North West Anglia
NHS Foundation Trust

Welcome to the
Special Care Baby Unit (SCBU)
Hinchingbrooke Hospital
Family Guide



If you would like this book translated, please use the following QR code to view the booklet on the East of England Neonatal Network website.

Glossary

You hear a lot of new words when you're on SCBU, so we've put together this alphabetical list to help you check anything you're not sure about. You might find it helps to have it with you when you're speaking to your nurses.

AHP - Allied Health Professionals

Bliss - A charitable organisation

Cares - The word we use to describe giving mouth care and changing nappies

CPAP - Continuous positive airway pressure

FICare - Family Integrated Care

LNU - Local Neonatal Unit (Level 2)

MNVP - Maternity and Neonatal Voices Partnership

NGT/OGT - Nasogastric or orogastric tube feeding

NICU - Neonatal Intensive Care Unit (Level 3)

NNAP - National Neonatal Audit Project

Outreach Team - Our team who visit you once you've gone back home

PAG - The Parent Advisory Group

PaNDR - Paediatric & Neonatal decision support & Retrieval service

ROP - Retinopathy of Prematurity

SCBU - Special Care Baby Unit (Level 1)

UNICEF - Baby Friendly Initiative

Family Integrated Care - FICare

The Family Integrated Care (FICare) philosophy is embedded on SCBU.
FICare is a model of neonatal care which promotes a culture of partnership between families and staff; **enabling and empowering parents to become confident, knowledgeable and independent primary caregivers.**

Throughout the SCBU family guide, you will find that there are one or multiple coloured circled after each heading, which relate to the five pillars of FICare.

The five pillars of FICare are:

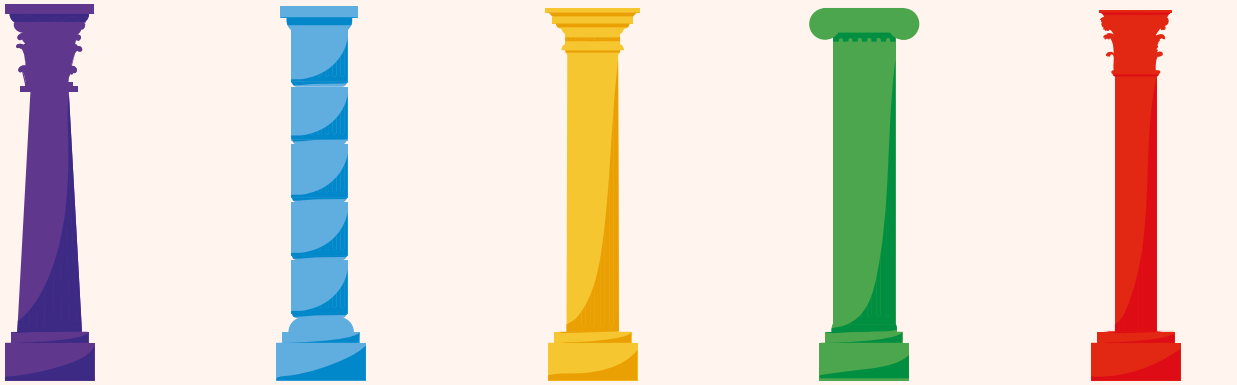
Partnership with families on the Neonatal Units

Empowerment on the Neonatal Units

Wellbeing on the Neonatal Units

Culture on the Neonatal Units

Environment on the Neonatal Units



Dear Family

Congratulations on the birth of your baby!

Here on SCBU we provide specialist care for babies born prematurely, too small, and those who are born unwell.

Whilst on the unit, you will be the primary carer for your baby. You will be involved in decisions about your baby's care with the support of the neonatal staff, so please talk to us about anything you are unsure of, we are always happy to help.

As this is not somewhere you probably expected to find yourselves after having your baby, we hope that the information in this booklet is useful and explains some of the aspects of neonatal care, from when you first arrive to going home.

Welcome to SCBU

The SCBU team are here to provide the specialist neonatal care your baby needs. Our aim is to ensure that you become confident and skilled in looking after your baby, as soon as possible. From day one you can be involved in some aspects of your baby's care, no matter how sick or small they are, such as containment holding, mouth care or skin-to-skin (this booklet talks more about each of these later). How much or how soon you want to be involved in your baby's care will differ from person to person. There are no set rules and our staff are experienced in supporting you, however confident you feel.

Our ultimate goal is to help you get home as a family when the time is right.

Our Philosophy of Care

While your baby is with us on SCBU, we will strive to provide you and your baby with the best in family centred care facilitating a healing, nurturing environment which provides developmental and emotional support to meet the diverse needs of every family.
We view parents/carers as partners in care and ensure every baby and family are treated with respect and dignity throughout their neonatal journey. Any feedback you have to support us to improve our service, is highly valued.

Safety and Security

The doors to SCBU are locked at all times. To gain access, please ring the doorbell and we will answer as quickly as possible. You may be asked to identify yourself as a safety precaution if we do not recognise you straight away. You will also need to inform a member of staff when you are leaving so the door can be opened for you.

Key Phone Numbers

SCBU Nurses station 01480 416250
Outreach Team 01733 677235 (this is a non-emergency answer phone, please leave a message and the outreach team will get back to you. If you are very concerned and have had no answer on the above number, or it is outside working hours please call SCBU and ask to speak to the sister in charge - 01480 416250)

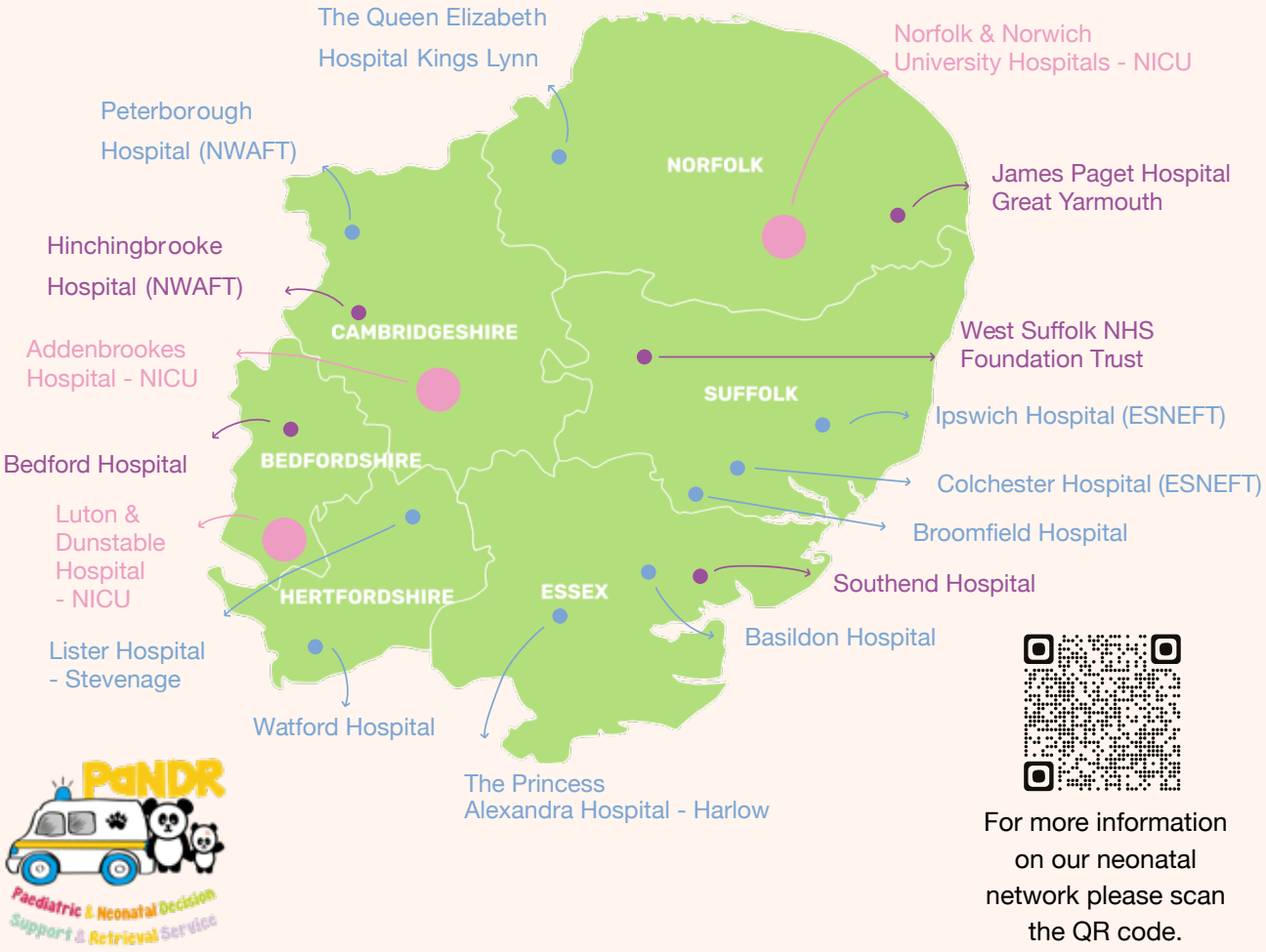
Parents/carers - please feel free to phone us for an update at any time of the day or night. It can take longer for us to get to the phone during handover times which we know can be worrying for you (see handover times on page 8)

