



About neonatal care

An introduction to your baby's care in hospital

Bliss

for babies born
premature or sick



First edition

Information previously featured in *The Bliss Family Handbook* (third edition) and *Your Special Care Baby* (first edition)

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Written, edited and researched by:

Rachel Jarmy,
Content and Information Lead

Mary-Clare Ridge,
Content and Information Officer

Gemma Collins-Ellis,
Senior Communications Officer

Mehali Patel, Senior Research Officer

Designed by:

Joana Águas, Design Lead

Acknowledgements:

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Healthcare professional members:

Alan Fenton, Consultant Neonatologist,
Royal Victoria Infirmary, Newcastle upon Tyne

Dr Angela Davidson, Grid Neonatal Registrar, Royal Infirmary Edinburgh

Carol Sullivan, Consultant Neonatologist, Singleton Hospital, Swansea

Rachel Lomax, Neonatal Transport ANNP, Greater Manchester Neonatal Service

Public members:

Stephanie Chadwick	Shanaz Khan
Anna Verghese	Paul Thomas
Neal Smith	Holly Jordon
Paula Oliveira	Preeti Varu
Philip Lund	

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Introduction

Arriving in the neonatal unit felt like landing on another planet. The sounds, smells, machines, medical terms, routines and even my own baby were all unfamiliar. I remember watching my partner's hands shaking when he was dressing our baby. It was overwhelming, but being involved in our baby's care helped us come to terms with the situation and bond with him.

Abigail, mum

Congratulations on the birth of your baby – this is one of the most exciting things that can happen in a family. But finding out that your baby is going to spend time in a neonatal unit can be a very difficult experience.

Bliss is the UK's leading charity for babies born premature or sick. We know that having a baby in a neonatal unit is hard and emotional – it is often described as a rollercoaster.

This information has been written to help you find your way when you first arrive on a neonatal unit. It explains some of the equipment you might see, the hospital staff and support workers you might meet, and the medical words you might hear. It also gives some ideas of how to start caring for and getting to know your baby, and some simple suggestions of what you can do as a parent to support your baby. This guide can also help you think through any questions you may have for the doctors and nurses looking after your baby.

There is some space for you at the back of this booklet to write down your thoughts – anything you'd like to talk to someone about, or just somewhere to record the moments you want to remember.

Whatever the situation you are facing, you are not alone. Bliss provides information and support for parents, whatever stage of your neonatal journey, and we are always here to support you.

About us

We're Bliss, the leading UK charity for babies born premature or sick. We were founded in 1979 by parents determined to give babies on the neonatal unit the very best care. Today we're just as committed to giving each and every baby the best chance of survival and quality of life.

If you would like to support our work and help babies across the UK, visit bliss.org.uk and discover all the ways to get involved.

How we can help

We offer free information at:

- bliss.org.uk
- Or in print from your unit or our online shop – shop.bliss.org.uk

We offer emotional support through:

- Our free confidential helpline service - call us on **0808 801 0322** (visit bliss.org.uk/helpline for opening hours) or email us at hello@bliss.org.uk
- Bliss Champions – volunteers offering support on the neonatal unit. Look for a poster or ask a member of staff if a Bliss Champion is available on your unit.
- The Bliss Netmums forum – a community of parents with experience of neonatal care. Visit bliss.org.uk/netmums-forum

Before you read on

This information has been written to give you a greater understanding of neonatal care. It is designed to help you understand the specific medical advice you will be given about your baby's care from health professionals, as well as to help you settle into routines on a neonatal unit.

The information is written with parents of premature and sick babies born in the UK in mind. We try to make sure our information reflects current practice across the UK, but there may be some differences in how the care of your baby is managed between units.

Bliss provides information and support to parents, and does not give specific or individual advice on medical care.

What is neonatal care?

Neonatal care is the type of care a baby receives in a neonatal unit. Units are a part of hospitals which provide care for babies who are born prematurely (before 37 weeks' gestation), with a medical condition which needs treatment, or at a low birthweight.

The word 'neonatal' means newborn, or the first 28 days of life.

Over 100,000 babies are born premature or sick and in need of neonatal care in the UK each year.

We know that having a baby in neonatal care is likely to bring up a whole range of emotions, and some of these can be hard to face.

It may be that you feel anxious about why your baby has been born prematurely or sick, or about the treatment they are receiving. The team of health professionals can give you more information about your baby's condition and the needs they have.

Babies are admitted into neonatal care for many different reasons.

The main reasons for a baby to be admitted are:

- They are born prematurely.
- They have a low birthweight.
- They have a specific medical condition which needs treatment in hospital.

More information on each of these is given in the following pages.

Remember

You need to register your baby's birth. Find out more at [gov.uk/register-birth](https://www.gov.uk/register-birth)

Why is my baby in neonatal care?

Sometimes, the cause of premature birth or a medical condition will not be known, and you will not know exactly why this has happened to you. You can always talk about why this might have happened at postnatal check-ups, with your midwife, or with a member of the neonatal staff on the unit.



You are not alone. You can read other parents' stories on our website – bliss.org.uk/your-stories

I found the fact that I couldn't hold my twin boys very difficult. It felt as though they weren't my babies at some points. I found it helpful to keep telling myself that I was their mum, and whilst medical care was obviously vital, no one knew or loved my babies like I did.

Deborah, mum to Nathaniel and Alexander

Premature birth

A baby who is born before 37 weeks of pregnancy will be called a premature baby. The neonatal team have different words for different levels of premature birth. They may also use the word 'preterm' to talk about your baby being born early.

