

# East of England Neonatal Operational Delivery Network

## NEONATAL PASSPORT

My NICU Journal

My Name is:



East of England  
**Neonatal**  
Operational Delivery Network

Collaborative working to deliver high quality care to our babies and their families



## Acknowledgement

The East of England Neonatal ODN would like to give special thanks to the North West Neonatal ODN, East of England Neonatal Outreach Group, Paula Peirce-NICU Junior Sister and Feeding Specialist, Sophie Phillips-Senior Specialist, Speech and Language Therapist and Nigel Gooding-Consultant Pharmacist from Cambridge University Hospital, Emily Gorrod ODN Parent Representative and Kelly Hart Administrator to the ODN for all of their help with our Parent Passport.



# East of England Neonatal

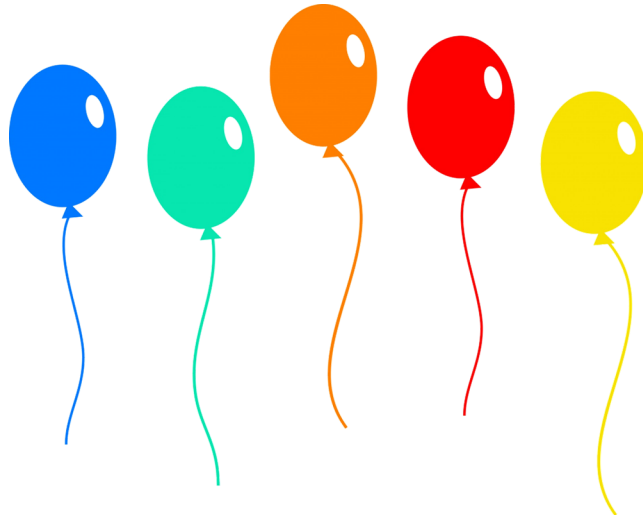
Operational Delivery Network

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## Congratulations on the birth of your baby!



We hope you will be able to visit your baby on the unit as much as you can however we understand that it is not possible for you to be here all of the time. Please let the staff know when you are coming so that we know if you are able to be here for your baby's cares and feeds.

Whilst your baby is being looked after on the Neonatal Unit, you will be able to carry out many of the day-to-day cares your baby needs. To ensure your baby's comfort and safety you will be taught all of the skills you need to provide all of the non-medical care for your baby. It may seem frightening and overwhelming at first but with the right support and guidance your confidence will soon grow.

We promise never to hide anything from you about your baby and if you are here on the ward round you will get a full update. If you miss the ward round the nurse will update you and you can ask to see the doctor if you wish.

This passport will ensure that both you and the neonatal unit staff know what you feel confident to do for your baby. This will be particularly helpful if your baby is transferred to another hospital.

It is very important to us that you as parents are as involved with your baby's care as possible. The Neonatal team are here to offer you support and guidance throughout your baby's journey on the Neonatal unit.

Please ensure the passport is kept with your baby during their Neonatal stay.

## All about me!

Name:

Born on:

Time of birth:

Gestation:

Weight:

Hospital I was delivered at:

My expected due date was:

My first language is:

My religion is:



## My Family

My parents/carers are called:

Their phone numbers are:

My siblings are called:

My home address is:

Other significant people:



## My Healthcare Professionals

Neonatal Consultant:

Neonatal Nurse on admission:

Surgeon:

Physio:

Dietitian:

OT:

Specialist Support:

Neonatal Nurse on discharge:

Outreach Nurse:

Social/Family Worker:

GP:

Health Visitor:



