

NICU Family Guide



Baby's Name

Hospital No.



The key telephone numbers are

NICU Reception	01603 286865/286866
Room 1 Intensive Care	01603 286867/286869
Room 2 Intensive Care/High Dependency	01603 286868
Room 3 High Dependency/Special Care	01603 286847
Fledglings Nursery	01603 286872
Family Care Team	01603 289489
Nurse in Charge	01603 286043
NICU Nurse Manager	01603 646622
Outreach Team	01603 286838
	07771 881389 (Mobile)
Children's Assessment Unit (CAU)	01603 289774

Nursing hand-over

Morning	07:30 - 08:00hrs
Evening	19:30 - 20:00hrs

Medical handovers and review ward rounds	09:00 - 09:30hrs
	17:00 - 17:30hrs
	21:00 - 21:30hrs

Please try to avoid phoning during handover times





Dear Family

Congratulations on the birth of your baby. We appreciate that this may be a difficult time for you. We hope that this information is useful and will help take some of the stress away from having your baby on NICU. Our aim is to ensure that all parents are confident and skilled in looking after their baby and to help you to get home as a family as soon as possible. The Neonatal Team are available to help you at all times. We ask that you work with the nursing team to enable us to support you in caring for your baby. A member of the Family Care Team will meet you after admission and will help familiarise you to NICU and the team.

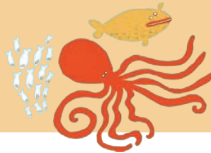
The aim of this booklet is to provide you with information about NICU. However it may not answer all your questions; if there is anything you do not understand please ask a member of staff.

Within the NICU, you will find that we provide many different types of care, both for babies that are born too soon or too small as well as more specialist nursing for full term babies with problems at birth and those needing surgery.

We are happy for you to phone at anytime to ask about your baby, please be aware that we can only give information to parents, unless we have permission given by a parent to inform other named family members. There is a security system of passwords which will be explained and discussed.



Welcome to NICU



What you can expect of NICU staff

- The NICU team are committed to working in partnership with families to ensure your baby has the best care available.
- Our staff are here to help you at all times and ensure you are kept up to date about your baby's progress.
- Our aim is to ensure that all parents are confident and skilled in looking after their baby.
- We want to help you get home as a family as soon as possible.



Our Values



Our vision is to 'provide every patient with the care we want for those we love the most', **Our PRIDE values support our vision and guide the behaviour of everything we do.**

- **People-focused:** We look after the needs of our patients, carers and colleagues, to provide a safe and caring experience for all.
- **Respect:** We act with care, compassion and kindness and value others' diverse needs.
- **Integrity:** We take an honest, open and ethical approach to everything we do.
- **Dedication:** We work as one team and support each other to maintain the highest professional standards.
- **Excellence:** We continuously learn and improve to achieve the best outcomes for our patients and our hospital.



What we expect of parents on NICU

- Please read this booklet which will be given to you on arrival. This has important information about having a baby on NICU and hospital facilities such as car parking and meals.
- Follow infection prevention and control guidance, and handwashing instructions.
- Work with the nursing team to enable us to support you in caring for your baby.
- Care for your baby as much as possible, participate in skin-to-skin care and attend ward rounds.
- When staying in the NICU parent rooms or at McKee House, we ask that you are present on NICU during the day and evening caring for your baby.
- As parent accommodation is so limited, you may be asked to leave your room when another family has a more urgent need.
- All parents are expected to provide nappies, cotton wool and muslins as soon as possible after admission. Your baby may also have their own clothes and soft bedding if desired. Please label your baby's clothes and bedding and take them home to wash.
- In exceptional circumstances, it may be possible for you to take your baby for a walk around the hospital in a pram. As we are responsible for the care of your baby whilst on NICU, we ask that you do not leave the unit for more than an hour and let staff know when you return.
- There is a zero tolerance policy for any aggressive or discriminatory behaviour towards staff. Security will be contacted in the event of this happening.
- If you have any queries about these expectations, please do not hesitate to speak to a member of the NICU Team.

Infection Prevention and Control

Please be aware that restrictions and the use of personal protective equipment (PPE) may apply due to the COVID-19 pandemic and any other current infection risks. Please discuss with nursing staff if you are unsure of the correct procedures on NICU or have any questions. Please inform the Nurse in Charge if you see anyone not following the hand washing policy. Gloves should be worn for nappy changes.

Why is hand washing important?

To help protect all the babies on NICU from infection risks, all parents and visitors are asked to follow the hand washing policy at all times. Babies on NICU are particularly vulnerable to infection. By washing your hands, you can remove bacteria, which might be unsafe for your baby. Please familiarise yourself with the correct technique. There are posters at each sink too.

When should I wash my hands?

- Every time you enter NICU. This will help reduce germs being carried into the unit from outside
- Before and after you touch your baby
- After removing gloves, following a nappy change
- Before and after expressing breast milk
- Before and after preparing a feed for your baby
- Each time you leave the nursery
- Before you leave NICU. This helps prevent germs being carried out of the unit