Extremely preterm	Very preterm	Moderate to late preterm	Preterm	Term
A baby born at or before 28 weeks' inside the womb (gestation)	A baby born between 28 and 32 weeks' gestation	A baby born between 32 and 37 weeks' gestation	A baby born before 37 weeks' gestation	A baby born at 37 weeks' gestation or after

Low birthweight

Babies who are born small may need to spend time in the neonatal unit. You might hear the staff use these words if your baby has a low birthweight.

Extremely low birthweight	Very low birthweight	Low birthweight
Born weighing less than 1000g (2lbs)	Born weighing less than 1500g (3lbs)	Born weighing less than 2500g (5lbs)

Medical conditions

Neonatal units treat a number of medical conditions. This can include problems found before your baby was born. These might be conditions which are carried in your family (called genetic or inherited conditions) or where your baby has developed in an unusual or different way in the womb (called congenital conditions). Your baby may have a condition because they were born early, or if they were born at term. The staff will give you information about your baby's medical condition, but if you ever want to know more, you can ask them. They will be happy to talk to you about any questions you might have.



Find out more about some common words and conditions on our website, [bliss.org.uk](https://www.bliss.org.uk). NHS Choices have useful pages on lots of conditions. You can search via [nhs.uk](https://www.nhs.uk)

How does neonatal care work?

Levels of care

There are different types of neonatal units in the NHS, and they are named depending on the level of specialist care they offer. Have a look at the list below to find out more about different types of unit.

Babies admitted to a neonatal unit get care according to what they need, and this care may change during the time they spend in hospital.

It is possible that your baby might have to be moved (often called 'transferred') to another hospital. You might also have been moved to a different hospital before your baby was born. This might not always be the hospital that is closest to your home, or where your baby was born. However, staff will be specially trained to look after your baby. Take a look at the section called 'Transferring your baby to another hospital' on page 13 for more information.



You can find out more about neonatal care on our website –
bliss.org.uk/in-hospital



Special care baby unit (SCBU, sometimes called low dependency)

This is for babies who do not need intensive care. Often this will be for babies born after 32 weeks' gestation.

Care can include:

- Monitoring their breathing or heart rate.
- Giving them more oxygen.
- Treating low body temperature.
- Treating low blood sugar.
- Helping them feed, sometimes by using a tube.
- Helping babies who become unwell soon after birth.

Sometimes, a baby might be admitted to a special care baby unit for phototherapy to treat jaundice. But sometimes, this condition is treated in transitional or postnatal care.

I will never forget walking into the neonatal unit and seeing Jemima in the incubator, surrounded by machines and covered in wires and tubes. Add in the alarms, darkness and the warmth of the room it all felt rather overwhelming. The nurses on the unit were great at answering my questions and were always willing to help. I soon learnt what each wire was for, what each monitor recorded and what the alarms all meant.

Ben, dad to Jemima



Local neonatal unit (LNU)

Babies who need a higher level of medical and nursing support are cared for here. If your baby was or will be born between 28 and 32 weeks' gestation you may be transferred to an LNU. Care on an LNU might include:

- Breathing support given through their windpipe (called ventilation).
- Short-term intensive care.
- Care during short periods where they stop breathing (called apnoea).
- Continuous positive airway pressure (called CPAP) or high flow therapy for breathing support.
- Feeding through a drip in their vein (called parenteral nutrition).
- Cooling treatment for babies who have had difficult births or are unwell soon after birth (before being transferred to a neonatal intensive care unit – see below).
- Helping babies who become unwell soon after birth.

Neonatal intensive care unit (NICU)

This is the level of care for babies with the highest need for support. Often these babies will have been born before 28 weeks' gestation, or be very unwell after birth. You might have been transferred to a different hospital which has a neonatal intensive care unit before your baby was born. This is usually because the staff feel your baby would benefit from this level of care, but that it is safer to transfer your baby before they are born. Babies are cared for here when they:

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

At a neonatal intensive care unit, all levels of care may also be given to babies from the local area.

Transitional care

This is where you and your baby stay together in hospital whilst you and the team care for your baby. It means your baby is well enough to stay with you, either in the postnatal ward or a room on the neonatal unit, with support from the hospital staff. You will be in the hospital for 24 hours a day.

Some babies born between 32 and 37 weeks' gestation, or babies with mild jaundice (see our section on the care your baby will get on page 42 for more information) or feeding problems, get the care they need in this way.

Good to know

It can be confusing to understand your baby's level of care. Sometimes babies might be treated in different types of units because their condition has changed. It might not be clear straight away what type of care your baby is getting. For example, your baby could be in a neonatal intensive care unit, but getting special care. You can always ask the staff if you want more information about the level of care your baby is getting.

Transferring your baby to another hospital

We were moved to our local neonatal LNU. We felt scared at how the new unit would be - would they allow us to be as involved? We were so reassured by the friendly staff at the new unit and were shown exactly how they did our baby's cares so we could stay involved from day one. To us, this was really important.

Vicky, mum to Alexander

Transferring a baby to another hospital is quite common. Units are very used to moving babies and will help you through the process.

Moving a baby makes sure they get the care they need. We know that moving your baby to a different hospital might be really difficult for you and your family. Your baby's care team will talk to you about possible or likely transfers. You might also find the following information helpful to explain things.



Why is my baby being transferred?

There are a few reasons why your baby may be transferred. A health professional should explain why your baby is being moved. Here are some common reasons:

- If they need specialist care, equipment or surgery that is provided at a different hospital.
- If your baby's health is improving and they no longer need higher levels of care. At this stage they might be moved closer to home.
- Sometimes a unit becomes full. It may not have enough cots or staff to care for another baby. In this case your baby may need to be cared for at a different hospital.
- For an appointment with a specialist doctor.
- If your baby needs an operation they will need to go to a hospital that has a surgical centre. When the operation is over your baby will be moved back to the neonatal unit. They will only be transferred when the neonatal team feel they are well enough for the journey.

