North West Anglia
NHS Foundation Trust

Welcome to the Neonatal Intensive Care Unit (NICU) Family Guide

My name is

I was born on

My Hospital Number is

When I was born I weighed

Introduction

Dear Family

Congratulations on the birth of your baby. We appreciate that this is a particularly 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 the unit. The neonatal staff are there 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.

Within this NICU you will find that we provide many different types of care to babies. We care for babies born prematurely, too small, or who are very sick when born and require specialist care.

Our Vision

“The staff who work on NICU have a strong commitment to providing exceptional care to infants and their families. We believe that the parent-child relationship should be nurtured from the beginning, throughout and beyond their time on NICU.

In order to facilitate this, we work with specific goals in mind:

- Provide a high standard of medical and nursing care to all infants.
- Enhance clinical skills through evidence-based practice.
- Encourage and support parents to become involved in their baby’s care with an aim to becoming proactive in planning and delivering the care.
- Create a healing, nurturing environment which provides developmental, educational and emotional support in order to meet the diverse needs of staff and families.”

Welcome to NICU

What you can expect of NICU staff

- The NICU team 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.

To do this, we need you!

- Please read this family guide which you should receive on arrival to NICU. This has important information regarding your baby's stay with us.
- Please work with the nursing team to enable us to support you in caring for your baby.
- You need to be involved in your baby's care as much as possible; attending to cares, participating in skin-to-skin and attending ward rounds wherever possible.
- All parents are expected to provide nappies and cotton wool for their baby's. Your baby may also have their own clothes and blankets- please make sure they are washed before use. We will give them back to you to take home to wash when they are dirty. We will make every effort to ensure your personal clothes and blankets are given to you, however, there is a small chance they may get lost- please avoid bringing any particularly special clothes or blankets.
- There is a zero tolerance for aggressive, discriminatory or threatening behaviour towards staff. Security will be contacted in the event of this happening.
- Parents rooms are available when preparing to take your baby home, however, we expect parents staying in these flats to take the opportunity to care for their baby day and night.
- If you have any questions, please do not hesitate to ask any of the NICU team.

Key Phone Numbers

NICU Reception	01733 677236
NICU Nurses station	01733 677233 or 677234
Outreach Team	01733 677235

Parents/guardians- please feel free to phone us for an update at any time of the day or night. Please also be aware we will not be able to update family members and friends.

Nursing handover times

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

Doctors Ward Round times

Morning	08:45 – 09:30 (approximately)
Evening	20:45- 21:00 (approximately)

We encourage parents to be present for ward rounds wherever possible. On Thursday mornings we have the 'grand round' where all the doctors and other disciplines involved in your baby's care will be present.

Confidentiality

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).

Please be aware that during ward rounds, you may be asked to leave the bed space while the team discusses other babies on the unit. There is the parent's room available to sit in and get a drink, and we will come and get you once it is appropriate. If you are having cuddles with your baby during ward round times, we can now provide you with headphones to listen to music on your phone during discussions regarding other babies.

Contents

Nappy Cares

Mouth care

Keeping your baby warm

Developmental Care

Quiet Time

Pain Management

- Containment Holding
- Sucrose
- Swaddling Non-nutritive Sucking
- Pain Medication

Jaundice

Screening Tests for your baby

- Newborn Blood Spot
- Newborn Infant Physical Examination (NIPE)
- Infection Screening (Sepsis Screen)
- Retinopathy of Prematurity
- Hearing Screening

Common Equipment used in NICU

- Ventilator
- CPAP
- Vapotherm
- Nasal Cannula Oxygen
- Apnoea Alarms
- Monitoring

Our NICU

Peterborough NICU has a team of paediatric and neonatal medical staff including; consultants, registrars, senior house officers (SHO's) and the advanced neonatal nurse practioners (ANNP's).

Our nursing team consists of our manager, senior sisters, deputy sisters, neonatal nurses, staff nurses, nursery nurses and the outreach team (nurses and nursery nurses).

There are 2 main areas in our NICU:

1. ***Intensive Care or High Dependency (Beds 1-8)***- this is where the sickest of babies are nursed, or those babies who were sick and who now need close monitoring to ensure they are getting better. There will always be nurses caring for these babies, most are trained specifically in neonatal intensive care.

2. ***Special Care Nursery (Beds 9-15)***- is for babies who clinically stable are getting ready to go home. They are normally establishing feeds and having discharge paperwork completed. Both nurses and nursery nurses work in this area. The Nursery Nurses are very skilled in discharge planning, feeding and teaching you to care for your baby at home.

Who's Who?

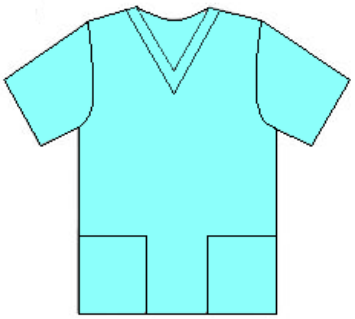
Ward Manager
& Neonatal Sisters
Navy Blue

Advanced Neonatal
Nurse Practioners
Olive Green

Deputy Sisters
Royal Blue

Staff Nurse (Speciality
and non-speciality)
Ciel Blue

Nursery Nurses
Lilac



Support Workers
Mali Blue

NICU has a huge team of amazing people working to help your baby get better.

The consultants will wear their own clothes, and the doctors working on the unit will be wearing blue scrubs. They should always introduce themselves so you will know who you are speaking to, every member of staff should be wearing an ID badge.

We also have support workers & ward clerks. These specific roles ensure that the nursing staff have greater ability to focus on your baby. They will always be happy to help you if you have any questions.

Occasionally, you may find that a student nurse or midwife is working alongside the nurse caring for your baby. They will be dressed in blue scrubs and should introduce themselves as students. We will ensure that they are supervised and are competent in the tasks they perform.

Visiting Times

Parents can visit at any time of the day or night; we ask that baby's siblings only visit between 08:00-20:00. Other visitors are asked to only visit between

- 17:00-19:00

Children who are not siblings to the baby are not permitted to visit if they are under 14 years old.

Please understand that the babies on the unit need a quiet environment to grow and develop, therefore we ask that during visiting times only 1 extra visitor in addition to parents are present.

Please do not allow or encourage any family members or friends to visit who are or have been poorly (cold/flu or diarrhoea/vomiting) in the past few days. Your baby is too precious to risk passing on an infection.

