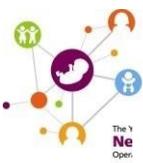


Our Neonatal Journey

Supporting you and your family throughout
your baby's neonatal journey





Your Voice Matters

Your feedback helps us to understand what is important to you and your family, and how we can improve your experience whilst your baby is on the neonatal unit. It also helps us to develop and improve neonatal services for everyone. We welcome all feedback, positive and negative.

Your unit will have a variety of ways that you can share your thoughts and feedback at any stage during your baby's time on the neonatal unit and once they have gone home. Please speak to staff for more information or look for signposting around the unit.

You can also share your feedback anonymously via our Network survey. Simply scan the QR code below to take you to our short online survey.



The Yorkshire and Humber Neonatal Network is working with parents and staff across the region to develop and improve neonatal services. To find out more about what we do or how to get involved follow us on social media



@Neonatal_YH



@YHNeonatalParentsandfamilies

Alternatively, you can email our Parent and Family Engagement Lead
karen.williams132@nhs.net

Family Care– Our Neonatal Journey

This booklet contains information and resources that will support you in caring for your baby.

It has been produced with the aim of supporting and empowering you as parents/carers to work in partnership with the neonatal team. It is important that you feel involved in any decision making and planning of daily care for your baby.

Each section is colour coded to make it easy for you to find the section you are looking for.



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Congratulations on the birth of your baby/babies and welcome to the beginning of your neonatal journey

‘Our Neonatal Journey’ has been created by parents who have been in your shoes/had a neonatal experience, and staff, to help make the journey easier and guide you through this time. Whether your stay is long or short, ‘Our Neonatal Journey’ aims to provide answers to some of the initial questions you might have, and to share some of the things that helped us when our babies were on the neonatal unit.

Whilst this might be a scary time, and there are lots of medical professionals involved in your baby’s care, you are the most important person in your baby’s life. You are encouraged to be involved in their care as soon and as much as you feel able to.

You are welcome to bring in items from home i.e., clothes, blankets, muslin cloths to make your baby’s space more personal. You might want to bring in photos of family members or pets, and siblings might want to draw pictures for their new baby.

Some of the things which you can start doing for your baby as soon as you are ready are:

Nappy changes, feeding your baby, talking, singing, or reading to your baby, comforting, and holding your baby, being involved in ward rounds etc. Bonding does not always happen straight away and for some parents and babies it can take time, but all these suggestions can help.



We hope you find this useful, we would love to hear your feedback



HEY
it is
OKAY

To experience a range of emotions

There is no 'right' way to feel. You might not feel an immediate attachment to your baby, you might feel overwhelmed, sad, angry, guilty, like no-one understands, scared, numb, protective, proud or happy at times. If you feel like you need help then please seek out support by talking to your partner, a family member, a friend, a nurse, your health visitor, or your GP. Some units have Psychology service too. There is support out there for you. You are not alone.

To have a cry

This is not a sign of weakness, and it might help you to get everything out. It's also OK to not cry; we all cope in different ways.

To look after yourself

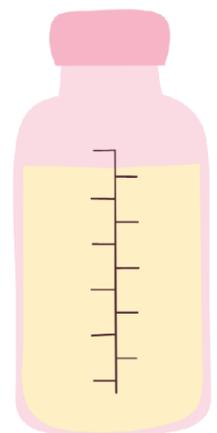
Your birth may have been straightforward or with added complications.

Physically and mentally your body will need some time to recover, and you will need to rest. Don't feel bad about this, be kind to yourself.

To find expressing hard

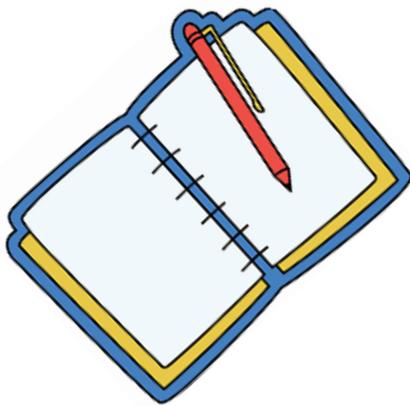
Being 'milked by a machine' is not the most natural thing in the world and probably something you never imagined yourself doing!

Some people find they produce lots of milk and others not so much – this is normal. Your nurse can support you to optimise what you produce and answer any questions.



To ask for help – Don't feel like you must do everything alone. Everyone has a different amount of support from family and friends.

Remember the staff on the unit can be part of this support.



To forget things – To begin with, everything may be unfamiliar and there are new faces everywhere!

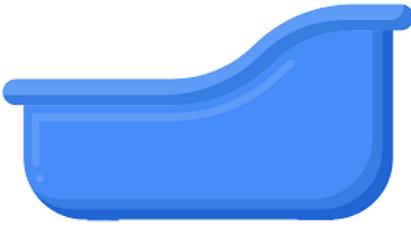
You might feel like you're being bombarded with medical information and terminology, and struggle to keep up. You can always ask staff to repeat information.

Some parents find it can help to keep a diary so you can take note of important details and jot down any questions you have, or make a note of important milestones and events.



To not want to talk about your experience

You'll probably feel like you're living and breathing the Neonatal Unit, and it can be hard when your family and friends all want to know the latest. Don't feel under pressure to keep everyone updated.



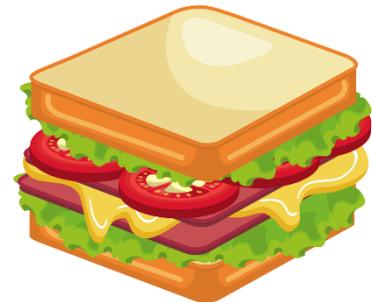
To focus on the positives

The first time you hold your baby, getting involved in cares, the first feed, baby gaining weight, giving baby a bath, your baby coming off their monitors!

To talk to other parents on the unit – Other parents on the unit might understand more than anyone else what you're going through. Some parents find talking to other parents helpful.

Take a break away from the unit

Getting a drink or something to eat, maybe even a bath or a sleep is okay. It's okay for you to spend time away from the unit. Your mental health is important, be kind to yourself!



To be nervous about moving to a different hospital

There are many reasons that your baby may need to transfer to another hospital. It can be an unsettling time and take a while to become familiar with the new staff and routines. Our Neonatal Journey resource has been developed to take with you to help with the transition.

To ask questions – No one expects you to understand everything about Neonatal Care, so it's okay to ask if you need further explanation.



To not want to go back to work – leaving your baby and partner might feel like the last thing you want to do, especially if your baby is still poorly. It can be useful to explore all options available to you with your employer, such as taking paternity/compassionate leave or holidays.

If you are struggling, please talk to someone.

To speak up – Shifts change, nurses and doctors can rotate between rooms but you will get to know about your baby in ways that others don't. If you are unsure or worried about anything, it is okay to say something to your baby's nurse.





TOP TIPS

Some parents find it helpful to keep a diary or start a memory box.

Your neonatal unit may provide this.



Some units have coffee mornings or parent groups where you can meet other parents.

Taking time out to have a break, go for a walk or even just get a drink can really help.



Feel free to bring in things from home that will help you feel more comfortable on the unit, such as slippers or a book to read.

Take photos - your baby will change and grow so quickly. Photos are a great record of their journey.





Getting to know the Neonatal Unit

When entering the unit

Your Neonatal Unit may have a buzzer intercom system. Please ensure nobody follows you in after you have entered and close the doors behind you.