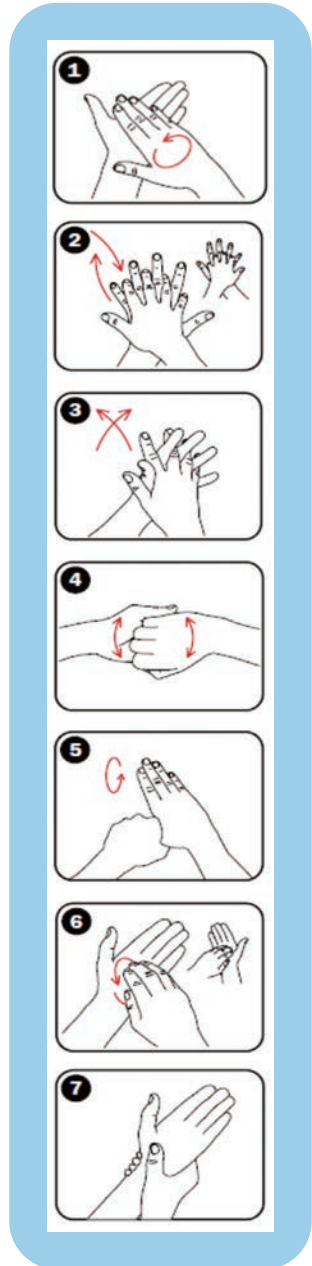


Hand washing technique for parents and visitors on NICU

Follow these steps and the diagrams below to effectively wash your hands

1. Take off your outdoor coat and hang it on the hooks at reception. Keep your valuables with you or use a locker.
2. Roll up your sleeves and remove any watches, bracelets and rings. Keep them securely in your pocket or bag until you leave NICU.
3. Wet your hands. Turn the tap off using your elbow.
4. Apply soap from the dispenser and wash your hands, wrists and lower arms following the instructions in the diagrams.
5. Dry your hands, wrists and lower arms using the paper towels provided.
6. Finally, apply the hand sanitiser provided in the dispenser, using the same technique as when washing your hands. It will dry in a few seconds.

If you have any questions please don't hesitate to ask a member of staff.



Frequently asked questions



What are the differences between the nurseries?

Q

A There are four main nurseries:

- Rooms 1 and 2 are the intensive care and high dependency rooms; this is where the sickest babies come for intensive care. The equipment and monitoring can be quite daunting.
- Room 3 has high dependency and special care babies. Babies may still require specialist equipment and monitoring.
- Fledglings Nursery is for babies getting ready for home. There is a lot less monitoring and equipment. Babies in Fledglings Nursery are reviewed less.

Is there a difference in how the nurseries are run?

Q

A Doctors are present on NICU 24 hours a day, 7 days a week. There is a doctor's round every day in Room 1, 2 and 3. Babies in Fledglings are reviewed less frequently but a doctor is always available if required. Nurses are likely to have more babies in their care in the less intensive rooms.

Who are the members of the team looking after my baby?

Q

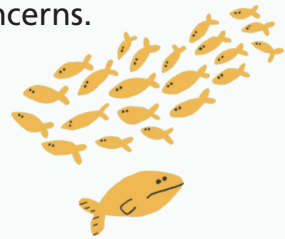
A There are both doctors and nurses responsible for each room. All rooms have a lead nurse, there is also a shift coordinator who is the nurse overall in charge, (usually located in Room 1). There will be a named nurse looking after each baby. No room is left unattended throughout the day and night. All staff are competent in neonatal resuscitation.

When will my baby move to another room?

Q

A As babies get better they are moved to the appropriate nursery. Our aim is to gradually help parents feel confident in caring for their babies.

We understand that this transition can be difficult. Please speak to NICU staff about any concerns.





Every baby has a named Consultant Neonatologist who is responsible for their care. There are wipe boards outside each of the nurseries showing the names of the nurses working that day/night and who is looking after your baby.

We have a team of paediatric medical staff consisting of Consultant Neonatologists, Consultant Paediatric Surgeons, Registrars, Junior Doctors, Physician's Associate, and Advanced Neonatal Nurse Practitioners (ANNPs). ANNPs are highly specialist neonatal nurses who have undertaken extensive training and qualifications to work alongside the doctors on the medical rota.

Our specialist nursing team consists of Matron, Nurse Manager, Senior Nursing Sisters, Neonatal Nurses, Neonatal Nursery Nurses and Assistant Practitioners, Practice Development Nurses, Clinical Educators, Neonatal Outreach Nurses and Family Care Team.

The Paediatric Surgical Nurse, Dietitians, Physiotherapists, Speech and Language Therapists, Clinical Psychologists, Occupational Therapists, Play Specialists, Pharmacists and Social Workers all come to NICU as part of the multi-disciplinary team. We also have Student Nurses and Midwives on placements as part of their training.



Taking part in ward rounds



Every day there is a ward round where your baby's progress and care is discussed by a multi-disciplinary team of nurses, doctors and other health professionals. Parents are always encouraged to be present for this. You will usually be asked how you feel your baby is getting on, whether you understand the care plan and if you have any concerns.

As the team changes with each shift, part of the discussion includes reviewing the details of your pregnancy and delivery, as well as the journey you have been on since you arrived on the unit. A member of the care team will 'present' your baby's journey, including their current situation, so that a care plan can be decided.

If it is a consultant-led ward round and there are junior doctors and ANNP's (Advanced Neonatal Nurse Practitioners) present, this is often used as an opportunity for teaching. Sometimes there might be discussions that are related to your baby's problems but not specifically about them. The language used may include words and phrases that you might not understand, but staff should explain these to you and you will be surprised how quickly you get to know the terms used. No information will ever be kept from you about your baby; staff will always tell you the truth. If you want to have further discussions with the consultant following the ward round this will usually be arranged for later in the day after all babies on the unit have been seen.

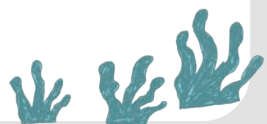




You as parents will understand your baby better than the staff and will quickly notice changes in their behaviour. You will therefore have a valuable contribution to make to ward rounds. Once you have sat through a few ward rounds you will have an idea of the sort of things the team need to know, and you may feel you would like to present your own baby at ward round. Below is a list of the sort of things that are useful pieces of information. You might just want to give a few points and then let the team take over.

- Name of baby, sex, gestation at birth, current age in days
- Birth weight, current weight
- Hospital born at and when transferred, type of delivery, where parents are staying now
- Breathing support needed at birth (e.g. CPAP, ventilation, high flow) and now
- How your baby is being fed (e.g. nil by mouth, TPN, nasogastric tube, orogastric tube, breast or bottle), type of milk, how often your baby is being fed, how your baby is coping with feeds
- Has your baby done a wee or poo?
- What infusions are in place
- Generally how do you feel your baby has been over the last 24 hours?
- Do you think your baby is comfortable?