Visitors will not be permitted onto the unit without a parent present.

2nd visitors

We will not give out any information regarding your baby to anyone on the phone that is not a parent.

In certain circumstances, we can arrange for there to be an alternate '2nd Visitor' that is not a parent, who could potentially visit outside of normal visiting times and who could receive updates by phone. This is not applicable for every family and is primarily aimed where only 1 parent is involved. Please speak to your nurse if you would like to discuss this.

Safety and Security

The doors to NICU are locked at all times. To gain access, please ring the doorbell and we will answer as quickly as possible. Please be patient at busy times, we will open the door as quickly as possible. You may be asked to identify yourself as a safety precaution if we do not recognise you straight away.

Please be aware that while your baby is on NICU, baby's surname will be the same as Mum's. When we are asking who you are here to see, please make sure you use this name.

Infection Control

It is important to us that we protect your baby from infection risks. All visitors must wash their hands with warm water and soap on entering the unit. All outside coats must be left on hooks at the entrance to the unit.

We also ask that only parents and siblings touch their new baby to reduce the risk of germs- we know this might seem strict but it is all to keep your baby safe!

Parent & Family Facilities

Our family room or parent's 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 and microwave for your convenience, and we have limited food supplies and drink donated to the unit for parents by previous families and 'Give Back Peterborough' and other charities, for those families that have been admitted quickly and have not been able to get home.

We understand that you may not want to leave your baby for meals, however, we strongly urge parents to take regular breaks to eat and drink. There is a small shop and limited hot and cold food in the Women and Children's Atrium, Costa and WH Smiths are in the main atrium and the hospital restaurant is located in Core A on level 1 of the main hospital.

NICU is a very warm environment, so please ensure you have a drink with you.

We also have some lockers available for parent and family use in the reception area. 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.

Fire alarms

We do not routinely run fire drills on this unit, therefore in the event of a fire or an emergency please follow the NICU team's instructions.
On a Tuesday morning at 9am there is a fire alarm test which you may hear.

Smoking

The hospital building is a no smoking zone, outside there are smoking shelters which we ask families to use should they wish to smoke. If you would like any smoking cessation advice, please speak to your nurse who can get you relevant information. If you do smoke, please try and wear something over your indoor clothes to keep them as smoke free as possible. We would 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).

Mobile Phones

Mobile phones are allowed on the unit, but we ask that you have them on silent while with your baby and answer any calls in reception or in the parent's kitchen and not at the cot side. **If you use your phone as a camera, please ensure the flash is not on.**

Car Parking

Car Park D is the closest car park to the Women and Children's entrance. Parking for parents is free; please ask your nurse or the ward clerk on reception for a parking voucher.

Take your voucher and parking ticket to the reception in the main atrium to be validated.

Safeguarding Children and 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 and other professionals deemed necessary if we have concerns about a baby on NICU.

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.

Consent

If your baby requires any procedures, investigations or treatment we will discuss this with you and gain consent (for example blood transfusion or vaccinations), if there is an emergency then we will always act in the best interest of your baby.

Consent must be given by someone with both capacity and parental responsibility- the nursing and medical staff will explain everything to you to ensure that you understand what it is you are consenting for. If you have beliefs that you feel may affect the treatment you wish your baby to have, please speak to a nurse or doctor to make us aware as soon as possible. Similarly, if there are any treatments or procedures that you do not wish your baby to have then speak to the nurse looking after your baby.

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 NICU and check that everyone is doing well and offer their services.

Complaints and Feedback

If, for any reason, you do have any concerns about your baby and the care they are receiving then please ask to speak to the Nurse in Charge or ward manager and we will try and resolve this wherever possible.

However, if you have a complaint that you feel cannot be resolved by us, then PALS (Patient Advice and Liaison Service) are available to help. They are there to help deal with issues and try to prevent formal complaints where possible by resolving a situation to the best of their ability.

To contact PALS:

- Visit their desk in the main atrium between 08:30am-4:30pm Monday to Friday
- Phone number 01733 673405 (you may have to leave a message and they will get back to you)
- Email nwangliaft.pals@nhs.net

Parent Support & Information

For many parents, 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.

Bliss

for babies born too soon, too small, too sick

Bliss is a charitable organisation for babies born prematurely, sick and small. They offer a wide range of information booklets for families and their website has lots of information you may find useful and interesting.

www.bliss.org.uk

free phone 0800 801 0322

the lullaby trust

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

www.lullabytrust.org.uk

NHS SMOKEFREE

If you want help to stop smoking, or need some advice then NHS Smokefree helping offer free help, support and advice and can give you details of local support services.

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

DOMESTIC ABUSE SUPPORT

Your baby's nurse wants to ensure they are going home into a safe and happy home, please speak to them if you have any worries or concerns. Please speak to a member of staff if you want to discuss anything regarding abuse.

www.domestic-abuse.org

0808 802 3333

The mind website has a wealth of information on maternal mental health.

Call 0300 123 3393 or Text: 86463
www.mind.org.uk

The 'Parents of Peterborough NICU' Facebook page has been set up by Peterborough parents who have been on our unit. The staff have no control over the page.

Best beginnings work to inform and empower parents who want to maximise their children's long term development and well-being. They also have a 'baby buddy' app which provides evidence-based information and self-care told to help parents build their knowledge and confidence.

Search 'Baby Buddy' App on the apple store or Google play.

PANDAS Foundation are able to support and advise parents with perinatal mental illness.

Free Helpline 0808 1961 776 Monday-Sunday 9am-8pm

Email info@pandasfoundation.org.uk

PANDAS Facebook pages.

The Netmums forum and website can give online support from mums who have shared the experience or who are currently going through it themselves.

www.netmums.com

Financial Support

If you receive any form of income support it may be possible for you to claim additional funds to help you meet the additional costs associated with having a baby on NICU. If you do not receive income support, but are struggling financially, please speak with your baby's nurse who will offer advice on potential additional sources of income for which you may be eligible.

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 care 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). A booklet entitled "Your Baby's Care- A parent/carer guide to the Neonatal National Audit Programme" is available. Do please ask your nurse for it if you are interested.

