



About neonatal care

An introduction to your baby's care in hospital

Bliss

for babies born
premature or sick





Trusted Information Creator

Patient Information Forum

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or sick

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Written, edited and researched by:

Connor Lane
Rachel Jarmy
Mary-Clare Ridge

Designed by:
Joana Águas

Acknowledgements:

We would like to thank the following
members of the Bliss Involvement
Group for their help developing this
information.

Healthcare professionals:

Alan Fenton
Tim van Hasselt
Emily Prior
Fauzia Paize
Sara Clarke
Cheryl Curson
Anna Francis
Katy Parnell
Charlotte Xanthidis
Lorraine Cairns
Emily Hills
Gillian Bowker
Claire Campbell

Public members:

Catia Martins
Katherine Bailey
Sophie Amey
Thomas Padden
Louise Bryant
T'Lise Gibbs-Ward
Charlotte Howell
Ashleigh Fallows
Gemma Lovegrove
Molly Fieldhouse
Dolly Emerson-Smith
Hannah Salton



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Introduction

“For anyone just starting their neonatal journey, my best advice would be to take it one day at a time. Accept any bit of help from family and friends that’s offered without feeling guilty about it. Be kind to yourself.”

– Sara, mum to Ben

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.

This booklet has been written with parents and healthcare professionals, to help you find your way when you first arrive on a neonatal unit. It explains daily routines, some of the equipment you might see, the hospital staff and support workers you might meet, and the medical words you might hear.

It offers ideas on how you can look after your baby and bond with them. We have included some simple suggestions of what you can do as a parent to support your baby, in partnership with your care team. We have also included some things you can do to look after yourself during your time on a neonatal unit.

This guide can help you think through any questions you may have for your baby’s care team. There is space for you to write down your thoughts throughout this booklet and at the back. This could include 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, at every stage of your neonatal journey, and we are always here to support you.

About us

We are Bliss, the leading UK charity for babies born premature or sick. We were founded over 40 years ago by parents determined to give all 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.

How Bliss 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 and practical support through:

- **Our email service:** hello@bliss.org.uk
- **Bliss Champions:** volunteers offering support on the neonatal unit and via video call. Ask a member of staff if a Bliss Champion is available on your unit or book a one-to-one conversation on our website.
- Our video call service with one of our trained volunteers:
bliss.org.uk/support-via-video-call-form
- Our moderated peer-support group on Facebook.
Search '[Bliss community support group](#)' on Facebook.

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.

Before you read on

This information has been written to give you a better understanding of neonatal care. It is designed to help you understand the medical advice you might be given about your baby's care. It is also designed 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, as well as the doctors, nurses, midwives and other staff who help to look after their babies. 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.

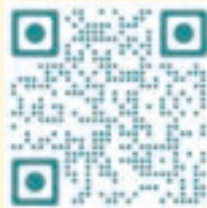
Bliss provides information and support to parents, and does not give specific or individual advice on medical care.



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We hope you find this helpful and comforting and if you have any feedback, we would be glad to hear it.



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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 soon after they are born. The word 'neonatal' means newborn, or the first 28 days of life.

Over 90,000 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 neonatal team of healthcare 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 are born with, or develop shortly after birth, a medical condition which needs treatment in hospital
- they have a low birthweight
- they experience a difficult birth

More information on each of these is given below.

Why is my baby in neonatal care?

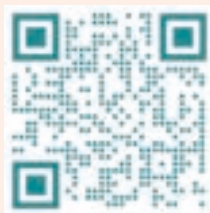
Sometimes, the cause of premature birth or a medical condition will not be known, and you will not know exactly why this has happened. You can always talk about why this might have happened at postnatal check-ups or with your midwife.

“It was a massive shock to me as I was at full term and had no complications in my pregnancy. I felt like I couldn’t talk to anyone because everyone tries to relate as though they have been through something similar, when they haven’t had a baby in neonatal care. Reading the stories on the Bliss website helped me to feel less alone.”

– Jasmine, mum to Tobias

Remember

You are not alone. You can read other parents’ stories on our website, including those featured in this booklet – bliss.org.uk/your-stories



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Premature birth

A baby who is born before 37 weeks of pregnancy is 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.

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

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. Your baby may have a condition if they were born early, or if they were born at term. 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'). 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. NHS Choices also have useful pages on lots of conditions. You can search via nhs.uk



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Difficult birth

If your baby had a difficult birth that required some extra medical attention (for example using forceps), they may receive care in a neonatal unit. This could be to treat them for any injuries or just to keep an eye on them for a short time before they go home.

Good to know

Sometimes your baby may be separated from you shortly after they are born. This could be for a number of reasons but usually means they require special care somewhere outside of a maternity ward. The maternity care team will do everything they can to give you some time with your baby before they are moved, but this may not always be possible.