How will my baby be moved?

Babies on the unit are moved by ambulance in a special incubator. A trained transport team of neonatal doctors and nurses will care for your baby throughout the journey and until they are settled in their new unit.

You should be offered the chance to travel with your baby, but this might not always be possible. If it isn't possible for you to travel with them, talk to your baby's care team and the transfer team about how you can make other arrangements and how they can help you with this.



What if my baby is moved far away from home?

Your baby may get the care they need close to home, but this is not always possible. Your baby may need to be moved to a unit that is far from your home. We know that it can be very hard to be far from your baby or home. It can be tiring and expensive travelling a long way to see your baby. You may be offered accommodation near the hospital if you are a long way from home, or help with the costs of travel or parking.

Staff might be able to put you in touch with a dedicated member of staff, who can support you with information about travel and accommodation.

If the mum who has given birth is also being treated in hospital, for example after a C-section, they might also be transferred to the same hospital to make sure parents can stay with their baby.



You are not alone. We can support you. Find out more about transfers from a Neonatal Senior Sister, via our website – bliss.org.uk/transport-nurse-tips

You might want to ask your baby's team if they have a Bliss Champion volunteering on the unit as they can provide face to face support at this difficult time. You can also contact the Bliss helpline by phone or email.

You can also find more information and support about being separated from your baby on page 34.

Routines on the unit

When your baby arrives on the neonatal unit, one of the nurses should show you around and explain the routines. Each unit works differently, but there are standard policies that apply in most hospitals.

The staff should also keep you up to date on your baby's care during the first few hours. They will know that you are likely to feel worried and anxious. They will do what they can to put you at ease.

For me, the most important part was to embrace the routine. I quickly figured out what time ward rounds were, and I tried to relax with a cup of tea in the family room beforehand. I asked plenty of questions. The doctors always put me at ease. Sometimes I thought of something later and the nurses were always on hand. I also made sure that I took a breather later in the day. I'd go for a walk or a cuppa. By breaking up my day, it made me feel like I was making a difference to our daughter by being there for her.

Anna, mum to Jemima



Staff schedules

Staff on the unit work in shifts, coming on duty and going home at set times. The handover between shifts, where different staff take over, can be a busy time on the unit.

The medical and nursing team's rounds (called ward rounds) usually happen once or twice a day. During a morning round, the doctors and nurses plan your baby's care. An evening meeting called a handover allows the day and night staff to share information and agree overnight plans. Nursing staff will also have handover, where they share information with different staff starting their shifts.

You should be able to stay when your baby is being talked about. Feel free to ask the doctors questions or share any thoughts you have about your baby's condition or treatment. Rounds are an important time for you to stay informed and be fully involved in decisions about your baby's care. You can also use this time to tell the staff how your baby has been doing that day.

Updates on your baby

The nurse helping you to care for your baby can update you on their progress when you are on the unit, or you can phone for an update. 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.

If you can't be on the unit for any reason, you can always call 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 allowed to read these at all times. You should also be able to leave notes about your baby for staff to read. Your baby's full medical record, which give details of their condition and treatment, are kept securely. These medical records are protected by laws to make sure they remain confidential, 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 coming into the neonatal unit must wash their hands and forearms thoroughly and, after drying, use the sanitising hand gel provided. The unit might also have what's called a bare arm policy. This means no clothing or loose jewellery can be worn below the elbow.



For more info on washing your hands thoroughly, and how to reduce infection, visit our website – bliss.org.uk/winter



1. Wet hands and squirt soap into the palm of one hand



2. Rub hands together palm to palm, spreading the soap



3. Rub back of each hand with palm of other hand with fingers interlaced



4. Rub palm to palm with fingers interlaced

Family members may need to stay away if they have a cold, the flu or a tummy bug, or if they have whooping cough, measles, chickenpox or other contagious infections. This will apply to siblings and other family members, and may also apply to you if you are seriously ill. This can be hard. If you are not able to be with your baby because you are sick then the unit will arrange other ways for you to stay up to date with their condition.

Your baby might be swabbed for infections when they are first admitted into the unit. This is to help the staff know what they might need to treat.



Visiting

Parents are not considered visitors, as you should be able to be with your baby 24 hours a day. In some units, parents might be asked to leave the room if staff are having confidential conversations about other babies. It will be very important to the staff that you are not separated from your baby unnecessarily and they will do everything they can so that you can stay with them as much as possible. To do this, units are encouraged to have confidential conversations away from the cot or incubator, so that as many parents as possible can stay with their babies.

For security, the unit will only be accessible to staff with relevant passes. Parents and visitors will usually be let in by the staff.

Each unit has its own visiting policy. The unit may have set visiting hours for other family members, and might 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. If you can, it may be helpful 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. You might like to give your child a picture of the baby to keep. 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 can be a difficult time when your baby is in hospital and privacy for you and your family is important. Most units will:

- Make sure you have private space for feeding, expressing, cuddling and medical procedures. 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 place for discussions about your baby's condition and treatment.

Peace and quiet

For premature or sick babies, it is very important to make sure their environment helps them to respond to treatment, grow, and develop. Neonatal units help keep the environment calm for babies, by:

- Turning lights low and shielding the babies from bright lights as much as possible.
- Protecting them from loud or continuous noises from equipment.
- Keeping conversations and phones at a quiet level.
- Making sure babies have lots of quiet time.
- Asking everyone to put mobile phones on silent.