National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)- **If your baby is born with an anomaly or rare disease.**

This database records those people with congenital anomalies and rare diseases across the whole of England. Rare diseases affect a small number of people compared with the general population and, because they are rare, can be difficult to diagnose, treat and or/prevent. A disease is considered rare when it affects 1 in 2,000 people or fewer. However, collectively rare diseases are not rare. 1 in 17 people will be affected at some point in their life. The aim of this registration is to:

- Provide a resource for clinicians to support high quality clinical practice
- Support and empower patients and their carers by providing information relevant to their disease or disorder.

- Provide epidemiology and monitoring of the frequency, nature, cause and outcomes of these disorders
- Support all research into congenital anomalies, rare diseases and precision medicine including basic science, cause, prevention, diagnostics, treatment and management.
- Inform the planning and commissioning of public health and health and social care provision.
- Provide a resource to monitor, evaluate and audit health and social care services, including the efficacy and outcomes of screening programmes.

As with the National Neonatal Database, no patient identifiable information is shared. NCARDRS hopes to register everyone who has a rare disease or congenital anomaly to help plan and improve healthcare services for future generations. However, you can ask to have your baby's details removed from the register at any time. These requests will not affect treatment or care. To opt out, please email: optout.ncardrs@phe.gov.uk.

Your Baby & Family Time

We aim to work in partnership with families when caring for babies, and like you to feel as involved as possible in your baby's care. We will encourage you to be with your baby and ask you to take responsibility for aspects of care as you feel able.

We welcome parents and siblings to spend as much time with your new family member as you would like and suggest that you prepare your other children by telling them a little about their new sibling and showing them some photos of what to expect.

Things you can bring in

Nappies and Cotton Wool

We ask that you please provide nappies and cotton wool at the earliest opportunity for your baby.

Clothes

Not all babies will be able to wear clothes straight away, some are too small, and others need to be in a nappy only so the nurse can observe them easily. Please speak to your nurse about when to bring in clothes, and when you do bring clothes in, please ensure they are washed beforehand.

We will change baby's clothes when necessary (i.e. baby has been sick or nappy has leaked), and bag them up for you to take home and wash.

If your own clothes go into our washing by mistake, let your nurse know and we can have a look for them. All our baby clothes get washed on the unit, so they can't go far!

Bottle Brushes

Please bring your own bottle brushes for cleaning bottles and/or breast pump equipment.

Blankets

Feel free to bring in washed blankets for your baby- if they can't be used when the baby is in bed then you can use them during cuddles.

Teddies and Toys

Teddies and toys can also be brought in, but we ask that large teddies are not put in the cot or incubator and no more than 2 teddies in the bed please. Please also ensure that these have been washed before going into your baby's cot.

Caring for your baby

The NICU team 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. We can teach you many aspects of caring for your baby as soon as you feel comfortable to be involved.

It is important to take into consideration though, that your baby needs as much rest as possible to allow growth and development, please keep in touch with your baby's nurse that shift to see when nappy changes are, we can alter plans to allow your participation in cares.

Kangaroo Care or Skin-to-skin

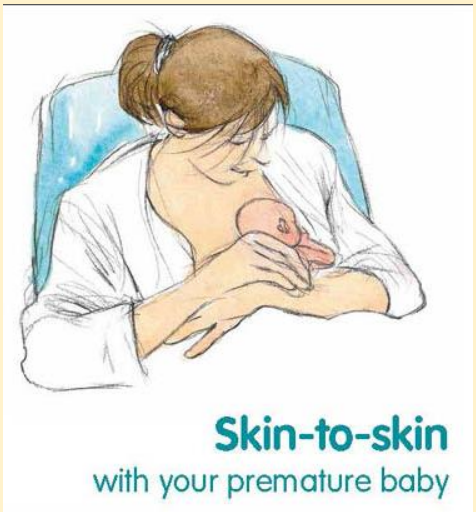
Kangaroo care, or skin-to-skin cuddles encourages you to have close contact with your baby. This is proven to have positive benefits for you both. The Bliss booklet 'Skin to Skin with your premature baby' has a lot of information about the mutual benefits of skin to skin.

If your baby is stable enough to come out for cuddles, we will encourage you to do kangaroo care. We can pull the curtains round, so you can have private time with your baby and we will try to leave you as much as possible. Please understand that if we need to come in because an alarm is going off, we can't help it- we must make sure baby is safe and well.

We try and encourage cuddles for at least 60 mins (but longer is preferred!), transferring premature and sick babies can be very stressful for them, so they need a nice long cuddle with you settle. Make sure you are ready for a long cuddle; go to the toilet, have a bottle of water with you and maybe a book to read to baby.

We try to 'cluster' care together for your baby, so they are disturbed as little as possible, keep in touch with the nurse looking after your baby to find out when they are having a nappy change. That way, you can help with the nappy change, learn all about mouth care, and then be ready to have baby out for cuddles as well.

It is normal that you might want to have your baby out multiple times in the day, but please understand that your baby may not cope with lots of transfers, so we need to work together to find a good time to have cuddles.



(Bliss, 'Skin to skin with your premature baby', 2006).

Feeding your baby

We actively promote the benefits of breastfeeding and using breastmilk for preterm or sick babies. Research and evidence show that every drop of breastmilk (whether you chose to exclusively breastfeed or not) is of benefit to your baby. **However, we want to support all mothers however they choose to feed their babies.**

Breastmilk and expressing

Your nurse or midwife will discuss with you the benefits of breastmilk, and if you do choose to breastfeed or express breast milk then there are some important tips to help you establish your milk supply.

- Start expressing within 6 hours of delivery if possible.
- Express regularly, every 2-3 hours or 8-10 times a day with at least one expression overnight.
- Start hand expressing and move onto using a breast pump once you are getting around 10mls by hand expressing, or you can use a pump straight away to stimulate and then hand express to get every drop into the syringes!
- Use bonding squares, put one in with baby and keep one in your bra or down your top and swap them over to get to know each other's smell.
- Express at the baby's cot side or while you are having skin-to-skin cuddles as this will increase your milk supply. (Bliss, 'The best start', 2013).

Sterilising equipment and breast pumps are available to you on the unit, please ask your nurse for more information.