How does neonatal care work?

“The whole experience was an absolute journey – it was the last thing I expected to happen. At the time it feels so difficult, shocking, and it’s really hard to process. I struggled with post natal depression, but I promise that it does get better, and it will get easier.”

– Sandra, mum to Saint

Neonatal networks

Neonatal care in the UK is organised into geographical areas where hospitals work together to share knowledge, skills and care. These networks create smooth care pathways so the right level of care is accessible to all babies and as near to home as possible.

Levels of care

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

Babies admitted to a neonatal unit receive 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 15 for more information.

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

Transitional care

This is where you and your baby stay together in hospital during their care. 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.

Some babies born between 34 and 37 weeks' gestation, or babies with mild jaundice or feeding problems, get the care they need in this way. If you are re-admitted into care after going home, this is where you and your baby might be cared for.

Not all hospitals support transitional care so talk to your care team if they have not spoken to you about it.

Special care baby unit (SCBU or SCU) – Level 1

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

In some hospitals 'phototherapy' (treatment for jaundice) may be given in the postnatal or transitional care ward, so that your baby can stay with you while being treated.

Local neonatal unit (LNU) – Level 2

This is for babies who need a higher level of medical and nursing support. If your baby was, or will be, born between 27 and 31 weeks' gestation you may be transferred to an LNU. Care on an LNU might include:

- Short-term intensive care (usually up to 48 hours).
- Short-term ventilation, continuous positive airway pressure (called CPAP) or high flow therapy, for breathing support.
- Care during periods where their breathing pauses briefly, called 'apnoea' (pronounced ap-knee-ya).
- 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) – Level 3

This is for babies with the highest need for support lasting more than 48 hours. 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. Some of the reasons babies are cared for here are when they:

- Need help with their breathing (called ventilation)
- Need help with their heartbeat and blood pressure
- Have a moderate to severe condition affecting their breathing (called respiratory distress)
- Need longer-term feeding support through an intravenous (intra-venous) tube or general nutritional support
- Need or have just had surgery – including cooling treatment for brain injuries

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

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. 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 unit. 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 help you to make your decision 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 healthcare professional should discuss 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 or specialist treatment. At this stage they might be moved closer to home. This allows another baby to have access to the care your baby received when they were unwell.
- 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 can be moved back to the neonatal unit depending on their condition. They will only be transferred when the neonatal team feel they are well enough for the journey. Sometimes, they might not return to a neonatal unit and could be cared for on a paediatric unit closer to where they had their operation.

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 or 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 is not possible for you to travel with them, you can discuss this with your baby's care team and the transfer team. They will talk to you 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 be with 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.

You can talk to your care team about what support is available to you for 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.

Care on the unit

When your baby arrives on the neonatal unit, one of the nurses or another member of your care team should show you around and explain the routines. If you know you have a higher likelihood of spending time on a neonatal unit, you may be offered these explanations before giving birth. Some units have virtual tours which you can watch before arriving and some offer in-person tours. Talk to your antenatal care team or midwife to see if this is available for the hospital you are booked in at.

Remember

You need to register your baby's birth.
Find out more at gov.uk/register-birth.



Scan me

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 and at regular times after that. They will know that you are likely to feel worried and anxious and will do what they can to put you at ease.

"My advice to every other parent would be that every milestone reached should be celebrated. I think that talking to the other parents on the ward is vital, as they are truly the only people who know what you are going through. Parents should really try to get involved in their baby's care such as feeding and changing. Although it is very scary, it does help with the bonding process. I know this first hand."

– Tom, dad to Gracie

Staff schedules

Staff on the unit work in shifts, coming on duty and going home at set times.

Handover allows the day and night staff to share information about your baby's care. Ward rounds happen once or twice a day. This is where you and your neonatal care team plan your baby's care.

Being there when your baby is being discussed and their care is being planned is helpful to being a partner in your baby's neonatal care. 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

In addition to being part of ward rounds, the nurses helping you to care for your baby can update you on their progress when you are on the unit. If you are not on the unit, this can be done over the phone or through a video call. 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 one of your nurses.

If you aren't on the unit, 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.

Some units use direct video services, such as **'vCreate'**. These allow staff to securely record videos of your baby and send you regular updates. Not all units use this service but you can ask the staff on your unit if this is available.

Information about your baby's daily nursing care will be recorded in their bedside notes or recorded electronically. If these are stored electronically, you can ask your care team to explain them to you. You should also be able to leave notes about your baby for staff to read. Your baby's formal 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 hygiene policies to protect them. The nurses on your unit can explain the details to you.

Good to know

Because of COVID-19, some units might be using extra protection measures to control infection. You may also be asked to wear some personal protective equipment (PPE), for example, face masks. These measures can regularly change, so it is worth talking to your care team about this.