Being quiet in the unit does not mean that you can't talk softly to your baby. In fact, doing this can really help you and your baby to connect and to feel reassured.

Neonatal staff and what they do

Don't be afraid to ask the nurses again or even other parents. One thing I did learn is you can never ask too many questions - you'll always find somebody ready and willing to answer. The first few days will be daunting and you'll wonder how you're going to get through, but with the help of the neonatal staff you'll soon feel confident caring for your child and get into your own routine.

Laura, mum to Jaxson

The neonatal team

Different health professionals work as a team on the neonatal unit. You will see different faces looking after your baby, with staff coming and going on different shifts. You will probably get to know some of the staff, but it can feel confusing at first to know who's who, and what their job is.

Use this guide to help you work out who's who. You can fill in details below on what each role wears on your unit – different roles wear different colours to help people know what job they do, but this can be different on every unit. Your unit may have their own chart of the staff on the unit, and the uniforms they wear.





Nurses

- Nurses provide most of the day-to-day care for your baby.
- They can answer 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 called advanced neonatal nurse practitioners (ANNPs) or nurse consultants. They often perform similar duties to doctors, and can supervise teams of junior doctors.
- The matron or charge nurse coordinates your baby's care.
- Talk to the nurses right away if you are ever worried that your baby is in pain, or you feel something isn't right.
- Nurses can also help you with kangaroo (skin-to-skin) care and breastfeeding.

The nurses on my unit wear

Doctors

- Doctors coordinate your baby's treatment. They can answer your questions about your baby's treatment, medical condition and progress.
- 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 the other doctors.
- You can ask doctors for a second opinion on your baby's care.

The doctors on my unit wear



Other staff you might meet

All units have different staff, depending on the level of care that needs to be given. Ask your unit staff if you want to find out more about the people listed here.

Nursery nurses

- In some units, nursery nurses contribute to the smooth running of the unit by supporting the nurses with a number of different tasks.
- They work with other members of the neonatal team.
- They also often work with the community outreach or discharge team to help parents and babies prepare for going home.

Pharmacists

- Pharmacists 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 parts 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 what nutrition your baby needs.

Ophthalmologists and auditory technicians

- These members of staff will check your baby's eyes and ears.

Radiographers

- You will meet these staff members if your baby needs an X-ray or scan.
- If your baby needs an ultrasound this will be carried out by a consultant who specialises in X-rays and scans.

Students and trainees

- You may meet newly-qualified doctors who have just finished medical school, medical students or nursing or midwifery students.
- You should always be asked whether you are happy for students to watch and learn from the health professionals providing care for your baby.

Psychotherapists, psychologists and counsellors

- These professionals can help you to talk about how you are finding your time on the neonatal unit.
- Looking after your own needs on the unit, as well as your baby's, is very important. Your unit can provide you with details of someone who you can talk to.



Community neonatal nurses/discharge nurses

- Some units might have dedicated staff to help you through the process of leaving the unit, and adapting to your baby's care at home.

Social workers or family support workers

- These members of staff can support families and carers with emotional and practical needs . This may include advice and support around the cost of having a baby in hospital, and adjusting to the hospital environment.

Porters and cleaners

- The members of the team who keep the day-to-day maintenance of the unit running, and clean the unit and equipment.

Clerical staff

- Members of the team who manage the office work of the department.

Faith leaders/chaplaincy team

- Some parents find it helpful to speak to a member of the hospital's chaplaincy team. This team provides support from members of many different faiths. If you would like a visit, ask a nurse if this can be arranged.



We are here for you. You can contact the free confidential Bliss helpline service by phone or email for emotional support and information. Call 0808 801 0322 or email hello@bliss.org.uk

Some other staff I'd like to talk to are

Being a parent on the unit

At the beginning I really struggled to understand my role, and felt very disconnected from being my baby's mother. I spoke to one of the nurses. She said "You have a very important role. You see your baby every day - you really do know them best. We make clinical decisions but she is your daughter. Don't ever forget that".

Katy, mum to Vivian

If your baby was born prematurely or sick, they were probably taken away from you soon after birth. Arriving on the neonatal unit and watching the staff care for your baby can make many parents feel like they aren't doing what parents should do for their baby. Some parents feel helpless and worried.

You may have imagined your first moments with your new baby being full of joy - being in a neonatal unit often takes those moments away from you.

Health professionals understand that it is really important to support families to parent their baby when they are on the unit. They also know that it is really important that you always know what is happening with your baby, and that you have the information you need. This type of care for you and your family is called **family-centred care**.

Family-centred care helps parents and families connect with their baby. It also helps your baby to bond with you, be comforted, and get used to things like kangaroo (skin-to-skin) care and breastfeeding. Parents being involved with their baby's care is shown to help their baby's progress and development. We've included some things you might like to try to get more involved in your baby's care. Talk to a nurse or member of the team about what else you can do to parent your baby on the unit.



Watch our video to find out more about family-centred care
bliss.org.uk/family-centred-care

Remember

You are your baby's parent. Your baby knows your voice, your smell, and will be comforted by you being there. No one else can take your place.

Skin-to-skin

Sometimes called kangaroo care, this means placing your baby undressed onto your bare skin on your chest, so that your skin touches. This is shown to help you to connect with your baby, as well as calming your baby if they are feeling pain or stress. Mums, dads, brothers, sisters and other family members can do skin-to-skin. Staff will let you know if your baby is ready to have skin-to-skin with you – sometimes you might need to wait until they are more stable.