Breast pumps are also available to hire at a discounted rate for mothers of baby's on NICU. Please see the website below, and ask your nurse for a discount code.

https://www.medela-rental.co.uk

When you express for your baby, please label each bottle or syringe with:

1. Baby's name
2. Baby's DIS number
3. Date and time you started expressing.

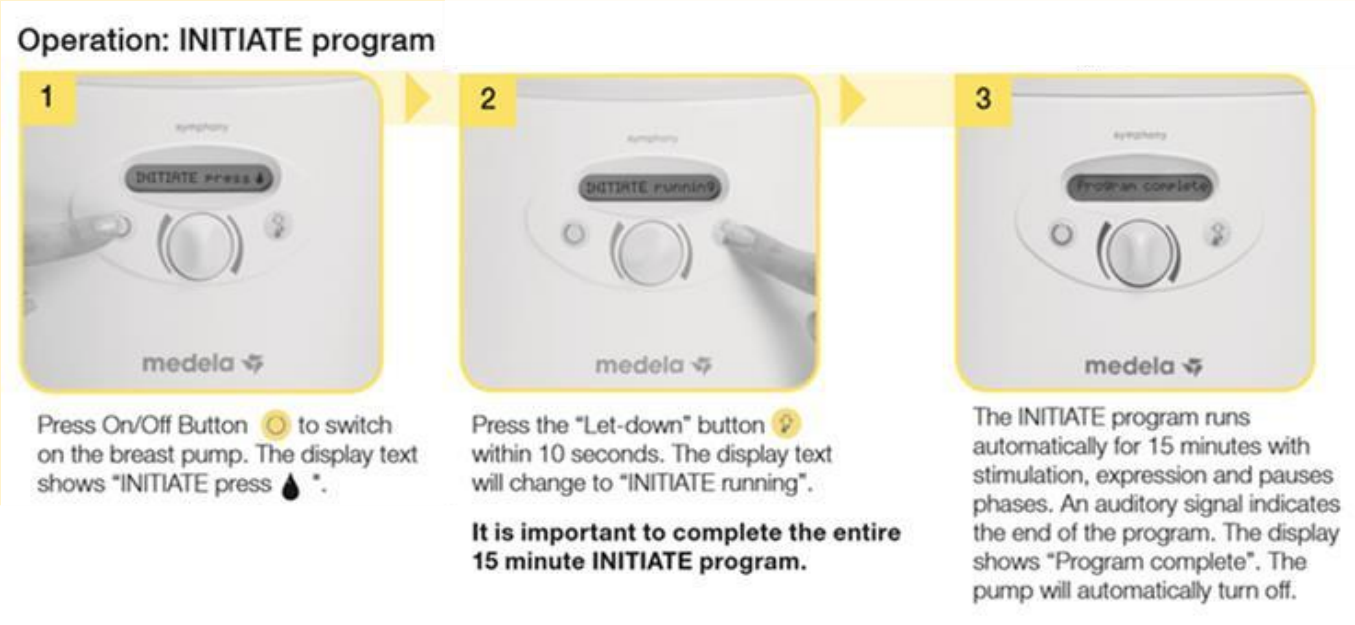
There is lots of information regarding expressing in the booklets we can give to support this booklet.

Using hospital breast pumps to express

The Breast Pumps that we have on the unit, are available for you to use whenever you like. We encourage expressing by the bedside, so you can spend time with your baby while expressing (this will encourage milk flow), but if you prefer we do also have a private room which you can express in- just ask your nurse.

Medela pumps - Initiate Program

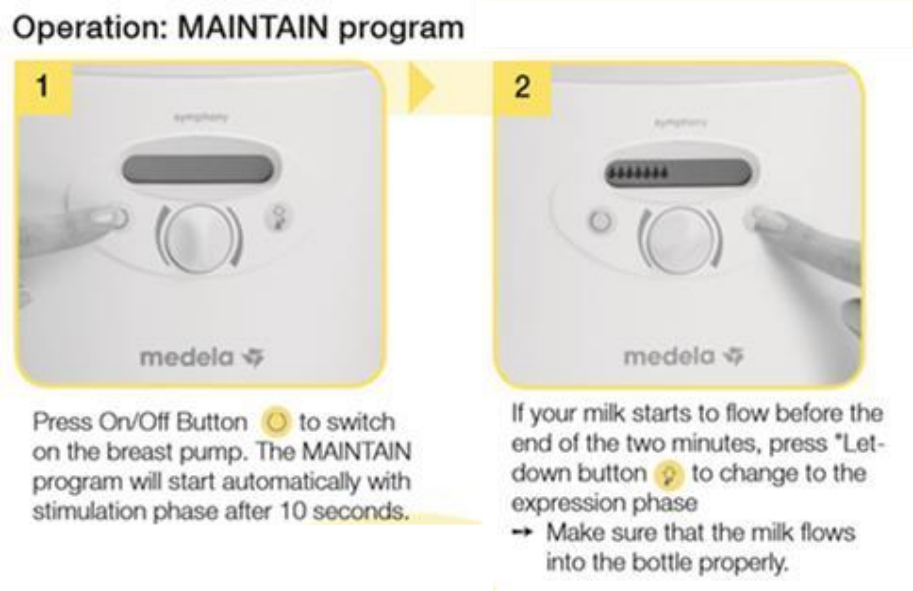
This is for the first few days after your baby is born until your milk comes in. It runs for 15 minutes and goes through a cycle of 'sucking' phases which simulate a baby's uncoordinated sucking in the first few days of life.



Remember that in the first few expressing sessions, we expect you to only get very small amounts of colostrum (the yellow thick milk). This 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, it is the best milk to help get their gut working properly. It might be best to collect this colostrum in a syringe rather than use the pump, because it might the small amount may get lost or wasted on the inside of the shields- we want your baby to have every drop possible!

Medela pumps - Maintain Program

This is for use once your milk has come in. This is normally when you have expressed at least 20mls (from both breasts) for the last 3 pumping sessions. If you are not getting 20mls by day 6, then start the maintain program anyway.



