were so worried and scared of what this would mean, but the staff were amazing. They told us everything we needed to know, what the monitors were showing and what the terminology meant. We were offered lots of info on Bliss and also given a contact name for us to phone and talk to someone about how we were feeling. ”

David & Danielle, parents to Mia and Carlo, born at 34 weeks

## Medical language: prematurity and birthweight

Medical language to describe premature babies - who are sometimes referred to as preterm - is 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):

**Term:** Born after at least 37 weeks in the womb

**Moderate to late preterm:** 32 - 37 weeks

**Very preterm:** 28 - 32 weeks

**Extremely preterm:** Less than 28 weeks

**Low birthweight:** Born weighing less than 2,500g (5lbs)

**Very low birthweight:** Less than 1,500g (3lbs)

**Extremely low birthweight:** Less than 1,000g (2lbs)

## If your baby was born early

Much of what you may have heard about prematurity may relate to babies who were born very early. They are more likely to face serious medical problems, which can be worrying to read about.

But the situation is a lot different for babies who are born just a few weeks early. Each week they have to grow and develop in the womb makes them stronger.

However, being born a few weeks early (sometimes called 'moderate to late preterm') can still have important effects on a baby's health. For example, breathing problems, jaundice and low blood sugar are more common than in babies born at term. They also need more protection from infections or viruses like the common cold. You can read more about this on page 62 of this guide.

Being born a few weeks early can also affect a child's behavioural, social and educational development in the longer term. You can speak to your child's

GP and health visitor and ask them to follow your child's growth carefully, and to check they are developing as expected with milestones such as walking, co-ordination and communication.

You may be feeling anxious and concerned at this moment, but you should be reassured knowing that by being cared for by the doctors and nurses in hospital, your baby has the best possible chance of overcoming this difficult start and reaching their full potential.



## If your baby needs extra medical care

The information in this book can also help you care for your baby if they were born at term and they need to remain in hospital because of a medical condition, an infection or a serious illness.

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

One frequent reason for needing hospital treatment is jaundice. This is a condition where a yellowish pigment called bilirubin builds up in the body. This is common, even in otherwise healthy babies. Your baby might need light therapy (also called phototherapy) for jaundice. See page 40 for more information about jaundice.

**“ I found the transition from intensive care and high dependency down to special care quite overwhelming. I felt lost for the first couple of days. I was so delighted she had moved down a level, and keen to get involved. But I was scared to touch her, and silly things like not knowing where things were had me in tears all the time. The staff were amazing. No matter how busy they were they always had time for you. ”**

**Niki, mum to Lucy, born at 40 weeks weighing 11lbs 3oz**

Other babies may need help with breathing problems. These can happen for several reasons, and are often due to a slow clearing of fluid from the lungs, a problem which resolves relatively quickly.

Perhaps your baby has gone home, but is now back in hospital. Returning to hospital is more likely to happen to premature babies, compared to babies born at term. Although this is distressing, your baby will only be in hospital for as long as necessary.

If you are feeling worried or upset, you may want to talk to another parent who has gone through a similar experience. Call the Bliss helpline on 0500 618140 and ask about how we can put you in touch with a Bliss volunteer.

## Family focus

Our daughter was born after a quick and traumatic labour at 33 weeks. My pregnancy had been problem free and I had no idea I was at risk of preterm labour. The first few days after her birth were a blur, and looking back I was in a state of total emotional and physical shock (I had also lost a lot of blood during delivery). I remember feeling helpless, overwhelmed and nothing had prepared me for seeing my little first born baby in an incubator all hooked up to wires and tubes and beeping machines. I felt so guilty that she had come into the world early and needed help with breathing, fighting infection, jaundice and feeding. My husband was my rock and stepped up to do those things for her that I couldn't, including changing one of her first nappies through the incubator port holes.



Having to leave our daughter in the hospital when I was discharged several days later was the hardest thing I've done in my life. It went against every instinct but I learned to trust the staff there.

There was one nurse in particular who had had her own 33 week premature baby. She was fantastic as she could really understand how I was feeling, and also reminded me to do the essential things for myself too, like have a hot meal and short break from the ward environment. The Bliss website, forums, and leaflets on subjects such as breastfeeding premature babies were also really helpful. Finally, after what felt like a very long four week stay in hospital we brought her home on Christmas Day. Best Christmas present ever!

I am now expecting our second baby, a boy this time, and am at risk of preterm labour again. I am getting a lot of extra monitoring and support from the hospital though, and feel better informed and equipped to deal with things following on from our experiences with our daughter.

**Julie, mum to Kaitlyn, born at 33 weeks**

A newborn baby is lying in a hospital bed, wearing a white and green patterned onesie and a nasal cannula. A man in a red shirt is holding the baby. The background is a hospital room with medical equipment.

# About neonatal care

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The first time you see your baby in the special care baby unit can be distressing. They may be surrounded by lots of equipment that looks frightening. Other babies on the unit may seem fragile. It might all feel quite overwhelming. It helps to remember that all the technology is there to protect and support your baby.

Having a premature or sick baby can be traumatic, but all the staff members know you are under stress and they are there to help you, as well as your baby. Having some information about the unit can also help you feel more confident and in control, and parents say they really appreciate this. So this section explains how neonatal care is provided, and what you might expect.

## Levels of care

There are different types of neonatal units in the NHS, and they are classified according to the level of specialist care they offer. Your baby will be in the unit that best meets their current needs. The unit might not always be in the hospital that is closest to your home, or where your baby was born.



Watch our short video clip about neonatal care:  
[bliss.org.uk/video1](https://bliss.org.uk/video1)

### Level 1 Special care baby unit (SCBU)

This is for babies with more straightforward needs, including:

- Monitoring of their breathing or heart rate.
- Additional oxygen.
- Tube feeding.
- Light therapy for jaundice.

Your baby might also be in a special care baby unit if they are recovering after an operation or illness.

### Level 2 Local neonatal unit (LNU)

Babies who need a higher level of medical and nursing support are cared for here. Their needs might include:

- Short term intensive care.

- Care during short periods where they stop breathing (called apnoea).
- Breathing support given through their nose (CPAP, or continuous positive airway pressure).
- Feeding through a drip (parenteral nutrition).

### Level 3 Neonatal intensive care unit (NICU)

This is the level of care for babies with the highest support needs. Babies are cared for here when they:

- Need breathing support given through their windpipe (a ventilator).
- Have severe respiratory disease.
- Need or have just had surgery.

### Transitional Care

This is where your baby is in hospital but you provide much of the care. It means your baby is well enough to stay with you, with support from the hospital staff. Many babies born premature, or babies with jaundice or feeding problems, receive care in this way. This might be on the postnatal ward, or in a room on the neonatal unit. If your baby has been receiving specialist care, they might be moved to transitional care when they are almost ready to go home. This gives you a chance to become your baby's main carer, with help at hand from staff when you need it.





## Staff – who's who

The team on the neonatal unit provides care for your baby 24/7. You won't always see the same people every day because they work on a rota. The people you are likely to see include:

- Neonatal nurses, who spend the most time with your baby.
- The nurse in charge, usually called the nurse manager or the ward manager.
- The consultant, who is the senior doctor in charge of your baby's medical care. They supervise a team of junior doctors who will also treat your baby.
- Other specialist doctors, such as surgeons, may also be involved in your baby's treatment.