My favourite time of each day was after my baby's cares when I could hold her, which was about every six hours. Having that skin-to-skin contact was amazing and I used to talk to her about everything and anything, particularly about who was waiting to meet her and what we would do when she came home.

Sarah, mum

The nurses will help you to get your baby onto your chest. This might take a little time if your baby is attached to many wires or a ventilator. They will show you how to support your baby and make the most of this time together.

For kangaroo care to really benefit your baby it's helpful if you can do this for at least one hour if possible. Make sure you are really comfortable, and have everything you need before you start.



Find out more about skin-to-skin care on our website – bliss.org.uk/skin-to-skin



 **Things I'd like to ask my
health professional about skin-to-skin**

Feeding your baby

Babies on the neonatal unit can have breastmilk, donor breastmilk, or formula milk. Your baby may not be able to be breastfed straightaway, but can have expressed breast milk through a tube. If mum is unable to express breastmilk or you as parents choose not to, your baby can also have formula. This can also be fed by a tube (called enteral nutrition, or EN) if your baby is not ready to take milk by themselves. Sometimes a baby's stomach might not be mature enough to have any kind of milk, and so they are given their nutrition through a vein, called parenteral nutrition, or PN. Parenteral nutrition is a special liquid which has the right balance of nutrients to help the growth of babies who aren't able to have milk yet. This is likely to be the case for babies born very early. This type of feed can also be given through a vein in their umbilical cord.



Find out about research Bliss funded into PN feeding via our website - bliss.org.uk/scamp

Your baby might also be given formula if mum is on certain medication which might affect your baby. Sometimes a fortifier is given to some babies to make sure they receive all the nutrients they need on top of the breastmilk. This is added straight into the milk.

Whether you are tube feeding, breastfeeding or bottle feeding your baby, you can get involved. Many parents tell us that having skin-to-skin whilst feeding, expressing breastmilk or giving their baby their first bottle feed gives them lasting memories that they treasure.

Things I'd like to ask my health professional about feeding my baby

Washing and changing your baby

The nurses and neonatal team can support you to wash your baby and change their nappy. This can feel hard when they are connected to wires and monitors. The nurses will show you the best way to do this to make sure your baby feels comfortable. Doing these things, sometimes called your baby's cares, helps parents play more of a hands-on role in their baby's day-to-day needs. This can help parents feel connected with their baby.



If your baby was born prematurely, regular nappies might be too big. Ask your unit if they have some Pampers Preemie Protection nappies – they have three sizes, specially made for the smallest babies. These are available for units to order for free. Visit bliss.org.uk/pampers for more information.

Things I'd like to ask my health professional about washing and changing my baby



Making decisions and getting consent for your baby's care

Your baby is at the heart of your family, and so the neonatal team must include you when talking about your baby and support you when decisions need to be made. Your unit should encourage you to be there and talk with the doctors during their rounds. Ask if you can read your baby's medical notes too.

The health professionals need to get written consent from you for operations and some other procedures. This means getting your agreement that the operation or procedure can happen to your baby.

If you are not on the unit, for example in the middle of the night, and your baby is unwell, urgent decisions might be made quickly to make sure your baby gets the best care. This may also happen if there is an unexpected change in your baby's condition. The team should talk to you about these decisions as soon as possible.

Things I'd like to ask my health professional about making decisions

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Watching your baby

I didn't feel like my daughter was mine, or if she knew me, for the first few days. One day a nurse said to me "She knows her mummy. Look how her head turned when you said hello as you walked in". It was at that point I realised that, yes, I am a mummy.

Emily, mum to Violet

Sometimes you might feel like you spend a lot of time just looking at your baby. This is really important. It can help you to learn how your baby shows signs of pain and being uncomfortable, as well as when they are calm and content. This, combined with your natural intuition as a parent, will help you to help the doctors and nurses – together you can tell when your baby might not be feeling very well, or might be in pain. The unit should have a place for you to write some of this information in your baby's notes.

Things I've noticed about my baby

Feeling closer to your baby

For some parents, the first time they hold their baby may be some time after they are born. Not being able to hold them whenever you want, or take them home to show your family and friends, can make you feel like you are very distant from your baby, physically and emotionally.

There are some things you can try to help with this feeling of separation. Talk to a member of the neonatal staff about how they can support you to try some of these:

- Putting a small square of material that smells of you in your baby's incubator. They will recognise your smell and it can help to calm them. This can also help you to feel you are there, even when you aren't physically there.
- Having something which smells of your baby close to you. This can help them feel nearer to you. If you are expressing milk for them, the smell of your baby can also help your milk to flow.
- Marking important milestones with your baby – gaining weight or coming off a piece of equipment are big steps for babies in the unit, and celebrating these can help you feel like you are making progress, together.



You can celebrate each milestone in your baby's journey with Bliss Baby Cards, specially designed for babies in neonatal care. You can order these for free via our online shop – bliss.org.uk/bliss-baby-cards



Things I'd like to ask my health professional about feeling closer to my baby

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Equipment on the neonatal unit

As soon as you understand what all the machinery surrounding your baby does, and why they beep and alarm, the sooner you will feel more comfortable in this unfamiliar place. So ask questions - no one will judge you for not taking it all in the first (or even the fifth) time.

Annie, mum to Alfie

We hear from parents that the equipment on the neonatal unit can seem overwhelming when you first arrive. You might not have had any time with your baby after they were born and before they went to the unit. Many parents tell us that their baby being in the incubator and attached to wires makes them feel distanced from them. There can also be sounds from equipment which can seem alarming at first. This can feel very upsetting.

Some parents find it helpful to know what the equipment does and how it helps to monitor and provide support for their baby.