If you would like to discuss the parent led ward round for your baby, please speak to a member of staff and we will come and talk to you.



Family time on NICU



We value parents as partners in care and hope you feel fully involved in your baby's care. We will help you to do this by encouraging you to be with your baby and take on responsibility for most of the care of your baby as you feel able. We aim for you to feel as in control as possible, taking into account your confidence and the condition of your baby. Unless there is an emergency or exceptional circumstances, we will not prevent you from being with your baby at any time. We welcome parents, brothers and sisters to spend as much time with your baby/babies as you wish. We suggest that you



prepare your children by telling them a little about their new brother or sister, the surroundings and by showing them a picture and perhaps this booklet, so they will know what to expect. We do ask that you supervise young children at all times.

Skin to Skin

Evidence shows that babies with high medical needs, in a stable condition benefit from kangaroo care (skin to skin contact), comfort holding (gently laying your hands over your baby) and being read to from parents. Please ask our staff for further information.





Parenting skills

The NICU Team are committed to family-centred care. Staff will help you to adapt to being a parent with a baby on NICU and start to focus on developing your own role in supporting your baby's care. Staff will help you become confident in looking after your baby as appropriate, based on their individual needs. We will teach you to tube feed your baby as soon as you feel comfortable. This will help you to get more involved in your baby's care and may enable your baby to get home more quickly. If your baby goes home still requiring some tube feeds you will have support from the Neonatal Outreach Team. We would be grateful if you could provide nappies, cotton wool and muslins while your baby is in NICU. We have clothes that you can use, however, if you wish to provide clothes please do so. It is helpful if you label them with your baby's name and ensure that there is a note on the cot to say you are using your own clothes/bedding.



Nappies

If your baby weighs less than 1.2kg, we will provide premature nappies that fit comfortably.

If nappies are too big this can cause discomfort by leaks and forcing your baby's legs apart which hurts their hips.

Once your baby reaches a weight over 1.2kg, please supply your own nappies and nappy sacks which are available in supermarkets.

We will provide size 0 and size 1 nappies if yours run out but we request that you keep an adequate supply for your baby. Please ask your nurse which size if you are unsure.



Feeding and caring for your baby



We are a UNICEF Baby Friendly Initiative fully accredited hospital having achieved our Stage 3 award. This means we actively promote breastfeeding and we value it, like “medicine” for preterm or ill babies. We know that every drop of breastmilk you can give your baby has value, even if you are not able to exclusively breastfeed. We want you and your baby to enjoy a responsive, positive and rewarding feeding experience whether you breastfeed or not. We will discuss with you why your breast milk is so important. We take pride as a unit, in supporting all mothers; however they choose to feed their babies. We have access to donor human milk when required.

All the nurses have received training to UNICEF standards to support mothers with all aspects of expressing and breast feeding. NICU is currently part of the UNICEF Baby Friendly Initiative accreditation. You may be approached by the NICU Infant Feeding Team to participate in an audit to find

out about your experience on NICU.

We have one expressing room that can accommodate two mothers. Sterilizing equipment and electronic breast pumps are available to use on the unit and we have breast pumps available for short term loan. Please ask a member of staff for further information.

We know that close and loving relationships are incredibly important for all babies and parents. We will support you to understand your baby’s behavioural cues and to touch, comfort hold and talk to your baby as soon as possible after birth. You will be given small knitted cloths to place on your skin, some will be placed with your baby. By swapping these you will both get to know each other’s smell, helping to promote bonding between you and your baby. We value skin to skin very highly as it is beneficial in many ways, not just for your baby’s development and for bonding, but also for enhancing breast milk production.



Infant Feeding Team



they are learning. You will be asked to bring in your own feeding bottles and teats. It is important that your baby is feeding competently with them before they go home. If you plan to formula feed, you will be taught how to make up feeds and sterilise the equipment, as well as tips on how to responsively bottle feed.

The NICU Infant Feeding Team have dedicated hours to offer additional support to all families with their feeding choices. You will be given a booklet called First Drops which will give you information and advice. The Team can help you with expressing of breast milk and transitioning to either breast or bottle feeding when the time is right. They can offer support to ensure your milk supply reaches its full potential and solve any issues that may arise. When your baby is ready to start oral feeding, you will be advised how to hold your baby and position them at the breast.

Parents are encouraged to learn to tube feed their baby and also to insert feeding tubes. The guidelines are in the First Drops booklet. Please ensure you are aware of these documents and sign them when you have had the appropriate training. This will form part of your discharge document.

If you have made an informed decision to formula feed or bottle feed your breastmilk, you will be given advice on what bottles to buy and how to feed your baby safely whilst



Caring for yourself

If your baby has been transferred from another hospital, midwifery care and follow up can be arranged. Please ask a member of staff. Please ensure that following discharge you continue to receive midwifery care.



Protected time

We aim to give babies a period of complete uninterrupted rest between 12:30 – 14:00 and 20:00 – 22:00hrs. Whenever possible we avoid undertaking any routine procedures or interventions during these times. This gives parents/carers an ideal opportunity to enjoy skin to skin care or positive touch as appropriate.

Visiting



Following consultation with families, visiting for family members and friends is now between 16:00 - 18:00. We would ask for your understanding and respect for other families individual circumstances if it appears that exceptions are being made.

- Siblings can visit at anytime with parents. Please ensure that siblings are well enough when they visit. This is particularly important during the winter months as children who are under 2 carry the bronchiolitis virus which is very contagious and can be dangerous for vulnerable babies.
- Children under sixteen years of age other than brothers or sisters will not be permitted to visit.
- It is essential there is adequate space around each cot especially in the case of emergencies. To avoid overcrowding around cots we ask you to restrict visitors to two at a time (this includes parents).
- We would ask you not to visit if you have cold/flu symptoms, diarrhoea and vomiting, or if you or a member of the family develops chickenpox, measles or shingles. If you are unsure please discuss with the nurse looking after your baby.
- No visitors will be allowed to visit without the parents being present unless prior arrangements have been agreed with the nursing staff.