Other professionals may help with your baby's care, including physiotherapists, radiographers, pharmacists, dietitians, speech and language therapists, occupational therapists and counsellors.

Social workers, who may not be based at the hospital, can help you with practical things like claiming benefits and your rights at work.

Every hospital has a Patient Advice and Liaison Service (PALS). This can give you information about the hospital and your rights. The service is confidential and can also help if you have a complaint or a problem that you can't sort out yourself with the neonatal team.





## 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. Each unit works differently, but there are standard policies that apply in most hospitals.

### Staff schedules

The unit runs on a schedule and staff work in shifts, coming on duty and going home at set times. The handover between shifts can be a busy time on the unit.

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.

### 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 doctor 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 or recorded electronically. 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 or at the bedside. These medical notes are protected by laws to guard confidentiality, so you may need to make a formal request to see them.

## Protecting against infections

Babies in the neonatal unit are vulnerable to infections so there are strict policies to protect them. The nurses on your unit can explain the details to you.

Everyone entering neonatal units must wash their hands and forearms with a special disinfectant and, after drying, apply the sanitising hand gel provided.



Visitors should stay away if they have a cold or the flu, a tummy bug, whooping cough, measles or chickenpox. It's hard but this applies to your baby's brothers and sisters, too.



Watch our short video clip about visiting your baby and protecting against infections about neonatal care:

[bliss.org.uk/video2](https://bliss.org.uk/video2)

## Visiting

The unit will be locked for security, and visitors usually need to be let in by the staff.

Each unit has its own visiting policy. Your baby's unit may have set visiting hours, and ask you to limit the number of people. This allows the babies to get enough rest and lowers the risk of infections. Sometimes there is not much space and the staff need room to work safely.



Some hospitals allow brothers and sisters to visit and if you can, it's important to bring your older children to see the baby in hospital. 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 your baby a present or make cards and paintings to hang near your baby's cot.

## Privacy

It's an emotional time when your baby is in hospital, and privacy for you and your family is important. Most units will:

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

There should also be a sitting room nearby for parents to relax and a small kitchen for making tea and snacks. Some units offer accommodation to stay overnight somewhere near your baby.



## Peace and quiet

Unfortunately, hospitals are not very quiet places. Staff and visitors come and go, there are tests and scans and medical procedures, beeps and alarms are sounding all the time.

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.
- Protecting them from loud or continuous noise from equipment.
- Keeping conversations and telephones at a quiet level.
- Scheduling quiet times for babies and parents.
- Asking visitors to turn off or silence mobile phones.

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

## Family focus

I had a healthy normal pregnancy and labour but when Daniel was born at full term, our happiness soon turned into our worst nightmare. When he was born we were so happy, crying tears of happiness and joy – I couldn't wait for a cuddle. But I knew something was wrong. No cries. No movement. He was resuscitated and taken to intensive care.

My midwife came back in, gave me a hug and took me down to see my baby. He was covered in tubes and all I could hear was beeping from different machines. I have never felt a feeling like I felt when I saw him in his incubator. I felt like the whole world was against me, like it was just me suffering, like nobody else could feel the way I felt. Then when I saw my partner sobbing in the hall outside with his head in his hands, my heart sank. I realised it's not just affecting me; everyone's feeling bewildered.



The doctor said he had hypoxic-ischaemic encephalopathy (HIE). This is a lack of oxygen and blood to the brain, so he was having a cooling treatment. We had never heard of HIE, or cooling. We were so scared.

After 72-hours of cooling, the team caring for him began the warming up process that took nearly 24-hours. This was the most crucial part, where the monitoring of his progress was very important. His medication intake was decreased bit by bit, he began to come round and they moved him first to high dependency and then to the special care unit.

He had his eyes and ears tested and an MRI, and I took him home the following day. Being at home after two weeks, I thought we would be overjoyed but realising there's no nurses or doctors on hand to help was very scary.



Daniel is doing fantastic at seven months old. I am thankful everyday for my beautiful baby boy and the whole thing still seems quite surreal. As much of a bad experience it was, it made me realise how precious life is, and I met some amazing people in special care and I will treasure the memories.

**Tanya, mum to Daniel, born at term**



## You, your family and your baby

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Having a child in the neonatal unit is a very emotional time, and this section of the guide explains common feelings you might expect, who can help, and how you can build a strong bond with your new baby.

## Dealing with emotions

Having a premature or sick baby can come as a shock for any parent, even if your child is not extremely early, tiny or ill. Your baby might have a good birthweight and medical outlook, but for you as a parent, the stress is still there.



You do have a lovely new baby – which is something to celebrate – and there is a lot you can do to take care of them, as this guide will explain. You'll also find there are many people who can help, if you want support.



Watch our short video clip about dealing with emotions:  
[bliss.org.uk/video3](https://bliss.org.uk/video3)

## Be kind to yourself

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. Take care of the basics, like eating well and getting enough sleep. Stay in tune with your partner and support each other. And try talking about your feelings, to someone who understands.

## Bonding with your baby

Being separated from your baby, even for a little while, can be really distressing when they are unwell.

Once you're together, it might not be possible to hold them right away, or for very long.

But even when your baby is in special care, there are many ways to build a strong bond – and feel more in control as a parent.



### What you can do for your baby

These are all ways you can let your baby know they are safe and sound, with their mum or dad nearby.

- Become involved with feeding your baby as soon as possible (see page 28).
- Try Kangaroo Care. This means holding your baby against your chest, skin-to-skin (see page 34). Ask the nurse to show you the best way to do this.
- Talk, read or sing to your baby in a quiet voice.
- When your baby has a medical procedure or is upset, you can soothe them with Comfort holding (see page 32). Ask the nurse, the physiotherapist or the occupational therapist to show you how.
- Ask the nurses when you can change your baby's nappies, and wash and dress your baby.
- Let your baby get to know their brothers and sisters by having them visit.



## Where to find help

Having a baby in special care can feel like a lonely time, even if you have family and friends to rely on. The doctors and nurses know you are stressed and they are there to listen and help.



Watch our short video clip on where to find help:  
[bliss.org.uk/video4](http://bliss.org.uk/video4)

Talking to other parents can be an enormous relief, because they understand what you're going through. Bliss offers a network of volunteers for families with a premature or sick baby. The support network provides everything from one-to-one support, to group meetings, social events, family fun days and fundraising.

To find out what's available in your hospital and community, ask your baby's nurse, call the Bliss helpline or check the Bliss website – you'll see the details below.

If you're spending a lot of time at the hospital, social media can be a great source of support. You are very welcome to join the parents' messageboard on the Bliss website, or visit our facebook page.



[bliss.org.uk/messageboard](http://bliss.org.uk/messageboard)



[facebook.com/Blisscharity](https://facebook.com/Blisscharity)



[@Blisscharity](https://twitter.com/Blisscharity)

### Bliss is here to help

Call the Bliss helpline on 0500 618140, or go to [bliss.org.uk](http://bliss.org.uk) for information, support and advice.



# Caring for your baby

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Every parent is a bit nervous about caring for a new baby, especially if it's their first child. When your baby is in hospital it's even more daunting, but please be reassured that you can do a lot for your baby - and because you're their mum or dad, you can do it best.

## Parents in charge

Many parents of special care babies say they feel helpless when their child is in hospital. It can feel like your role as a parent has been taken away, and like you have no control.