In the section below, we explain what some of the equipment looks like and what it does. Some units might have equipment which looks a bit different from the pictures we've used here. If you are ever unsure about the equipment used for your baby, ask the neonatal team – they will be happy to explain.



Common equipment on the neonatal unit

Incubator

Incubators are clear boxes which help keep your baby warm. Premature or sick babies can struggle to stay warm on their own.

Some incubators are closed boxes with hand holes on the side. This helps keep the heat and humidity in the incubator, stopping too much moisture evaporating from your baby's fine skin.

Other incubators have open tops and an overhead heater or heated mattresses.

The temperature is controlled in two ways – either with controls or using an automatic sensor on your baby's skin. If the sensor falls off or is not working properly, an alarm sounds, and a nurse will check the temperature of the incubator.





Ventilators and breathing machines

Before your baby was born, they received all the oxygen they needed from mum. The oxygen in the mum's blood passes across the placenta and into the umbilical cord (the cord that connects the baby to the placenta and which is cut at birth).

Once they are born, babies get their oxygen by breathing. If a baby is born prematurely or with a medical condition, they may struggle to breathe by themselves. Premature babies' lungs in particular might not be developed enough to manage breathing by themselves yet.

Depending on what your baby needs, they might be put on a machine called a ventilator – this helps your baby to breathe. There are two types of basic ventilator:

- **Positive pressure ventilators** blow air with or without added oxygen (depending on what your baby needs) gently into your baby's lungs through a tube which is passed through their nose or mouth. This inflates your baby's lungs. How quickly the lungs are inflated is kept regular, and adjusted depending on what your baby needs.
- **High frequency oscillating ventilators** blow small amounts of air with or without added oxygen (depending on what your baby needs) into the lungs very quickly, hundreds of times a minute. Your baby's chest will look like it is vibrating. This might look worrying, but it can work very well for some kinds of lung conditions.



Other breathing machines can include:

- **Heated, humidified high-flow nasal cannula (also called HHHFNC, high-flow or optiflow)**
Some babies need help with their breathing but do not need something as strong as a ventilator. Heated, humidified high-flow nasal cannula is where warm, moist air with or without oxygen (depending on what your baby needs) flows into your baby's lungs through small tubes in their nose.
- **Continuous positive airway pressure (CPAP)**
Continuous positive airway pressure (often shortened to CPAP) is similar to high-flow, and passes air with or without oxygen (depending on what your baby needs) through two thin tubes in your baby's nose, or through a small mask over their nose. CPAP slightly raises the pressure of the air, which helps keep your baby's lungs inflated.

Endotracheal (pronounced en-doe-track-eel) tube

This is put down your baby's windpipe (called a trachea by health professionals) if they are on a ventilator. It is either put in through your baby's nose or mouth. It is the tube which passes the air into your baby's lungs from the ventilator.

Vital signs monitor

These machines pick up electrical signals given out from your baby's heart, and always check that it is beating properly. They can also pick up changes in your baby's breathing. These monitors pick up these signals through small pads put on your baby's chest. Wires run from the pads to the monitoring machine.

Oxygen saturation monitor

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.



▲ Vital signs monitor (above) and temperature monitor (below)



▲ Infusion pumps provide fluids, medicine or nutrients into the blood



Intravenous (pronounced in-tra-vee-nus, and sometimes shortened to IV) drip

Your baby might have thin tubes (sometimes called IVs, drips or cannulae) put into a tiny blood vessel. The IV is usually put in a hand, foot, arm or leg. Sometimes the staff might have to use one of the tiny veins on the surface of your baby's head. These tubes are there to give fluids or medication, like antibiotics.

Feeding tube

We talked about the different types of feeding on page 30. If your baby can't feed by themselves yet, they might be able to have breastmilk or formula through a tube that goes down their mouth or nose and into their stomach. Doctors might use a nasogastric (pronounced nase-oh-gas-trick) or orogastric (pronounced or-oh-gas-trick) tube.



Phototherapy lamp or light blanket

When red blood cells are broken down in the blood, products such as bilirubin are released. The liver usually removes this, but sometimes, it can't do this properly. Jaundice in newborns is where there is a higher level of bilirubin in your baby's blood stream than there should be. Special lamps and blankets, which give out blue light, can be used to break down the bilirubin. Your baby's eyes will be covered to protect them. Phototherapy sometimes takes place in transitional care (with you giving the care at your bedside in the maternity ward) or in the special care baby unit (SCBU).



**I'd like to ask the neonatal team
these questions about the equipment on the unit**

A series of horizontal dotted lines for writing.

Medical tests, scans and care

I struggled with seeing my baby boy in an incubator in the first few days. However, talking to the nurses really helped. They encouraged me to see past the incubator and focus on my little boy, how I could help him and what I could do. They encouraged me to be a mum regardless of where we were.

Claire, mum to Joshua

Medical tests and care

It is likely that your baby will have different tests whilst they are in the unit. This is so that your baby's changing needs can be met, and the neonatal team can monitor how they are responding to their care. This helps them make decisions about whether to continue with a treatment, try something new, and whether your baby needs to be moved to a different hospital for more specialist care.

Tests and procedures will only be done when your baby needs them. The neonatal staff will always try to reduce pain, discomfort and the disturbance caused to your baby. During these procedures you may be able to comfort your baby to reduce their discomfort, for example through comfort holding (cradling their hands and feet) or breastfeeding when the test is done.

There are some common tests and procedures you might come across.





Blood tests

Blood is the body's transport system, moving oxygen, nutrients, waste products and chemical messages to all the right places. Your baby's blood does many jobs, including fighting infection. Because of this, blood tests can show how your baby is progressing.