Please also be aware we will not be able to update family members and friends if they call.

Our Neonatal Network

There are 17 units in the East of England Operational Delivery Network.

- Level 3 ⟶ 3 Neonatal Intensive Care Units (NICU)
- Level 2 ⟶ 10 Local Neonatal Units (LNU)
- Level 1 ⟶ 4 Special Care Baby Unit (SCBU)



For more information on our neonatal network please scan the QR code.

Transfers between neonatal units

Occasionally, your baby may require treatment at another hospital for medical, or very rarely for capacity reason. This may be due to SCBU not having enough cots. If your baby has been referred for a neonatal transfer in the East of England (Norfolk, Suffolk, Cambridgeshire, Hertfordshire, Bedfordshire and Essex) the PaNDR team will coordinate and deliver the transfer and the care of your baby between the referring hospital and receiving hospital. All units within the EOE network have Repatriation Link nurses who will be in regular contact with your prior to your baby being repatriatited back to SCBU.

For further information, please visit the PaNDR website by scanning the QR code.

Finding your way here



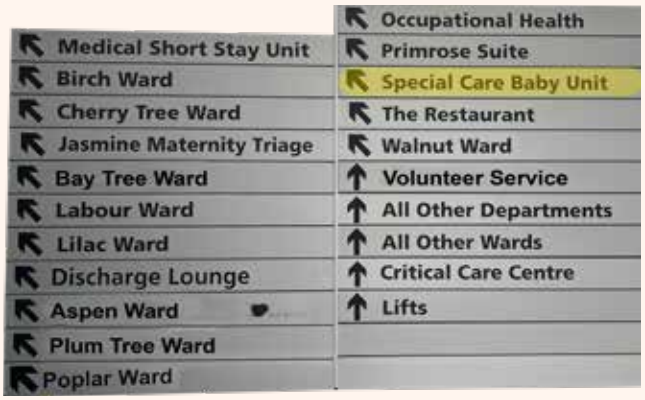
Scan here to open the hospital website which has more information on how to get here.

If you are driving here, please park in the main car park and ask a member of SCBU staff for a concession ticket so parking is free during your stay. Take your voucher and parking coin to the reception in the main entrance to be validated.

1. The Main Entrance



2. SCBU is located on the first floor



3. SCBU Entrance



Who's Who

SCBU has a huge team of people working to help your baby get better. There is a board on the unit with photos of each staff member so you can see who we all are.



Matron
Purple Uniform



Lead Nurse
Black Uniform



Sister / Ward Manager
Navy Blue Uniform



Neonatal Feeding and FICare Advisor
Brown with White stripes



Deputy Sister
Royal Blue Uniform



Staff Nurse
Light Blue Uniform



Nursery Nurse
Pink Uniform



Feeding and FICare Nursery Nurse
Lilac with White stripes



Housekeeper
Teal Uniform



Physio
White Uniform



Dietitian
Bright Purple Uniform

The doctors working on the unit will wear their own clothes or scrubs, and the nurses wear scrubs. We also have a housekeeper and ward clerk who are in their own uniforms. Everyone should always introduce themselves so you will know who you are speaking to, and every member of staff should be wearing an ID badge.

We also have other AHP's who you may see wearing their own clothes. You may find that a student nurse or midwife is working alongside the nurse caring for your baby. They will be dressed in their student uniform and should introduce themselves as students. We will ensure that they are supervised and are competent in the tasks they perform.

Nursing handover times

Morning 07:45 - 08:15
Evening 19:45 - 20:15

Doctors Ward Round times

Morning 09:30 – 11:30 (approximately)
We cannot guarantee this time as the doctors may also have patients in other areas of the hospital to see. We encourage parents/carers to be present for ward rounds wherever possible.

This is the ideal opportunity for you to be involved in the decision making process and to ask any questions, supporting us to work with you as partners in care.

If you require an update from the senior doctor if you have been unable to be present on ward round, please just ask your nurse.

Confidentiality and your baby's medical records

Information regarding your baby's heath is strictly confidential and will only be given to you. We cannot give information to any other family member unless it has been discussed with a senior member of staff (see section on 2nd Visitors on page 10).

To access your baby's medical records, please scan the QR and follow the instructions on the North West Anglia NHS Foundation Trust website.

Smoking

The hospital building is a no smoking zone, outside there are smoking shelters. If you would like any smoking cessation advice, please speak to your nurse who can get you the relevant information. **If you do smoke, please wear something over your indoor clothes to keep them smoke free.** We recommend you avoid smoking around the time you plan on having baby out for cuddles to reduce the risks associated with second-hand smoke (Lullaby Trust). If you want help to stop smoking, or need some advice then NHS Smokefree offer free help, support and advice and can give details of local support services.

0300 123 1044
Monday to Friday **9am-8pm**
Weekends **11am-4pm**

Chaplaincy Team

The Chaplaincy team is available to support you and your family, **whether you have a faith or not.** The team provides spiritual and pastoral care for families, and sometimes just someone who isn't a nurse to chat to. They offer a **24-hour trust wide on-call service** and are happy to come up to the unit if you would like to speak to someone Just ask your baby's nurse if you would like more information. Occasionally, the chaplain team will come up to SCBU and see how everyone is doing.

Safeguarding Families

As a trust we have a legal duty to protect and promote the welfare of all children and young people. This means that sometimes we may need to contact Children's Services an other professionals deemed necessary if we have concerns about a baby on SCBU. If your baby has any input from children's social care, or you have been seen by the safeguarding midwife during pregnancy, we ask that you are open and honest with us so we can support you and your baby. It is important when on the unit to respect the privacy and dignity of all other babies.

Respecting Privacy

It is important when on the unit to respect the privacy and dignity of all other babies. **We cannot give you any information about the other babies**, and you must please ensure you do not approach their cots.