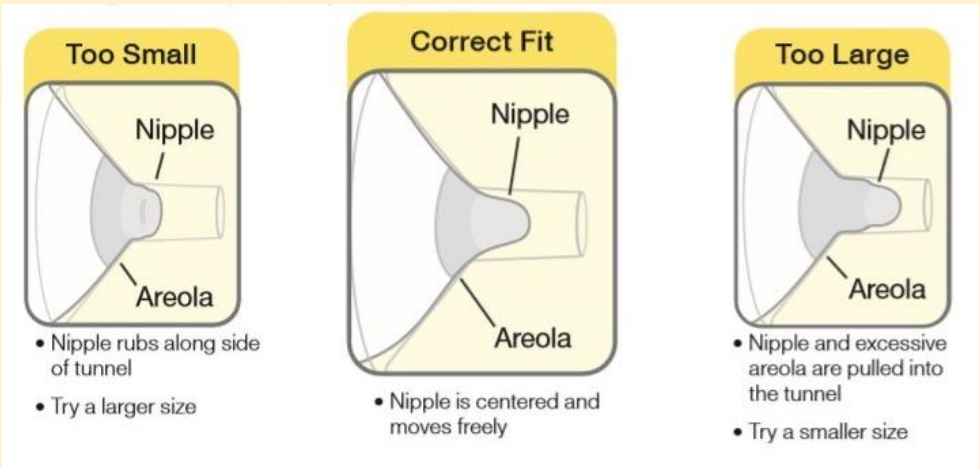
Once you are happy with the settings and program, you can increase the intensity of the 'sucking' by turning the dial to a level you are comfortable with.

Images and information from: Medela, Symphony Instruction Manual, 2017.

Are you comfortable?

While your baby is growing, you might be expressing for a little while so it is important to make sure that you are comfortable when expressing. If you are finding that your nipples are becoming very sore, or you don't feel like you're emptying your breasts properly then speak to your midwife or your baby's nurse and we can try and help.

You might need a different size shield. We have a variety of sizes on the unit, please just ask your nurse.



Nasogastric or Orogastric Tube Feeding (NGT/OGT)

While your baby is on NICU, it is likely that they will have either an oral, or nasogastric tube. This may be referred to as an OGT or NGT. Essentially it is a tube that passes through the nostril or the mouth, down the oesophagus and into the stomach. Majority of the time, we will use this to feed premature and sick babies through, sometimes we have to attach a bag or syringe onto it to allow air to pass out of the baby's stomach. Your nurse will explain this to you, if it is the case.

The tube is inserted by a nurse or nursery nurse after being measured to work out how far in to put it. Babies often don't like having feeding tubes inserted because it can be uncomfortable as it passes down the back of the nose/throat, but mainly because they don't like to be held for the procedure! If you don't want to see the feeding tubes being inserted, please feel free to go to the parent's kitchen, or wait outside the bed space- it does not take long to insert.

Once the tube is in position, your baby can be fed (if able to) through it. Every time the tube is used, we have to check that it is still in the correct place. It is possible that it can move and therefore may not be safe to use for feeding- we check this by pulling a little bit of the stomach contents (usually milk!) out of their tummy and testing the acidity of it. This is called 'aspirating', and we test the acidity by monitoring the pH using pH sticks.

If the tube is in the correct place, the 'aspirate' should be acidic with a pH of less than 5.5. This is because the stomach has lots of gastric acid to help digest milk, if the pH is high then this may be because the tube has moved or may be because stomach contents haven't been aspirated properly. If all is okay, we can feed your baby!

We can teach you how to feed your baby through the tube if you would like to- you will have to complete a competency to demonstrate your ability. It's not a test! We demonstrate it to you a few times, then help you to do the feed, and then before you know it- you're an expert!

Transition to Oral Feeding

Even very small and premature babies have the ability to suck, you may see this if your baby is given a dummy, or if you watch them and they try to suck on their fists/fingers. However, just because they are sucking does not mean they are ready to feed orally. To feed effectively, baby must be able to suck, swallow and breathe in a coordinated way- this may not happen until they reach 34-35 weeks gestation (or corrected gestation).

Some babies may feed sooner than this, which we will be able to assess with you, and some later- this is an individual skill that some learn quicker than others.

Once your baby starts to show us the signs of being ready to feed (i.e. sucking on dummy or fist, crying, frequent waking etc), then we may be ready to offer an oral feed.

It is not unusual for babies to take only a few sucks of the breast, or a few millilitres of milk from a bottle on their first feed. Please don't be disheartened, it does not mean they can't or won't feed, it's just something very new for baby and it's a skill they have to learn with practice. Learning to feed orally is very tiring for baby, and they may get worn out quickly.

Sometimes during the first few feeds (and occasionally even when they are more experienced), a baby may suck, suck, suck… pause… and then forget to swallow or breathe effectively. This can cause them to have a bradycardias and desaturations, don't be alarmed, your nurse or nursery nurse will be supporting you and be there if this does happen.

Formula milk

If you have made the informed decision to formula feed or bottle feed your baby breast milk we will support you in ensuring baby is feeding competently before discharge. We have a range of teats available for the babies and can give advice when it comes to buying your own bottles prior to discharge.

If you are formula feeding, you will also be taught how to make up formula feeds correctly and how to sterilise equipment effectively.

There is every possibility that your baby may require specialist formula depending on their gestation or condition while on NICU. We will arrange for certain non-standard formulas to be on repeat prescription from your GP once baby is discharged and will go through this with you.

If your baby is on a preterm specialist formula, don't be alarmed if this changes before you go home. There are different formulas for those babies below 1.8kg and above 1.8kg; we will inform you when these are due to change.

Breastfeeding

If you were planning on breast feeding your baby, we can offer lots of advice to help ensure it works successfully. Please don't be upset if breastfeeding doesn't work perfectly every time, there are lots of options for you.

Even very premature babies can be put to the breast. They probably won't do very much, but sometimes just smelling your milk and being in that position can be comforting for them. Please discuss this with your nurse and they will let you know if it is appropriate for your baby.

When breast feeding does start, your nurse or nursery nurse will be able to give you lots of advice on positioning and latching. Ideally, we are looking for a good latch with continuous sucking. You can tell a baby who is breast feeding well because they have nice full cheeks and mum's often say they can really feel them sucking.

If your baby was being tube fed, it is likely that for a little while they will still need tube feeds even though they've 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.

When to top up?

- If baby latches but does not suck well, then a full feed will be given through the NGT.
- If baby latches and sucks well, but for less than 10 minutes, we will often give them a half feed through the tube.
- If baby latches and sucks well for 10 or more minutes, we will assess the feed and decide whether baby needs any more milk, or whether they have taken a full feed. This will often be the case if you are available for a while after the feed and can put baby back to the breast if they show signs of wanting another feed.

Nappy cares

Changing the nappy is a big way that you can be involved in your baby's care. Even if you have changed nappies many times before, we understand that it may be daunting when there are wires and tubes, and if your baby is premature or sick. We will always be happy to go through the process with you and support you in changing nappies.