Most blood samples are taken by pricking the skin to get blood from the back of your baby's hand or heel. The team might check the following things:

Sugar levels

Blood carries energy in the form of sugar. This test tells the doctors whether your baby's blood sugar levels are being properly controlled. Babies born to mums with diabetes (a condition which causes blood sugar levels to be too high) or babies born with a very low birthweight may have problems keeping a healthy blood sugar level, and so will be monitored more closely.

Blood gases

As well as carrying oxygen from the lungs, blood also carries carbon dioxide back to the lungs so we can breathe it out as waste gas. Measuring the levels of carbon dioxide, as well as other waste chemicals carried by the blood, can give clues about how your baby is breathing. It can also help tell how other organs, such as kidneys, are working.

Platelets

These are important for controlling bleeding. In premature and sick babies, the platelet count can be too low. This is why this is monitored. If the level does get too low, your baby could need a platelet transfusion.

Haemoglobin (pronounced hee-mo-glow-bin)

This chemical helps blood to transport oxygen. It is carried by red blood cells. If your baby does not have enough red blood cells, the body may not get enough oxygen. This is called being anaemic (pronounced an-ee-mick). If your baby's haemoglobin gets very low, they might need a blood transfusion.

White blood cells

These cells play a big role in fighting infections. Checking these levels helps to see how well your baby is fighting an infection, or if an infection is starting.





Scans

Scans can help doctors to see inside your baby's body. Your baby may have one of the following types of scan:

Ultrasound

This type of scan uses ultrasound waves to build a picture of inside the body. No harmful radiation is used. A common use of these scans is to see if there is bleeding or other problems on your baby's brain. You can stay with your baby when they have an ultrasound scan.

Magnetic resonance imaging (MRI)

Many units have access to an MRI scanner, which uses a magnetic field to show pictures of your baby's internal organs. No harmful radiation is used. These scanners are usually in a different part of the hospital from the neonatal unit. This means your baby might have to wait until they are strong enough to be moved. Sometimes, your baby might need to be sedated for their scan to make sure they stay still enough for the scanner.

X-ray

X-rays are often used to look at your baby's chest, especially when they are having breathing support. They are also sometimes used to check for problems in the gut if your baby is not feeding well. X-rays do use ionising radiation, so they are only used when they are really needed. You might need to leave the room when the X-ray is taking place.

Lumbar puncture

Some babies can get a very bad infection around the outside layers (called meninges) of their brain and spinal cord. This infection is called meningitis. If doctors are worried your baby might be getting this condition, they will take action quickly, as it can become serious. In a lumbar puncture, the liquid around the spinal cord is taken and sent for testing. To do a lumbar puncture, the doctor or nurse will gently put your baby in a curled position on their side – this helps to make the space between the bones in their spine bigger. Then, whilst a nurse is watching your baby closely, a doctor or nurse practitioner will put a small needle into one of the spaces low down in your baby's back. The team will offer your baby things like expressed breast milk to help ease any pain.

Screening for genetic conditions

Sometimes, the neonatal team might want to check to see if your baby might have a condition which is passed on genetically – this means that it is passed down from parents to their children. The doctors will talk to you about these tests, if they think they are needed.



Vision and hearing tests

Babies who are born prematurely may have problems with their sight and hearing. Some babies with particular medical conditions may also have their sight and hearing tested whilst on the neonatal unit.

Babies born before 32 weeks gestation or below 1500g of weight at birth will be tested for a condition called retinopathy of prematurity (ROP). This can be a serious eye condition, and so babies who are at risk are screened as soon as their eyes have developed enough. The specialist doctors who carry out these tests (called ophthalmologists) can also look for other eye problems. Babies born prematurely can also be at risk of hearing problems. Their hearing will be tested before they leave hospital.

Emergency resuscitation (pronounced ree-sus-a-tay-shon)

It is possible that your baby might need urgent help with their breathing if they are not breathing by themselves. If your baby can't breathe for themselves, this can mean that their heart stops beating properly. This can happen straight after they are born, or during their time on the unit (if they have a serious infection, for example).

Resuscitation is where doctors help your baby to start breathing again and for their heart to start beating properly. This is usually done with equipment on the unit which focusses on your baby's airway and breathing.

Sometimes, doctors might press on your baby's chest in a special rhythm which can help start their heart again. These are called cardiac (pronounced car-dee-ack) compressions.



**I'd like to ask the neonatal team
these questions about my baby's care**

A series of 20 horizontal dotted lines spanning the width of the page, providing a template for writing questions.

Support for you and your family

It is quite normal to feel lost and bewildered, and not know where everything is. Don't be afraid to ask, even for the most basic things, not just about your baby. If you're in a strange hospital, where nothing is familiar, even finding a toilet or a shop is a challenge!

Jo, mum to Leo

Having a baby in neonatal care can cause many different feelings. There is no right or wrong way to feel.

You may also have practical things which are made harder by your baby being in hospital, for example, family finances, travelling to and from hospital, or looking after your other children.

You are not alone. There is support for you and your family. Here are some ways that your family can be supported during this time.

There's space for you to write down some ways you could feel more supported. You might like to share what you write with your friends and family, or the neonatal team. The people around you will want to help.

Partners

Sometimes, it might feel that there is a lot of focus on supporting the mum who has given birth, so they can do things like breastfeed or express milk. We sometimes hear that partners can often feel helpless, and unsure what they can do.

Family-centred care helps to involve the whole family in the care of the baby, not just the mum who has carried the baby.