Infection Control

It is important to protect your baby from infection risks. Everyone must clean their hands with alcohol gel on entering the unit and then warm water and soap in your baby's room. **All outside coats/outerwear (e.g hoodies) must be left on hooks at the entrance to the unit.**

Mobile Phones

Mobile phones are allowed on the unit, however we encourage you to limit the use of mobile phones when your baby is awake, feeding or having skin-to-skin with you. Phones must be kept on silent and answer any calls in the kitchen, not at the cot side. **If you use your phone as a camera, please ensure the flash is not on.**
To protect the other families, if you take photos, please ensure there are no other babies or families in the photo.

Consent

What is consent?

Parents should be included in making decisions about their baby's care. Fostering a good relationship and developing trust with parents by effective communication is key to getting valid consent Consent means giving permission to the neonatal unit staff to care for and treat your baby. We will discuss with you the relevant information so you can understand your baby's condition and the treatment/tests required so you can make an informed decision about your baby's care. There will be opportunities for you to ask any questions.

Consent is obtained from someone with 'parental responsibility' and involves both communication and understanding by the parent. If parents are married, valid consent can be obtained from either parent. If parents are not married, valid consent can only be obtained from the father if he is to be named on the birth certificate, and the mother confirms she wishes him to have parental responsibility.

Types of consent

Implicit Consent Implicit (or implied) consent refers to clinicians proceeding with a non-urgent low-risk intervention without necessarily having specific prior discussion for the procedure at that time with the parents. Implicit consent procedures should have been described to you prior to or on admission, supported with written information, and expanded on by healthcare professionals as the opportunities arise. Implicit consent is dependent upon the building up of rapport and trust between clinicians and parents. The assumption that implicit consent has been gained must be made with caution unless a thorough discussion has taken place. Procedures considered to be routine and low risk for healthcare professionals may be seen as invasive to a parent.

Explicit consent, involves a discussion whereby the purpose and risks of an intervention are formally explained and consent, either verbal or written, is obtained prior to the intervention; this should be recorded in the notes.

Emergency situations

Emergency situations arise when treatment must be given immediately to save the life or to prevent serious deterioration. Here time does not permit seeking reasonably informed consent. Emergency procedures are exempt from information disclosure/consent at the time as the action is considered to be under the 'best interest' of the baby. Ideally the possibility of this course of action will have been discussed with you previously, such as antenatally for predictable problems at birth. However some situations may not be foreseen or occur before these discussions could take place.

Examples of treatments/procedures

Implicit (implied) consent examples:

• Clinical Examination and assessment
• Portable X-rays
• Routine blood sampling
• Gastric tubes (insertion and use)
• Administration of barrier cream and frequently used drugs with a good evidence base e.g. caffeine to nappy area or skincare and protection.
• Umbilical arterial and venous catheter insertion
• Peripheral arterial line insertion
• Cerebral function monitoring
• Cranial ultrasound
• Parenteral nutrition

Explicit verbal consent examples:

• Breast milk fortification
• Donor breast milk
• Formula
• First blood transfusion
• Postnatal corticosteroids to facilitate extubation
• Screening of babies in high risk situations with no prior knowledge of maternal status e.g. suspected Human Immunodeficiency Virus (HIV)

Explicit written consent examples:

• All surgical operations involving regional or general anaesthetics
• Any biopsy
• Clinical photography and video-recordings
• Immunisations
• Treatment for retinopathy of prematurity

If you have any questions about consent, please speak to the nurse or nursery nurse looking after your baby. Open communication and working together with you as partners in care are priorities for us as a neonatal unit.

This document has been produced using the BAPM Enhancing Shared Decision Making in Neonatal Care A Framework for Practice (November 2019). If you would like to read this document please ask a member of staff, or you can access it via this QR code.

Spending time on SCBU

As parents, you are welcome on the unit at any time and have unrestricted access to your baby, this includes overnight. We encourage you to be with your baby as much as you are able, you are their primary care-giver.

We have open access for parents with the option of nominating a support person if required. Please speak to the nurse in charge if you would like to discuss this.

Siblings are welcomed on the unit between 8am and 8pm.
Other visitors are welcomed between 8am and 2pm then 4pm until 8pm.
Quiet time is between 2pm and 4pm.

If you would like to have other visitors on the unit, please be aware that we can only have one parent and one visitor by the cot side at a time.

No visitors will be allowed to visit without a parent being present unless prior arrangements have been made. In certain circumstances, we can arrange for there to be an alternate 'supporting partner' that is not a parent, who could potentially support you and who could receive updates by phone. This is not applicable for every family and is primarily aimed where only one parent is involved. Please speak to your nurse if you would like to discuss this.

If parents would like to request privacy with your baby then we are able to put up privacy screens that you can use around the cot side, or (when we have capacity to facilitate and baby's condition allows), move your baby into a separate environment to support this.

Fire Alarms

On a Tuesday morning there is a fire alarm test, which you may hear. We do not routinely run fire drills on this unit, therefore in the event of a fire or an emergency please follow the SCBU team's instructions.

Feedback

If you have any concerns about any aspect of the care you are receiving, please speak to a staff member, or ask to speak the Nurse in Charge. If you feel you would like to take any concerns further than this, the hospital **Patient Advice and Liaison Service (PALS)** can be contacted on 01480 428964 or hch-tr.pals@nhs.net

Further information is available on the Trust internet by scanning the QR code. PALS can also be contacted for compliments or suggestions in addition to concerns/complaints.

FaB (Family and Baby) Project

We are fortunate to have a group of FaB workers who can link families in to local community support available, including Family Centres. They are able to offer emotional, practical and financial support and signpost to relevant agencies where appropriate. They visit SCBU regularly, if you wish to see them between visits, please see the poster on SCBU or call them on **01480 376242.**

From our family to yours...

The Parent Advisory Group (PAG) is a group of parents/carers who have used neonatal services in the past. The group represents the views and experiences of parents and families whose babies have been cared for on a neonatal unit and play a vital role in driving forward improvements and changes in neonatal care within the region. For further information including finding out how to become a PAG member, please email **EoENeonatalPAG@gmail.com**

"Chat to other families on the neonatal unit - talking to other people having a similar experience can really help you feel less alone and they may well end up being part of your support network beyond your neonatal stay"

"Don't be afraid to ask questions about your baby; it is your baby and you need to understand and be involved in their care"

"Trust your parental instincts; you are the experts of your baby and if you are worried about your baby, let the nurse or consultant know your concerns"

East of England Neonatal
Parent Advisory Group

CAMBRIDGESHIRE & PETERBOROUGH
Maternity & Neonatal Voices Partnership
Working together to improve maternity & neonatal services

Cambridgeshire & Peterborough Maternity & Neonatal Voices Partnership (MNVP) is a group of parents and families, NHS health professionals and independent providers working together to improve maternity and neonatal experiences for everyone.

Your voices matter. Sharing your experience of maternity & neonatal services means we can work together to improve care.

What was good?
What could have been better?
What improvement could be made?

Use the QR codes to tell us about your care or find out more about the MNVP and how you can help to make change in maternity & neonatal services.

Tell us about your maternity or neonatal care

Find out more email us **mnvp@barnardos.org.uk** or us the QR Code to find use on Facebook

IN PARTNERSHIP WITH BARNARDO'S

NHS Cambridge University Hospitals NHS Foundation Trust

NHS North West Anglia NHS Foundation Trust

NHS Central East Integrated Care Board

Updated 6th Oct 26

SCBU Parents Support Group

The SCBU Parents Support Group is run by SCBU staff in collaboration with a parent representative. The support group is run monthly, and is for exclusively parents who have had a baby on SCBU or who have had support from the neonatal team. This group is for your baby up until they're mobile. You are welcome to come alone or with your child.