Infection control

Everyone who enters the Neonatal Unit must wash their hands and use alcohol gel. You must wash your hands before touching your baby. If you are unwell, please talk to the neonatal staff before travelling to the unit.

Being with your baby

Parents have 24/7 access to the neonatal unit. Check with the staff on your unit for visiting times for other people. You can phone your neonatal unit any time to check on your baby.

Parking at the hospital

Staff can advise you on accessing a parking permit or discount for parking as necessary.



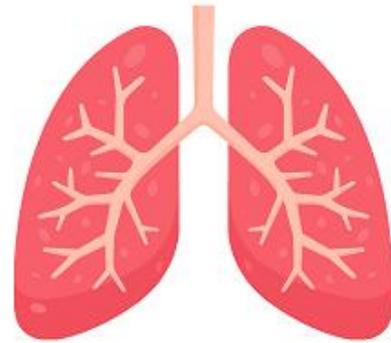
Facilities on the neonatal unit may include:

- An expressing room/screens to express at the cot side
- Parent kitchen/ bedrooms/bathroom facilities
- Meal/snack provision
- Waiting room/sibling room/sensory room



Ventilators and breathing machines

If a baby is born prematurely or sick, they may need some help to breathe. Here are some of the types of breathing support your baby might require. Not all babies will need all types of breathing support and some might not need any.



Ventilator – A Ventilator provides intensive breathing support for your baby. It helps support the lungs until your baby can breathe for themselves.

Nitric Oxide – This is normally made in the body to relax blood vessels. It enables blood to flow to all parts of the body. When the blood vessels to the lungs stay narrow, nitric oxide can be added in the air and oxygen given to your baby. This helps them to relax and allow blood flow to the lungs.

High Frequency Oscillation – A type of ventilator used to blow small amounts of air with or without added oxygen into the lungs very quickly. Your baby's chest will look like it is vibrating.

BIPAP (Biphasic Positive Airway Pressure) – A form of Non-invasive ventilation like CPAP. It provides oxygen and pressure to help stop the lungs from collapsing. Your baby will wear a special mask and hat when needing this support.

CPAP (Continuous Positive Airway Pressure) – Provides pressure to help keep the lungs inflated and be used with or without oxygen. Your baby will wear a special mask or prongs and hat when needing this support.

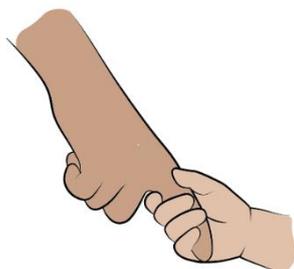
High Flow – A form of breathing support. It is given to your baby through nasal prongs and gives warm, humidified pressurised oxygen/air. Vapotherm is one of the systems used to deliver High Flow.

Low Flow – Oxygen given to your baby through nasal prongs. Your baby may require this when they are able to breathe by themselves, but their lungs may need some time to grow and develop.

**This section is for you to write
any questions you might have about your baby's
breathing support**



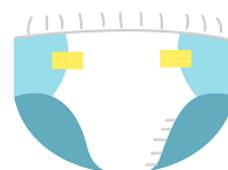
Getting involved in your baby's care



All babies need positive touch. Skin-to-skin, hand hugs and kangaroo care can help your baby to feel calm and comforted, help with bonding and milk supply.

Over time you will understand more about what your baby prefers and learn ways in which you can help them to settle.

Your baby will require eye, mouth, and nappy care. Speak with staff so that these cares can be done when you are on the unit. Mouth care is done with the milk your baby is receiving or sterile water. Nappy cares are done with water and cotton wool or gauze.



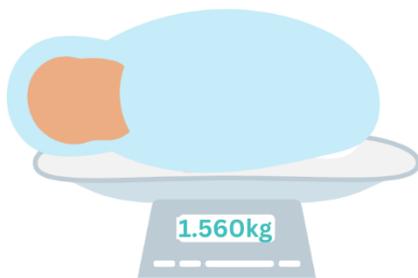
It is important that your baby's temperature is taken 3 to 6 hourly. This is something that you will be supported to do.

Daily ward rounds are carried out to discuss your baby's needs. Neonatal staff on the unit will support you to take part in ward rounds as much as you want to/are able to.

You know your baby best and sharing your thoughts and information can be really helpful to the staff caring for your baby.

If you are unable to be present for any of the ward rounds the staff caring for your baby can update you.





You will be supported and encouraged to weigh and bath your baby. Wrapping your baby for both of these will help them to feel more relaxed and your nurse will support you to do this safely and record the correct weight.

*Please refer to the All Wrapped Up Package for more information.

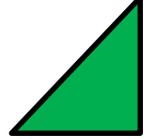
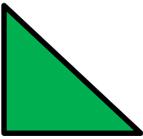
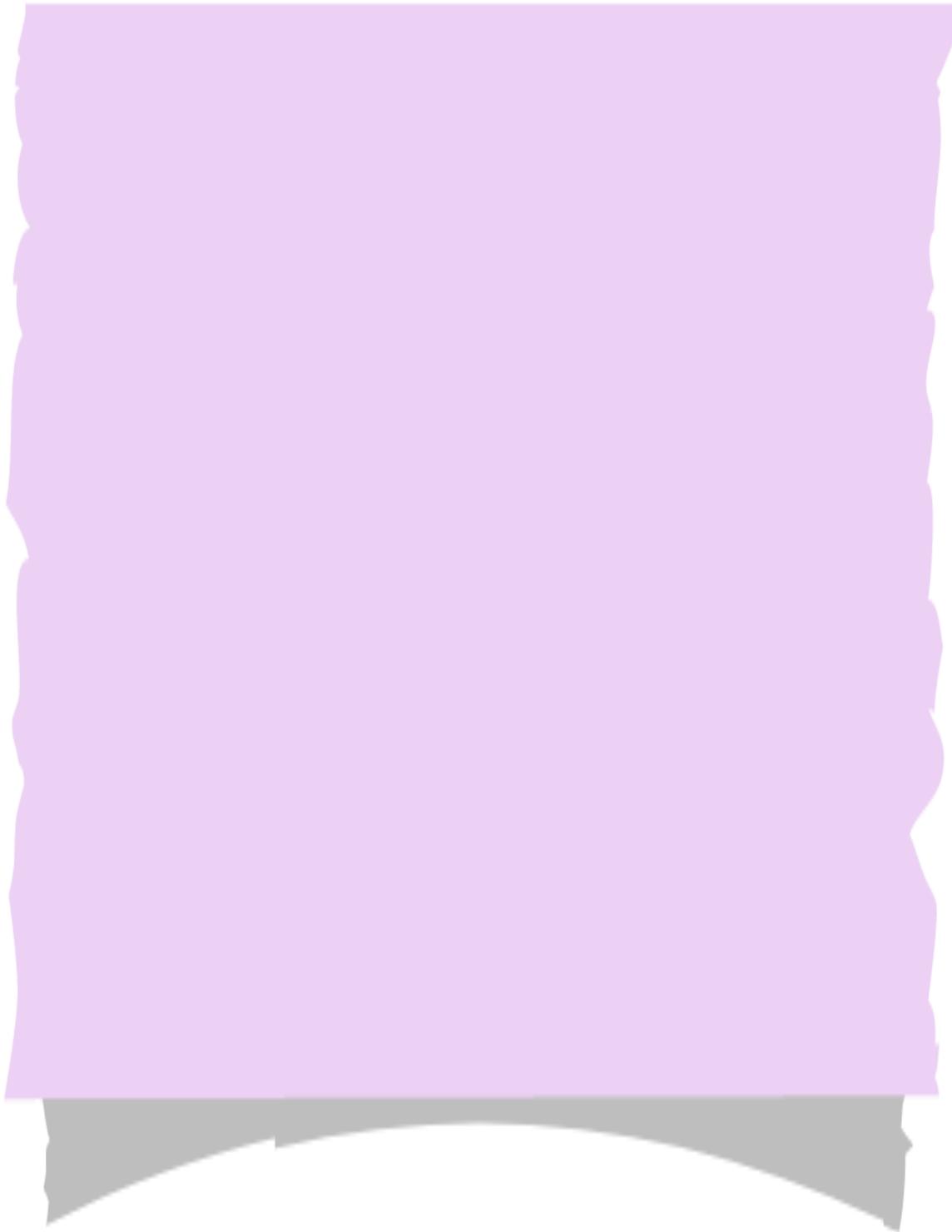
It is important for your baby to hear voices which are familiar to them. Reading and singing softly to your baby will be calming and is good for brain growth and development.