It is important to remember that 'cares' tend to disturb baby, so we encourage them to only be done when necessary (this will depend on baby's condition, but usually is 6-8 hourly), or when baby is awake and uncomfortable in a dirty nappy.

We will let you know when nappy cares are due and encourage you to be involved.

Any babies under 35 weeks gestation will have a bottle of clean water at their bedside for nappy cares, once they reach 35 weeks, normal tap water will be fine to use. We encourage you to use cotton wool balls to clean baby's bottom, this prevents unnecessary chemicals on such delicate skin.

Mouth care

Whether your baby is very premature, sick or only staying on NICU for a short time, mouthcare is very important. If expressed breast milk (EBM) is available and you are happy to use it, then this is the best thing for mouthcare, however, sterile water can also be used. Your nurse will show you how to complete mouthcare, as it is something, we encourage families to participate in whenever possible.

Mouthcare should be a positive experience for you and for baby- so try to only do it when baby is awake so you can bond with them while you're doing it and they can appreciate the stimulation it provides.

- Make sure you wash your hands thoroughly and make sure you have; EBM or sterile water, sterile gauze, sterile cotton buds and a bag for the rubbish.
- Soak the sterile cotton bud in the milk or water, press of excess and then use the tip to sweep the inside of your baby's mouth including the gums, roof the mouth, lips and cheeks.
- Don't push the tip too far into baby's mouth as it could make them gag. Rolling the cotton bud instead of wiping it around their mouth may be nicer for the baby- it won't tickle or over-stimulate them!
- Use a piece of sterile gauze and the EBM/sterile water to wipe baby's lips, removing any coating and keeping them from getting dry.
- Let your nurse know that you have done the mouthcares, or we can show you were to write it in baby's notes if you would like.
- Throw away all the rubbish in the black and yellow striped bin bags.

(East of England Neonatal Network Guidelines, 2019).

Keeping your baby warm

One major part of NICU is making sure your baby stays warm. Most of our babies will have a temperature probe stuck underneath their arm which will help us monitor their temperature effectively.

We like their temperature to be between 36.5-37.5°C when they are in their incubators, cots or out for cuddles. The nurse looking after your baby will ensure that they are kept warm and will change the heating around your baby if they get too cold, or too hot. While on NICU, your baby may transition through many different types of bed, all of which are aimed at keeping your baby warm and protected.

Overhead beds

If your baby is term, or over 32 weeks, they will usually be admitted onto an overhead. This is an open top bed, with a pre-warmed gel mattress and an overhead heater. Your baby will be fully monitored while on the overhead, and the thermometer under their arm will give us a good indication of their actual temperature and whether we need to adjust the heat of the mattress or the heater.

These overheads are also able to deliver phototherapy to your baby, so we can keep them warm while also treating their jaundice levels.

Incubators

We have 2 different types of incubators on this unit. If your baby is very premature or small, they may be admitted directly into a ‘giraffe’ incubator, otherwise your baby may go into one of our normal smaller incubators. Caring for a baby in an incubator means the nurse can control the temperature of the air in the incubator to make sure your baby stays warm. This temperature may be increased or decreased depending on your baby’s needs. Once your baby is stable enough, you can put a baby vest on them while they are in the incubator. This helps give 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.

Giraffe Incubator

Standard Incubator

Normally, we will keep a baby in an incubator until they can show us that they are not needing the warmth it provides. This may be when they reach a certain weight, or a certain gestation. Usually babies smaller than 1.5kg or less than 32-33 weeks will stay in an incubator, however, this may change depending on your baby!

Kanmeds or Hot Cots

Kanmeds are heated water mattresses that we use for those babies who need to come out of an incubator but may not be able to control their temperature well.

They are often used in the blue kanmed cots, however, can be used in a normal cot also. When your baby first goes into a kanmed cot, the mattress will be started at 37°C and reduced according to your baby's temperature. Usually, we will stop reducing when we reach 36°C and may go straight into a normal cot!

When your baby is in the kanmed cot, it is important that they don't have too many layers on.

They should have: 1 sheet covering the mattress, 1 layer of clothing (i.e. babygrow OR vest), no more than 3 blankets. If they need more than this then they may not be ready for a kanmed, or may need the mattress temperature increasing.

Cots

Once your baby is stable enough to be fully dressed and has shown us, they can maintain their temperature to a certain level, they can be nursed in a normal cot. When nursed in a cot, they must be fully dressed, including:

- A vest (long or short sleeved)
- A babygrow/sleepsuit
- Adequate blankets
- Socks if babygrow has open feet.

By this point, your baby may no longer have a continuous temperature probe in place, and we may monitor them using a manual thermometer every couple of hours or if we have concerns. We always assess a baby's temperature by feeling the back of their neck or their chest to see if they are

Developmental care

As parents, you are the best people to care for your baby and have the biggest influence on their health and well-being. Developmental care is what we do on NICU to try and make the baby's environment as pleasant and stress-reducing as possible, but also to improve the attachment and bonding between you and your baby.

Things we can do on NICU to help provide a developmentally friendly environment:

- Keep a quiet environment wherever possible:
    - Please don't talk over incubators or cots
    - Close incubator doors quietly
    - Turn phones to silent
    - Please don't play music through your phone to baby, you'd be surprised how loud these could be to baby even if you think it is very quiet!
    - If baby is out for cuddles then talk in a quiet calm voice, they will like to hear the sound of your voice.

- Reduce light levels wherever possible:
  - Premature babies have thin eyelids so even a little bit of light can affect them significantly- please don't use flash photography.
  - Keep the incubator covers over the incubator, but please feel free to lift up a side to look at your baby while you're at the cot side.
  - As your baby grows, having some periods of light can help them with their sleep-wake cycles. Ask your nurse for more information about this and how you can help us.

- Communicating with your baby:
  - Babies on NICU need parents to provide positive touch through holding and gentle pressure and cuddles.
  - Positive touch communicates love and reassurance to your baby so is very important whenever possible.
  - Containment holding when baby is not able to come out for skin-to-skin or cuddles.
  - Skin-to-skin cuddles for long periods of time (minimum 1 hour).
  - Placing a bonding square in your bra and giving it to baby (and vice versa) can help settle baby as they can recognise Mum's smell and it can help your breast milk supply.
  - Holding hands near baby
  - Talking, finger grasping etc.