We ask for your understanding and cooperation if restrictions are put in place in order to protect the babies on NICU.



Mobile phones



Mobile phones are allowed on NICU but we ask that calls are taken in the corridor or family room and not at the cot side and are kept on silent mode. To maintain confidentiality and privacy on NICU, do not make live calls or Facetime at the cot side. Only video your baby and no one else. WIFI is available in the hospital.

Parent/family facilities

Our family room provides a quiet space to rest, and make use of the kitchen area. There are toys and books for children. Please supervise young children at all times.

We have limited rooms available on the unit for parents to stay overnight and priority is assessed on a daily basis. We encourage parents to stay overnight with their baby prior to going home. There is further accommodation available within the hospital grounds at McKee House, for which there is a £20 deposit. The Family Care Team will discuss booking a room with you. Availability of these rooms

is limited and you may be asked to leave at short notice as priority is given to those parents living out of area.

Meals



We understand the difficulties of leaving the unit for meals but we urge parents to take regular breaks, to eat well and drink plenty of fluids. There are various cafes throughout the hospital. Vouchers are available from NICU Reception for subsidised meals for parents and these are valid in the main restaurant only. Mothers staying in the rooms on NICU are provided with meals. These need to be ordered by placing an order slip in the clear wallet on the door.

Car parking



Car parking is free if your baby is on NICU. Our Receptionist will give you a voucher each time you use the car park. Parents will need to take the voucher and their parking ticket to the Main Reception in the West Atrium to have it validated.

Safety and security

Doors to NICU are locked at all times. To gain access, please use the doorbell and a member of staff will release the door. Please be patient at busy times, we will open the door as quickly as possible. You may be asked to identify yourself; this is a safety precaution so that we are aware of who is visiting at all times.

The Trust is not responsible for loss of valuables and personal belongings. Lockers are available at reception for parents, please ask at reception desk for a key if you wish to make use of a locker.

Confidentiality

All information concerning your baby's health is strictly confidential and will only be given to you. A member of the medical team will be happy to update you regularly on your baby's care and progress. If you wish to talk to your baby's named consultant, please ask a member of the nursing team so that a convenient time can be arranged. You are welcome to be with your baby while the

team are discussing their care. In order to promote parents unrestricted access you may be asked to wear ear plugs or ear phones while other babies are being discussed. There is a password system in place to receive information about your baby on the telephone.

Consent

If your baby requires any procedures, investigations or treatment, you will be asked to give verbal or written consent. In normal (non-urgent) circumstances, consent must be given by the person with legal parental responsibility. The medical team will explain everything to ensure that you fully understand what you are consenting to.

Videos and photographs of your baby may be taken on admission for you and during their stay for medical reasons. You will be given consent forms on admission.



Fire policy

Your baby's safety is of paramount importance and in the event of an emergency, NICU staff will inform you of what to do. The fire alarms are tested on Wednesday mornings.



Smoking

The hospital building and grounds are designated 'NO SMOKING' areas.

Zero tolerance

The Hospital Trust will do all it can to prevent abuse, assault and discrimination towards its staff. Aggression, threatening and racist behaviour is unacceptable and will not be tolerated.



The Family Care Team

For many parents the first few days, weeks or months with a premature or sick baby are extremely tough. The Family Care Team can offer families additional support to help them cope through this difficult time. There is also limited financial help available for families experiencing severe problems with transport costs.

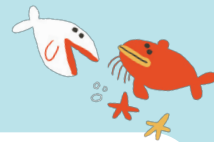
The Family Care Team liaise closely with the Neonatal Outreach Team, and all the hospital and community professionals involved in the care of your baby to ensure that your baby is able to go home as soon as possible. Discharge planning meetings may be organised for babies with complex needs or being transferred to the paediatric ward.

The Team Leader is the Children's Safeguarding Link Nurse for NICU and there is close communication with Children's Services when necessary.

If you wish to speak to the Family Care Team just let a member of staff know.



Therapists on NICU



Clinical Psychology

Being a parent with a baby on NICU can bring up all sorts of difficult thoughts, feelings and reactions. Parents come to NICU with individual personal stories, and both what you are dealing with now and experiences from the past are likely to be affecting you. Every parent's journey to – and on – NICU is different. But no matter the length of stay, or suddenness of arriving here, we expect you to feel like you are on a rollercoaster. Whatever your background, having a baby on NICU is challenging and there is no way to prepare yourself for it. Parents often feel really fearful, sad, angry, guilty – and a thousand things more. It's like being in an emotional pressure cooker and that makes it hard to understand what's going on. But there is no right or wrong way to think, feel or behave right now. NICU doesn't come with a road map. Your responses to what you are going through are normal – it is the situation that is 'not normal'. The NICU Clinical Psychologist

can help to make sense of whatever you might be feeling or thinking about, whether it is about your baby or something else in your life. This can be anything from a one-off chat or more regular conversations. No issue is too big or too small! Just ask a member of staff and they will put you in touch.





The Speech and Language Therapist

The Speech and Language Therapist on NICU is available to help with establishing feeding skills. Whilst not all babies will need this specialised help, some babies will need some extra support to establish oral feeding (that is breast or bottle feeding by mouth). The Speech and Language Therapist may begin work with you and your baby well before the introduction of oral feeds. This might include working on your baby's tolerance of touch around the mouth and sucking practice on a finger or dummy. The Speech and Language Therapist will work alongside staff on the NICU to support you and your baby on the safe and timely introduction of oral feeding.

Occupational Therapy and Physiotherapy

A Physiotherapist and Occupational Therapist visit NICU to support babies with developmental care and individualised support as required.

Some babies will meet the criteria for further support with development after discharge. All babies born at 33 weeks and under are routinely offered referral to Occupational Therapy for support after discharge. Referrals will be discussed with parents as appropriate.

Complex needs

Parents with babies with long-term complex needs, will be kept informed and given the opportunity to meet other professionals from the multi-disciplinary team who may be involved in supporting your baby and family in the future. Please speak to your baby's named consultant and the Family Care Team if you have any questions.