It is important to remember that you are still your child's parent, there to look out for them and make the best choices for them. You can help your child feel safe and comforted, and take care of many of their practical needs too. The nurses on the unit can teach you what to do, and as you get used to caring for your baby, your confidence will grow. Being closely involved in their care helps you build a strong bond with your child.

**“ I used to chat to her all day long, I'd tell her what I was doing and what we would do when we went home. I'm sure I drove everybody mad, but she always reacted to my voice. ”**

**Emma, mum to Evelyn and Oliver, born at 34 and 33 weeks**

## 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.

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

The doctors and nurses will work with the whole family when they are looking after 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 practical 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 give you confidence, strengthen your relationship with your baby, and help them develop into a healthy and happy child.



## Feeding your baby

Before your baby was born, you probably dreamed about what it would be like to hold and feed them. When your baby is in the unit, that dream might seem very hard to reach. But don't give up. You can still help your baby make a good start with feeding, and they will develop at their own pace.



Watch our short video clip about feeding your baby:  
[bliss.org.uk/video5](https://bliss.org.uk/video5)

### Benefits of breast milk

Breast milk has so many health benefits for your baby.

Breast milk provides antibodies that protect against bacteria and viruses. Formula milk does not have this advantage.

Mums transfer protective antibodies to their baby in the womb during the last three months of pregnancy. This process is interrupted when a baby is born early and this is one reason why premature babies can be more prone to infections - and why breast milk is so beneficial. It also helps boost your baby's immune system.



It is also rich in nutrients, special fats and hormones that help your baby to grow and develop during the vital early weeks after birth. Breast milk is also easy to digest and absorbed more easily than formula milk.

Breastfeeding is good for your health. It can also help to build a strong bond between you and your baby.

### Getting started

Maybe it wasn't possible to put your baby to the breast right after giving

birth, but try not to get discouraged. If your baby is not ready to feed from the breast right now, you can provide milk by expressing. It is a skill that can take time to learn, and the staff looking after your baby can help with this.

If you choose to breastfeed, you should express your milk as soon as possible after giving birth and at regular intervals. Breast milk can be frozen and stored until your baby is ready for it.

The first milk that new mums produce is called colostrum. Don't expect a large volume because colostrum comes in small amounts. Colostrum is thicker and can be more yellow in colour than breast milk. It contains a rich mix of proteins, including antibodies that can help protect against infections. Hand expression is the simplest way of expressing colostrum. For information on hand expression techniques, see the Bliss booklet *The best start: A guide to expressing and breastfeeding your premature baby*.

Even if you have decided against breastfeeding, you could express your breast milk for a little while and see how it goes.

In premature babies, the co-ordination of sucking, swallowing and breathing needed for feeding is not established until about 34 to 36 weeks' gestation (how long they have been in the womb).

Your baby can have your expressed breast milk through tube feeding. They can also have formula milk this way, or breast milk that has been donated to a hospital milk bank. Ask the nurses when you can give your baby tube feeds. They will show you how to do it, and it's a great way to get involved in your baby's care. When your baby is strong enough, you can give them a cuddle while they have the feed. Holding them skin-to-skin is called Kangaroo Care (see below), and it's a very helpful way for your baby to get ready for breastfeeding.



### Who can help with breastfeeding?

- Nurses on the neonatal unit
- Breastfeeding co-ordinators
- The Bliss helpline
- Other mums on the unit
- Speech and language therapists
- Breastfeeding support groups

## Establishing breastfeeding

Almost all babies born early, or term babies who've been unwell, will take time to learn breast or bottle feeding. It's easier for these babies to suck at the breast than the bottle. It's important to ask for help if you or your baby is having difficulties. You are not alone and lots of help is available.



Getting some advice from a knowledgeable person, who understands what you're experiencing, can really make a difference and help you succeed with breastfeeding. So if you're worried about your baby's feeding, you can ask your health visitor, phone the Bliss helpline, or contact the breastfeeding groups listed on our website [bliss.org.uk/usefulorgs](https://bliss.org.uk/usefulorgs).

Breastfeeding also promotes your child's development and can help strengthen the bonding process between mum and baby.

### Bliss is here to help

You'll find detailed advice on expressing in the Bliss guide *The best start - expressing and breastfeeding your premature baby*. It's available to download from our website at [bliss.org.uk](https://bliss.org.uk)



## Feeding twins or more

About half of twin pregnancies result in premature birth. So if you are expecting more than one baby, it helps to think ahead about how this might affect feeding. Before the birth, you can start gathering information about nutrition, and get advice on the practical aspects of feeding your babies.

However, you needn't be anxious about this. While it's obviously true that feeding two or more babies takes more time and organisation than feeding one, it can be just as enjoyable and fulfilling.

It can be a nice family event if you ask dad, relatives and friends to help. They can position the babies, wind them, change nappies and give cuddles.

You'll find practical advice on feeding multiple babies – including diagrams on breastfeeding positions – in the booklet we've produced with the Twins and Multiple Births Association (TAMBA). It's called *Multiple births: A parents' guide to neonatal care*, and it's available from our website at [bliss.org.uk](http://bliss.org.uk) or call the Bliss helpline on 0500 618140



## Comfort holding

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. It also helps your baby feel safe, especially if they are stressed at times by their experiences in hospital.

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: the basic steps

Ask the nurse to show you how to do comfort holding. Here are the basic steps:

- Before you start, remove watches and jewellery, pull your sleeves up to the elbows, and wash your hands and lower arms.
- 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 your hands and the baby.
- 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.





Comfort holding can:

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

When you finish comfort holding, move your hands away from your baby slowly so they aren't startled.

This is a way of communicating your love and reassurance to your baby and sensing 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 soothing.



Watch our short video clip about comfort holding:  
[bliss.org.uk/video6](http://bliss.org.uk/video6)



## Kangaroo Care

Many babies are well enough to receive Kangaroo Care when you visit them on the special care unit. It is a way of holding your baby, skin-to-skin on your chest.

It's much more than a cuddle. Kangaroo Care has many physical and emotional benefits for your baby if they were born early and even if they were born at term. It helps establish breastfeeding, 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.

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.

If your baby is happy, you can continue Kangaroo Care for as long as you are both comfortable.

Sit back, relax and enjoy.



Watch our short video clip about Kangaroo Care:  
[bliss.org.uk/video7](https://bliss.org.uk/video7)

## Kangaroo Care: the basic steps

Here are the basic steps for having skin-to-skin time with your baby:

- Kangaroo Care is based on direct skin-to-skin contact so usually, your baby wears just a nappy. 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 their head is well supported.
- Hold a mirror up to your baby's face so you can see them while you are doing this.



## Your baby's daily cares

As soon as your baby is well enough, it is ideal if you start to look after their daily needs, just like any parent. 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.

### 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.

### Bathing

You should be able to give your baby their first bath, with help from the nurse. This may feel quite daunting, but you can do it with some support from the staff. Bathing can be an enjoyable experience for both you and your baby.





## Your baby's medical care

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Babies who are born even a few weeks early are more likely to need hospital care, compared to babies who are born at term. Most of the time, they just need to be monitored for a short period. Or your baby may need some extra treatment.

This section of the guide gives you basic information about some of the medical conditions that most commonly affect babies born who are born a little early or who need to spend some time in hospital. It also explains effective steps you can take, to help your baby feel more comfortable during and after medical procedures they might need.