## What my parents/carers like

My parents/carers like

\*Please circle

|  |            |           |                   |
|--|------------|-----------|-------------------|
| Present at ward round                                    | <b>Yes</b> | <b>No</b> |                   |
| To be contacted about changes when not on the unit       | <b>Yes</b> | <b>No</b> |                   |
| To read to me  | <b>Yes</b> | <b>No</b> |                   |
| To change my clothes                                     | <b>Yes</b> | <b>No</b> | <b>Assistance</b> |
| To do my cares-<br>change my nappy, top<br>and tail wash | <b>Yes</b> | <b>No</b> | <b>Assistance</b> |
| To give me baths   | <b>Yes</b> | <b>No</b> | <b>Assistance</b> |
| To get me out  | <b>Yes</b> | <b>No</b> | <b>Assistance</b> |
| To give my feeds   | <b>Yes</b> | <b>No</b> | <b>Assistance</b> |



On admission to each Neonatal Unit staff should discuss the points below to make you familiar with the unit in which your baby is being cared for

|              |             |             |             |             |
|--------------|-------------|-------------|-------------|-------------|
| On admission | Parent(s)   | Healthcare  | Parent(s)   | Healthcare  |
|              | Date & sign | Date & Sign | Date & Sign | Date & Sign |

Hand washing

Security

Tour of the Unit

Visiting Times

Car Parking

What you can provide for your baby while on the unit (nappies, cotton wool)





## What is Family Integrated Care?

Family integrated care (FICare) is a way of working that supports and educates parents and carers on the neonatal unit to become fully involved in their baby's care. Within FICare, families are included as equal partners as part of the neonatal team. Evidence shows that babies looked after this way have fewer infections, are more likely to breastfeed, gain weight more quickly, have fewer complications and go home sooner.

We want you to be involved in as much of your baby's care as possible and the nurses will teach you everything you need to know as soon as you feel ready. This is likely to happen gradually over the first week or two on the unit, as immediately following delivery you may feel too unwell, tired or shocked to take anything in. You will be amazed at how your confidence in caring for your baby grows so quickly.

We will support you closely with some cares such as tube feeding to ensure you feel confident to carry them out safely. There are some things, such as turning alarms off or altering oxygen levels that you must never do.

In this passport is a list of the main things you will learn, to enable you to look after your baby on the neonatal unit. If you are unsure about anything then please ask a member of staff.





## The Neonatal Network and Transfer of Your Baby

Neonatal units work within a network, which aims to provide ‘the right care for the right baby in the right place’. Within the East of England Neonatal Operational Delivery Network there are:

- 3 NICUs (Neonatal Intensive Care Units) who provide all levels of care, two of which also provide surgery
- 10 LNUs (Local Neonatal Units) who provide short term intensive care, high dependency and special care
- 4 SCBUs (Special Care Baby Units) who provide stabilisation, short term high dependency care and special care.

All units have access to skilled nurses and clinicians 24 hours a day and are able to provide high quality care.

To enable the network to achieve the right baby in the right place and to ensure that all babies within the neonatal service receive the highest standard of care it is sometimes necessary for babies to be moved to other units. This may happen for a number of reasons

- Your baby requires intensive care, which needs to be provided within one of the 3 NICUs (Addenbrookes, Luton and Dunstable or Norfolk and Norwich)
- Your baby has received a period of intensive care at one of the 3 NICUs, now no longer requires intensive care and is transferred back to your local LNU or SCBU
- Your baby does not require intensive care and is transferred to a local unit for on-going care. This is occasionally necessary to ensure that the intensive care units cots are available when they are needed for sick infants.

It is the aim of the neonatal network to try where possible to keep families as close to home as is appropriate, this may not necessarily be your local hospital or where you booked your maternity care depending on the level of care your baby needs.

For parents who have booked their maternity care at one of the 3 NICUs but live closer to another hospital, there may be occasions where your baby is transferred closer to your home address. This supports family life, improved family support and earlier discharge as your baby may require on-going out-reach support which can only be provided by the team at your local hospital.

Please be assured that prior to any transfer of your baby you will be fully informed of the reasons for transfer. The local team will explain these to you. Transfer to other hospitals is often difficult for parents when you have built a relationship with the team at the NICU.

Where possible we would encourage parents to visit the hospital their infant will be transferred to so that they can be reassured before the transfer. This is of course not always possible if your baby is transferred for emergency care. Usually, one parent can travel with your baby but it is not always possible. All units have information on the transport service within the East of England.