Quiet Time

We like to try and give the babies periods of uninterrupted rest through the day, so we may close blinds and ask for quiet from staff and families between 14:00-16:00. We will try and avoid unnecessary procedures and interventions during this time, and it may be used as an ideal opportunity for skin-to-skin, cuddles, or positive touch.

Pain Management

Preterm and full-term babies will feel pain differently, and different things may feel uncomfortable or painful to them.

As nurses and nursery nurses, we will assess your baby's pain score regularly to ensure that they are comfortable. We can also teach you ways of reassuring your baby and give guide you on how to recognise and relieve discomfort.

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

- Crying
- Restlessness/squirming
- Not sleeping properly
- Facial grimacing/frowning
- Fingers and toes clenched or splayed
- Changes in baby's observations which the nurse will recognise and act on.

Containment holding

If your baby is on their tummy, then placing your hands firmly on their head and bottom my help to calm them if they are upset. If they are on their back or side, then one hand on their head and the other cupping their feet may also help to keep them calm.

Containment holding is comforting for the baby because it makes them feel safe and secure, mimicking a feeling of being in the womb. It helps to settle a restless baby but can also prepare them for being awake, placing your hands-on baby slowly and gently while they are asleep will start to wake them up in a more pleasant way than just being moved straight away (Bliss 2019)

Sucrose

If your baby is allowed sucrose, then it should be used before blood tests or other potentially painful procedures. The nurse or doctor can give a small amount in the baby's mouth (tip of the tongue) which will taste sweet and helps to reduce procedural pain. (East of England Neonatal Network, 2018)

Swaddling

Swaddling has been shown to reduce pain and discomfort during certain procedures like passing a new Nasogastric Tube or during an eye test. It can reduce stress levels, leaving more energy for feeding, growth and development.

Swaddling or wrapping should also be done when a baby is being weighed. Babies do not cope well with exposed and free to move too much on the scales, and swaddling helps to keep them comfortable and calm (Çaka and Gozen, 2017).

Non-nutritive sucking

Even very small, premature babies have the ability to suck (usually from around 28 weeks gestation), and there is evidence to suggest that by using a dummy during potentially painful or stressful procedures, such as a heel prick test, effects can be minimised.

We will ask for your consent before giving your baby a dummy, as it is a personal decision. If you decide that you would rather not have your baby use a dummy, please discuss this with your nurse for our records. Some parents have agreed to use a dummy during these procedures only, and not for regular use.

Pain medication

If your baby is likely to require a painful procedure, if possible we will discuss this with you. We will also administer pain relief medication to help your baby. This can include sucrose orally or paracetamol through their feeding tube if they are able, or through their cannula if baby cannot have medication orally yet.

Some babies may require constant pain relief or sedation if they are very poorly. Your nurse will discuss individual medications with you and rationalise what they are for.

Jaundice

Jaundice is very common in all newborn babies, not just those that are admitted to the NICU. It is estimated that 80% of preterm babies and 60% term babies will develop some kind of jaundice, with breastfed babies, potentially, being jaundiced for up to 1 month.

Jaundice causes a yellowing of the eyes and the skin and is caused by a raised bilirubin level in the body. Bilirubin is completely normal and is produced when red blood cells break down, the body has lots of ways of getting the bilirubin out of the body (including through faeces and urine), but jaundice develops when there is an excess of bilirubin.

While on NICU, your baby will be monitored for jaundice through blood tests. Some of these can be done on the unit, while others have to be sent away to the laboratory for testing.

If, when the results come back, we say that your baby needs phototherapy, this is a treatment for jaundice and is where your baby will be cared for under phototherapy lights (they may be blue or white). They will need to wear goggles to protect their eyes from the bright lights and remain under the lights as much as possible.

We will only turn off the lights when the jaundice level or SBR- Serum Bilirubin Result is below a certain level. This level varies depending on the gestation and age of your baby, please as your nurse if you have any questions (NICE, 2016).

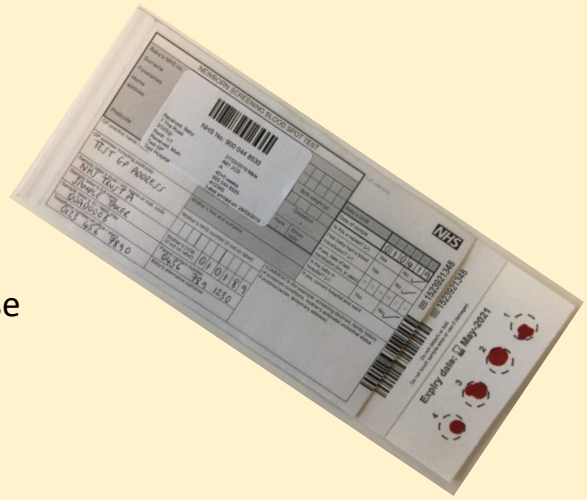
Occasionally, jaundice can be caused by infection, bruising or due to the reaction between mother's and baby's blood. If this is the case with your baby, your nurse or doctor will explain this to you in more detail.

Screening tests for your baby

Newborn Blood spot Screening

The newborn blood spot screening test is usually done on day 5 of your baby's life. It is usually taken from a heel prick blood sample, where 4 spots of blood are put on to a screening card which is sent away to test.

It tests for 9 serious inherited health conditions:



- Sickle cell disease (SCD)
- Cystic Fibrosis (CF)
- Congenital Hypothyroidism (CHT)
- Phenylketonuria (PKU)
- Medium-chain acyl-CoA dehydrogenase deficiency (MCADD)
- Isovaleric acidaemia (IVA)
- Glutaric aciduria type 1 (GA1)
- Homocystinuria (HCU)

Any baby that is admitted to the neonatal unit, will have a sample of blood taken as soon as possible in case they need a blood transfusion. If your baby is born before 32 weeks gestation then another sample should be taken to test for Congenital Hypothyroidism (CHT), this is done on day 28, or when you take your baby home (whichever comes first).

You should receive the results by letter from your health visitor or GP within 6 weeks.

Newborn Infant Physical Examination (NIPE)

The NIPE test is offered to all newborn babies, no matter of their gestation or how sick they are. The tests will not be done until your baby is stable enough.
It includes an examination of your baby's heart, eyes, hips and testes (in boys). The medical professional completing the exam will ask you about your immediate family history regarding any conditions with these body parts.