## Breathing problems

Breathing problems can happen to babies born at term, as well as premature babies. They often breathe more quickly, may make a grunting noise while trying to breathe, and have difficulty feeding.

Compared to babies born at term, those who arrive a few weeks early are more likely to experience breathing problems. This is because their lungs have not had time to fully develop before they were born. The risk decreases as the baby spends more time in the womb. For example, a baby born at 36 weeks has a lower risk of breathing problems than a baby born at 34 weeks.

If your baby has breathing problems, their care and treatment will depend on the cause and their individual needs. It may include oxygen, given through two fine tubes placed in your baby's nose (nasal cannula). They may also have antibiotics and intravenous (IV) fluids.

Some babies need additional help with breathing. Often this support is provided by continuous positive airway pressure (CPAP). Air and oxygen flow 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.

A few babies will have more serious problems and might need the help of a ventilator. A ventilator blows air and oxygen gently into your baby's lungs, through a tube that is placed in your baby's windpipe.

If your baby requires this type of care you may find it helpful to read the *Bliss Family Handbook*, which includes a more detailed section on breathing problems and medical care.





## Intravenous (IV) drips

Your baby may have a fine tube (called a drip or cannula) inserted into a tiny blood vessel. The IV is usually placed in a hand, foot, arm or leg. These tubes are there to give fluids or medication, such as antibiotics. They will be removed as soon as possible.

## Jaundice

Jaundice is quite common in all newborn babies, and even more so in babies born early. It affects about eight in ten premature babies.

Jaundice is caused by a build-up of a normal chemical in the blood, called bilirubin. It is produced naturally when red blood cells are broken down by the liver. In some babies, the liver is still developing and takes a while to function properly. As a result, excess bilirubin remains in the body, causing a yellow colour in the skin and whites of the eyes.



Most of the time newborn jaundice clears up on its own. But if bilirubin builds up to very high levels in the blood it can be serious, so this is monitored closely with blood tests.

If the levels are too high, your baby may need a treatment called phototherapy. The bilirubin is broken down by blue phototherapy light, and then passed out of the body in the baby's urine.

Usually, the baby is placed naked under a phototherapy lamp or on top of a light blanket. Your baby might need eyeshades to protect their eyes from exposure to the light.

## Low blood sugar

Our bodies are fuelled by glucose, which is a type of sugar. It circulates in the blood and it's especially important for the brain to have a steady supply. In the womb, babies get glucose from the mum and after the birth, they get it from breast milk or formula milk.

Having low blood sugar can happen to any baby but it occurs more often in premature babies, including those born just a few weeks early. It's important to recognise and treat it quickly, especially to protect the baby's brain.



Other possible symptoms of low blood sugar include:

- A pale or bluish colour
- Being cold, and unable to warm up
- Seeming listless, floppy and unresponsive
- Not feeding well
- Vomiting
- Breathing problems.

If you notice any of these symptoms in your baby, tell staff on the unit right away

## Low body temperature

Babies who arrive a few weeks early may have trouble regulating their body temperature. They have not fully built up the layer of fat that a newborn baby needs to keep warm.

If this is a problem for your baby, they may be placed in a special cot called an incubator, to keep them warm.

Some incubators are closed boxes with hand-sized holes on the side. Other incubators have open tops and an overhead heater. This style makes it easier for you, the doctors and nurses to reach your baby.

It is also worth noting that having Kangaroo Care (skin-to-skin) time with your baby can help protect from low body temperature.

**“ I remember feeling helpless, overwhelmed and so guilty that she had come into the world early and needed help with breathing, fighting infection, jaundice and feeding. However there were moments in our journey which I look back on now as the ‘silver linings’. The first time I got to hold her, when she was two days old, is the happiest memory in my life. Then there were all the lovely sessions of Kangaroo Care I got to do after that. ”**

**Julie, mum to Kaitlyn, born at 33 weeks**

## Pain relief

As a parent, you do not want to see your child suffer in any way. That's why this section explains the many ways you can help your baby cope with pain and keep their distress to a minimum.

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

Very simple steps can help a lot.

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.

### Pain relief: things you can do

Things you can do to help soothe your baby's pain include:

- Breastfeeding your baby during the test or treatment.
- Putting a little bit of expressed milk on your baby's tongue.
- Comfort holding
- Kangaroo Care.
- Watching your baby for signs of distress, and alerting the staff that your baby might need more pain relief.



# Family matters

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## Financial support

Having a baby in special care brings expenses like travel costs, parking, more childcare, and missed days at work.

For these reasons, many parents come to Bliss and say they are worried about money. Although we can't provide financial support, we can tell you where to find information and advice.

Claiming benefits can boost your family's income at this difficult time, so it's important to make sure you're receiving all the assistance and entitlements available.

Some help is available to most families, even if you are working.

Some of the main benefits for families include:

- **Child benefit**  
A regular payment if you are raising a child. You may have to explain that your baby has arrived early.
- **Child tax credit**  
A regular payment for families with children. Despite the name, it is not actually deducted from your tax. This benefit is paid directly to the person caring for the child and the amount depends on your family circumstances and your income. It is in addition to Child Benefit.
- **Statutory maternity pay (SMP)**  
Helps mums take time off work when they have a baby. It's a temporary



payment until you go back to your job. You apply through your employer and, if you qualify, you get it through your wage packet. The payment will be taxed, just like income. If you're not sure whether you want to go back to work, you can still ask for SMP. You do not have to pay it back if you do not return to work and it is the legal minimum amount your employer has to pay. Your employer may offer additional maternity benefits.

- **Maternity allowance**

If you don't qualify for SMP, you might be able to get Maternity Allowance. This is a temporary benefit, paid in the late stages of pregnancy and while your baby is young. The money goes straight into your bank account. You do not have to pay tax or National Insurance on it.

- **Statutory paternity pay**

This benefit helps dads take time off work when their babies are born. You apply through your employer. If you qualify, you receive it through your wage packet. The payment will be taxed, just like income. In addition to Statutory Paternity Pay, you might also be entitled to unpaid time off work to deal with family emergencies or to care for your child.

You may also get help from other benefits if your child has a disability, or if you're on a low income.

Many benefits are the same across the UK but others are different if you live in Scotland, Wales and Northern Ireland.

Although the information in this section is correct at the time of writing, benefits are always subject to change. For the latest information on benefits, go to the main government website [gov.uk](http://gov.uk)

### Bliss is here to help

You can find more information about family finances from the Bliss helpline. They are also many organisations to give you free advice, listed on our website [bliss.org.uk/usefulorgs](http://bliss.org.uk/usefulorgs).

## On a low income

The benefits system is complicated and it can help a lot to have advice from an expert. This will make it easier to apply and ensure that you get the benefits you're entitled to.

Hospital staff, the Patient Advice and Liaison service (PALS) or Sure Start (a government programme for parents, children and local communities) might know about people who can help you claim benefits. This could be a social worker, your local Council or the Citizens Advice Bureau, for example.

Try not to feel embarrassed about asking. Professionals know that having a sick baby causes hardship, and pointing the way towards these services is part of the care they provide for your family.

Another source of help is the Family Fund. It's a charity, supported by government and donations, which gives grants to families with disabled children. Find out more at [familyfund.org.uk](http://familyfund.org.uk) or phone them on 08449 744 099 (your phone company may charge you for this call).

## 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. Encourage your child to talk about the new baby, and involve them by taking photos or drawing pictures they can share with other family members.