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.

Find out how to wash your hands thoroughly to help reduce infection on our website –

bliss.org.uk/winter



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Family members will need to stay away if they have COVID-19, 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 tested for infections when they are first admitted into the unit. This is done by lightly brushing your baby's skin with a cotton swab. This is to help the staff know what they might need to treat.

Being with your baby

Parents are not considered visitors, as you should be able to be with your baby as much as you would like. It will be very important to the staff that you are not separated from your baby unnecessarily.

For security reasons, the unit will only be accessible to staff with relevant passes. Parents and visitors will usually be able to ring a doorbell to gain access.

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.

Most units encourage brothers and sisters, grandparents and other family members to visit. This will depend on current restrictions which can change due to infection control measures.

If you can, it may be nice to bring your children to see their new sibling in hospital. Even when they can't visit, your children can stay in touch with your new baby. You might like to give your child a picture of their sibling to keep, or organise a video call with the staff or when you are there.

Good to know

If you have other children, you can encourage them to make cards or drawings to hang near your baby's cot. This can help them to bond with their new sibling.



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 other parents and visitors to respect the space around babies' cots and to not disturb them while they rest. They will also be asked to not read care or medical notes of other babies on the unit.
- Provide a private place for discussions about your baby's condition and treatment.

In some units, parents might be asked to leave the room if staff are having confidential conversations about other babies. 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.

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

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 right environment 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 at a quiet level
- Making sure babies have lots of time to rest
- Asking everyone to not use their phones while around babies and their medical equipment

Good to know

Being quiet in the unit does not mean that you can't talk or sing to your baby. In fact, doing this can really help you and your baby to connect and for your baby to feel reassured. Listening to the sounds of your voice also helps with their early language development.

Being a parent on the unit

“I remember holding her for the first time – it wasn’t what I envisioned while pregnant. All the wires, the sounds of the beeping machines, the cluttering of hospital noises, babies crying, the feeling of complete fear. Yet also, the wonders of the little life you made. How precious. How tiny. Yet in those moments, you find that your strength returns. So does your hope, your love and even though you are scared, just for those few minutes, life is perfect.” – Sherry, mum to Jevonne

If your baby was born premature or sick, they were probably moved to a neonatal unit soon after birth. Arriving in the neonatal unit can make many parents feel like they aren’t doing what parents should do for their baby. Parents often feel helpless and worried. This is completely normal.

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.



Healthcare 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.

Some units now use a model of care, called 'family integrated' care – often called 'FICare' by staff. This is a model of neonatal care designed to make families the primary care givers for their baby, in partnership with their care team. On a FICare unit, the care of the baby is often planned around the needs and availability of the family. There is more information on FICare further down in this section.

We've included some things you can do to be more involved in your baby's care over the next few pages. Talk to a nurse or member of the team about what else you can do to parent your baby on the unit.

Remember

You are your baby's parent. Your baby knows your voice, your smell, and will be comforted by you being there.

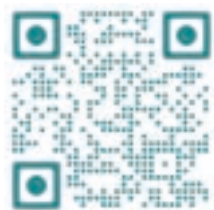
Feeling closer to your baby

For some parents, the care needs of their baby may mean that there are limitations on how much they can physically care for them. 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 distant from your baby.

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:

- If your baby is in an incubator and isn't ready to be picked up, ask your care team about 'comfort holding'. This involves placing one of your hands on your baby's head and the other at the base of their feet.
- 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



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Good to know

It's recommended that you have two pieces of cloth or clothing to put in your baby's incubator. Keep one in the incubator and one on yourself. Change these regularly so they keep your smell. Ask your care team if they have any materials you can use, or if they can recommend material that is safe for your baby.

“Seeing your baby wired up to machines or in an incubator is so difficult. As tough as it is, do what you can to build your relationship. Read stories to your baby, sing them a song, hold their hand through the portholes. Take part in the care routine, learn how to tube feed and take part in skin-to-skin. Your bond with your baby is just as important as your partner’s.” – Carl, dad to Stanley and Hayden

 Things I'd like to ask the care team about feeling closer to my baby

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Watching your baby

It is really important to spend time getting to know your baby. Sometimes you might feel like you spend a lot of time just looking at them. Watching your baby can help you to learn how they show signs they might be uncomfortable or in pain, as well as being calm and content. This can help you to know what you can do to soothe and comfort them.

Combined with your natural intuition as a parent, watching your baby 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

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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. It also has been proven to help your baby's sleep, growth and has other physical benefits. 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.