You might want to bring items in to personalise your baby's space such as family photographs, blankets, muslin clothes, nappies, clothes, and religious items.

Your baby may require monitoring leads which will need to be moved and replaced. This is something that you can be involved in.

**This page is for you to write
any questions you might have about
being involved in your baby's care**



Moving to a different neonatal unit

The Yorkshire and Humber Neonatal Network is made up of 19 units that offer different levels of care.

Most babies will receive all their care at one neonatal unit. However, it is sometimes necessary for your baby to be transferred to a different neonatal unit. This might be because your baby:

- Needs a different level of care
- Has been receiving care at a different unit and is now well enough to move closer to home.

In most cases one parent/carer will be able to travel in the ambulance with their baby. You can find out more information on this in the [Embrace Parent Information leaflet](#) on their website.



All information about your baby (Medical/nursing etc) will be shared with the new hospital directly from the old hospital. In addition, Embrace will also include a comprehensive handover to the staff on the new unit



The Neonatal Unit – Your baby’s surroundings

Babies can be sensitive to light, noise, and smell. The neonatal unit can be a very busy and noisy environment at times. Your baby’s surroundings will be adapted to provide and improve your baby’s comfort. Your gentle voice, touch and smell are all comforting and familiar for your baby.

Light - Soft lighting and incubator covers can help. For procedures where brighter light is necessary, your baby’s eyes should be shaded. You can use your hands to shade your baby’s eyes.

Noise - Speaking softly and reducing background noise during procedures, can help. You can use your hands to cover your baby’s ears.



Privacy – You and your baby will always be cared for with dignity and respect. Screens can be provided to ensure privacy if you wish.

Smells - Perfumes and strong fragrances should be avoided. You can reduce strong smells, such as hand gel, by making sure your hands are completely dry following application.

Physical environment - While your baby is on the neonatal unit, we aim to copy the womb environment by using nests and boundaries around your baby.

Check out these resources for more information:

Caring for your baby on the neonatal unit, a parent's handbook (Warren and bond 2015)

[Resources for nurturing sensory environment | Sensory Beginnings](#)

Supporting your baby through medical interventions/ cares

During your baby's time on the neonatal unit, we may need to perform necessary tests and procedures including blood sampling, feeding tubes (NGT), hearing and eye tests. Extra support may be needed for your baby when bathing and weighing.

Supporting your baby through these experiences can improve their comfort. Where possible, we encourage you to be present and involved in supporting your baby, and we will always plan your baby's care with you.

There may be circumstances where this is not possible due to urgent situations. If you cannot be present during a procedure, a member of staff will be available to comfort your baby.

Here are some ways that you can support your baby before, during and after procedures/cares:

Positive, comforting touch with your baby

Your baby's sense of smell helps them to recognise you, and your baby will find this comforting and help them to feel calm. Bonding squares are also useful for this if procedures are carried out in your absence.

Your baby can be easily overwhelmed by sudden, unpredictable movements. Use your voice to gently prepare them. If they appear unsettled, pause. Keeping your baby's arms and legs tucked close to their body can help calm them (this can be achieved using wrapping techniques).



Your voice will be familiar to your baby, and they may find it soothing if you talk, hum, or sing to them

Comfort holding (hand hugs) – Use warm hands to cup your baby's feet/body or head. Start by offering your finger to hold

Skin-to-skin/kangaroo care is holding your baby in just a nappy against your bare chest. There are many benefits of this for both you and your baby. The staff on the unit will support you to do this as often and for as long as possible.

Your Baby's Behaviour



Your baby has a unique way of communicating with you and letting you know when they are happy, anxious, or uncomfortable. Learning to understand your baby's expressions and movements is a valuable tool to help you all as a family to get to know each other and improve your baby's development.

Your baby's behaviour will be unique to them. Here are a few examples of what they might be trying to tell you.

“I'm tired, feeling a bit overwhelmed and need to rest”



You may see me yawn, hiccup or turn away when I need to rest.

Placing your baby skin to skin or positioning them comfortably in their incubator in a nest allows them to rest. Putting your hand or a muslin square with your scent on them can also help.

“Sometimes when it all gets too much, I will put my hand in front of my face or raise my arms with my hands wide open”



Pause what's going on and let me rest in a supportive position. Adjusting the environment around me or kangaroo care/ skin to skin might also help.

“I am curled up with my hands near my face, my feet are together and supported by a high boundary, and I have a relaxed expression on my face, I am feeling comfortable”



Talking to your baby, singing, or reading to them at this time helps with their brain development. If your baby starts to show signs of being over stimulated such as yawning, putting their hands in front of their face or turning away, gently lower your voice and pause your interaction

Check out these online resources for more information and ideas:

[Look at me – I’m talking to you | Parent resources | Bliss](#)

[Home - Ei SMART](#)

[Sensory Beginnings | Training Courses for neonatal & early intervention providers](#)



Your baby's feeding journey

Feeding a premature, small or ill baby will take you on a journey which may have many ups and downs. Your baby may not be able to suckle for some time, but staff can support you with ways to achieve this.

The following information will explain how you can support your baby along the way.

Providing breastmilk

However you choose to feed your baby in the long term, you will be asked to provide your breastmilk for your baby whilst they are on the neonatal unit. This is because your breastmilk is uniquely made for your baby and has many benefits for them now and as they grow. Your breastmilk:

- * provides the antibodies that help protect your baby against bacteria and viruses
- * boosts your baby's immature immune system
- * reduces the risk of a life-threatening gut infection called necrotising enterocolitis (NEC)
- * provides nutrients, growth factors and hormones that are crucial for the growth and development of your baby

Colostrum

Colostrum is the first milk you produce and comes in small amounts; every drop is precious and acts like a medicine for your baby. Your colostrum will be given to your baby as their first feed and then in the order you express it, this helps your baby's gut to grow and develop. A member of staff will help you to hand express and collect your milk in a small syringe.

Don't worry if you don't initially get any milk, it can be difficult to express when you are worried about your baby. It may take a few attempts, ask a member of staff to help you.

Your colostrum can also be used to give your baby mouth care, not only does it taste nice, it also helps protect your baby from infection. You may hear staff talking about buccal colostrum, this is when your baby is not yet ready to have your milk as a feed but it can be given in very small amounts into their cheek so it can be easily absorbed. Your baby can have your colostrum this way, even if they are ventilated or nil by mouth.