The arrival of a new sibling 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 as important as ever.

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.





## Help from family and friends

Family and friends can be such a big help at this time. They can provide a listening ear and a hug when you need it most. If you have other children, familiar relatives and friends can be reassuring company for them.

When people ask how they can help, it's useful to have a few ideas ready. Here are some possibilities:

- Babysitting.
- Doing school runs.
- Being on call for emergency child care.
- Driving you to the hospital.
- Shopping.
- Cooking.
- Running errands.
- Doing housework.

If you are getting a lot of calls and messages from people who want to know how the baby is doing, a friend or relative can take on the job of updating everyone. Ask them to set up a Facebook page, or give updates on Twitter.

All of this assistance takes some of the strain off you, and gives you more time and energy for your baby and your partner. And when your family and friends are anxious, they might feel better, too, if they can do something to help.



# Preparing to go home

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It's the news you have been waiting for - soon your baby will be ready to go home. Thinking about this can make you happy and anxious at the same time, though. On the neonatal unit, there are always people around to help and answer questions. You're never alone if you are worried or just want a chat.

When it's time for their baby to go home, some parents feel anxious. Remember, though, your baby is coming home because they are well enough to leave the hospital. The staff are confident that you and your partner can look after your baby at home. You'll also have support from your GP and health visitor, and of course you can always call us at Bliss for information and support.

## When the time is right

To decide if your baby is ready to go home, the staff on the unit will assess several steps in your baby's progress. It depends on whether:

- Your baby can control their own temperature now.
- How well they are feeding.
- How well your baby's lungs are working.
- If their care can be continued outside the unit, without constant professional support.



First you may need some training and preparation from the staff. For example, you might need to learn about giving your baby medications.

It's also important that the right support is arranged, in case you need help once your baby is home. Well before the time arrives, staff should discuss a clear discharge plan with you. Everyone should agree on what care your baby and your family will need. You should know which professionals will support you, and how to contact them.

If you have questions or concerns, make sure you discuss them with the staff or discharge team.

## More than one baby

When you have twins or triplets, sometimes one baby will be ready for discharge before the other/s. Of course, this can be very difficult for parents, both on an emotional and practical level, with visiting and caring for two or more babies in different places.



Your babies will only be separated if there is likely to be a long period between them being ready for discharge; if it's a matter of a few days, it would be reasonable to expect them to come home at the same time. If one of your babies does need to stay at the unit, staff will support you with your visiting plans, and your other baby/babies will be able to visit and room in with you when you need to stay overnight.

It's crucial to continue bonding with the babies or baby that remains in hospital, and the best way to do this is with skin-to-skin contact when you are visiting. You can also leave a photo near the baby's cot, and take one home for the rest of the family.

If you need information or just someone to talk to, you can contact Bliss or the Twins and Multiple Births Association (TAMBA). See page 67 for contact details.

## Rooming in

Before going home, all hospitals should offer the chance to 'room in'.

This means that for a few days you stay in a room on or near the unit and care for your baby overnight. However this may not be the case if your baby's stay was for a very short time.

It's a good idea to use this opportunity if you can. It will give you more confidence, while the unit staff remain on hand to help you if necessary. It will also show you whether there are any gaps in your knowledge, so you can ask for information and advice on specific aspects of caring for your baby.



If you will be expressing or bottle feeding your baby at home, it is helpful to bring in the bottles and teats so that your baby can start to get used to them.

You can help your baby get ready for the transition by introducing some sights, smells and sounds of home. You could bring in a brightly coloured or musical toy for your baby's cot (check whether it's appropriate with the staff first). Another idea is to bring something that smells of home, such as a special blanket. This way, once your baby arrives home, they will be comforted by familiar objects and smells.



Watch our short video clip about rooming in:  
[bliss.org.uk/video8](https://bliss.org.uk/video8)

## Learning first aid

If an emergency happens, giving resuscitation fast can save a baby's life. So you may be offered some training on infant first aid, before you take your baby home. The staff will teach you what to do if your baby chokes or stops breathing. You'll also feel more confident once you have these skills.

### Bliss is here to help

Bliss provides a resuscitation training DVD, which you can request from staff on the unit. You can also order a free copy from our website at [bliss.org.uk](http://bliss.org.uk)

### Checklist for going home

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.

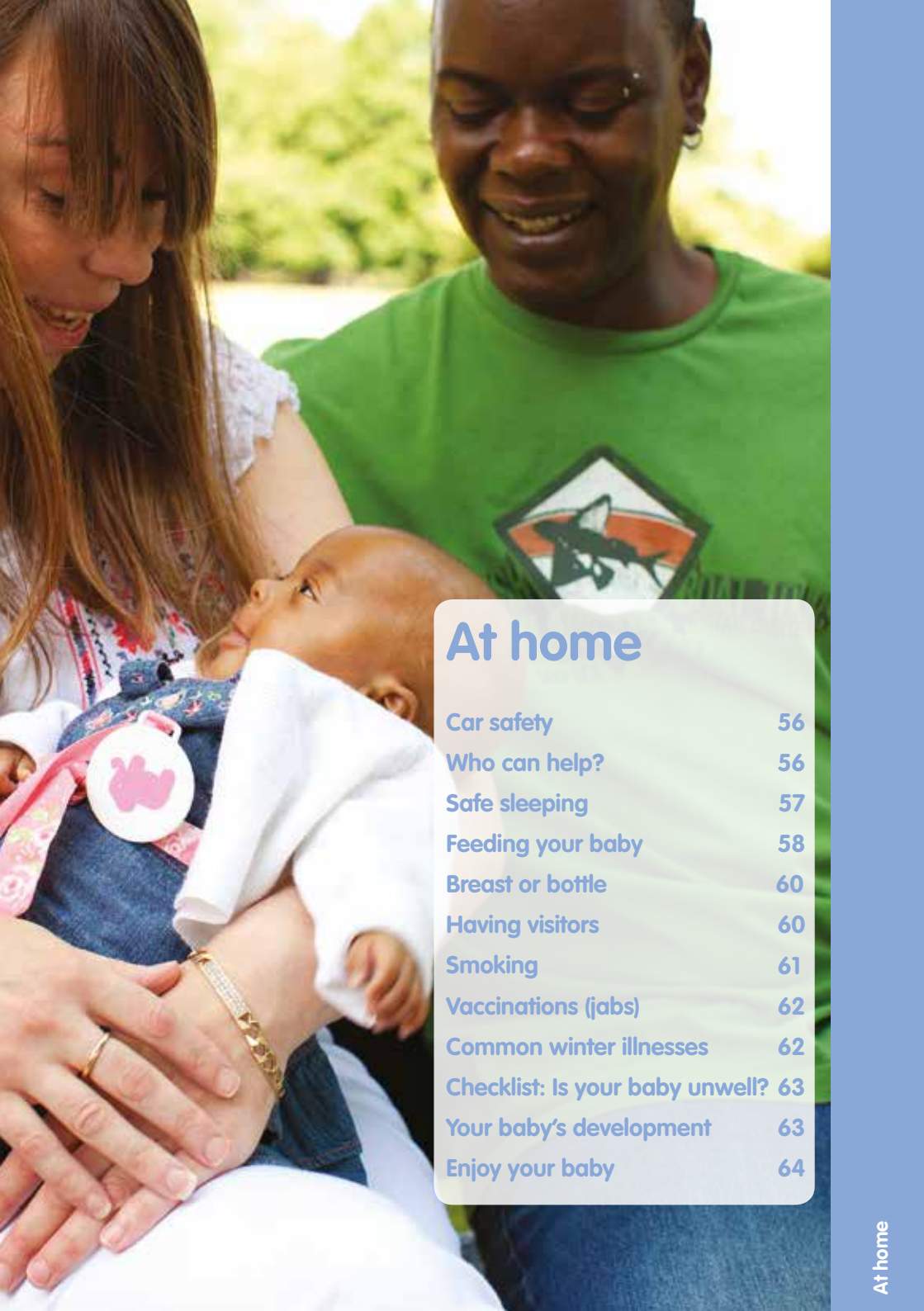
Check that you have contact phone numbers for the neonatal unit in case you need advice.