"I finally got to hold him and have my first skin-to-skin experience when he was five days old. It was an amazing feeling, but I was also very nervous about holding him because he was so small and fragile. The nurses were very reassuring that I wouldn't be causing him any discomfort or pain." – Roshni, mum to Ivan

The team will help you to get your baby onto your chest. This might take a little time if your baby is attached to 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



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Good to know

If your baby was born very prematurely or with complex care needs, it may be a while before you can hold them. By spending time watching your baby, they will be comforted as they learn your face and your smell. Just by being there you are doing enough.

 Things I'd like to ask the care team 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 have suck feeds straight away but can be fed milk through a tube straight into their tummy. This is called 'enteral nutrition'.

Sometimes a baby's tummy might not be mature enough to digest any kind of milk, and so they are given their nutrition through their veins. This is 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.

Sometimes a fortifier is given to some babies to make sure they receive all the nutrients they need on top of their breastmilk. This is added straight into their milk.

Moving on from tube feeding to suck feeding (or breastfeeding) is a milestone which most babies will take time to master before leaving the neonatal unit. Your baby will start to show signs they are ready to try suck feeding by their own patterns of hunger, wakefulness, feeding cues and communication. You may notice these during skin-to-skin or at tube feed times. Offering your baby opportunities to suck in response to these cues allows them to develop their suck feeding skills at their pace and following their developmental skills. Your care team will be available to help you with this transition.

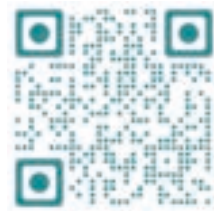
Breastmilk and breastfeeding have specific benefits for preterm babies. It can take time for your baby to learn to breastfeed. With support though, they will be able to receive the nutrition they need from breastfeeding. Your neonatal team will help you and your baby to practise their suck feeding and to need less tube feeding so they are ready to go home.

Feeding is a great time to be involved with your baby's care and make lasting memories you can treasure as they move from skin-to-skin to sucking and feeding without a tube.

“Finding resources like Bliss and other parents in similar situations on Facebook support groups has been a lifeline. There is plenty of advice out there for breastfeeding and bottle-feeding, but long-term tube feeding can be a lonely and isolating road. Seeking support can give you the courage to get through the early days – it does get easier.”

– Sheelagh, mum to Rhea

Lots of mums have difficulties with breastfeeding and expressing - this is completely normal. The NHS website has lots of information and links to breastfeeding support groups who can help.



Scan me



Things I'd like to ask the care team about feeding my baby

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Washing and changing your baby

The nurses and neonatal team can support you to wash your baby and change their nappy. This can feel difficult when they are connected to wires and monitors. The nurses will show you the best way to do this to make sure your baby is comfortable when you feel ready. Doing these things, sometimes called 'your baby's cares', helps parents to be more involved in their baby's day-to-day needs. This can help you to bond with your 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.

Good to know

If you are not always able to be on the unit, it is worth asking your care team when the 'first time' for things will be, for example, washing, changing and feeding. This will help you plan your time on the unit and be there for important milestones in your baby's early life.



Good to know

There are some things you can bring into the unit with you to help you feel more comfortable for long periods of time. This could be something like a blanket or pillow, book or phone charger. This can be different across units, so it's worth asking your care team about what you can bring and what they think might help.



Pampers Preemie Protection nappies
are specially
designed for
premature babies.



Pampers smallest nappies are designed to be extra-gentle on their delicate skin and protect it as it continues to develop.

P3



For babies
weighing <500g

P2



For babies
weighing <1000g

P1



For babies
weighing <1800g

Pampers Preemie Protection nappies are now available for free from any Tesco Pharmacy.

In-store only and subject to availability. Parents and families of premature babies can ask for free packs from any Tesco Pharmacy during pharmacy opening hours. To find your nearest Tesco Pharmacy, please visit the Tesco website.

in partnership with

TESCO Pharmacy+

#PampersForPreemies
Pampers.co.uk



Premium softness

Silky soft, smooth fibres and cuffs provide comfort to babies' delicate skin.



Breathable layers for skin dryness

Thousands of micropores let air circulate through the diaper to help keep babies' skin dry.



All around leakage protection

Wick away liner pulls urine and mess away from skin. The soft wraparound sides and deep dual-layered cuffs help prevent leaks.



Making decisions and getting consent for your baby's care

Your baby is at the heart of your family. 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.

You may not always be able to see a physical copy of your baby's medical notes because they are stored digitally. You may need to make a formal request to see your baby's full medical record but your care team can help you do this. They will be happy to talk to you about anything that is unclear.

The care team 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 the care team about making decisions

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Family-integrated care

This model of neonatal care is an extension of family centred care. The aim of family-integrated care – often called FICare – is for parents to become the primary care giver for their baby while on the unit. The unit care team will provide a structured programme that helps parents to be as involved as possible in their baby's care. It also supports parents to make the most of their time on the unit.