How to express your milk by hand

1. Have your feeding syringe ready before you start, and try and find somewhere you feel comfortable either by your baby or in a room where you won't be interrupted
2. Start with a gentle breast massage, stroking from the back of your breast towards your nipple for one or two minutes
3. Cup your breast with your thumb and fingers in a 'C' shape about 2-3 cm back from the base of your nipple



4. Gently squeeze your fingers and thumb together in a rhythmic action; it may take a while before you see any milk appear



5. If no milk appears after a few minutes, simply move your fingers a fraction back or forward and try again to find the right spot
6. Only expect a few drops at a time
7. When the drops stop, move your fingers around to try a different section of your breast and then swap to the other breast
8. Once you have finished, place a bung on the end of the syringe and label with your details.
9. Please take your milk to your baby as soon as possible or ask a member of staff to take it for you.

If you find hand expressing is not working for you, speak to your midwife or nurse and she will give you some tips, there is also an excellent video:

[Expressing milk for your baby on the neonatal unit - Baby Friendly Initiative \(unicef.org.uk\)](https://www.unicef.org.uk/expressing-milk-for-your-baby-on-the-neonatal-unit-baby-friendly-initiative)

Tips to help your milk flow

Look at me - Express near your baby whenever you can. Have a lovely photo of your baby or a video to use when you are not together



Remember my smell - Borrow a toy or blanket from your baby's cot, or you may be given a bonding square/heart to help you to connect when you are not together.

Touch - The more skin to skin contact (kangaroo care) you have, the more relaxed you will both be and the more milk you will make. Relaxing in a nice warm bath or shower, a back or foot massage and relaxation techniques will all help.



Night times - Instead of setting an alarm to express at night, try drinking a big glass of water before you go to sleep so you will need to get up to go to the toilet, it is always easier to waken naturally

Relaxation - Find a comfortable place to express where you're not worried about being disturbed. Make yourself a drink and get comfy. Close your eyes and imagine kissing your baby from the tips of their toes all the way up to their nose



Remember - You are doing an amazing job; it is easy to get discouraged but every drop matters.

Skin to skin contact, talking, reading, and quietly singing to your baby will not only soothe your baby but will help you relax too.

Expressing by pump

Expressing can feel like a big pressure, it is important to remember that no matter how much or how little you express, your baby will benefit. Your midwife or nurse will show you how to use the pump and how to clean and sterilise your equipment in between uses.



Tips to get your milk supply established

 You will be supported to use an electric breast pump at a time right for you. Combining hand expression and using a breast pump is the best way to establish your milk supply

 A member of staff will sit with you to check you're happy with expressing, including making sure the equipment fits you and that you have the pump on the best settings for you. Please ask a member of staff if you need help



 Try and express at least 8 times, but if possible 10 times in a 24-hour period, including at least once in the middle of the night

 Expressing frequently in the first two weeks sets up your milk supply for months to come



 You don't have to express every 2-3 hours, you can express a few times close together, this is called cluster expressing but avoid leaving gaps of longer than four hours in the day and six hours at night between expressions

 Try and massage your breasts before expressing this can help with your milk flow

💧 If you manage to get 800mls or more in 24 hours by around two weeks, you have switched on your milk, you may now decide to express less often and express only enough for your baby's current needs. As your baby feeds more, your milk will naturally increase again to meet their needs (ask your nurse for more information)

💧 If your milk supply suddenly drops, don't panic, it hasn't disappeared. Try lots of skin-to-skin contact, breast massage and follow the tips on relaxation, your milk will then begin to flow again

Having an ill or preterm baby can be stressful for the whole family and sometimes this anxiety can affect your milk supply. Often when milk supply is slow to increase, it resolves when your baby is well enough to have increased skin-to-skin contact or begins to have a go at breastfeeding.



You can use the box below to write any questions you might have about expressing for your baby

What you can do to support your baby with feeding

While babies are still in the womb they start learning to feed. They have touch receptors around their mouth at just 7 weeks gestation, and they can also smell, lick, taste, and root (turn their head and open their mouth in response to stimulus). Babies also start sucking their fingers around 12 weeks. This is all in preparation for feeding.

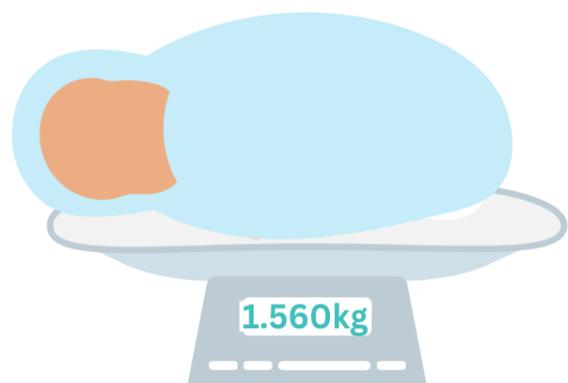
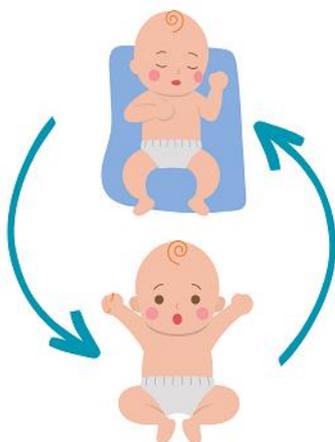
Babies generally go on to:

- Attach and do some suckling – around 28 weeks
- Suckle and swallow – around 31 weeks
- Co-ordinate sucks, swallows and breathing – around 32-34 weeks
- Become more established with feeding around 36-40 weeks but this can be later and is very individual to your baby.

We know that letting your baby go at their own pace helps with feeding/eating all through their life.

Skin to skin contact / kangaroo care and feeding

When babies are in skin contact it helps them regulate their sleep / wake cycles, calms them so they are more interested in feeding and helps them with weight gain. When your baby is ready, they will be able to move down towards the breast and lick, nuzzle and eventually attach. The more practice they have the better. If you choose to give bottles, feeding your baby in skin contact will also support all the above. [Skin-to-skin contact - Baby Friendly Initiative \(unicef.org.uk\)](https://www.unicef.org.uk/skin-to-skin-contact)





Non-nutritive sucking

Babies suck on their hands and fingers to calm themselves.

This is called non-nutritive sucking. Non-nutritive sucking has many benefits, it helps with feeding, gives your baby a positive oral experience and also helps them soothe and calm themselves. Non-nutritive sucking can also help with pain relief. You can do this by letting your baby suck on your finger, use a dummy or recently expressed breast.

Parenteral feeding (PN feeding)

Sometimes babies are not able to have milk straight away, in this case your baby will have an IV which is a thin tube that goes directly into a vein to give the nutrients they need. Your baby will still be able to have your colostrum given into their cheek (buccal colostrum) and be supported with non-nutritive sucking.

Tube feeding

If your baby is premature or ill it is likely they will need a feeding tube. This is a fine soft tube that goes through the nose or mouth and into their tummy. They will need to be tube fed until they are able to coordinate sucking, swallowing, and breathing.

You will be asked if you and your partner wish to learn how to tube feed. This is beneficial for both you and your baby. You can hold your baby in skin-to-skin contact during tube feeds or if this is not possible you can position your baby in a more upright position in your arms which will be more comfortable and help their tummy empty better. You can also offer them your finger, a dummy, or an expressed breast to suckle. This helps with their digestion and helps your baby build a connection between suckling and feeling full.

Watching and interacting with your baby when they are tube feeding will help you notice signs such as different facial expressions and body movements that may mean the feed is too fast. You can lower the syringe to slow down the milk flow and this will help your baby to be more comfortable when feeding.