You can contact the unit at any time if you have questions while you are getting settled in at home.



# Notes





## At home

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Taking your baby home is a happy time but you might feel anxious, too. This section of the guide helps with common questions about keeping your baby safe and well at home, and encouraging their development.

## Car safety

The first step is ensuring a safe journey home for your baby. Under UK law, all babies must use a car seat. Only use a rear-facing car seat for a newborn, and keep your baby in the back seat. The Bliss Family Support Team can advise you on where to purchase the best car seat.

Premature babies may have breathing difficulties in a car seat if it is not fitted properly. This may also be a problem for term babies with certain medical conditions. Do ask the staff on the unit for advice about the best way to place your baby in the car seat.

### Bliss is here to help

You can learn more on the Bliss website and in our booklet *Going home: the next big step*.

## Who can help

After you take your baby home it can feel like you are all alone, without the hospital nurses and doctors there around the clock. However, help is still at hand if you need it. You can rely on:

- Health visitors.
- Your baby's GP.
- A practice nurse.
- Your local pharmacist.
- Other parents.
- The Bliss helpline.
- Your family and friends.

Your baby may have follow-up checks with the unit. It depends on your baby's individual needs, such as how early they were born, any medical conditions they might have, and how they are progressing.

Other parents can give you common-sense advice and lift your spirits, too. Bliss can put you in contact with other parents who've had premature or sick babies. Just call the helpline on 0500 618140 and we can match you with another parent.

## Safe sleeping

Coming home is a big change for you and your baby. Everything is new and different: noises, temperature, smells, colours. They may need lots of cuddles for reassurance, while they adjust to being off the unit.

If your baby is unsettled, you can try comfort holding them to reassure them you are there. You could also try leaving a night light on.



You should place your baby on their back at the start of sleep time. This significantly reduces the risk of cot death (Sudden Infant Death Syndrome, or SIDS). Make sure your baby's feet are at the bottom of the cot. Use a light blanket firmly tucked in, no higher than their shoulders, or a baby sleeping bag.

Sleeping with your baby on a chair or sofa is dangerous and increases their risk of SIDS. For the first six months, the safest place for your baby to sleep is in a Moses basket or cot, in the same room with you.

It's also important to make sure your baby is not too cold, or too hot. The best room temperature is between 16C and 20C.

You can find more information about safe sleeping for babies from The Lullaby Trust: [lullabytrust.org.uk](http://lullabytrust.org.uk) or phone 0808 802 6869.

## Feeding your baby

Feeding problems and worries about weight gain are more common in premature babies, even if they only arrived a few weeks early. So don't feel discouraged if it's not always easy. On the other hand, many babies who were born a little early will feed well when they come out of hospital, so you may find it goes smoothly.

### Is my baby getting enough?

All babies who are getting enough to drink have six to eight wet nappies every 24 hours, consisting of pale urine that does not have a strong smell, and regular bowel movements.

Babies should be passing lots of soft yellow stools in the first few weeks and there should be at least two the size of a two pound coins in a 24 hour period. Stooling patterns are usually the most reliable sign that your baby is getting enough milk.

Your baby will seem content and happy after a breastfeed and grow steadily, at their own pace.

Some premature babies are discharged from hospital taking vitamins and iron. Your health visitor can tell you how long your baby should continue taking vitamins.

If you are concerned about your baby's growth or feeding at any time, ask your health visitor, GP or community neonatal nurse.



## Reading your baby's signals

The key is listening to your baby. If they give you a signal they are hungry, feed them. If you offer the breast and your baby starts to feed, they must be hungry!

You should particularly look out for:

- Rooting for the nipple.
- Hand to mouth movements.
- Sucking movements.
- Sucking on fingers and hand.
- Opening their mouth in response to touch.

Watch your baby closely while they feed, so you can be sure they are swallowing and sucking well. You may have to remind them to keep sucking and swallowing, by stroking their cheek gently.

### Information and support

Bliss is here for you if you need more information or support with feeding your baby.

You can call the Bliss helpline and speak to someone about whether your baby is getting enough to drink, for more information about reading your baby's signals or for any other feeding related questions you may have.

You'll also find information on our website, including the following useful booklets:

- *The best start: A guide to expressing and breastfeeding your premature baby*
- *Going home: The next big step*
- *Weaning your premature baby*

You can get breastfeeding support from groups like the National Childbirth Trust and, if you have more than one baby, from the Twins and Multiple Births Association (TAMBA).

Go to our website for a full list of organisations who can give breastfeeding support [bliss.org.uk/usefulorgs](http://bliss.org.uk/usefulorgs)

## Breast or bottle

Remember, it is entirely up to you whether to breastfeed or not and – if you do – how long you breastfeed your baby for.

When deciding how to feed your baby, it is worth remembering that research shows that a mum's breast milk is the best source of nutrition for any baby and that this is especially true for babies born premature or sick. One of the best ways to help your baby is to give them breast milk which has many advantages over formula milk.



## 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, how to prepare feeds and sterilize equipment. They can also show you how to feed your baby with a bottle and how to pace feeding for your baby.

## Having visitors

Your baby will need to get used to a new environment when they come home from the unit. This is true for you and your partner too. Everyone has to adjust and this may take some time. Try to limit how many visitors you have at home until you are feeling settled and comfortable.

Once everyone has had a chance to get used to the new situation and your baby is progressing well, it's important to start getting back into a normal routine. You can decide to have more people over to see you at this stage, or organise to meet them somewhere else.

Your baby can become seriously unwell if they pick up colds, flu or tummy bugs, so ask people not to visit if they are ill.

## Smoking

It is recommended that you do not smoke near your baby. This is because babies who were born early or required time in special care are more vulnerable to lung problems and infections, and being exposed to smoking really increases their risk.

If your baby comes home to a house where people smoke regularly, their health can be quite seriously affected, even if they are not in the room where someone is smoking.

Smoking also increases the risk of cot death. For every hour of the day that a baby is in a room where people routinely smoke, the risk of cot death increases by 100 per cent.

The risk of cot death is also significantly increased for babies who share a bed with a parent who smokes, even if the parent smokes outside.

This is the perfect time for you or others living with you to try and stop smoking, for the sake of your own health, and for your baby's. Quitting smoking is not easy, but it's really worth it.

If you're finding it hard to stop smoking completely, try to only smoke outdoors with an outdoor coat on, when your baby is not with you. Wash your hands thoroughly afterwards.

### Get help to stop smoking

You can get help, encouragement and support from the NHS to stop smoking. Ask your GP, practice nurse or health visitor about stop smoking services near you.