If you are on a 'FICare unit', it is important to remember that you do not have to do all the FICare activities if you do not feel comfortable. The staff will guide you every step of the way and these responsibilities will become easier to deliver over time.

FICare activities may include:

- Supporting the preparation of care plans on a daily basis, whether you are on the unit or not.
- Contributing to your baby's ward rounds e.g. introducing your baby and updating staff on how your baby is progressing.
- Carrying out basic day-to-day cares e.g. washing and changing, as well as more advanced cares, such as attaching monitoring equipment.

If you would like some more information about FICare, your care team will gladly talk to you about it.

Good to know

Parents often find the best support during this time by talking to other parents on the unit who are going through similar things. You might like to try spending some time in the family room or kitchen on your unit.

Looking after yourself on the neonatal unit

“It’s much easier said than done, but focusing on the things I could control really helped me through those months. Eating decent meals, getting some kind of exercise, writing in my diary, or talking to other people gave me a focus and helped me feel I was doing something useful.” – Hannah, mum to Max

Having a sick or premature baby in a neonatal unit can have a huge impact on you. The experiences you might face on the neonatal unit, and while you are away, can affect your emotional wellbeing and mental health.

It is very common for parents to forget about taking care of themselves while they are on a neonatal unit and if they are unable to be with their baby on the unit. Your thoughts are likely to be almost completely about the care of your baby.

It can be difficult to think about yourself and your own needs. But remembering that you are a person that also needs care is very important to yours and your baby’s wellbeing.

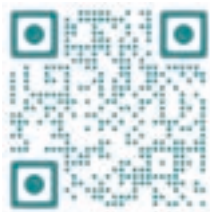
Here are some of the things that parents have shared with us that helped them through their time on the neonatal unit:

- Writing a diary of how you are feeling day-to-day.
- This can also include writing down questions that you would like to ask your care team. There are some common questions you might like to ask your care team further on in this section.
- If you are staying on the unit, it can help to spend some time outside each day – this could involve going for a walk or just finding somewhere outside to sit down and get some fresh air.

- Spending some time at home while your care team looks after your baby – going home for a good night's sleep or a good meal can really help to improve your wellbeing. This can feel really difficult but your baby will be well looked after while you are away.
- Asking your care team how you can be most involved in your baby's care. If you are only able to be on the unit for a certain time, ask your care team if they can make a care plan with you so you can get the most out of your time with your baby.

You can also join our private peer-support group on Facebook which is moderated by our support team. This is a safe space for parents to share their thoughts and concerns, and offer emotional support and practical advice to each other.

Search **"Bliss community support group"** on Facebook or scan this QR code using your phone camera.



Scan me

Good to know

Having a baby in neonatal care is like no other experience. All of your feelings and emotions are normal, even if they feel irrational. Everyone is different and there is no 'right way' to feel. Take each day as it comes and be kind to yourself.

Neonatal staff and what they do

The neonatal team

Different healthcare professionals work as a team on the neonatal unit. You will see different people 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.

Your unit may have a chart of the staff on the unit, and the uniforms they wear.

Nurses and nurse associates

- Nurses will support you in providing most of the day-to-day care for your baby.
- Nurses can also help you with kangaroo (skin-to-skin) care and breastfeeding.
- 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.
- Talk to the nurses right away if you are ever worried that your baby is in pain, or you feel something isn't right.

Remember

You can always ask your care team about anything that is unclear. Don't be afraid to question things that don't seem right to you. Your care team will understand and will want you to be as informed as possible about your baby's care.

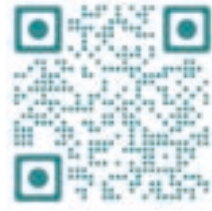
Doctors

- Doctors coordinate your baby's treatment in partnership with you.
- They can answer your questions about your baby's treatment, medical conditions 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.

"We are so thankful to the doctors who saved Saoirse's life and to the nurses who looked after not just my baby, but me as a parent. They offered words of encouragement and support and became like family. They shone a light when things seemed dark." – Pia, mum to Saoirse

Other staff you might meet

All units have different staff, depending on the level of care that needs to be given. There are a lot of other people that might help to look after your baby. Scan the code on this page to find out more or ask your care team about these roles if you want any more information.



Scan me

“Soon the day came when they informed us that my kids were ready for us to take them home. It was an emotional and extremely cooperative journey with the NICU staff. I am so thankful to them for their support and help. Be brave, it may be hard initially but you can handle it.” – Mubeen, mum to Muhammad Ali and Muhammad Hussain

 **Some other staff I'd like to talk to are**

Things you can ask your care team about

You are encouraged to ask your care team about anything you are curious about or anything that is unclear. Parents often tell us that knowing what to ask or even remembering what you have been told can be difficult during this stressful time. This is completely normal. Your care team will understand and will be happy to answer your questions or repeat anything you have forgotten.