Whilst we understand that having a sick baby is very stressful for the whole family we will aim to keep transfers at a minimum however provision of cots for sick babies is essential to ensure that all infants across the East of England have the opportunity to receive the right care.

Please support us to ensure that all babies have the opportunity to receive high quality care as close to home as is possible.



## Taking part in ward rounds

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

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

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



If you want to have further discussions with the consultant following the ward round this will usually be arranged for later in the day after all babies on the unit have been seen.





## Taking part in ward rounds

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

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

| <u>PARENTS TAKING PART IN WARD ROUNDS</u>  |
|--|
| Baby's Name and Sex  |
| Gestation and Current age in days  |
| Birth Weight and Current Weight  |
| Hospital where baby was born and date when transferred                                       |
| Type of delivery   |
| Respiratory support needed at birth and currently.   |
| Nutrition - TPN, Type of milk, how much and how milk is given                                |
| Has baby had a wee or a poo?   |
| What lines/drips are in place?   |
| How do you feel your baby has been over the past 24 hours?                                   |
| How are you coping as a family? Where are you staying? Are there other children to consider? |
| Any questions for the medical and nursing team today?  |
| Anything else you would like to share with your baby's health care team                      |



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| <b>Baby Cares</b>   | Demonstrated/Discussed<br>(Nurse Signature)<br>Date | Competent*/Confident<br>(Parent/Nurse* Signature)<br>Date |
|---|---|---|
| Skin care   |   |   |
| Eye care  |   |   |
| Mouth care  |   |   |
| Nappy change  |   |   |
| Changing bedding  |   |   |
| Swaddled bathing  |   |   |
| Weighing  |   |   |
| Dressing  |   |   |
| Taking your baby out of<br>their cot / incubator for<br>cuddles |   |   |

| <b>Developmental Care</b>                   | Demonstrated/Discussed<br>(Nurse Signature)<br>Date | Competent*/Confident<br>(Parent/Nurse* signature)<br>Date |
|---|---|---|
| Noise and light                             |   |   |
| Smell and taste                             |   |   |
| Positive touch                              |   |   |
| Skin-to-skin                                |   |   |
| Quiet time with your baby                   |   |   |
| Understanding your<br>baby's cues           |   |   |
| Managing your baby's<br>pain and discomfort |   |   |
| Positioning                                 |   |   |

It is your decision whether to breast or bottle feed your baby and the neonatal staff will support you with whichever choice you make.

| <b>Feeding</b>  | Demonstrated/Discussed<br>(Nurse Signature)<br>Date | Competent*/Confident<br>(Parent/Nurse* signature)<br>Date |
|---|---|---|
| Benefits of breast milk   |   |   |
| Hand expression of breast milk                                      |   |   |
| Expression using breast pump & storage of breast milk               |   |   |
| Hiring/borrowing of breast pump                                     |   |   |
| Sterilising dummies /<br>expressing equipment / bottles             |   |   |
| Tube feeding competencies   |   |   |
| Assessing readiness and<br>infant led feeding                       |   |   |
| Position and latching onto<br>breast                                |   |   |
| Positioning for bottle feeding                                      |   |   |
| Teat selection for bottle<br>feeding                                |   |   |
| How to pace your baby during<br>bottle feeding and when to<br>stop. |   |   |



## Tube feeding competency



A nasogastric/orogastric (NG/OG) tube can be used to deliver expressed breastmilk or formula milk directly into the stomach of babies who are unable to take all feeds by breastfeed or bottle feed. Babies may be unable to feed due to being born prematurely; being too ill to feed orally or have difficulties such as cleft palate.

If you would like to be involved in tube feeding your baby the nursing staff can train you to give your baby feeds via the NG/OG tube. You will be shown and supervised before being signed off as competent by staff. Some parents may also want to learn to insert the feeding tube when it becomes dislodged or requires changing, but please don't feel you have to.