Visit the NHS website: [smokefree.nhs.uk](http://smokefree.nhs.uk) or call the freephone Smokefree National Helpline on 0300 123 1044.



## Vaccinations (jabs)

Premature babies receive less immunity from their mums, because they do not spend the full time in the womb. This is one reason why they are more vulnerable to infections. So it's very important for your baby to receive their vaccinations (immunisations or jabs) on time. According to NHS guidelines, this should start at eight weeks after your baby's birth (not their due date).

## Common winter illnesses

Everyone gets coughs, colds and sneezes, but for babies who were born early or who have been sick in hospital, it can mean more than just a few days of feeling under the weather. They have a higher risk of becoming seriously ill with lung and breathing problems, and with infections that cause vomiting and diarrhoea.

Most babies will at some point be exposed to a virus known as RSV (respiratory syncytial virus). This is a very common virus which causes cold-like symptoms, but it can lead to breathing difficulties if the lungs become infected. It is most prevalent between October and March each year and two thirds of all babies will catch RSV before they are one year old. Catching it once does not give your baby immunity, and there is not a vaccine against it yet. Some high-risk babies can have a monthly antibody injection against RSV during the winter, and you can ask the neonatal staff or your GP whether it's right for your baby.

It helps to take what steps you can to protect your baby against infections all year round. This includes:

- Washing your hands often, especially before handling your baby.
- Using disposable tissues to catch runny noses and sneezes.
- Cleaning toys, high chairs and worktops regularly.
- Try to keep your baby away from adults and children who have symptoms of colds and flu, or vomiting and diarrhoea.

For further information or to order a free copy of the *Bliss Common winter illnesses* book call the helpline on 0500 618140.

## Checklist: Is your baby unwell?

Know the signs so you can get care for your baby quickly when they need it.

When a baby is ill, sometimes they can get worse very quickly. Take your baby to a doctor if they:

- Have a fever (above 38C, or about 100F).
- 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'.
- Start to breathe rapidly, noisily or with long pauses between breaths.
- Seem pale and colder than usual.
- Get a rash.
- Higher than normal temperature.

You know what is normal for your baby. If you ever have a feeling that something is not right, trust your intuition and take your baby to a doctor.

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



## Your baby's development

You might be wondering what effect your child's premature birth or time in hospital could have on their development, as they grow and progress.

Research on babies born a few weeks before their due date suggests that there may be some subtle but important differences as they grow up.

In some recent studies that followed late preterm babies into their early school years, they were more likely to have educational challenges, compared to babies born at term. But in these studies, the longer the babies spent in the womb before birth, the less likely this was to happen.

Another study, which followed children up to the age of 15 years, found that late preterm birth had no effect on their behavioural, social or emotional development, or on their achievements.

For babies who were born around their due date and required some extra time in hospital, each case is different - most babies will experience no problems as they grow and develop, but some may experience a few challenges.

It's important to realise that every child is unique, and being born early, or spending some extra time in hospital, is just one factor among many that can influence your baby's development. Your health visitor will monitor your child's progress, and you can always turn to them if you are ever worried. You can also raise any concerns with your child's GP or teachers. These professionals will be able to advise you, and help arrange any extra support your child might need. You can also call Bliss or visit the website, for information on topics such as starting school.

It's reassuring to remember that many special care babies grow up with no problems at all, learning and getting along just as well as any other child.

## Enjoy your baby

It can be a really emotional time when your baby is in hospital or if you are finding it hard to cope at home, with lots of worries about the future. But try to enjoy the good moments, too, like those first cuddles.

It does help to know that many families have been through the same experience.

Bliss is here to offer advice and support both while your baby is on the unit and after they've gone home.

For confidential advice and information call our helpline on 0500 618140 or visit our website [bliss.org.uk](http://bliss.org.uk)

Talk to other parents of special care babies on our online messageboard [bliss.org.uk/messageboard](http://bliss.org.uk/messageboard)

We can also put you in touch with Bliss volunteers and family groups in your area who can provide direct support to you also.



## Information and support

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

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

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, or raising funds to help other special care babies.

## Useful organisations

### **Citizens Advice**

Provides advice, information and details of your local bureau.  
[citizensadvice.org.uk](http://citizensadvice.org.uk)

### **GOV.UK**

Information and factsheets about benefits and other money topics.  
[gov.uk](http://gov.uk)

### **Group B Strep Support**

Offering support and information to families affected by group B Streptococcus.  
† 001444 416 176  
[gbss.org.uk](http://gbss.org.uk)

### **National Childbirth Trust (NCT)**

Antenatal support and breastfeeding advice.  
† 0300 330 0770  
[nct.org.uk](http://nct.org.uk)

### **NHS Direct**

Health information and self care advice.  
† 0845 4647  
[nhsdirect.nhs.uk](http://nhsdirect.nhs.uk)

### **UK Association for Milk Banks (UKAMB)**

Offers information on your nearest milk bank and also how to become a milk donor.  
† 020 8383 3559  
e [info@ukamb.org](mailto:info@ukamb.org)  
[ukamb.org](http://ukamb.org)

### **UNICEF UK Baby Friendly Initiative**

Leaflets, information and research about breastfeeding.  
† 020 7375 6052  
e [bfi@unicef.org](mailto:bfi@unicef.org)  
[unicef.org.uk](http://unicef.org.uk)

### **Start4Life**

Information service for new parents and parents-to-be from the NHS.  
[nhs.uk/information-service-for-parents](http://nhs.uk/information-service-for-parents)