We have listed below some of the common questions from parents that you can ask your care team. This will help you to be more informed and involved in your baby's care:

- When will their first time be for: getting dressed, coming out of the incubator, changing nappies, feeding, bathing?
- Where can I find clothes and nappies that fit my baby (if they are born smaller)?
- What can I do to look after my baby and strengthen our bond while they are in an incubator or connected to other medical equipment?



- How can I plan my time on the unit to maximise the time I spend with them?
- What is this procedure/treatment/medicine? How does it work? How is it supposed to help my baby?
- Are there any procedures I can be taught to be more involved in their care?
- When can I talk to a senior member of the team and how often?

It is also important to think about looking after yourself during this time. Here are some questions you can ask about what kind of support is available for you and the rest of your family:

- What sort of mental health and wellbeing support is available for me?
- What facilities are available on the unit for me and my family?
- When can my other children or the rest of my family come to see my baby?
- What can I bring onto the unit to help look after myself and my baby?
- What sort of support is available in my area once we are home?
- Where can I look for peer-support from other families who have experience of neonatal care?
- What sort of practical planning do I need to think about for when we go home? E.g. insurance, equipment at home and follow-up appointments.

We are here for you. You can contact our support team via email or book a video call with one of our volunteers at bliss.org.uk/parents/support/emotional-support or scan this QR code using your phone camera.



Scan me

Equipment on the neonatal unit

"We were then taken into the NICU. It was a room that never slept, surrounded by tiny incubators, all producing different beeps and flashing lights – it was a sensory overload. It's crazy that today, at one year old, Leo's favourite things are flashing lights and saying 'beep'."

– Destiny, mum to Leo

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 seeing their baby 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 or the birthing parent. The oxygen in the mum or birthing parent's blood passes across the placenta (afterbirth) 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 to help them breathe. There are a few different types of breathing machine:

- **Ventilators** blow air with or without added oxygen (depending on what your baby needs) gently into your baby's lungs through a tube. This is placed into their windpipe through their nose or mouth. This inflates your baby's lungs and is 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 lung conditions.

Other breathing machines can include:

- **Continuous positive airway pressure (CPAP)**
Continuous positive airway pressure (often shortened to 'CPAP') blows 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.
- **Non-invasive positive pressure ventilation (also called 'BiPap')**
This is given through a mask or a small tube in your baby's nose and helps to regulate their breathing.
- **Humidified high-flow nasal cannula (also called HFNC, or 'high-flow')**
Some babies need help with their breathing but do not need something as strong as a ventilator. High-flow 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.

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

This is put down your baby's windpipe (called a 'trachea' by healthcare 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 to check that it is beating properly. They can also pick up changes in your baby's breathing. The monitors pick up these signals through small pads put on your baby's chest. Wires run from the pads to the monitoring machine.



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



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

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.

Intravenous (pronounced in-tra-vee-nus) drip

Your baby might have thin tubes (sometimes called IVs, drips or cannulas) 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 32. If your baby can't feed by themselves yet, they might be able to have breastmilk, donor milk or formula through a tube. This tube 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.



Other equipment you might find

Umbilical catheter (pronounced umm-bill-like-al cath-it-er)

These long, soft tubes are put into the blood vessels in your baby's belly button. Umbilical catheters are mostly used in the first few days after birth. There are two types – one goes into an artery (blood vessels which carry blood full of oxygen from the heart and to the rest of the body) and is used to measure blood pressure and to take blood samples to check levels of certain important gases. The other kind goes into a vein (smaller blood vessels which take blood with less oxygen back to the heart) and gives your baby nutrition or medicine. These catheters can have one or more tubes, allowing for different tests to be taken at the same time and avoiding disturbing your baby.

Long lines

These are very thin tubes passed into one of your baby's larger veins. Long lines are often used for giving nutrition and certain medication. This can be a fiddly procedure if your baby is very small, but it is non-invasive. It might need to be done in a sterile environment where you are not able to join. Your care team will explain all of this to you.

Phototherapy lamp or light blanket

If your baby has jaundice, they may be treated with blue light lamps (called 'phototherapy lamps') or a special light blanket (called a 'bili-blanket'). Jaundice (pronounced 'jawn-diss') is the name for yellowing of the skin and the whites of the eyes. It is very common for newborn babies to get jaundice. In most cases it is harmless and goes away without needing treatment by the time your baby is about two weeks old.

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Medical tests, scans and care

“It broke my heart seeing my babies all wired and tubed up. The nurses were lovely and so much more than nurses – they are truly special people! Although NICU is so hard and you are constantly worrying when a beep goes off, I couldn’t have felt like I was in more caring hands.” – Samantha, mum to Bowie and Honey

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 needs can be met as they change. They allow the neonatal team to see how they are responding to their care. This helps with making 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.