Fourth Tuesday of every month

Huntingdon Youth Child and Family Centre, Sallowbush Road, Huntingdon, PE29 7AF

10am until 11.30am

VCreate and Facebook



VCreate is an NHS Trusted secure video messaging service that helps families stay connected throughout their care journey.
Photos and videos can be sent to you securely.

We welcome you to make the SCBU environment as familiar as possible for your family:

Your cot space

Please make your cot space your own, by bringing things that will make you feel at home – this can be difficult with the limited space, and we do have to keep the environment safe and free of trip hazards. Families often like to bring photos of the family, drawings that siblings have done or books. If you're unsure, speak to your nurse.



↑ We have a board at each cot, for messages to be written between your baby, you, and your nurse each day – please use this to write anything you like!

What to bring to SCBU

- ⟶ **Nappies**
- ⟶ **Cotton wool**
- ⟶ **Cotton wool buds**
- ⟶ **A new tooth brush** - For cleaning feeding equipment
- ⟶ **Blankets** - Feel free to bring in washed, labelled blankets for your baby - if they can't be used when the baby is in bed then you can use them during cuddles
- ⟶ **Clothes** - Babies only require a nappy when cared for within an incubator or under phototherapy lights. As their care changes their clothing requirements change. Babies cared for in a hot cot only require a long-sleeved vest with exposed legs. Premature babies and those with IV lines should wear clothes secured by Velcro instead of other fastenings, these are available in a range of supermarkets. Clothing should be free of zips on the back of the body or around the neck. Please be aware that zips may be uncomfortable for babies to lie in certain positions and are best to be avoided. If caregivers have difficulty providing clothing, there is a range of clothes available to use on the unit.
- ⟶ **Teddies & toys** - We adhere to the Lullaby Trust clear cot advice, which is having no teddies or toys in your baby's cot. Washed teddies should be kept outside of baby's cot and used when interacting with your baby. When your baby is monitored in an incubator, we do allow one small teddy/toy to be in with them as long as it is kept out of their reach. **When you go home, your baby MUST sleep with NOTHING else in their cot/crib.** (Lullaby Trust Safer Sleep for Babies - A Guide for Parents) View more information on this by scanning the QR.

Family Facilities

The sitting area in the kitchen provides a space for you to have a drink and something to eat while not being too far away from your baby. There is a fridge, freezer and microwave for your convenience, as well as a water cooler and facilities to make yourself a hot drink.

We strongly urge parents/carers to take regular breaks to eat and drink and are able to offer you free of charge hospital meals, please ask your nurse for the menu choices each day. Alternatively, there is a small shop and cafe at the main entrance, and the hospital restaurant is located just around the corridor. Please note, the shop and cafe close early at the weekends.

COLD DRINKS ARE ENCOURAGED AT ALL TIMES IN ALL AREAS OF THE WARD. You are welcome to take a hot drink onto the ward as long as it is in a secure, lidded cup which can be found in the parent kitchen.

You are welcome to store items under your baby's cot (although the space is quite small) and we also have some lockers available for family use. Please feel free to use these to store your personal belongings in, however, we are unable to accept responsibility for loss of personal belongings while on the unit.

Parent Sitting Room and Bathroom Toiletries

You have the full use of a parent sitting room.
This is a space for you to use for sitting, eating, or resting.

The unit has a well stocked unit in the toilet area consisting of personal items: toothbrushes, toothpaste, shaving equipment, deodorants, body wipes and sanitary products. Please help yourself.





Your baby and you

As parents or carers, you are the best people to care for your baby and have the biggest influence on their health and well-being. On SCBU, Family Integrated Care (FI Care) is at the centre of all we do, ensuring you are the primary care-givers within the team caring for your baby. We understand that this can be difficult in the SCBU environment, here are some ways you can be involved from the very moment your baby arrives on the unit.

Quiet Time

We like to try and give all of the babies on the unit, periods of uninterrupted rest throughout the day. This will be individualised for your baby, depending on when the right time is for them. However, to encourage a time when the whole ward is quiet, we dim the lights and **ask for quiet from staff and families between 2pm to 4pm.** We will try to avoid any unnecessary procedures during this time, and it may be used as **an ideal opportunity for skin to skin, positive touch, cuddles and for reading to your baby.**

SCBU Book Tree

Please choose a book from our book tree to keep for your baby, they will like the familiarity of the same book, and read about other benefits of reading to your baby on the posters by the book tree on SCBU. We also have a book library where you can borrow a book to read with your baby. We have books in a range of languages.



Looking after yourself

Having a baby on the neonatal unit can be a challenging time.
It is so important to take time for yourself, and to look after your wellbeing.

Bliss acknowledge that parents can sometimes feel that they have to put on a brave face when they might be struggling themselves. This can be especially true when your baby is in neonatal care. You might feel you need more support in facing these challenges, or you might feel as though you need to talk to a health professional about your mental health.

Bliss suggests some of the strategies that other families have found useful were:

1. Developing a flexible routine
'Each evening we'd plan the next day, ensuring we included time for breaks from the NICU. We accepted that we may not do what we want to do at the specific times – but by writing the plan down, each task or activity most often got done at some point during the day'.

2. Making time to talk
'We talked over a coffee each morning, allowing each other time to vent.
We made a rule: "No interrupting each other and no judging what the other person says". This helped us get everything off our chest without penalty'.

3. Accepting help
'We were at first reluctant to accept help from our immediate family, but their support through doing our laundry, cleaning and sometimes preparing food was invaluable – it allowed us to focus on supporting our baby'.

4. Talking in future tense
'We insisted that the practitioners discussed what the plans were for our baby the next day or week, which constantly reassured us'.

5. Managing visitors
'Our family were vising many times a day because we had told them that the NICU had an "open visiting schedule". Escorting them up to the ward regularly became stressful as we didn't have as much time for ourselves. We then dictated the schedule that worked for us'.

6. Getting some light

'The dimmed lighting of the NICU can be draining, especially when tired and hungry. Sitting all day in one place also causes exhaustion and back ache. We got outside a few times a day to get some light and exercise. We walked around the hospital grounds, took the stairs, whatever we were capable of doing. We reminded ourselves to put such activities into each day, which helped pick up our mood'.

7. Eating well

'We cooked our food in the slow cooker early in the morning. We'd cook enough for dinner that day and lunch the next day. This removed the demands of eating poorly and not having food ready'.

8. Making our experience normal

'We engaged with Family Integrated Care, made our "area" in the NICU our own by buying a memory box for all of our baby's milestones and by reading to our baby each morning and night. This helped us normalise the very weird situation we were in, and connect with our baby'.

9. Being informed

'Uncertainty was the biggest cause of anxiety for us, so we asked questions all the time – writing them down in advance of the ward rounds'.

10. Dealing with the volume of messages

'Feeling the need to respond to family and friends can add to stress. We created a WhatsApp group and included everyone who messaged us to update all in one go. We then enjoyed reading all the lovely responses on the group'.

Bliss
for babies born premature or sick

Please visit the Bliss website for more details by scanning the QR code.

Communicating with your baby

This is a perfect time to watch your baby and learn how they communicate with you. Babies can't speak to us, so they communicate in unique ways. Scan this QR code, to find out what your baby is telling you.

View the Bliss booklet 'Look at me, I'm talking to you' (2006) by scanning the QR code.