### **Twins and Multiple Births Association (TAMBA)**

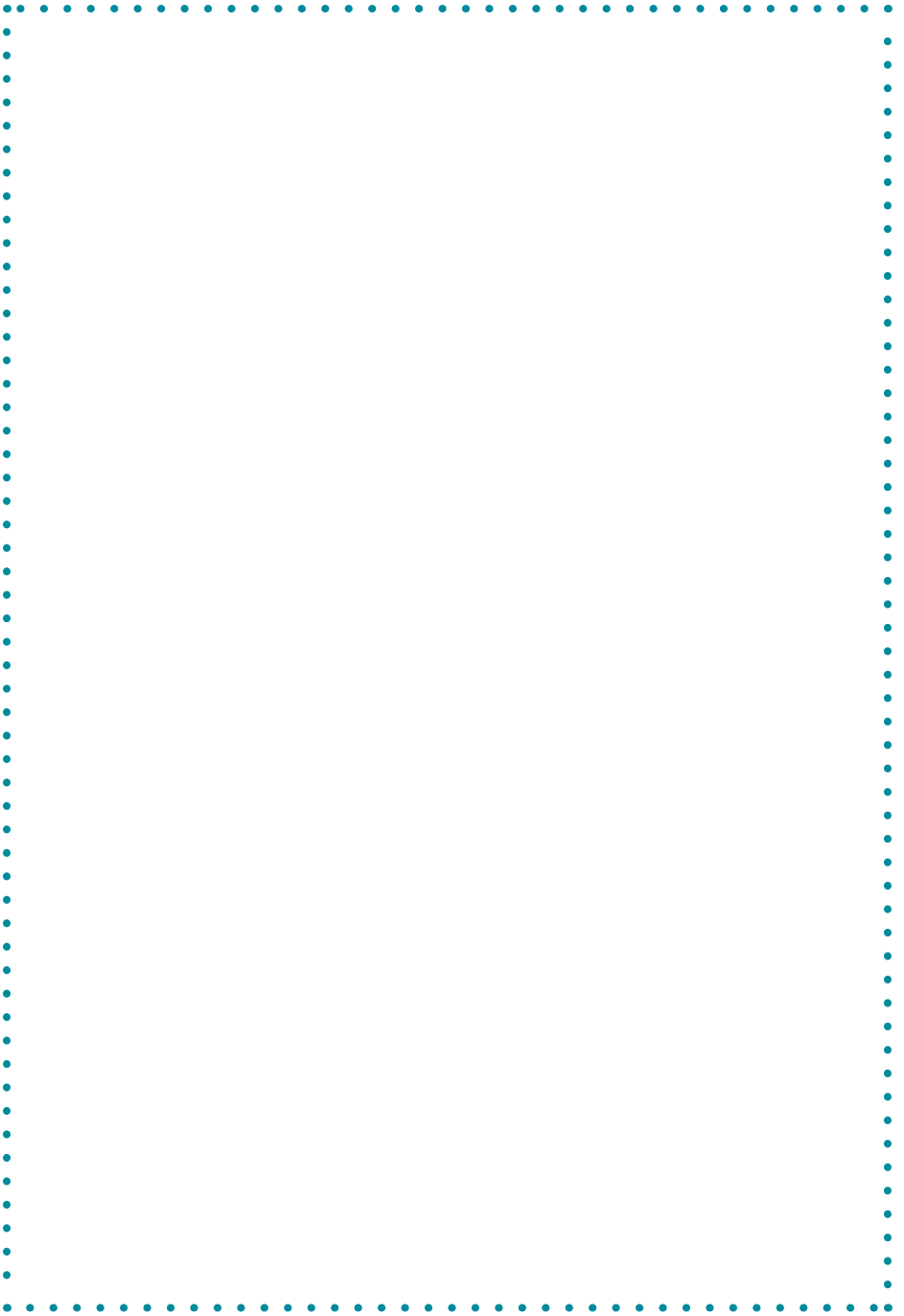
Helping parents to meet the challenges that multiple-birth families face.  
† 0800 138 0509  
e [asktwinline@tamba.org.uk](mailto:asktwinline@tamba.org.uk)  
[tamba.org.uk](http://tamba.org.uk)

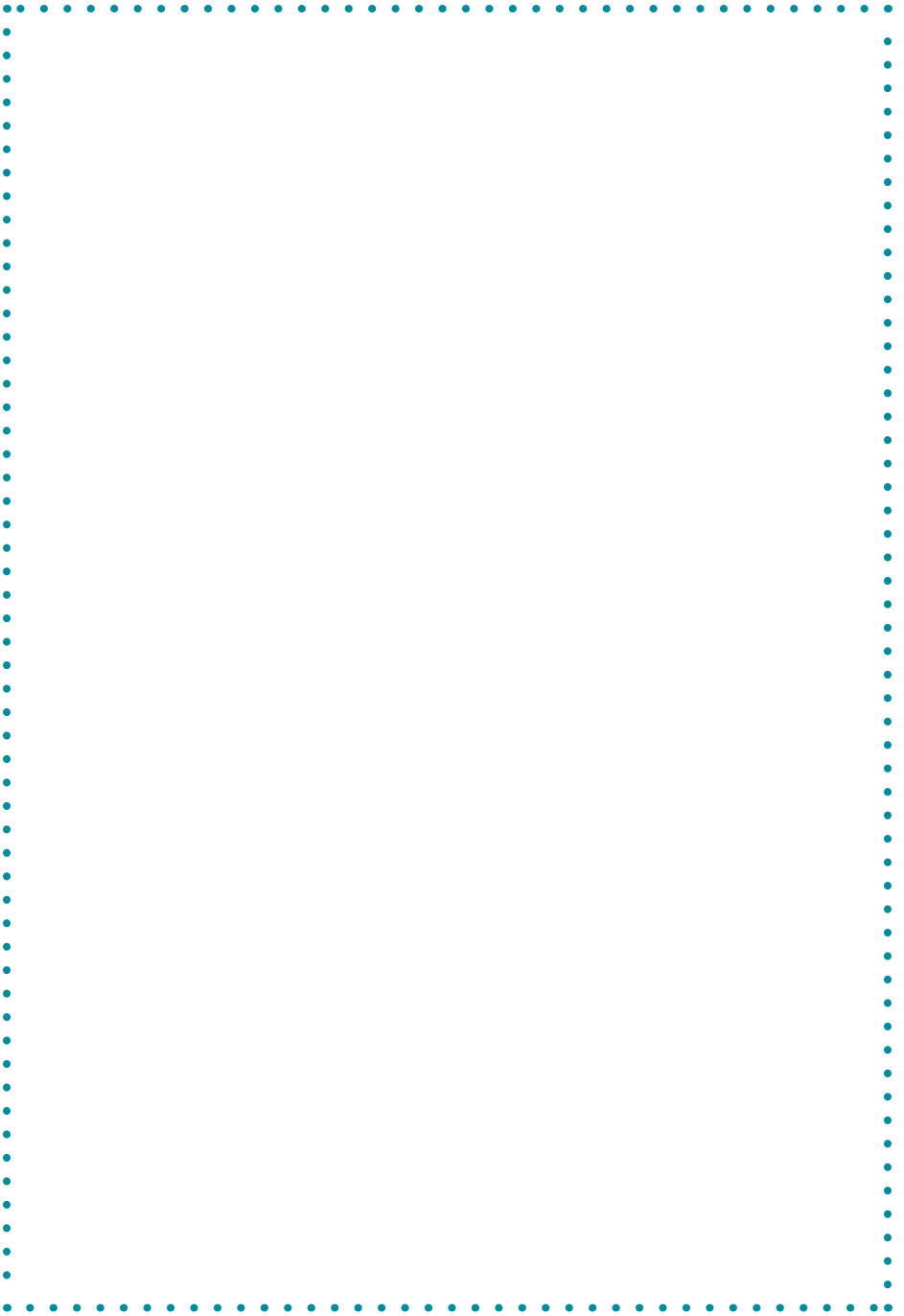
**For a full list of useful organisations, go to our website [bliss.org.uk/usefulorgs](http://bliss.org.uk/usefulorgs)**



# Notes







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*Your special care baby* is endorsed by the British Association of Perinatal Medicine and the Neonatal Nurses Association.

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While every care is taken in providing information, please note that it is of general nature and that readers should seek professional or expert advice as appropriate to their specific circumstances. Bliss does not accept any liability, including liability for any error or omission.



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For a full list of references for this handbook please visit our website [bliss.org.uk](http://bliss.org.uk)

To access support please call our helpline

**0500 618140**

or visit our parent messageboard  
[bliss.org.uk/messageboard](http://bliss.org.uk/messageboard)

To volunteer your time or to join our local  
network of support groups visit

**[bliss.org.uk](http://bliss.org.uk)**

**Text relay** 018001 0500 618140

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**[bliss.org.uk](http://bliss.org.uk)**

Like us at [facebook.com/Blisscharity](https://facebook.com/Blisscharity)  
Follow us on twitter @Blisscharity

Registered charity no. 1002973  
Scottish registered charity SC040878

**Bliss**

for babies born too soon,  
too small, too sick

**[bliss.org.uk](http://bliss.org.uk)**