Getting ready to suckle

Very early in their journey, when in skin-to-skin contact, your baby may move down to the breast themselves. They do this by shuffling, bobbing or sliding downwards. They will feel the texture of the breast with their cheek and will then lick and nuzzle or attempt to attach. The more your baby has this opportunity the quicker they will progress.

Once your baby is attaching and attempting to suck and swallow more frequently you can observe them for feeding cues and offer the breast when they show signs of readiness.

Feeding cues

Feeding your baby is an ongoing process and the goal is to establish positive feeding experiences. Your baby will need time to develop their strength and endurance for feeding. Watch your baby for feeding cues to make sure they are ready to try a feed, your baby's nurse will work with you to make sure your baby has feeding opportunities when it is the best time for both you and your baby. Following your baby's lead and responsively feeding your baby has longer term benefits with less problems when your baby is taking solid foods and in the early years.

Feeding cues include:

- Your baby is wakeful / alert
- Bringing their hands to their mouth and make mouthing movements
- Turning their head and open their mouth – may be in response to touch (rooting)
- Making sucking movements

Crying is a late indicator of hunger and can use up energy and make your baby less able to feed. If your baby has started to cry, place them in skin to skin or cuddle and calm them before starting to feed.



Positioning for Breastfeeding

As your baby gets stronger a member of the neonatal team will support you with getting the right position for feeding so your baby feels safe and secure and can feed effectively.

Please look at the following information.

[Positioning & Attachment - The Breastfeeding Network](#)

[Signs of Effective Attachment - The Breastfeeding Network](#)

Responsive bottle feeding

If your baby is having breastmilk by bottle or you decide to formula feed your baby, it is important that this is done by following their lead. Coordinating sucking, swallowing, and breathing is harder with bottle feeding as there is a free flow of milk so your baby will need support and time to get established.

Initially your baby may struggle to pause and breathe when bottle feeding. Help them pace the feed by watching their cues and they will tell you when they need a break. They may hold their hand up, splay their fingers and toes or spill milk out of their mouth, gently remove the teat or bring the bottle downwards to cut off the flow of milk, this will give them more control.

You may be shown different positions for feeding, your nurse will show you the best one for your baby's needs at the time. One position is the elevated side lying position, this can make feeding easier for your baby and takes less energy. It allows your baby to stop feeding and dribble any milk that they can't manage to swallow.

Your unit will use slow flow teats to support your baby when they start to bottle feed. Slowing the rate of the milk helps support your baby with their coordination and gives them more control.

Developing feeding skills

Babies develop their feeding skills at different rates. Your baby will need time to develop their skills and the stamina that is required to suckle for a full feed. In this time, they may continue to need nasogastric tube top ups. Occasionally babies breastfeeding may find it helpful to attach with a nipple shield, your nurse will discuss this with you if they feel it would help.

Focus on the quality of the feed, rather than worrying about how much they have taken and follow your baby's cues and behaviour. As your baby's feeding skills develop, they will need less and less top ups by their tube. Your nurse will help you judge when your baby needs a top up and when they are feeding well.

Feeding Environment

The neonatal unit is a busy place and even though staff try to keep noise to a minimum, it is a challenging environment for you and your baby. You can help by:

- Trying to make the area you are in as quiet and comfortable as possible
- Dim the lights around you if possible
- Take time to relax and not be rushed
- Watch your baby's behavior / communication
- Follow your baby's lead

Your baby's expectations when feeding is that it will be safe, familiar, rewarding and comforting.



Communication, Interaction, and bonding

WHY is communication so important?

A baby's behaviour is their language!

Babies love it when parents interact and respond to them as they build their special relationship, which is so important for their health, development, and happiness as they grow up.

You can talk, read, and sing to your baby as well as offer skin to skin and cuddles. Babies can recognise their parents voice and talking to your baby will also help develop their language.

Further information about supporting your baby's language and understanding their behaviour, can be found here:

[My behaviour is my language - HANDOUTS \(2\).pdf](#)
[neonatal_leaflet_online.pdf \(unicef.org.uk\)](#)

Giving medicines to your baby on neonatal unit

Learning how to give your baby medicines is a skill that the staff will support you with and this is known as parent administration.

Participation is not compulsory, and you do not have to do this whilst in hospital. However, it may help you to gain confidence to be able to practice in the safety of the hospital environment before going home.



Parent administration gives you an opportunity to learn about the medicines your baby needs, why they need them and how to give them.

Your baby's medicines will continue to be given by the nursing staff and they will ensure that you still have all the information you need and ensure that you receive guidance in giving your baby's medication prior to your baby going home.

If you would like to give your baby their oral medication whilst in hospital, a nurse will explain what is involved and answer any questions you may have.

Certain medicines may only be administered by a nurse, and it will be the nurse's responsibility to ensure these are given at the prescribed times. If you or your baby's situation changes or there is a change in medication this will be discussed with you.

Please note that the documentation for giving your baby's medicines may differ in each neonatal unit.

My notes and any questions ...



Preparing for your baby coming home



Although taking your baby home may feel a long way off, it is important that you to feel as prepared as possible for when the day comes.

It is normal to feel overwhelmed and anxious as well as excited about taking your baby home. If you haven't already done so you will be offered the opportunity to stay overnight in the parental accommodation rooms.

The staff on the unit are here to support and guide you through your neonatal journey and answer any questions you may have.

Some questions you may have might include:

- * What support will I have when I take my baby home?
- * What will I need at home to care for my baby?
- * What might I need when going out and about with my baby?
- * Will there be any follow up appointments?
- * How to respond to and soothe my baby when they cry?

There are some things that you will need to do in preparation for your baby going home such as.

- Register their birth
- Register your baby with a GP

The nurse caring for your baby will discuss.

- Car seat safety
- Safe sleeping
- Coping when your baby cries
- Introducing you to the community team and follow up appointments (If applicable)
- Medications at home
- Basic Life Support
- Immunisations



Some babies may continue to need oxygen and/or nasogastric tube feeding at home. If this is likely staff will explain how this will be organised and how you and your baby will be supported. ³³