Did you know… Eye flickering, yawning and high fiving are all ways your baby is trying to talk to you?

Positive touch communicates love and reassurance to both you and your baby. Skin-to-Skin is a brilliant way to do this, and is proven to have benefits for you both such as:

Skin-to-Skin (Kangaroo Care)

We try and encourage skin-to-skin for at least an hour (but longer is preferred!) Transferring premature and sick babies can be stressful for them, so they need a nice long cuddle with you to settle. Make sure you are ready; go to the toilet, have a bottle of water with you and maybe a book to read to your baby.

- ⟶ Bonding and attachment
- ⟶ Stabilising baby temperature, and other vital signs
- ⟶ Encouraging breast milk production
- ⟶ Protection from infection

View the Bliss, 'Skin to skin with your premature baby', 2006) PDF by scanning the QR code.

Containment holding

Containment holding makes your baby feel safe and secure, mimicking a feeling of being in the womb.

Placing your hands on your baby gently and firmly may help to calm them if they are unsettled.



Cares

“Cares” is the word we use to describe giving mouth care and changing nappies. This is very individual to your baby, it is vital to keep them clean and comfortable, whilst allowing them as much rest as possible to grow and develop. This will depend on your baby’s condition, but usually is 3-8 hourly, and when baby is awake or unhappy in a wet or dirty nappy. We are here to support you in providing this care for your baby, as soon as you feel ready to do so.

Nappy Care

Babies skin is very delicate, especially babies requiring SCBU care, so we encourage the use of cotton wool and water rather than wipes.

We use a barrier cream on all babies’ nappy area to try and prevent soreness. We may need to also use an emollient cream in the water used to clean your baby’s nappy area, and/or an ointment to treat sore areas if your baby’s skin shows sigs of soreness, despite the barrier cream. We will talk to you about these, and ensure you know how to use them for when your are providing your baby’s nappy care.

If you have your own you would like to use, please mention it to a member of staff so we can check it is appropriate for the level of care your baby is receiving.

Mouth Care

Whether your baby is very premature, sick or only staying on SCBU for a short time, mouth care is very important. It keeps your baby’s mouth clean, allows them early experiences of tasting/feeling milk or fluid at their lips, and is a great bonding opportunity for you both.

If colostrum or expressed breast milk (EBM) is available, then this is the ideal thing for your baby as it can also provide protection from infection.

Sterile water can be used as an alternative, and still provides many of the benefits of mouth care.

Parent Information

Activon Manuka Honey Barrier Cream

Why does my baby need Activon Manuka Honey Barrier Cream?

On SCBU and NICU, all babies will be given a hospital grade barrier cream called Activon Manuka Honey Barrier Cream, to use on their nappy area every nappy change.

This is to protect the baby's vulnerable skin which is higher risk of Moisture Associated Skin Damage (MASD) or Incontinence Associated Dermatitis (IAD). This risk is increased when a baby is preterm, gradually building up oral feeds and receiving many of the interventions that are common on the Neonatal unit, for example oxygen, antibiotics and phototherapy.

The tube your baby is supplied with will be enough for you to take home to apply to your baby for the days/weeks after discharge.

How is Activon Manuka Honey Barrier Cream used?

A "grain of rice" size amount is applied in the nappy area each nappy change, once the skin has been thoroughly cleaned and dried. The cream needs to be gently rubbed in until it has absorbed/disappeared which then provides a barrier to urine and stools.

As parents/carers, you will be encouraged to administer this cream when you change your baby's nappy, and the nurses will do the same when you are not able to be on the unit.

It is very important to wash your hands after applying the cream as there is a possible risk to babies under 1 year if they ingest (eat/drink) honey, because of the bacteria it can contain.

What are the risks of Activon Manuka Honey Barrier Cream?

Activon Manuka Honey Barrier Cream has been sterilised twice during production to reduce this bacteria content.

If your baby is under phototherapy lights, ensure any skin within the nappy area that has Activon Manuka Honey Barrier Cream applied is covered with the nappy. Please speak to the nurse caring for your baby if you need help with this.

Sometimes baby's skin can become red or sore despite applying a barrier cream, if you notice any concerns in the nappy area, let the nursing staff know.

Can I use my own preferred barrier cream?

If you would prefer to use your own barrier cream, please speak to your nurse. Not all products available contain suitable active ingredients, and some can be a fire risk if used near oxygen. The nurse may need to seek advice from the specialist Tissue Viability team or Pharmacists, and may not be able to answer your query immediately.

Developmental Care

Developmental care makes the baby's environment as pleasant and stress-reducing as possible, and also to improve the attachment and bonding between you and your baby. Things we can do on SCBU to help provide a developmentally friendly environment:

Developing your baby's experience of **sound** by:

- ⟶ Allowing them to hear your calm, quiet voice
- ⟶ Keeping the environment quiet wherever possible
- ⟶ Taking conversations away from incubators or cots, including phone calls
- ⟶ Closing incubator doors quietly and using the trays at the end rather than the tops of incubators to place things
- ⟶ Having dedicated "Quiet Time" during the day

Developing your baby's experience of **light** by:

- ⟶ Reducing light levels wherever possible
- ⟶ Keeping the incubator covers over the incubator, but do lift up a side to look at your baby while you're here
- ⟶ As your baby grows, having some periods of light helps them with their sleep-wake cycles

Developing your baby's experience of taste and smell

Newborn infants are born able to recognise the smell of their mother's amniotic fluid, breastmilk and the odour components of human sweat.

The sense of smell is key in the attachment process, so it is important that caregivers avoid using strong smelling personal hygiene products, perfumes and washing detergents which will hinder this. Infants should not be exposed to toxic smells such as alcohol or cigarettes, which leave 2nd hand residue on clothing.

Please allow alcohol gel to dry before handling baby. Bonding squares worn by caregivers and left in the baby's cot space can be used to facilitate this attachment process.

Providing comfort to your baby

Preterm and full-term babies feel pain differently, and different things may feel uncomfortable to them. We will assess your baby's pain score regularly to ensure that they are comfortable. You may have already read the section above on comforting you baby?

Below are some of the behavioural signs your baby may show when they need time to rest or further intervention for pain relief.

- ⟶ Crying
- ⟶ Restlessness/squirming
- ⟶ Not sleeping properly
- ⟶ Facial grimacing/frowning
- ⟶ Fingers and toes clenched or splayed

If your baby requires a painful procedure, where possible we will discuss this with you beforehand. Babies can be very successfully comforted during these using containment holding, skin-to-skin or by the following means:

1. EBM



Giving small drops of your EBM, if available, into your baby's mouth can act as really good pain relief before any uncomfortable procedures.

2. Non-Nutritive Sucking (NNS)

Enabling a baby to suck during an uncomfortable procedure is one of their inbuilt comforting techniques. This could be a clean finger, a dummy or a very recently expressed breast.

A dummy can really help a baby who needs to suck for comfort. Offering a dummy for this doesn't mean it needs to be long term. Please do talk to us with any questions you have. We will always ask your consent before offering your baby a dummy.



3. Sucrose

If there is no EBM for your baby and they are allowed sucrose, then it could be used as an alternative.



We can give small drops of this sugary solution on the tip of your baby's tongue which can help reduce procedural discomfort.

Feeding your baby

SCBU is a Unicef Baby Friendly fully accredited unit. Our accreditation ensures that we provide gold standard infant feeding support to our families. On SCBU, we actively promote the benefits of breastfeeding and using breastmilk (where possible) for preterm or sick babies. Research shows that every drop of breastmilk is of benefit to your baby. SCBU encourages and promotes informed choice, and however you decide to feed your baby, you will be fully supported.