Neonatal Surgical Team



The Norfolk and Norwich NICU is one of two Neonatal Intensive Care Units in the East of England equipped to carry out a variety of specialist surgery on the smallest of babies from across the region. The Paediatric Surgical Nurse Specialist supports complex surgical patients and their families on NICU and the Paediatric Ward throughout their journey. There is a link surgical nurse on NICU who has additional training in neonatal surgical conditions and also provides training and education to families prior to going home.

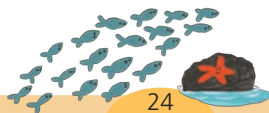
Transfer to other Neonatal Units or Paediatric Ward

If the NNUH is not your local hospital, our Repatriation Link Nurse will be involved with you from admission. When your baby's needs can be met at your local unit, the Link Nurse will ensure a smooth transition closer to home.

If babies have long-term care needs, it is more appropriate that they are transferred to a children's ward where the environment and specialist team can further support their development. Prior to transfer, you will have an opportunity to visit the ward, meet nursing staff and discuss how your baby will be cared for.

If a baby is born at term and transferred to another hospital for treatment, they may be re-admitted to the Paediatric Ward (Buxton), rather than NICU, on their return to NNUH.

The NICU Team and Neonatal Outreach Team liaise with the Children's Community Nursing Team (CCNT) locally and other Outreach and community nursing teams throughout the region.



Neonatal Outreach Team

The Neonatal Outreach Nurses are based on NICU and will be involved in discharge planning to ensure your baby is able to go home as soon as possible. They offer nursing support at home to a range of premature and newborn infants, up to 4 weeks post-term gestation, who have been discharged from NICU and Transitional Care. For longer term support, your baby's care may be transferred to the Children's Community Nursing Team. Ask to meet the Team prior to discharge home.

The Neonatal Outreach Team cover a large area of Norfolk, so families are asked to be understanding about punctuality for home visits as journey times and length of visits cannot always be anticipated. They will try and telephone regarding delays but this is not always possible in areas with limited phone signals.

The service runs Monday to Sunday 07.30 - 18.00. For non-urgent queries leave a message on the office number 01603 286838 or mobile 07771 881389. There is a voicemail service on both lines, you can also text us.

- All babies receiving outreach care have open access to the Children's Assessment unit (CAU) on Coltishall Ward Level 2 West Block. This ensures families have advice and support out-of-hours if there are concerns with feeding tubes or a baby is unwell. Telephone 01603 289774 and inform CAU that your baby is under the Neonatal Outreach Team.
- You may be advised to take your baby to CAU for a medical review or a new feeding tube.



Children's Community Nursing Team (CCNT)

The CCNT provide a community nursing service for children and young people from birth up to 19 years across central Norfolk. The team support families to care for their children at home and minimise hospital admissions. The service operates Monday to Friday 0800-1800 and 0900-1200 at weekends and Bank Holidays. Babies who have complex needs and require longer term nursing support will be referred to CCNT. If your baby is under the Neonatal Outreach Team, a joint home visit will be arranged to transfer care at 44 weeks corrected gestation. This gives parents the opportunity to meet the team with Outreach and discuss what support will be offered in the future. Visits may be less frequent as your baby gets older and CCNT will continue to liaise with all members of the multi-disciplinary team that are involved in the care of your baby. This includes your baby's Consultant, Dietician and Health Visitors for weight monitoring. Your baby will continue to have access to the Children's Assessment Unit for out-of-hours support.

Safeguarding Children

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 contact Children's Services and other professionals deemed necessary if we have any concerns about the babies on NICU. We routinely inform Children's Services if a baby has been in hospital for 12 weeks or more. We will usually discuss this with you prior to a referral and give you further information regarding this process. For anyone experiencing domestic violence, Leeways can offer support and advice tel: 0300 561 0077 www.leewaysupport.org



The Chaplaincy Team



The Chaplaincy Team is here for people of all faiths, as well as those who have none, and can also make contact with religious leaders appropriate to your faith tradition. They will visit anyone if asked and are happy to discuss spiritual issues or any other concerns. There is a multi-faith chapel complex and garden within the hospital, information leaflets are available at Reception and in the Family Room. Contact on 01603 287470. Baptisms and Naming Ceremonies can be performed on NICU.

East Anglia's Children's Hospice

NICU works closely with EACH (East Anglia's Children's Hospices) who offer Family Support to parents on NICU for babies with life-threatening and life-limiting conditions.



Bliss is a charitable organisation for babies born too small, too sick, too soon, and offers a wide range of information booklets and support for families.

Contact: www.bliss.org.uk for information, interactive message board and Dad's Forum.

Free phone **0800 801 0322**

Email: hello@bliss.org.uk

NICU Face book Support Group

www.facebook.com/#!/group.php?grid=12577414310

Screening tests on NICU

Retinopathy Of Prematurity (ROP)

Retinopathy of prematurity is an eye disorder affecting the blood vessels of the retina that may be seen in babies born prematurely or have a very low birth weight. All babies that are born at less than 32 weeks gestation or less than 1501g will be screened for ROP. ROP can occur when babies are born prematurely or at low birth weight due to their eye structures not being fully developed, and therefore completing their development after birth, where it may be different from that inside the womb.

We endeavour to screen all babies meeting the criteria whilst they are an in-patient on NICU and this will be arranged by the NICU link nurses. Your baby will have eye drops prior to the screening to aid the examination by the specialist paediatric eye doctors (ophthalmologists). Babies may be discharged home prior to the date they require screening. An appointment will be made for your baby to be screened as an out-patient on NICU. Babies may require follow up screening, often on a 2 weekly basis, in order to monitor their eyes until they are fully vascularised/developed and the risk of ROP is reduced.

For most babies that develop ROP, it is mild and will settle completely without requiring treatment. If the ROP is more severe then early treatment is required to prevent loss of eyesight. This may be in the form of injections or laser treatment. If you have any concerns or questions please ask the nurse caring for your baby.