Screening, Tests, and Immunisations

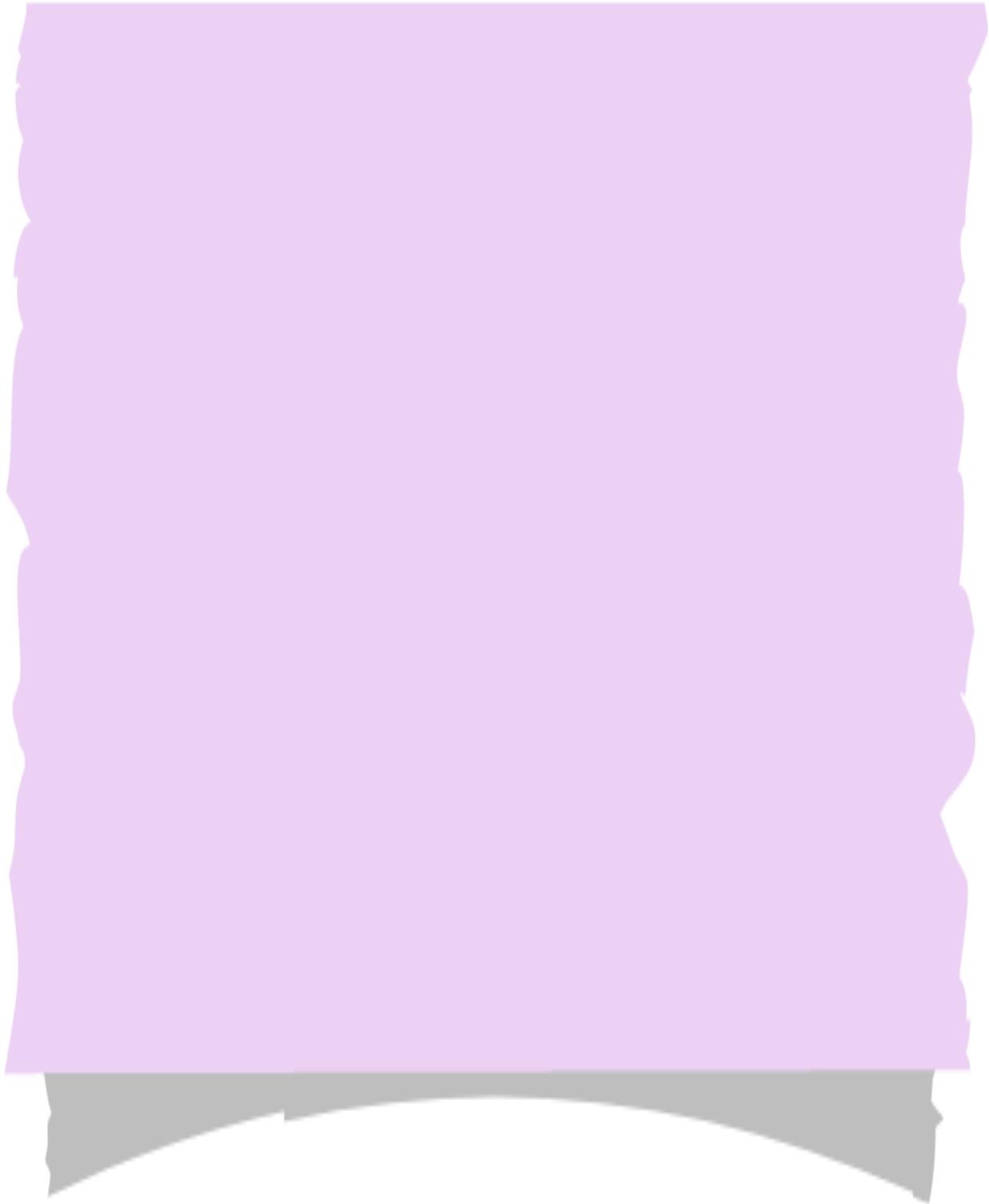
Below is some information about immunisations and screening tests your baby may have during their time on the neonatal unit. They are very common, and most are routinely completed on all babies who are born at full term and not requiring a neonatal admission. Before any of these tests are carried out on your baby a health professional will explain the reasoning for having them, and you will be asked for consent.

<p>Blood Tests</p>	<p>Most blood samples will be taken by pricking your baby's heel with a small needle, it is important to monitor your baby's blood as it's the transport system of the body and has many important jobs. Lots of information on how your baby is doing can be gained from blood tests.</p> <p>For more information, please scan the QR code.</p>	
<p>Blood Transfusion</p>	<p>Sometimes a blood test can show that your baby's blood has low levels of haemoglobin (HB), which is a chemical which helps transport oxygen around the body in our red blood cells. Low HB levels indicate low red blood cell levels, which may cause the body to not receive enough oxygen. Having a blood transfusion gives your baby extra red blood cells, which will increase HB levels.</p> <p>For more information, please scan the QR code.</p>	
<p>Newborn and Infant Physical Examination (NIPE)</p>	<p>This is a physical examination performed by a doctor looking after your baby. It should be completed within 72 hours after birth, sometimes this is not suitable if your baby is too unwell and will be completed as soon as possible. The examination is repeated at 6 to 8 weeks of age. The examination is used to prompt early referral for conditions relating to the eyes, heart, hips, and testes (if applicable).</p> <p>For more information, please scan the QR code.</p>	
<p>Head Scan</p>	<p>If your baby was born before 33 weeks gestation, they will have a head scan performed while on the neonatal unit. This is a painless procedure which is vital in detecting any brain abnormalities that can occur in premature babies. In some cases, especially babies born before 29 weeks these scans will be repeated over the first week of life. This is normal and is to monitor any changes that can occur in this time. The cranial ultrasounds are performed by a specialist radiographer, who will write a report on the findings and a doctor will then discuss these with you.</p> <p>For more information, please scan the QR code.</p>	

<p>Newborn bloodspot</p>	<p>Every baby in England is offered newborn blood spot screening also known as the heel prick test, ideally when they are 5 days old. The NHS screens babies for 9 conditions, including sickle cell disease and cystic fibrosis, plus some other rare conditions most families will likely never have heard of before.</p> <p>For more information, please scan the QR code.</p>	
<p>Newborn Hearing test</p>	<p>The newborn hearing screen test helps identify babies who may have permanent hearing loss as early as possible. However, it can be common to not get a clear response from the 1st test and this does not mean your baby has hearing problems.</p> <p>For more information, please scan the QR code.</p>	
<p>Retinopathy of Prematurity (ROP)</p>	<p>This is an eye examination for all babies who are born less than 31 weeks gestation or weighing less than 1.5kg at birth. They will have it at around 4 weeks of age. ROP is an eye disease that can happen to babies who are premature.</p> <p>For more information, please scan the QR code.</p>	
<p>Immunisations</p>	<p>Immunisations are an important way to offer protection from serious disease. All babies in the UK are offered immunisations, this is the same for babies born prematurely. In some cases, extra vaccinations will also be required for preterm babies. If your baby requires these extra vaccines this will be discussed in depth with you and the medical team looking after you & your baby.</p> <p>For more information, please scan the QR code.</p>	
<p>Discharge Examination</p>	<p>This is an examination performed on the day or days up to your baby been discharged. It is like the NIPE and is completed by a doctor. Anything highlighted on the NIPE or not picked up on the first examination can then be followed up in the community by the appropriate specialist professional.</p>	

Support and Charities

Some units have local support groups available. Please ask the staff and look out for any posters or leaflets they may have displayed. Use the space below



Useful Charities and Organisations

This section provides information about local and national charities that specialise in support for neonates and their families. The QR codes will take you straight to their websites or social media pages for more information, or alternatively use the web addresses.



Small Wonders are 12 bite-size films following families and their journey in neo-natal units.

Topics covered:

- Birth
- First hours
- Expressing breast milk
- Holding your baby
- Your time in hospital
- Feeding independently
- Preparing for home
- First months at home
- Twins and triplets
- Bereavement



Bliss' vision is that every baby born premature or sick in the UK has the best chance of survival and quality of life.

Bliss provides information about caring for premature and full term sick babies at every stage of their hospital journey, and after they have gone home.



A pack of laminated cards which contains practical information and advice on relevant matters. These include: how dads can best help themselves and their partners as they each deal with their feelings and emotions; where to go to seek further help, support and information; and practical guidance on holding, handling, bonding with and caring for their premature baby.



Our purpose is to improve the lives of low-income families raising disabled or seriously ill children and young people.

Our mission is to provide items and services to all low-income families in the UK raising disabled or seriously ill children, that they could not otherwise afford or access, and that help improve their quality of life, realise their rights, and remove some of the barriers they face.





Our sole purpose is to support LGBT+ women & people globally on the path to motherhood or parenthood. We provide guidance on the different family creation pathways through our website, social channels & support groups, whilst providing access to our global community to meet other like-minded families.



We provide support to parents, families & friends of those affected by HIE (Hypoxic-Ischaemic Encephalopathy), raising awareness of HIE.