During these procedures you may be able to comfort your baby to reduce their discomfort. This can be done through comfort holding (cradling their hands and feet), skin-to-skin or giving them a dummy and some expressed milk. 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.

Here 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. There are many reasons why your baby may need their blood sugar monitored. Most commonly, 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 will be monitored more closely. This is because they may have problems keeping a healthy blood sugar level.



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 information about how your baby is breathing. Blood gases 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 it is monitored. If the level does get too low, your baby might 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. You may hear your care team talking about 'C-reactive protein' or 'CRP'. These are part of your immune system and their levels go up with infection. Checking these levels helps to see how well your baby is fighting an infection, or if an infection is starting.

Good to know

Sometimes, your baby might need to have multiple blood samples taken over a short period of time. This might mean that they need a blood transfusion to replace the blood that is used for testing. This is nothing to worry about and you can ask the care team about comfort holding and other forms of parental touch to help soothe your baby during these procedures.

Scans

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

X-ray

X-rays are often used to look at your baby's chest, especially when they are having breathing support. They are sometimes used to check for problems in the gut if your baby is not feeding well. X-rays use tiny amounts of 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 but they are not harmful to your baby.

Ultrasound

This type of scan uses ultrasound waves to build a picture of inside the body. 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. These scanners are usually in a different part of the hospital from the neonatal unit. Sometimes they may be in a different hospital altogether and your baby will need to be transferred. This means your baby might have to wait until they are ready to be moved. Sometimes, your baby might need to be sedated for their scan to make sure they stay still enough for the scanner to work.

Lumbar puncture

Some babies can get an infection around the outside layers of their brain and spinal cord (called meninges). This infection is called 'meningitis' which can be serious if it is not diagnosed and treated. If doctors are worried your baby might be getting this condition, they will take action quickly. 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 or sitting up and leaning forward. 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, or a mild sedative may be used.

Screening for genetic conditions

Sometimes, the neonatal team might want to check to see if your baby could have a condition they were born with. These can be passed on genetically – which means they are passed down from parents to their children. They can also develop on their own for other reasons that are not genetic. The doctors will talk to you about these tests, if they think they are needed.



Vision and hearing tests

All babies will have vision and hearing tests after they are born. Babies who are born prematurely are more likely to have problems with their sight and hearing, so they may have some extra tests. Some babies with particular medical conditions may also have their sight and hearing tested whilst on the neonatal unit.

Babies born before 31 weeks' gestation or below 1500g of weight at birth will be screened for a condition called 'retinopathy of prematurity', or 'ROP'. This can be a serious eye condition if it isn't picked up and treated quickly. 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 (optal-molo-gists) can also look for other eye problems. Babies born prematurely or with other medical conditions can also be at higher 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, during their time on the unit or on the postnatal ward.

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 focuses on your baby's airway and breathing. Equipment may also be brought to the delivery room or postnatal ward if needed. The neonatal team will come to your baby to support them until they are stable enough to move to the neonatal unit if needed.

Sometimes, doctors might press on your baby's chest in a rhythm which can help start their heart again. These are called 'cardiac compressions'.

Good to know

If you think that your baby has stopped breathing, there will be a red button somewhere around their incubator or cot that you should press. This will sound an alarm that immediately calls the care team to come to your baby. The best way to help in this situation is to make sure you give the care team space to work. This can be extremely difficult but it is vital to allow space for them to help your baby.

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

[illegible]

Support for you and your family

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. Below 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.

You can use this booklet as a way to prompt discussions with your care team about any questions you have or anything you are not sure about.

Remember

There will be good days and bad days and it's okay to cry. Crying can help you express your feelings and relieve stress. Try to focus on the good things that happen and celebrate each milestone reached.

Dads and non-birthing parents

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 often hear that partners can often feel helpless, and unsure what they can do.

Family-centred care and family-integrated care helps to involve the whole family in the care of the baby.

Both parents are important to the care of their baby. This can include skin-to-skin contact, comfort holding, washing, changing and feeding. These can help you bond with your baby and be more involved in their care.

“Of course it’s all about the babies and naturally, my wife was the main parental focus for much of the time, but to have a moment to acknowledge the joy of being able to be Daddy to these two miracles meant so so much that day.” – Jason, dad to twins, Xavi and Anya





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 help to care for your 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 care team 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 personalised information based on your location offering helpful and practical information around finances for families on our Info and Support Hub –

bliss.org.uk/financial-info-support-hub



Scan me

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

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Talking to someone

“It’s so important to reach out for support – I really wish that I had reached out to Bliss after I had seen the leaflets on the unit. The NICU experience is so unique, you don’t understand it unless you’ve been there, so connecting with other parents is so important. We still have really good friends who we met on the unit.” – Thomas, dad to Joseph

It can feel very isolating 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 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.
- Talk to our support team or one of our Online Bliss Champions by emailing: hello@bliss.org.uk
- Our moderated peer-support group. This is a private group for parents who are on a unit, or are at home after spending time on a unit. It allows parents to talk to each other and seek support from other parents with neonatal experiences. Search '**Bliss support group**' on Facebook to join, or scan this QR code with your phone camera.