Newborn blood spot (heel prick) test

This test involves taking a small sample of your baby's blood to screen it for 9 rare but serious health conditions.

This test is done when your baby is 5 - 8 days old. Early treatment can improve your baby's health and prevent serious disability or even death. The results are available at 6 - 8 weeks.

You will be contacted earlier if there are any concerns. Further information is available on www.nhs.uk. You can also speak to your GP and Health Visitor if you have any questions.

Hearing

Screeners will test your baby's hearing on NICU. Sometimes further follow up is required after your baby has been discharged home. The Hearing screeners will give you The Red Book to take home.

Immunisations

Your baby may receive routine immunisations on NICU depending on their age. You will be given a Red Book which has a section about the immunisation programme. Further information is available on www.nhs.uk

Preparation for discharge home



The medical and nursing team have a weekly discharge planning meeting to discuss the progress of babies and readiness for discharge home. We will always try and keep you informed about plans and the expected date of discharge from NICU. We ask that you get everything prepared at home and work with us to feel confident looking after your baby independently. Prior to discharge we will do our best to give you the opportunity to come and spend a night or two with your baby in one of our parent bedrooms. However due to demand for the bedrooms this may not always be possible.

Feeding

In order to be discharged home your baby will usually need to be feeding effectively and safely from either the breast or the bottle. Your chosen feeding method may need to be supported with a nasogastric tube.

We strongly recommend that you learn to tube feed your baby as soon as possible as this will help your baby come home more quickly. You must complete the relevant paperwork for tube feeding and passing a feeding tube in the 'First Drops' folder. The Neonatal Outreach Team will support you at home and provide any equipment required.

Babies on Nutriprem 2 or other specialist milk will be given a tin of powdered milk on discharge. You will have a prescription to give to your GP for further supplies.

Don't forget to

- Complete 'First Drops' paperwork
- Ensure you have a breast pump at home if you plan to continue expressing
- Purchase your own bottles and teats to use on NICU prior to going home. Staff will advise which type are appropriate for your baby.

Temperature Control

Temperature control for babies is very important. Babies that are not warm enough will have less energy to feed and may struggle with weight gain. Normal range is 36.5 -37.5 degrees °C. (A high temperature or fever is usually considered to be a temperature of 38 degrees °C or above). Please ask staff for tips on how to keep your baby warm. We have blankets, hats and cardigans on NICU to give to parents if required. Safe sleep guidelines advise about the risk of overheating.

Don't forget to

- Buy a digital thermometer. We advise that you bring it in prior to discharge to check you are happy with your technique and the thermometer
- Familiarise yourself with the Safer Sleep Advice from the Lullaby Trust Website
- Ensure you are taught to do new born resuscitation and have been given the leaflet.

Medication

Many babies go home requiring vitamin and iron supplements. You will have the opportunity to start giving these yourself prior to discharge. Please ask staff to help you to do this. You will be given a supply of medications to take home. You will have a prescription to give to your GP for further supplies.

Don't forget to

- Complete paperwork with staff so you can give your baby's medications prior to discharge.
- Register your baby with your GP so that repeat prescriptions for medication and milk can be organised. It is important to do this as soon as possible as there can be a delay with repeat prescription requests and pharmacies ordering supplies.

Follow up

Your baby may require follow-up appointments with their Consultant, other specialists, occupational therapy, physiotherapy or have on-going tests. Appointments will be sent to you following discharge via an electronic link to a mobile phone or email. If the link is not opened in 3 days, an external company will send a paper copy to parents.

The Neonatal Outreach Team may be required to support your baby at home. Ensure you read the contact information and understand who to phone if you have any questions or concerns.

Your Health Visitor should have contacted you and will arrange a visit at home. The hearing screeners should have given you a 'Red Book'. This is an important record of your baby's progress, screening tests and immunisations.

Phone numbers are on the back of this booklet.

Don't forget to

- If you have been referred to Neonatal Outreach Team ensure you know how to contact them. It is useful to put their numbers in your mobile. Ask to meet the Team prior to discharge home
- Ensure you know how to contact your Health Visitor. For babies in Norfolk contact Just One Number 0300 300 0123
- Take your Red Book home. Staff will be able to give you one if this has not been issued.
- Keep your baby's information all together and make note of any other appointments. This may include coming back to NICU for follow up tests.



JustOneNorfolk.nhs.uk



Trusted help, advice and information during pregnancy, birth and throughout your parenthood journey.



A telephone and online advice service to support parents and carers, with infants who cry excessively or have sleeping problems.



Babies cry, and you can cope! ICON offers advice for parents on what baby's cry may mean and how you can safely manage it.



A variety of resources to help you and your family with the cost-of-living crisis and direct you to the correct support.



No one should go hungry, the trussell trust helps you find your local food bank and get the referred voucher to help. It also offers support with resources to access.



Preventing infections in babies saves lives we want to raise awareness around how to prevent infection in those first few months of life.



Top tips and important information after your baby has been discharged

Having visitors and going outside

- It is normal for you to feel anxious when you take your baby home. Some people, including close family, may not understand the journey you have already been on with your baby and the additional worries and anxieties you may have.
- Do not be afraid to take some time as a family to settle in, it is a good idea to limit the number of visitors you allow.
- Family, friends, and even strangers, will likely want to congratulate you and meet the baby, always encourage them to wash their hands and not to kiss baby.
- It is important that you keep your baby away from people with cold or flu - like symptoms or stomach upsets.
- Please be aware it is common for premature babies to pick up colds and sniffles and sometimes they will need to be readmitted to hospital. This is due to their immature immune systems. Keep them as safe as possible following the pointers above. But do not blame yourself if they do get poorly.



Nappy Care

- Change your baby's nappy when they are awake. Try not to disturb their deep sleep – this is when they develop and grow.
- Put a towel or muslin on the changing mat to make your baby warm and more comfortable.
- Check your baby's skin during a nappy change for any redness.
- Always clean from front to back, wiping the 'clean' area first and then their bottom or 'dirty' areas.
- Ensure the skin is dry before putting on a clean nappy.