- Some of the things we do include:
- Provide information about HIE
 - Buddy/peer support
 - Counselling and therapy
 - Funding for equipment



Rainbow Trust Children's Charity works with the whole family. We focus on supporting the baby's siblings, who are often very confused and upset, and unable to visit for a variety of reasons. We also provide a transition service for parents whose babies do recover sufficiently to go home and offer a continued service at home.



Due to our own personal experiences of neonatal care we understand and empathise with families who find themselves in similar circumstances.

Our primary focus is on supporting the whole family, practically and emotionally from admission to the neonatal unit and beyond, working collaboratively with our NHS colleagues and other services.



Dad's do NICU too

At The Smallest Things, we know that dads and partners face their own unique challenges after the premature birth of a baby or babies. Often juggling work and other children while caring for a newborn in NICU and supporting a partner, dads can and do struggle. How do we know? We've been there too.



The Smallest Things is dedicated to creating a better world for premature babies and their families after neonatal care.

We get it because we've been there too. The Smallest Things is run entirely by volunteers who've had premature babies.



Tommy's

Together, for every baby



The Queer Parenting Partnership



Tommy's is a community, a family. Women and their families are the heart of all that we do. We offer a wide range of resources, tools and services for families who experience baby loss or premature birth.

We recognise the need for additional services targeted at not only LGBTQ+ families but also at other families perceived to be minorities. That being said, everyone is welcome at The Queer Parenting Partnership.

Our values are of equality, fairness, power, love, community, laughter and fun. We aim to build a community for queer families to learn and grow together and to celebrate our presence in the world.



Unexpected Beginnings Neonatal Podcast

Through listening to other parents experiences and speaking to doctors, surgeons, mental health workers and everyone in-between, this podcast aims to make you feel less alone and more supported, signposting you to help and information along the way.



turn2us



Turn2us is a national charity providing practical help to people who are struggling financially.

We offer support to those of us facing financial shocks and together we challenge the systems and perceptions that cause financial insecurity.



This podcast has been recorded with the help and support of Leeds Children's Hospital, Leeds Teaching Hospital NHS Trust and funded by Leeds Hospital Charity.



The unicef Baby Friendly Initiative is a programme which supports maternity, neonatal, health visiting and children's centre services to transform their care and works with universities to ensure that newly qualified midwives and health visitors have the strong foundation of knowledge needed to support families.



ICON is all about helping people who care for babies to cope with crying.



Infant crying is normal



Comforting methods can help



It's OK to walk away



Never, ever shake a baby



Bereavement Charities



Aching Arms is a charity that gives its comfort bears to hospitals and hospices, for midwives and nurses to offer to bereaved parents in their care. Along with the bears, we also offer a support service to parents after their loss, whether it was during pregnancy, at birth or soon after



Sands is dedicated to providing emotional support and information right from the early hours after a baby's death, through to the weeks, months and years ahead.

Sands supports anyone affected by the death of a baby.



4Louis is a UK charity that works across the country to support anyone affected by miscarriage, stillbirth and the death of a baby or child. We also work to improve the care of bereaved families received from health care professionals.



Ibraheem's Gift

The Ibraheem's Gift pack was designed in close consultation with a hospital Imam and contains the immediate necessities that parents would need to help them prepare for their baby's Muslim burial.

Ibraheem's Gift is there to provide families with the immediate items to help with the burial process as we know Muslim burials happen very swiftly.

Jargon Buster

You will hear lots of medical words whilst your baby is on the neonatal unit. This Jargon Buster has been created to help explain some of the more commonly used ones. It is important to note that your baby's neonatal experience is unique to them and not all these conditions, medications or equipment will apply to your baby

A

AHP (Allied Health Professionals) – These are staff who work alongside the doctors and nurses caring for your baby and provide specialist care. E.g., Physiotherapist, speech, and language therapist etc.

Apnoea – Short bursts of time where your baby forgets to breathe.

Arterial Line – A cannula/umbilical catheter placed into an artery to monitor blood pressure (BP) and used for blood sampling.

B

Badger – The BadgerNet Summary system allows for the daily recording of events within a neonatal unit, including statutory data collection and reporting. In addition, the system includes an iPad app for easy information entry within the unit and Baby Diary, an app which enables parents to view regular updates and photos of their baby in the unit.

Bilirubin – Yellow pigment in your baby's blood (bilirubin) can turn the skin slightly yellow (Jaundice).

Blood gas – Routine blood gasses are taken via a heel prick and capillary tube. The blood will be taken to a blood gas machine and provides key information to help assess the effectiveness of/need for breathing support and how well your baby's blood is circulating around their body.

Blood glucose – Blood is taken usually from a heel prick to measure the level of glucose (sugar) in the baby's blood.

Blood Transfusion – Some babies may need a blood transfusion for several reasons, such as infection or bleeding before they were born. Premature babies may have a lack of red blood cells because they are not ready to make their own.

Bolus – A bolus is an extra dose of medicine or fluid given in one go rather than over a set time. It can also be used as a method when giving feeds too.

Bradycardia—Sometimes, a baby's heartrate can drop slowly or dramatically, this is known as a 'Brady'. Occasionally, this is accompanied by a desaturation (where baby's oxygen levels dip) and can be referred to as a 'Brady desat'

Caffeine – is a stimulant to help your baby’s breathing.

Cannula – This is where a needle is inserted into the skin to place a little plastic tube in a blood vessel (usually in their hands or feet) and is used to give your baby the medication that they need.

Capillary Tube – A very thin tube in which blood is collected.

Cares – This is when you change your baby’s nappy and/or clean your baby.

Central Line – This is an IV (intravenous) line which is a soft, flexible tube placed inside a vein which is close to your baby’s heart. It is also known as a long line.

Chest Drain – Some babies can get air which leaks into the space between the lungs and chest wall. Chest drains, which are little tubes, are placed into the chest cavity, and allow the excess air to drain off.

Chronic Lung Disease – Chronic Lung Disease is common in babies born premature who have needed longer term ventilation or needed it after 36 weeks. It means that your baby may need oxygen support once they are home.

Colostrum – Colostrum is the first milk breasts will produce.

Congenital hypothyroidism – Congenital hypothyroidism occurs when a newborn infant is born without the ability to make normal amounts of thyroid hormone.

Cooling blanket – A treatment which is given to some babies following hypoxia (see below) brain injuries. The blanket cools the body down and protects the brain and vital organs.

Comfort holding – Comfort holding is one of many ways for you and your baby to get to know each other and is a way to experience loving touch when your baby is not ready to be held.

Cardiopulmonary Resuscitation (CPR)– CPR is a form of resuscitation.

D

Developmental Care – Babies are cared for in an environment that supports their development.

Desaturation/Desat – When a baby’s blood oxygen levels drop below a certain percentage on the saturation monitor, the alarm will sound to alert staff caring for your baby. Most desaturations resolve quickly, but some require assessment and intervention.

Dietitian – Can have a significant impact on the care of sick and premature babies providing specialist individualised nutritional advice

Donor Expressed Breast Milk – Human milk expressed by a donor that is then processed by a donor milk bank.

E

EBM – Expressed breast milk

Echo (Cardiac Echo/Ultrasound Scan) – These are used to check for any heart problems. Your nurse and doctor will go through the procedure - with you before the scan happens.

Endotracheal Tube (ET Tube) – This is the tube which is placed in baby’s windpipe (breathing pipe) and is connected to a ventilator to help them breathe.

Expressing – Collecting breastmilk by hand or using a breast pump.

Extubate – This is where the breathing tube is removed.