The feeding tube is flexible and is inserted into the nose (or mouth), it passes down the back of the throat, through the oesophagus and into the stomach. Passing the tube is thought to be uncomfortable but not painful for a baby. Once in place, it is unlikely to bother them too much although some babies manage to pull them out repeatedly!

### How to give a tube feed.

|  |   |
|--|---|
| <b>1.</b> Collect the necessary equipment-5ml syringe for testing an larger syringe for feeding, pH strips   | Ensure equipment is to hand                   |
| <b>2.</b> Milk feed-EBM or formula:<br><br>If the milk has just been removed from the fridge, check the date and time that it was placed in the fridge or defrosted. Milk from the fridge will need warming. Check if any additives/ medicines needed. | Correct feed and amount given                 |
| <b>3.</b> Wash your hands  | To maintain hygiene                           |
| <b>4.</b> Check that the position of your baby's feeding tube is at the same length that is documented on the nursing chart and is taped securely  | To ensure the tube is in the correct position |



# Tube feeding competency



|   |  |
|---|--|
| <p><b>5.</b>Aspirate the tube using 5ml syringe and check for acidity using pH strip-should be 5.5 or less</p>  | <p>To ensure the tube is in the correct position</p>   |
| <p><b>6.</b>If no gastric aspirate is obtained:</p> <ul style="list-style-type: none"> <li>• Reposition the infant and try to aspirate again</li> <li>• If no gastric fluid is obtained after repositioning speak to a member of the nursing team</li> </ul> <p>Always assess the infant's colour and observations whilst carrying out the procedure</p>  | <p>To determine the position of the tube</p> <p>The pH should be 5.5 or less</p> <p>The tube may have kinked slightly in the stomach</p>   |
| <p><b>7.</b> Remove the plunger from the larger syringe and connect to the feeding tube</p> <p>Pour milk into syringe and continue topping up until total feed volume is given. (you may need to reinsert the plunger into the top of the syringe and give a gentle push)</p> <p>Observe the baby throughout the feed. If baby shows signs of not tolerating the feed (vomiting or gagging) lower the height of they syringe and pinch the tube to stop the flow of feed before reinserting the plunger and disconnecting the feed to provide a break for baby until they are ready to continue</p> | <p><b><u>Non nutritive sucking</u></b></p> <p>Babies are comforted by sucking. Sucking on a soother, a clean finger or a cotton bud dipped in breast milk during a tube feed can help them to enjoy being fed and associate sucking with having a full tummy. Having skin to skin or just being held during a feed can also be very comforting and enjoyable</p> |

## Tube feeding competency



When the feed has been completed, place the plunger back into the top of the syringe and remove from feeding tube. Place cap back on the end of feeding tube

### Troubleshooting

- Tape lifting or not securing tube adequately. **Action:** Tell the nurse who will help you secure the tube.
- Unable to obtain aspirate to test or pH not less than 5.5 **Action:** Tell the nurse
- Infant vomiting or distressed. **Action:** Kink the tube to stop the feed and alert the nurse
- Infant has colour change. **Action:** Kink the tube to stop the feed and alert the nurse
- Monitor alarming. **Action:** Kink the tube to stop the feed and alert the nurse

Preterm babies have lower muscle tone than term babies; they have difficulty lifting their arms and legs up against gravity. You may observe their movements are disorganised and very energy consuming. So they need a little extra help and support.

| <b>Positioning your baby</b>   | <b>Demonstrated/Discussed<br/>(Nurse signature)</b><br>Date | <b>Competent*/confident<br/>(Parent/nurse* signature)</b><br>Date |
|--|---|---|
| I recognise the need for my baby to have good postural support whilst in the NICU  |   |   |
| I have been shown how to use boundaries/nesting to support my baby`s arms and legs close to their body and to give them something to push against  |   |   |
| I have been shown how to use different positions to support my baby`s development including skin to skin   |   |   |
| I have been shown how to alternate the position of my baby`s head regularly to help maintain a rounded head shape and reduce flattening.   |   |   |
| I have been shown how to use the gel pillow and /or positioning aids if they have been provided to support my baby. know how to recognise when the head is turned flat to the side and how to avoid this |   |   |
| I have been shown how to support my baby keeping them close to me, with their arms and legs close to their body when being lifted, held or whilst feeding.   |   |   |
| I understand that towards the end of their stay on the NICU positioning aids will gradually be removed in preparation for going home.  |   |   |