Infection Screening (Sepsis Screen)

When babies are admitted to NICU, the doctors will make a decision as to whether they think baby needs antibiotics. This is to treat a suspected infection. Antibiotics are started if your baby is exhibiting certain behaviours or meeting certain criteria pre-disposing them to infection. These may include preterm labour, breathing problems or early jaundice levels.

We will monitor your baby's infection markers by doing blood tests, and once we are happy there is no infection, or 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 to come back, which can take up to 48 hours.

Sometimes, babies who have been on NICU for a little while may show signs of becoming unwell. In this case, the doctors may take blood samples and start antibiotics in case of a new infection. We will let you know if this happens, and keep you updated, as we know this can be quite worrying. This will mean that if your baby did not have a cannula in, then they will need one for the antibiotics. Occasionally babies also need increased respiratory support or monitoring.

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. It affects approximately 65% of premature babies, and those weighing less than 1.25kg. Usually, no treatment is needed, however, in some of those affected babies, ROP does not get better and 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. The ophthalmologist then examines the back of the eye using their special equipment. They normally use 'speculums' which hold the eyes open during the test and may use a tool to rotate the eye and get a better view.

These examinations can be uncomfortable for babies, so we will give a dose of paracetamol before the exam to make them more comfortable.

If the ophthalmologists find ROP has developed in your baby, they will discuss this with you and explain the next steps required. If the ROP is mild, your baby may need a follow up in 1-2 weeks, just to ensure that it is not worsening or that it is resolving on its own.

As nurses, we will always give you as much information as you need to understand ROP and the screening involved in your baby's care. The screening test is not the nicest thing to watch but a nurse will be your baby throughout the examination, so we do not expect you to stay. However, if you want to stay and comfort your baby, we will support you in this.

Hearing Screening

The newborn hearing screeners will perform the hearing test on your baby just before they are discharged from NICU. 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 NICU.

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.

Common Equipment used on NICU

When your baby was inside you, you did everything for them to help them grow and develop, as they should. Once babies are born, they have to breathe for themselves which can become difficult if they are premature or have a medical condition.

Ventilator

Sometimes, babies may need extra support in a variety of ways. The Doctors may need to insert a breathing tube (or ET tube- endotracheal tube) into baby's airway which will be attached to a ventilator. The ventilator has various settings/modes, we generally use a mode that delivers a set amount of breaths and can synchronise with breaths that baby takes on it's own. This ensures that the lungs are inflated adequately and also prevents damage to the lungs caused by over-inflation.

The breathing tube is very important and needs to be kept securely in place. Your nurse will help you to be involved in your baby's care where possible, but infants requiring ventilation often don't tolerate handling well, so we may suggest minimal handling at this time.

CPAP (Continuous positive airway pressure)

At the end of each breath, our lungs are deflated, but because we are well adults, we can easily take another breath in.

In some babies, particularly premature or poorly babies, when the baby breathes out, it can be difficult to open the airways back up and take another breath in.

CPAP pushes air into the lungs and keeps the airways open so that taking that next breath is a little bit easier for the baby.

The nurse caring for a baby on CPAP will regularly take the mask or prongs off and check the skin underneath to make sure it isn't getting sore or marked.

CPAP can only be held in place by using the hat and straps on baby's cheeks, we have measures to try and make sure their cheeks don't get sore.

Vapotherm (High Flow)

Vapotherm delivers a number of litres of 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.

At the end of a breath, there will always be some air left in the airways- vapotherm replaces this used air with fresh air/oxygen, making the babies breathing easier.

The white number is the number of litres per minute the baby is receiving. This will be turned down by the doctors when they feel the baby is ready.

The green number is the percentage of oxygen that baby is currently in. 21% is the same as the air we are breathing- so it's can't go any lower. If your baby is needing very high amounts of oxygen, they might need to be moved to another type of respiratory support. Your nurse and the doctors will discuss this with you.

The red number is the temperature of the air that is being blown into the baby's lungs- it should always be set at 37°C.

Nasal Cannula or Low Flow Oxygen

Nasal Cannula oxygen is sometimes needed for babies whose oxygen saturations are a little bit low, or when the baby is dropping their saturations more frequently than we'd like. 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.

It is measured in litres per minute (Lpm) instead of a percentage like the vapotherm, and we will let you know how much oxygen your baby is requiring. Usually, the lowest flow is 0.01Lpm and can go up to over 1.0Lpm.

Sometimes, if a baby is needing a large amount of oxygen, they may be put on a different support. This is because the nasal cannula oxygen is dry and cold going into baby's nostrils, and, in high amounts, this can dry baby's airway and cause the work of breathing to increase. Other supports are warm and humid which is advantageous if baby is struggling.

Monitoring

This is one of the normal monitors that we use on NICU. All babies will be monitored initially, and as they grow, we will gradually remove monitoring until it is turned off completely.

Green number = This is baby's heart rate which is monitored by the 3 pads and wires on your baby's chest It produces an ECG or electrocardiogram for us to read and assess.

Babies heart rates will vary depending on gestation, medications, and if they have any medical problems.

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 gets low and is often linked with a desaturation (see below). Some babies pick this back up quickly themselves and some may need a bit more help. We will let you know if this happens.

Blue number = oxygen saturation levels. This is a percentage, so the best it can be is 100%. However, we don't want all babies to have oxygen saturation levels of 100%, some we want to be between 90-96%. Please ask your nurse what your baby should be aiming for.

You might hear us say that your baby has had a 'desat' or has 'desaturated', 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 and help them, 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.

Yellow number = respiration rate. This is the amount of times that the machine thinks your baby is breathing every minute. You will see this number change and go up and down very quickly, which is why to monitor your baby's breathing rate more accurately, we will watch/feel them breathe for 1 minute.

White number = the temperature underneath your baby's arm. Sometimes this may suddenly drop- don't panic! It's probably because your baby is waving at you and has their arm up. Sometimes the probes aren't in quite the right place either, so we have to move it if this is the case.

The most important thing about the monitors is that you don’t panic if they alarm!

We need you to look at your baby, not at the monitors. They are there for us to worry about. Sometimes the alarm may indicate baby needs a bit of help, other times it may be because a probe has fallen off. This is for us, not for you- you need to be parents not nurses!