To feed safely and effectively, your baby must be able to suck, swallow and breathe in a coordinated way. The right time to begin oral feeding, is different for every baby, and every family. Please see the sections below on breastfeeding for further information. Don't hesitate to ask us if you have any questions.

Intravenous (IV) fluids

It is not always possible for a baby who comes to SCBU to take milk into their tummy straight away. A "drip" is often put into a baby's hand, arm, foot or leg so that a sugary fluid solution (IV fluids) can be given to keep them hydrated and blood sugars stable in the meantime.

Nasogastric or orogastric tube feeding (NGT/OGT)

Until your baby is ready to orally feed, they will likely use a nasogastric or oral gastric tube (NGT/OGT). These tubes are passed through the nose or mouth, then down the oesophagus and into their stomach. You will be fully supported to feed your baby via NGT or OGT, and staff on the unit will be with you every step of the way.

Every time your baby has a feed via their NGT or OGT, we need to check the position of the tube, by gently taking a small amount of their stomach contents out of their tummy, and testing the acidity of it. This is called aspirating, and staff on the unit will fully support you to do this. We have a package for us to work through together, which will help you to feel confident with tube feeding.



Breastmilk

We will discuss with you the benefits of colostrum (your first milk) and breastmilk for your baby. We know that research shows that every drop of breastmilk is of benefit to your baby.

Colostrum and breastmilk can support your baby by:

- ⟶ Offering protection for your baby's gut
- ⟶ Preventing harmful bacterial growth
- ⟶ Reducing inflammation
- ⟶ Absorbing easily into your baby's tummy
- ⟶ Protecting your baby from infections
- ⟶ And so many more benefits for both you and your baby!

Please use the following QR code for further information about breastmilk and donor breastmilk

Donor breast milk

There are some cases where you may be offered the choice to use donor breast milk for your baby.

Donor breastmilk is partially sterilised expressed breastmilk which has been donated to our local milk bank, which is located at Addenbrookes hospital in Cambridge.

This will always be fully discussed with you, and you will receive information in order to make an informed decision.

Hand and breast pump expressing

If you would like to give your baby your breastmilk, you will be encouraged to begin expressing using your hands. This is the most effective way to collect your first milk, which is called colostrum, and to get your milk production started.

In the first few sessions of expressing, it is likely that you will only get very small amounts of colostrum. Colostrum is amazing for your baby as it is very high in calories and contains lots of fats that they need to grow and antibodies they need to build their immunity. Your body produces milk that is perfect for your baby's gestation, so it is ideal for them.

Once you are confident expressing more milk by hand, you will be encouraged to use the hospital grade breast pumps on the unit.

Top Tips

- ⟶ Begin expressing as soon as possible after birth, ideally within the first 2 hours.
- ⟶ Aim to express at least 8-10 times in a 24-hour period.
- ⟶ Double pumping helps initiate and maintain milk supply. If you're unable to double pump, we recommend switch pumping (alternating between breasts regularly).
- ⟶ Having as much skin-to-skin time with your baby, can boost your milk supply.
- ⟶ Expressing by your baby's cot side, can boost your milk supply.
- ⟶ Using warm water (a flannel or bowl of water), can help to get your milk flowing.
- ⟶ Using gentle breast massage before and during hand expressing, can boost your supply. Using breast massage and a few minutes of hand expressing before pumping, will also support your milk supply.
- ⟶ It is very important to express at least once overnight, as this is when your milk hormone levels are highest to help boost your milk supply.
- ⟶ Ideally avoid long gaps between expressing sessions.
- ⟶ Aim to express for 2 minutes after the last drop of milk has been expressed, this promotes milk production. Aim for a minimum of a 15-minute expressing session.
- ⟶ On SCBU, you can store your expressed breastmilk in the fridge for up to 48 hours.
- ⟶ When transporting your milk from home, please use a cool bag and ice packs to keep the milk sufficiently cold, and place in the fridge as soon as you arrive on SCBU.

Breast pump loan

We have hospital grade breast pumps for you to loan out, and take home with you, please ask a member of staff for more details. **These are free of charge.**



Scan this QR code to view UNICEF's hand expressing video

Transition to breastfeeding

From around 32-36 weeks gestation, the suck, swallow, breathe coordination matures, and they may be ready to begin breastfeeding. However, this is very individual, and will depend on your baby and their condition.

When your baby begins to breast feed, we will be able to give you advice on positioning, latching and signs to look for that your baby is taking milk. Breastfeeding can take time to establish, this is normal for babies on the unit. They may just be ready to enjoy being close to you, smell your milk and be near the breast, as this can be comforting for them. We are always led by your baby's cues for feeding, and for when they tell us all they have had enough. Our nurses and nursery nurses, will support you to recognise these sometimes-subtle cues.

If your baby is also being tube fed, it is likely that they will still require "top ups" of their usual milk via their tube, even though they've just fed at the breast. This is because they may not be strong enough to take enough milk from you yet. This will come with time and practice.

UNICEF Breastfeeding assessment tool

UNICEF Position and attachment video

Keeping your baby warm

One major part of SCBU is making sure your baby stays warm. We like their temperature to be between 36.5-37.5°C as we don't want them to be using their energy reserves keeping warm, we want them to focus on growing!

We encourage you to feel your baby's chest and upper back to see how they feel when they are the right temperature, this is really important too for when your baby comes home.

Some common equipment used on SCBU

There is lots of equipment used on SCBU that you may not be familiar with, or may have never seen before. We hope that this introduction to some of the common equipment will explain some of the things you see on the unit, and you can always ask staff for more information.

Incubators

Caring for a baby in an incubator means we can control the temperature of the air in the incubator to make sure your baby stays warm.

Once your baby is stable enough, you can start to gradually put clothes on them while they are in the incubator.

This gives us an indication as to whether they are going to tolerate being out of the incubator and allows us to reduce the temperature of the incubator air.



Hot Cots

Hot cots are heated water mattresses that we use for those babies who might not need the heat of an incubator, but may not be able to control their temperature on their own. When your baby is in a hot cot, it is important that they are dressed suitably so they can gain the benefit of the heated mattress. They only require one layer of sheet covering the mattress, one layer of clothing and a maximum of three blankets. If they need more than this then they may not be ready for a hot cot, or may need the mattress temperature increasing.



Monitoring your baby

These are two of the monitors that we use on SCBU.

As your baby grows, we will gradually remove monitoring until it is turned off completely ready for you to go home.





They monitor your baby's heart rate (HR) and Oxygen Saturation levels (Sats), as well as sometimes Respiratory (breathing) Rate (RR) and Blood Pressure (BP).

You may hear the nurses or doctors say that your baby has had a 'brady' or 'bradycardic episode'. This is where baby's heart rate slows and is often linked with a desaturation.

You might hear us say that your baby has had a 'desat' or 'desaturation', this is where the oxygen levels drop to a level where the alarms will ring. One of the nurses will always come to your baby if this is happening, it is a fairly common thing that happens in a lot of babies and we will always keep you informed if it is something to worry about.

Supporting your baby's breathing

Some babies on SCBU will need some assistance with their breathing, if this is the case for your baby, the reason why will always be communicated with you. On the next page you will find a little bit of information about some of the ways we commonly help babies with their breathing.

1. Nasal Cannula or Low Flow Oxygen

Nasal Cannula oxygen is sometimes needed for babies whose oxygen saturations are a little bit low. It is a pair of nasal cannulas, or prongs, which sit in the baby's nose and have a long tube, connecting them to the oxygen supply at the wall or the cylinder.