Bathing and Washing

- You do not need to bathe your baby every day. You may prefer to wash their face, neck, hands and bottom carefully instead.
- Make sure the room is warm. Get everything ready beforehand. You will need a bowl of warm water, 2 towels, cotton wool, a fresh nappy and clean clothes.
- You do not need to add soap to the water within the baby's first month. The water should be warm, not hot. Check it with your wrist or elbow and mix it well so there are no hot patches.
- Start washing your baby from clean to dirty. Wash their face, ears and head first, then dry completely to stop baby getting cold. Move onto their hands, feet, arms and legs. Wash under their neck and armpits. Clean their chest, tummy, back, genitals and bottom. Ensure to wash and dry inside all their creases.
- Dry thoroughly after bathing.
- All information from www.nhs.uk

Quick guide to bathing your baby

Ensure the room and towels are warm and you have everything you need. Babies can get cold very quickly so make sure your baby's temperature is maintained at all times.

Check the temperature of the bath water with a baby bath thermometer or the inside of your wrist or elbow. This should be 37-38C. Bubble bath is not necessary when you baby is young as this can dry out their skin.

Place a clean towel on a changing mat, undress baby to nappy and wrap up.

Clean face first with cotton wool and dry.

With baby wrapped in a towel, securely hold baby under your arm and gently pour water over baby's head. Use very small amount of shampoo, rinse and dry.

Keeping baby wrapped, clean the nappy area.

To place in the bath, hold baby firmly so that their neck rests on your forearm, with your hand under their arm providing support. Let baby's feet feel the water and gently immerse. Use your other hand to wash baby.

Firmly grip your baby under both arms and place them back on the mat. Beware a wet baby can be slippery.

Dry nappy area first particularly skin creases and folds and put nappy on.

Ensure baby is kept warm and wrapped while you dry, paying particular attention to folds around the neck, underarms, elbow folds and between fingers and toes.





Before dressing your baby, you may moisturise and massage your baby with coconut oil or unperfumed baby cream.



There are videos on-line with bathing demonstrations.

www.nhs.uk/caring-for-a-newborn/washing-and-bathing-your-baby
www.nct.org.uk/baby-toddler/everyday-care/bathing-your-baby



Research Improves Neonatal Outcomes

Here at the NNUH, our NICU staff are extremely passionate about research. Follow us on twitter:  @RainbowTheRhino

NICU clinical research

The research we carry out enables us to safely collect information, always following strict regulations, to gain knowledge and understanding about how we can consistently improve and enhance the high standard of care all the babies on our unit receive.



There are different kinds of research studies that your baby may be able to participate in. Some studies may include monitoring aspects of your baby's care and reading through their notes a little closer, while others may involve a few extra procedures.

If your baby is eligible for any studies, a member of our dedicated research team will approach you to discuss this. You would be provided with all of the information about the research study and a full explanation would be given to you by highly qualified professionals.

We would never carry out research without your consent.

The information we gather is carefully analysed and may result in changes to our practices in future care. Choosing to take part in research might have benefits for your baby and it could also help to shape the future of specialised care for premature and poorly babies in the future.

If you have any questions or you would like to talk with one of the team please ask the nurse looking after your baby or alternatively, please contact the NICU research team:
01603 646106 or 07934508522

Meet Poppy!

Poppy was born at 26 weeks gestation. In the second picture, Poppy is proudly showing off all 5 of the studies she participated in during her NICU stay – ARCTIC, baby Oscar, BAMBI, Bear Men B and SPRING. This is Poppy now on the right!



Poppy holds the record for participating in NNUH NICU's most studies!

"I find it all very interesting, we were more than happy for Poppy to participate in as many trials as possible, in hope that it helps future premature babies and I always think some of them may have even helped Poppy along the way too. She's now a healthy, cheeky, walking, non-stop talking 2 ½ year old. Our little miracle!" - Poppy's Mummy.

Some examples of how research has improved our practice

Kangaroo care – research on the benefits of skin to skin for baby and parents mean that we encourage this on the unit and support parents to be more involved with their baby's care.

Surfactant – treatment identified to help babies with breathing problems. It has helped to save babies' lives and improve long term outcomes.

Probiotics – research has identified giving probiotics helps to prevent babies from getting a severe gut condition.

A guide to recording information on your baby's care in the neonatal unit

Badger Net Database



Your baby needs the expert care of the medical and nursing team on the neonatal unit. To help deliver the best care possible we collect information about all the babies we look after.

The Badger Net Database is being implemented within all the neonatal units across London and South East England. It is a web based system which collects clinical information regarding your baby.

Frequently asked questions

Why do we need this information?

We use the information we collect to help us:

- Collect accurate details about the care of sick or premature babies in the neonatal unit
- Monitor neonatal care and make sure it is always up to date
- Plan and develop services for you and your baby within your area

- Produce reports that highlight areas of good practice that we can share across the region Clinical information necessary to those staff directly involved in your baby's day to day care will be identifiable data. Clinical data required for all other purposes will be anonymised.

What information do we collect?

We record:

- The NHS number for you and your baby
- Personal detail such as your contact details
- Your baby's condition and treatment on a daily basis
- GP details
- Your baby's medication and follow up information
- Where your baby was born
- How many babies you had
- Your baby's birth weight
- How many weeks pregnant you were when your baby was born

Who collects the information?

The staff on the neonatal unit – usually this is a neonatal nurse, doctor or ward clerk. All information will be stored on a secure system and password protected.

When will we collect the information?

Information is updated regularly throughout your baby's stay in the neonatal unit

How will we collect the information?

We collect the information from the medical notes and nursing records. We enter it directly into the database system.

Who will see the information?

Only the people who care for your baby see all the details. There are very strict regulations controlling access to personal information like your baby's NHS number and date of birth. By law, everyone who works for the NHS must keep all personal information confidential and the Trust has strict confidentiality and security procedures in line with the Data Protection Act (1998).