Partners can get involved with caring for the baby too, by having lots of skin-to-skin contact with your baby, washing and changing them, and helping with feeding. This can help them be more involved in the care of their baby.

 **Some ways my family could be supported are**

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Grandparents, other family members and friends

Your other children, your baby’s grandparents and other family members and friends can also get involved with taking care of the baby. Every unit has different policies about visitors. Talk to a nurse about how your unit involves other members of your family.

 **I’d like to involve my family by**

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Money

Bliss research has shown that during the time they are on the unit, parents with a baby in neonatal care can spend a lot of money on extra things which they did not plan for. This can be things like travelling to a unit far from home, paying for childcare for other children, or paying for parking or food for the time you are in the hospital with your baby.

If you are worried about money, you can talk to your neonatal unit about what support might be available for you. Many units have options available for parents, for example, free parking or food vouchers.



You can find details of other organisations which might be able to support you, including by providing advice about money, on our website – bliss.org.uk/useful-organisations



**I'd like to ask more about money.
I am particularly worried about**

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Talking to someone

It can feel that you are alone when your baby is on the neonatal unit. But you are not alone. If you think that talking to someone about how you are feeling would help you, you might like to try...

- Talking to friends and family. They will want to support you. You might not know what to say at first - try explaining to them that you just need someone to listen. Sometimes it can feel easier to talk when you can see someone's face, so you might like to try video-calling. This can help if people live far away or are not able to visit you at home.
- Talking to someone in your neonatal team that you feel comfortable with. They will want to support you, and will let you know if there is someone in particular who could help you. This could be a counsellor to talk about how you are feeling, or a doctor to explain more about your baby's care.
- Your unit might have details of a counsellor, psychologist or psychotherapist you can speak to, if you think that could help you. You can also talk to your GP about how to access support like this.
- If you want to speak to someone from your faith, or from the hospital's chaplaincy team, ask the unit staff if there is someone available.
- Asking if there is a Bliss Champion on your unit. These are trained Bliss volunteers who provide emotional support to parents face-to-face on the neonatal unit. Ask your unit if they have a Bliss Champion, or look out for a poster which will give times and days they visit.
- The Bliss Netmums forum provides a place for people to talk about their neonatal experience. You can find more information about this at bliss.org.uk/netmums-forum



Facing the unknown

We often hear that parents can find it hard not knowing why their baby was born early or why they have a particular medical condition. It can also be hard when you do not know what the future might bring.

It is ok to feel this way. You might find it helpful to talk to your family and friends, or to keep a journal. Many parents find it helpful later on to look back on how they felt in these first few days.



You are not alone. You can read other parents' stories on our website – bliss.org.uk/your-stories

Sometimes, you might just want to talk to someone.

Our free, confidential helpline service provides phone and email support and information to anyone affected by neonatal care, at any stage in their journey.



You can call the helpline on 0808 801 0322.



Visit bliss.org.uk/helpline for the latest opening hours.



**You can also email us anytime at hello@bliss.org.uk
We will get back to you within 3-5 working days.**

What might happen to my baby next?

It is likely that you will be thinking about the future, and how this start to your baby's life will affect them.

You are at the beginning of your journey, and the health professionals will work with you and your baby every day to get more information about how they are doing. Each day will bring more information about what care your baby will need.

You will probably want to know when you can take your baby home. This can be really hard for families, as they want to start their lives together at home.

It is very hard to know how long your baby will need to stay in hospital, or what care they might need, at this early stage. You will always be kept up to date about changes in your baby's condition, how they are responding to their care and if they might be ready to go home. You can always ask for more information, or for someone to explain anything that you are not sure about.

Sadly, some babies who are born needing care in a neonatal unit do not survive. This is devastating for families, and can be one of the hardest times they will ever face. The unit staff will always work closely with families who are facing a bereavement, supporting them to spend time with and caring for their baby in the way that is right for them.



A number of charities provide specialist support for families who have experienced a neonatal death. These include Sands and Child Bereavement UK. You can find out more on their websites – [sands.org.uk](https://www.sands.org.uk) and [childbereavementuk.org](https://www.childbereavementuk.org)

Units should also have a bereavement nurse who can provide support at this time.

What does that word mean?

When you are new to the neonatal unit, it can feel like you hear many new words. You might hear medical words, or shortened or abbreviated words which you have not heard before. This can feel confusing and overwhelming at a difficult time.

You have the right to understand the care your baby is getting and how they are doing. The neonatal team will work to make sure they explain things in a way that you understand.

If you are ever unsure about your baby's care, or you do not know what some words mean, let the staff know. They will be happy to explain things in a different way for you, and explain anything you are unsure about.



For a list of common words you might hear on the unit and what they mean, visit bliss.org.uk/neonatal-words

We are here to support you

Whatever stage of your journey, Bliss is here to support you and your family.



Visit our website at bliss.org.uk



Ask the neonatal staff for other printed information they have from Bliss



Contact our helpline service by calling 0808 801 0322 or emailing hello@bliss.org.uk

Notes

I found it very helpful to keep a journal. This helped clear my head and meant when I wasn't with my son I was connecting with him by filling in his journal. The neonatal staff also used it to update me on what had happened when I wasn't there.

Zoe, mum to Quinn

You might like to use this space to write down any questions you have, moments you want to remember, or how you are feeling today. You can share this with others, or keep it for yourself to look back on.

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If you would like full details of these references, email us at informationteam@bliss.org.uk



Join the family

If your baby is on a neonatal unit because they were born premature or sick, you're not alone. Find practical information, emotional support and a community of families with a neonatal experience at bliss.org.uk

Join the family, search Blisscharity



Bliss
for babies born
premature or sick