2. CPAP (Continuous positive airway pressure)

CPAP allows warmed, humidified air into the lungs and keeps the airways open so that each breath is a little bit easier for the baby. The nurse caring for a baby on CPAP will regularly take the mask or prongs that your baby has to wear on their nose off and check the skin underneath to make sure it isn't getting sore or marked. CPAP is held in place by using special head gear. Speak to the nurse caring for your baby about providing containment holding or having skin-to-skin whilst your baby is on CPAP.



3. Optiflow – also called "High Flow"

Optiflow delivers air/oxygen depending on what the baby needs through some small nasal cannula or prongs. This air is warmed, and humidified to make it nicer for baby to breathe in.

Sometimes babies move between one type of breathing assistance and another in a very short space of time. Always ask us if you have any worries.



Probiotics on SCBU

What are probiotics?

When a baby is born at term their bowels are full of ‘friendly’ bacteria which help to keep the bowel healthy. When infants are born prematurely, they do not have the same range or amount of ‘friendly’ bacteria. This can lead to less ‘friendly’ bacteria increasing within the bowel, which, in turn, can put them at risk of developing a disease called necrotising enterocolitis (NEC). NEC is a condition that mainly affects premature infants.

It affects the bowels and, when severe, can be life threatening. There are many factors involved in the development of NEC, but we know that the type of bacteria in the bowel is one of them. Probiotics preparations contain the ’friendly‘ bacteria normally found in the bowels of babies born at term. They are given to preterm babies to grow in their own bowel and to help stop more ‘unfriendly’ bacteria from growing out of control.

Research studies have shown that giving probiotics to premature babies can reduce their risk of developing NEC. They may also help prevent other infections and improve overall survival. In the UK probiotics are classed as food supplements, not medicines. However, the probiotic preparation used in the neonatal intensive care unit (NICU) is produced under the same standards as medicines to ensure its safety and quality.

Will my baby receive probiotics?

If your baby is born at less than 32 weeks, probiotics will be given daily until your baby reaches around 34 weeks corrected age, as this is the age the risk of NEC is thought to reduce. However, if your baby is older than this but was started on probiotics because they were very small, the probiotics will stop as part of the discharge planning process. If, for any reason, your baby stops feeds, then the probiotics will stop as well. They will recommence once feeds are restarted.

How are probiotics given?

Probiotics are given as soon as your baby is ready to feed, at the same time as one of their milk feeds. It can be given down their feeding tube or in their mouth using a syringe once they have started to take their vitamins orally.

What are the side effects of probiotics?

Research has shown probiotics to be safe to use in preterm babies. There is however a very small risk that probiotics may cause an infection in some preterm infants. This infection can be treated with antibiotics. The risk of infection from the use of probiotics is much smaller than the risks associated with the development of NEC. In other words, the benefits of giving probiotics outweigh the risks of not giving them.

Probiotics



Vitamins



Vitamins on SCBU

If your baby has had a stay on SCBU, it may be that they will require some medication via mouth which could continue when you go home. Most commonly these medicines are iron and vitamins.

Vitamins, such as Vitamin A, D, E and Folic Acid, are often required for babies born prematurely or low birth weight, as they have lower stores and higher requirements than babies born at term. Vitamins may start when your baby is receiving their full amount of milk required for their weight. Premature and low birth weight babies are also at higher risk of iron deficiency, typically between 2-6 months of age, so may start an iron supplement at 4 weeks of age.

These supplements will be individual to your baby and any medication your baby requires will be fully explained to you, so do ask if you have any questions at all.

You will have the opportunity to start giving your baby this medicine on the Neonatal Unit with the support of the nurses, so you feel well practiced before you go home, if this has not been offered to you and you are already feeding your baby their milk feeds, please do ask your nurse.

When you go home you will be given a supply which will last you at least one week, and you will need to get more from your GP in time for when this runs out.

Jaundice

Jaundice is very common in all newborn babies, not just those that are admitted to SCBU. Jaundice causes a yellowing of the eyes and the skin and happens because of a raised bilirubin level in the body. The body has lots of ways of getting the bilirubin out of the body (including through faeces and urine), but sometimes these don't keep up with the amount of bilirubin in the baby.

While on SCBU, your baby will be monitored for jaundice through blood tests. If the results show your baby requires treatment for jaundice, they will be cared for under phototherapy lights. They will need to wear goggles to protect their eyes from the bright lights and remain under the lights as much as possible. How long your baby remains under phototherapy varies depending on their gestation and age. Please ask us if you have any questions.

Newborn Blood Spot Screening

The Newborn Blood Spot Screening test is usually done on day 5 of your baby's life, from a heel prick blood sample, which is sent away to test for serious inherited health conditions which have better possible outcomes for treatment if discovered early. Any baby that is admitted to the neonatal unit, will have an additional Newborn Blood Spot Screening taken as soon as possible after arriving on the unit.

You should receive the results by letter from your health visitor or GP within 6 weeks. There is the most up-to-date information about Newborn Blood Spot Screening by scanning the QR code.

Blood Transfusions

Occasionally, a blood transfusion will be needed for a baby who has either lost some blood, or is not producing blood cells as quickly as needed. The need for a blood transfusion will be fully discussed with you before it is given, except in very rare, extreme emergency situations. Blood is given through a cannula into your baby's vein.

This QR code contains general information about blood transfusion.

Infection Screening

When babies are admitted to SCBU, showing certain behaviours, or meeting certain criteria, which we know can be linked to the risk of infection, they may need antibiotics.

We will monitor your baby's infection markers by doing blood tests, and once the infection has been adequately treated, then the antibiotics will be stopped. This is usually a minimum of 48 hours after blood tests, because we have to wait for the 'blood cultures' results.

Sometimes, babies who have been on SCBU for a little while may also show signs of becoming unwell and require antibiotics. In nearly all cases, babies on SCBU are given their antibiotics via a 'drip', in their hand, arm or foot.

On admission, and then weekly thereafter, we will swab your baby for Meticillin Resistant Staphylococcus Aureus (MRSA). In the rare event that the result comes back as positive, treatment involves the use of a special wash and nose ointment. This will be fully explained if needed.

Retinopathy of Prematurity (ROP)

Retinopathy of prematurity or ROP is a condition where the blood vessels at the back of the eye (the retina) develop abnormally. Usually, no treatment is needed, however, in some of those affected babies, treatment may be required.

When a baby is born prematurely, the blood vessels of the retina are not fully developed. After birth, these blood vessels have to develop and may grow abnormally, if this happens there is a risk that the retina may become damaged.

Due to this risk, all babies who are born under 32 weeks gestation, or under 1.5kg are screened for ROP. If your baby needs screening, the nurses will give some eye drops about an hour before the examination. These are to dilate the pupils and make it easier to view the back of the eye during the examination, and a second eye drop offers pain relief during the procedure. The ophthalmologist then examines the back of the eye using their special equipment.

If the ophthalmologists find ROP has developed in your baby, they will discuss this with you and explain the next steps required.

BCG

In the UK, the BCG vaccination is offered to babies who are likely to spend time with someone with TB. The most up to date information can be found by scanning the QR code.

Hearing Screening

The newborn hearing screeners will perform the hearing test on your baby just before they are discharged from SCBU. It is aimed to find those babies that have permanent hearing loss and provide support and advice to those families.

1 in 900 babies have hearing loss in 1 or both ears, this increases to 1 in 100 for those babies that have spent 48 hours in SCBU.