What is the consent procedure?

If you are happy for your baby's details to be used for clinical care purposes, secondary analysis such as audits and for clinical information to be transferred between units should the need arise then you do not need to do anything. If however you do not want your baby's clinical information to be available for such purposes please ask a member of staff for an opt-out consent form. A signed copy of the opt-out consent form will be given to you for your information.

Can I see the records on the database?

Yes, you can see a copy of the information we have about you and your baby. To do this please talk to the nurse in charge.

How can I find out more?

Please talk to member of staff if you:

- Need more information
- Have any questions or concerns
- Want us to remove any information from the database

Feedback

Our aim is to work with you to give the best possible family centred care for you and your family. To do this we rely on your feedback to highlight what we are doing well or look at areas where we can improve. The Trust also have a feedback site which can be accessed from the QR code below, you will need this on your phone. If you could please take 5 minutes to complete this we would be very grateful. (Please put NA for the questions about mealtimes as they are not applicable to our area).



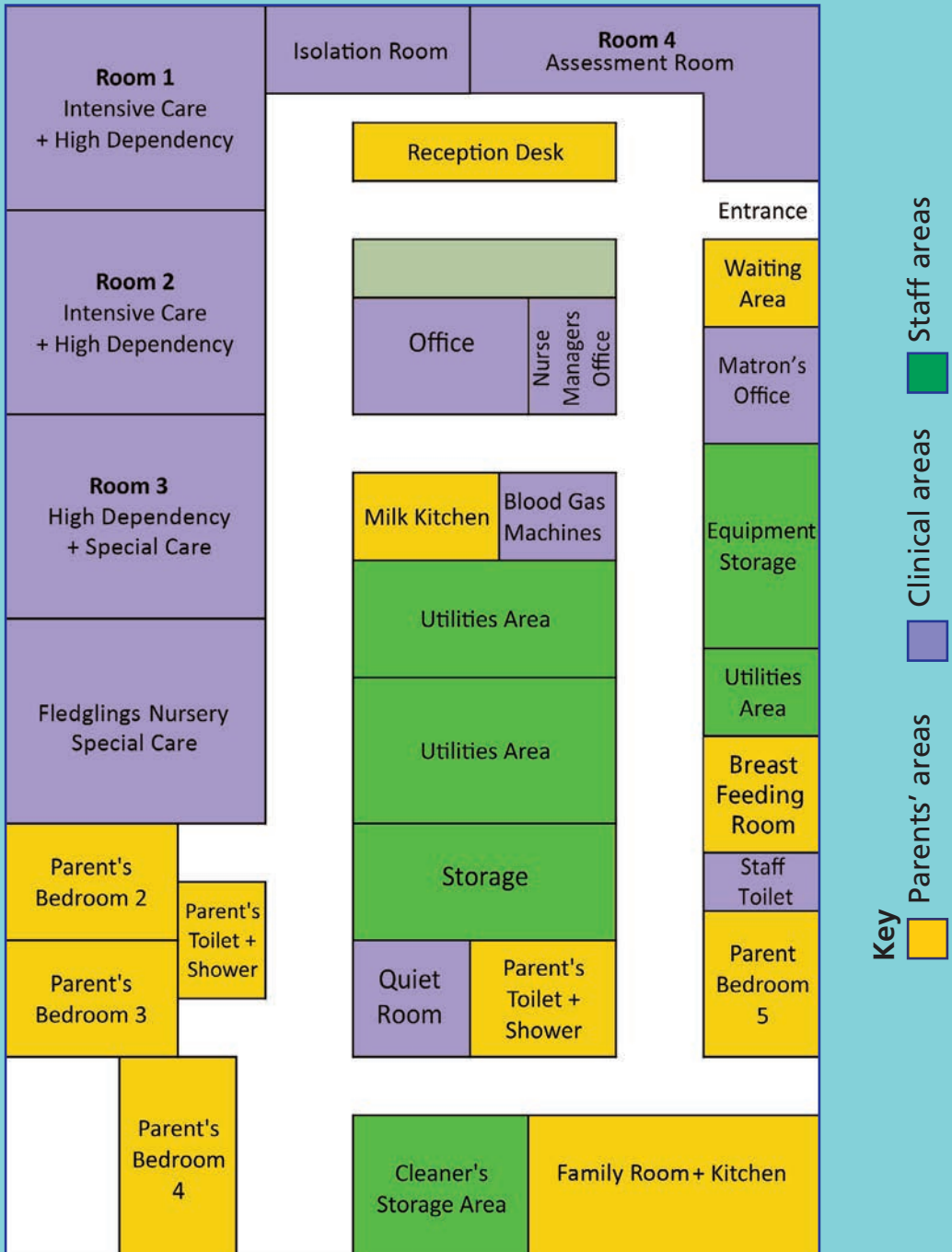
There are a number of posters around the unit where you can access this code. Please could you also feedback prior to your discharge.

If you have any suggestions, complaints or concerns regarding NICU, nursing or other issues, please make these known to a member of staff immediately as we can often resolve issues for you.

Alternatively you can ask to speak with the NICU Matron or contact PALS the Trust's Patient Advice and Liaison Service. PALS leaflets are also available. PALS leaflets are available at reception or in the family room for any complaints or compliments.



NICU floor plan



Who to contact for advice when you are at home

In the case of an emergency always call 999 for urgent medical assistance

Call 111 for immediate medical advice

GP for medical concerns or questions

Just One Number 0300 300 0123 for the Norfolk Health Visiting Team

Medicom for Midwifery support and advice 01603 481222

Neonatal Outreach Team office 01603 286838, mobile 07771 881 389

Children's Assessment Unit 01603 289774



Neonatal Intensive Care Unit

Level 3, West Block

Norfolk and Norwich University Hospitals Foundation Trust
Colney Lane, NR4 7UY



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Authors: Charlotte Devereux and Sarah Highton

A5 NICU Family Guide

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