F

Family Integrated Care – A model of care which integrates the family into the neonatal team caring for baby

G

Gastric Aspiration – A way to test if the NG/OG tube is in the correct position, the stomach. A small sample is taken using a syringe and placed on a PH stick to look for an acid response.

Grunting – A noise a baby makes when they are having difficulty breathing.

H

Heel Prick – A method of taking blood using a pinprick puncture in one heel.

Head scan – These routine scans are done to check for intraventricular haemorrhages, or abnormalities etc. Your consultant or nurse will go through this with you before the procedure happens.

Heart Murmur – See PDA

HDU (High Dependency Unit) – Looks after premature and term babies who do not need intensive care.

Humidity – Environmental humidity helps to support your baby’s temperature inside an incubator.

Hydrocephalus – Sometimes babies will get extra fluid on their brain, if this happens there is an increase in head size.

Hyperglycaemia – is where a baby has a very high blood glucose level.

Hypoglycaemia – is where a baby has a very low blood glucose level.

Hypoxia— is a condition where the brain has been starved of oxygen and there is little oxygen in the blood tissues.

HIE (Hypoxic Ischaemic Encephalopathy) — is where there is a lack of oxygen and blood flow to the brain. It can occur before, during, or shortly after birth.

I

Incubator – Incubators are keeping your baby warm, as they are temperature controlled, you will still be able to touch, cuddle and help care for your baby.

Intravenous (IV) drip – An IV drip gives your baby medicine directly into their veins.

Intubate – This is where doctors will place a tube down baby's windpipe and connect it to a ventilator to give them breathing support.

Intraventricular Haemorrhage – In premature babies, the brain and its blood vessels are still developing. The brain has spaces within it, called ventricles, which are filled with fluid. The new blood vessels near these are very fragile. IVH is when blood from these fragile vessels leaks out into the ventricles (spaces).

J

Jaundice – Is very common in preterm and newborn babies. It is caused by excess bilirubin in the blood (hyperbilirubinemia) which can result in yellow discolouration of the sclerae (whites of the eyes) and skin. It is treated using a special blue lamp over your baby (see phototherapy). The level is measured by a blood test. In more severe cases baby's sometimes need a exchange transfusion.

K

Kangaroo Care– Kangaroo Care is skin-to-skin contact when a baby is undressed and placed against the parent's chest. A hat and a blanket for extra warmth might be necessary for very small babies.

L

LNU (Local Neonatal Unit) – For babies who need a higher level of medical and nursing support are cared for here. If your baby was born between 28 and 32 weeks' gestation this is the level of care your baby may require.

M

MDT (Multidisciplinary Team) – This is the whole team of staff who will work together to care for you and your baby. They include doctors, nurses, health care assistants etc.

Meconium – A dark green substance which is produced in the baby's digestive system before birth and usually starts being passed as bowel movements in the first 24 hours after birth.

Meconium aspiration– Meconium aspiration is when a newborn baby breathes in a sticky substance called meconium just before or during birth.

Monitoring – You will see the monitor just above the baby's cot space. The monitors often display numbers and waveforms in different colours. Commonly measured parameters are Heart rate, ECG wave forms, Breathing rate, Oxygen levels and Blood pressures.

N

Nasal Flaring – Occurs when the nostrils widen while breathing. It can be a sign of difficulty breathing.

NEC (Necrotising Enterocolitis) – A serious condition which can affect newborn and premature babies where the tissue in the bowel (small/large intestines becomes inflamed

Newborn Blood Spot - All babies on the neonatal unit will be offered this screening. See 'screening section' within this package for more information. Sometimes this is referred to as the Guthrie Test.

NG tube – A nasal gastric tube is a thin tube placed into your baby's nose, and down into their tummy. This tube is used to give feeds and/or medicines.

NICU (Neonatal Intensive Care) – If your baby was born before 28 weeks gestation, or very unwell after birth. This is the level of care your baby will require.

O

O₂ – Oxygen

Occupational Therapist – Looks at the sensory environment and how this can support your baby's development. Also support the understanding of a baby's behavioural cues, aiming to reduce stress.

Oedema - Build-up of fluid in the body which causes the affected tissue to become swollen.

Oral Gastric (OG) tube – An oral gastric tube is a thin tube placed into your baby's mouth and into their tummy. This tube is used to give feeds and/or medicines.

Overnight Tracing – An overnight recording of your baby's oxygen saturation levels to guide the amount of supplementary oxygen needed.

P

PDA (Patent Ductus Arteriosus) – Also referred to as a PDA. An extra blood vessel called the ductus arteriosus. It is part of the baby's blood flow system in the womb. This will shrink and close on its own usually in the first few days of life but may take longer in premature babies. This is sometimes called a heart murmur.

PN (Parenteral Nutrition) – PN is often given into a vein (usually a central line) to very preterm babies until they can tolerate milk feeds. PN includes vital nutrients.

Phototherapy – Treatment using blue light for jaundice levels which need correcting. This can take several days. Your babies' eyes will be protected using an eye mask.

Physiotherapist (PT) – Supports neonatal units with developmental care practices and appropriate early physiotherapy intervention strategies.

Plasma – Plasma carries blood cells around your baby’s body and contain protein and minerals.

Platelets – Platelets will help your baby’s blood to clot. Sometimes, babies may need a platelet transfusion if they are unable to clot very well.

Pneumonia – Pneumonia is a lung infection that can be treated with antibiotics.

Pneumothorax – A pneumothorax occurs when there is air between the chest wall and the lungs if a lung has leaked some air. (**See Chest drain**)

Psychologist – Clinical Psychologists and other accredited psychological professionals, with specialist expertise in neonatology, are key providers of evidence-based psychological assessment and interventions for parents, infants, and staff on neonatal units.

R

Respiratory distress – Respiratory distress happens when a baby’s lungs are not fully developed and cannot provide enough oxygen causing breathing difficulties. It usually occurs when a baby’s lungs have not produced enough surfactant (see Surfactant).

ROP (Retinopathy of Prematurity) Screening – ROP is a condition that can occur in babies born very prematurely, where abnormal blood vessels develop at the back of the eye. If required screening will take place on the Neonatal Unit.

S

SCU (Special Care Unit)– This can sometimes be called low dependency. Often babies born after 32 weeks gestation will require this level of care.

Sepsis – Sepsis is where infection goes into the blood stream.

Speech and Language Therapist (SLT) – Helps parents to manage their baby’s feeding and developmental needs.

Surfactant – Surfactant is usually produced naturally in the lungs to support breathing. Some babies may need artificial surfactant which is delivered directly into their lungs via ET tube.

T

Tachycardia – Sometimes, a baby’s heart rate can become increasingly fast. It can be caused by an infection, baby being too hot, upset, or uncomfortable.

U

Umbilical Artery Catheter – This line can be used to record continuous blood pressures and take blood samples

Umbilical Venous Catheter – A UVC is an umbilical venous catheter and is used to give your baby the medications and fluids that they need.

Ultrasound – This can be a head scan, a tummy scan, or a heart scan. All are harmless to baby but will help give doctors a better idea of how to help your baby.

Acknowledgments and Thank You

This package has been co-produced by The Yorkshire & Humber Family Care Team, Network Parent Advisory Group (PAG), Network Allied Health Professionals & Psychologist, Neonatal unit staff across the network, and The Neonatal Voice Co-production Group.

We would like to thank all the people who have helped us with this project, without their support and contribution it would not have been possible.

The Neonatal Operational Delivery Network– 1st edition Ver 1.0

Publication date: July 2023

Review date: July 2025