Once your baby is more than 34 weeks corrected gestation, but less than 3 months old and they are ready to go home, the hearing screeners will be able to complete the test. The test doesn't take long but needs to be done when they are asleep and calm. The hearing screeners will need to get your consent before completing the test and will document the results in baby's red book.



Getting ready to go home

One of the most frequent questions we are asked is when a baby will be ready to go home. This will be very individual to your baby and your family, and we won't always be able to give you a definite answer.

Babies often go through stages of slower progress (which can feel really frustrating to families) and sudden bursts of progress.

It's most important that you talk to the doctors or nurses if you have questions about when you will be able to go home, and we'll also do our best to keep you updated. Please don't wonder or worry in silence.

There are some things we need to have happened before you can go home:

⟶ Your baby needs to be able to control their own temperature in a normal cot.

⟶ They need to be showing us they are putting on weight.

⟶ Babies can usually go home with their feeding tube in, but we need them to be able to have at least two oral feeds per day, for at least a couple of days.

⟶ We strongly encourage you to listen in to the Basic Life Support training we offer, and stay in our parents room for at least one night before going home.

⟶ We need you to have registered your baby with their GP before you can leave the hospital.

⟶ Your baby will have had to have their hearing screening completed.

Discharge Links

Safer Sleeping
Safer Sleeping advice for premature babies, from the Lullaby Trust

Off to the best start
Important information about feeding your baby.

Infant CPR
Scan the QR. This will take you to a YouTube video by the Bliss baby Charity, on how to resuscitate an infant.

Guide to immunisations
Summary of immunisations up to one year of age.

ROSPA - Car Safety
Information on car seats and positions.

Smoking
Information on smoking and your baby.

ROSPA Nappy Bags
Information leaflet on the dangers of nappy bags.

Taking your baby home
Information on taking your baby home from NICU.

Meningitis
Information poster with the symptoms of meningitis.

Dog Safety
Information to keep your baby safe around dogs.

Baby Check
Baby check is provided by the Lullaby Trust and contains different questions to help you decide what appropriate help you need.

On ‘Going Home’ Day!



When the day comes to go home, it is very normal to have very mixed emotions. We’re always here to support you if you need to ask any last minute things, or just talk. There are some things we will need to do with you on your last day before you can go, so it’s best not to expect to be able to leave until the afternoon (although we will always work with you as best as we can if you need to arrange a specific time).

These will include:

- ⟶ Weighing your baby and measuring their length and head circumference.
- ⟶ Preparing your baby’s final paperwork to send to their GP and Health Visitor, giving details of their stay.
- ⟶ Contacting any services who will need to know your baby has been with us and is now going home (e.g. Midwives if your baby is still under 28 days old, Health Visitors, any specialist teams your baby may be under).
- ⟶ Being seen one last time by the doctor on the unit.
- ⟶ Ensuring you have all your belongings, including any frozen/refrigerated expressed breast milk from the milk kitchen.
- ⟶ Explaining any medicines your baby is going home on.
- ⟶ Giving you details of any follow up appointments you may need.
- ⟶ Signing back in the breast pump if you have borrowed this for your baby’s stay.

Some families like to write a list of anything they want to ask on going home day. Don’t forget you might want to take a photo at the front door of SCBU as you leave with your baby – we’re always more than happy to help with this as we wave you goodbye.

Once you have gone home

Going home can be overwhelming, and you may have questions over the following days once you’ve gone home. You can phone the unit if you have anything urgent you want to ask. **You may be visited at home by our Outreach Team.** They will introduce themselves to you whilst you’re still on the unit, discuss with you what you will need from them, and give you a leaflet explaining what they do.

The Outreach Team is contactable Mon-Fri during office hours on **01733 677235** or the mobile number you are given when you meet them. **You will also be contacted when you have been at home for about 6-8 weeks, and invited to a baby massage course run by SCBU staff.** *Please note, this may be dependent on staff availability.*

Support & Information

For many families, the first few days, weeks or months with a premature or sick baby can be extremely tough. We are very happy to support you and your family and signpost you to relevant information sources should you need them. We are so fortunate to have Family and Baby (FAB) support workers who will check in with all families weekly, more details about what they do is on the notice board in the kitchen.

If you are with us for more than a couple of days, we will provide you with a Journey Box for you to keep anything you wish. Other parents/carers have kept items such as their baby's first ID band, wires & stickers we use for monitoring, masks or nose prongs from any breathing support… but this is entirely up to you!

Transport – if you are struggling to get to the hospital to be with your baby, please talk to us, there are many community transport services that we may be able to point you in the direction of.

Data and Research

National Neonatal Research Database

All infants within the Eastern Region (and most of the UK) have data entered onto the National Neonatal Research Database. We collect data to allow us to improve and make sure we are always providing the best care for our patients. It also allows us to compare practice between units both within the Eastern Region and beyond. Data is used for the National Neonatal Audit Project (NNAP), a national project to maintain and improve standards. No reports created at any time contain any information that could identify you or your baby and the only people able to access any identifiable information are the clinicians looking after your baby. We record all the following data:

- ⟶ Demographic details (i.e. address, GP details, date of birth, NHS number etc.)
- ⟶ Pregnancy, labour and delivery history
- ⟶ Baby's diagnosis and treatments
- ⟶ Baby's monitoring, weight, respiratory and feeding status
- ⟶ Tests on baby and the results
- ⟶ Details of where your baby was born and any hospitals involved in your baby's care.

This data is all collected by the clinical staff involved in your baby's care. All data is stored and handled in adherence with The Data Protection Act (1998). Guidance is available by scanning the QR code.

Helpful Links

Bliss is a charitable organisation for babies born prematurely, sick or small. They offer a wide range of information booklets for families and their website has lots of further information about SCBU families. Scan the QR or call the Free phone 020 7378 1122 or email hello@bliss.org.uk

The Lullaby Trust offers advice on safe sleep for babies and gives emotional support to bereaved families. There are lots of information on their website regarding the best way to keep your baby safe when they are asleep. Scan the QR code to find out more.

ICON is a programme that provides information about infant crying and how to cope. There are videos on the website about infant crying, how to comfort your baby and Dad's talk. Scan the QR code to find out more.

It's impossible to know what it's like behind NICU doors unless you've walked those corridors, scrubbed your hands, heard the alarms and felt the fear of losing the most precious thing in the world to you. We get it because we've been there too. The Smallest Things is run entirely by volunteers who've had premature babies. And that's exactly what inspires us to support families, raise awareness and instigate change. Scan the QR code to find out more.

Domestic violence or abuse can happen to anyone. Find out how to recognise the signs and where to get help. Domestic violence, also called domestic abuse, include physical, emotional and sexual abuse in couple relationships or between family members. Scan the QR code to find out more.

The mind website has a wealth of information on maternal mental health. Scan the QR code to find out more, call 0300 123 3393 or Text: 86463

Unicef Baby Friendly is all about transforming health care for babies, their mothers and families in the UK. It is a world wide programme of the World Health Organisation and Unicef which aims to improve standards of care for breastfeeding within health care settings. Scan the QR code to find out more.



Family Guide updated in November 2026 by **Lyndsey Jolly** and **Chloe Milham,** for review in May 2027.

This Family Guide has been adapted from the original work by **Chevvy Bryan** (NICU Neonatal Nurse), by **Lyndsey Jolly** (Neonatal Feeding and FICare Advisor) and **Amie Thorpe** (Clinical Educator) with the kind assisstance of **Angela Edmonson** (PA to Lead Nurses for Neonates and CYP services).

Thank you to all who have contributed.