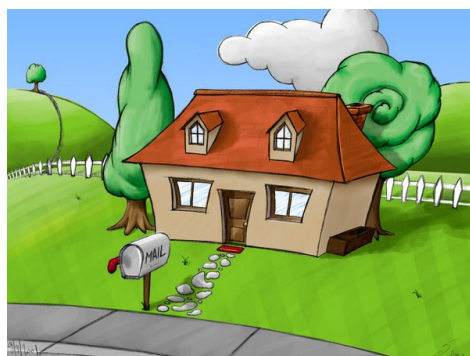
Just like all of us, preterm babies enjoy a comfortable bed with fresh linen. However, it is important to know when and what to change .

| <b>Changing bed linen</b>  | Demonstrated/Discussed<br><b>(Nurse signature)</b><br>Date | Competent*/confident<br><b>(Parent/nurse* signature)</b><br>Date |
|--|--|--|
| I have been shown how to change my baby's sheets when being nursed on breathing support in an incubator  |  |  |
| I understand that whilst in critical care it is not always appropriate to change bed linen, as my baby may need more time to rest without being disturbed. |  |  |
| I know I can give my baby a bonding square, breast pad or muslin that I have worn; placed under or close to their head and changed after feeds             |  |  |
| I understand that the incubator will be changed weekly   |  |  |
| The cot sheet can be changed every day by me, or more frequently should they become soiled; whether that is an overspill from nappy or possets             |  |  |

| <b>Administration of medicines</b>                              | Parent(s)<br>Date & sign | Parent(s)<br>Date & sign |
|---|--------------------------|--------------------------|
| I understand why my baby needs vitamins                         |                          |                          |
| I know how to give my baby vitamins                             |                          |                          |
| I know what other medications my baby needs and the reasons why |                          |                          |
| I know the dose of medicines my baby needs                      |                          |                          |
| I understand how to draw up and administer medicines            |                          |                          |
| I know which medicines I can give in bottle feeds               |                          |                          |

| <b>Screening tests</b> | Parent(s)<br>Date & sign | Healthcare<br>Date & sign | Date test completed |
|------------------------|--------------------------|---------------------------|---------------------|
| Newborn blood spot     |                          |                           |                     |
| ROP (if applicable)    |                          |                           |                     |
| ROP                    |                          |                           |                     |
| ROP                    |                          |                           |                     |
| Hearing test           |                          |                           |                     |
| immunisations          |                          |                           |                     |

| <b>Preparation for home</b>   | <b>Parent(s)<br/>Date &amp; sign</b> | <b>Healthcare<br/>Date &amp; sign</b> |
|---|--------------------------------------|---------------------------------------|
| Basic life-saving (BLS) skills  |                                      |                                       |
| Introductions to key people<br>(outreach, paediatric team,<br>home oxygen team, stoma<br>nurse, etc.) |                                      |                                       |
| Safe sleeping   |                                      |                                       |
| Car seat safety   |                                      |                                       |
| Breastfeeding at home   |                                      |                                       |
| Preparation of bottle feeds at<br>home  |                                      |                                       |
| Giving medications  |                                      |                                       |
| Child health book (red book)<br>given and discussed   |                                      |                                       |
| Rooming in  |                                      |                                       |
| Registered with GP  |                                      |                                       |
| Follow up appointments  |                                      |                                       |
| Home oxygen   |                                      |                                       |
| Tube feeding at home  |                                      |                                       |
| Play and advice/activities to<br>promote development  |                                      |                                       |





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