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I'd like to get more support by talking to

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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 okay 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 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



Scan me

You can also listen to a growing number of these stories on Spotify. Search '**Bliss charity Your Stories**' or scan this code.



Scan me

We're here to support you

Sometimes, you might just want to talk to someone. Our email and video call support and information is available to anyone affected by neonatal care, at any stage in their journey.

You can organise a video call with one of our online Bliss Champions – bliss.org.uk/call



Scan me

You can also email us anytime at hello@bliss.org.uk

What might happen to my baby next?

“To anyone going through this now, I am so sorry. I know you will suffer, you will hurt, but you will dig deep, you will find the strength and you will find your path. I promise.” – Jessica, mum to Hettie

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

You are at the beginning of your journey, and the healthcare 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 included in decisions that affect your baby's care and discussions about changes in their condition. This will include how they are responding to their care and if they might be ready to go home. As your baby gets closer to going home, you will be involved in the planning for their discharge. 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 to care 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, Child Bereavement UK and Together For Short Lives. You can find out more on their websites – sands.org.uk childbereavementuk.org and togetherforshortlives.org.uk

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

Even though you may not experience this yourself, there may be others in the same room as you who do. This can be very difficult to deal with. Parents have told us that this can cause feelings of guilt because their child was doing ok, or serve as a reminder of the possibility. All the feelings you might have about this are valid. You can talk to the care team or contact us if you would like someone to talk to, using the information on the next page.

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, 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 getting on. The neonatal team will work in partnership with you 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



Scan me

We're here to support you

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

Visit our website at support.bliss.org.uk

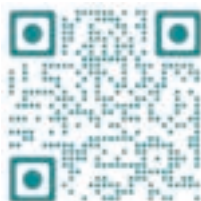
You could also ask the neonatal team if there is a Bliss Champion on your unit.

Contact our email support service hello@bliss.org.uk, or book a video call with one of our volunteers through bliss.org.uk/call

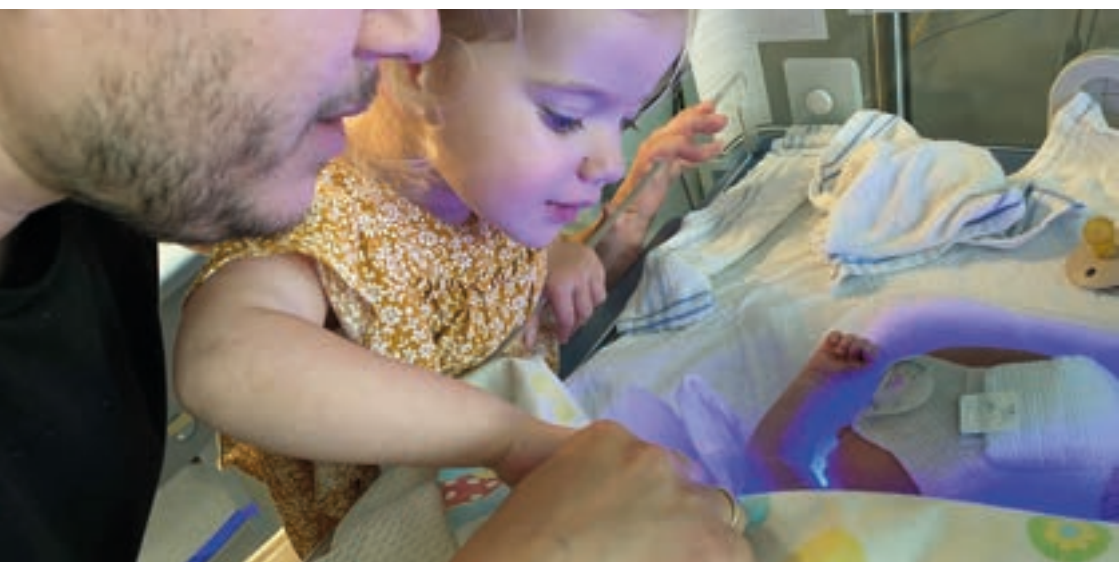


Scan me

Ask the neonatal team for our **'Going home from the neonatal unit'** booklet, or order for free from our online shop through bliss.org.uk/info-shop



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 Your 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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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 on Facebook, X and Instagram



Bliss
for babies born
premature or sick

