

STEPS TO HOME

You and your Baby's Journey through
The Neonatal Unit from Birth to Home



Parents as Partners in the Neonatal Journey

Baby's Name

NHS Number

Hospital of birth

Welcome to our Neonatal Units,

As your baby is admitted to one of the neonatal units within the North West London Perinatal Operational Delivery Network, we know that this may be a very challenging time for you.

The neonatal team within our network is strongly committed with a shared vision to provide excellent, family centered, compassionate care to all babies and their families.

Our units provide care to high risk, often critically ill babies and family integrated care is one of our guiding principles. We understand and believe that even the best medical care cannot replace your presence and the love you can provide to your baby.

The aim of this booklet is to give you guidance and support throughout your neonatal journey. The seven chapters follow the timeline from admission to discharge and enable you to highlight the milestones and achievements of your baby and give you somewhere to record your skills and competencies. The overarching goal of family integrated care is to support parents in becoming equal members of the neonatal team and participate in providing active care for their baby.

We hope to empower you to become an expert in your baby's care, enabling you to become confident parents.

The **IFDC mobile application** (see appendix) has been designed to support you through your time on the neonatal unit with veteran parents. We hope that with this material we can help you to prepare and engage in this journey, and understand what is happening to your baby.

The 12 **Small Wonders** films have also been designed to help you on your journey. The first five will be helpful to watch just before or soon after birth and others, which may be useful along the way, are indicated in this booklet. You will find links to the Small Wonders films embedded in the **IFDC App** and are also available online at www.bestbeginnings.org.uk/small-wonders.

Please make a note of any questions or concerns you have so you can discuss them with a member of the team.

North West London Perinatal Network

There are six hospitals in the network indicated on the map. Once intensive care is no longer needed your baby's care may be continued at one of the other network hospitals. This will be discussed with you if it is appropriate for you and your baby. It is usually a hospital that is nearer to where you live that can offer the care you and your baby need to get ready to go home.

If you live outside the network, we will let you know which network covers your local area and will liaise with the appropriate hospital for continuing care.

It may not always be possible for you to travel in the ambulance with your baby.



How will my baby be transferred?



Transfer into
transport
incubator



Ready for
transfer



Dedicated
transport team

Specially
equipped
ambulance



Safety checks in
preparation for
travel

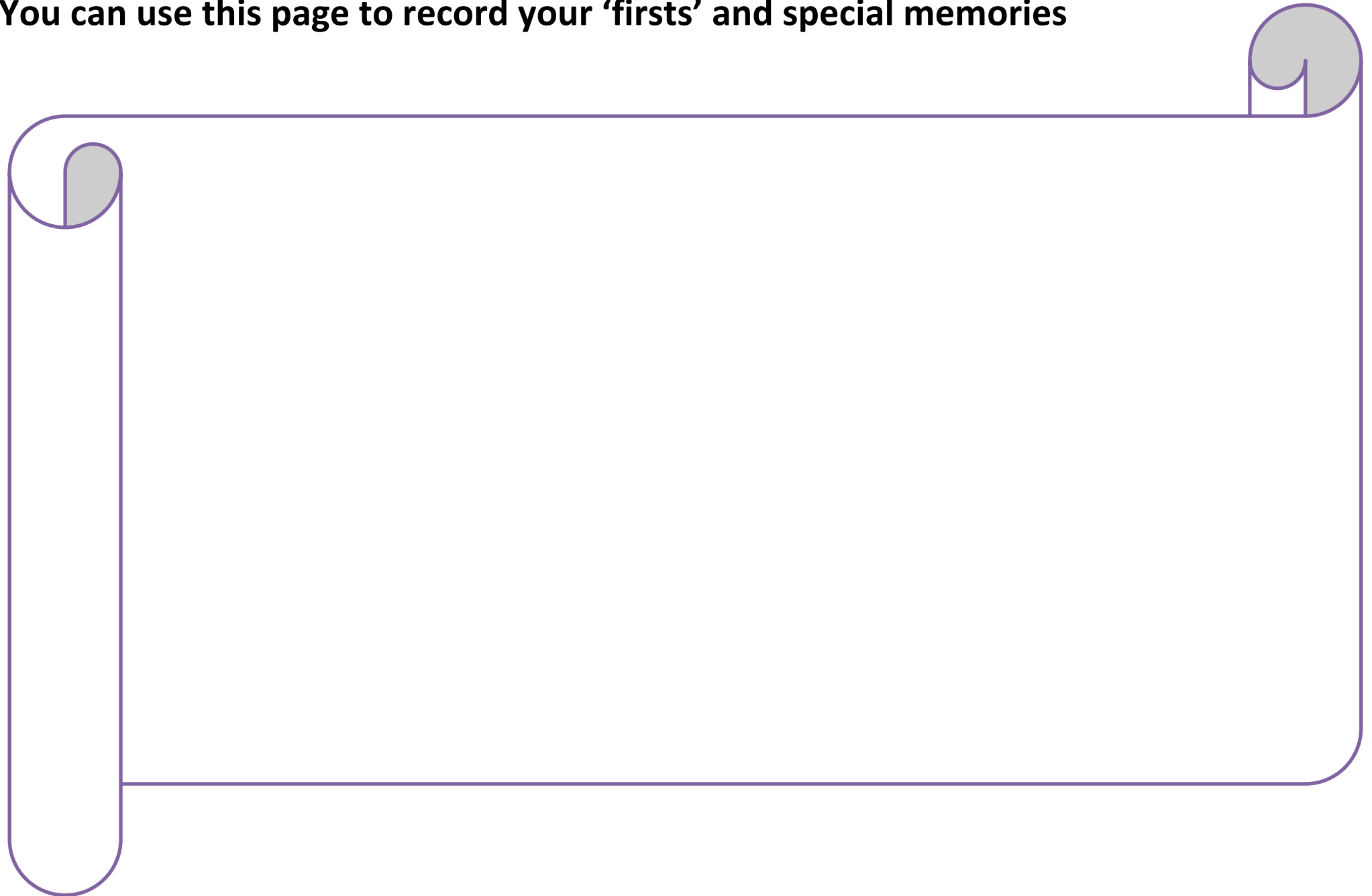


Me and My Family



My name	Date of birth	Gestational age	Birth weight
Hospital of birth Hospital number	NHS number	Hospital for continuation of care	
Mother's name	I like to be called	Telephone number	
Father's name	I like to be called	Telephone number	
My siblings			
My family address		Telephone number	
GP		Telephone number	
Health visitor		Telephone number	
Discharge address		Telephone number	

You can use this page to record your 'firsts' and special memories





1. Early Days

Watch Small Wonders films 1,3 and 6
Read chapters 2 and 5 of IFDC App

Helpful things for you to do in the early days following admission	Parents thoughts and special milestones	Completed / Confident	Date / Parent Signature
Be oriented to the resources for parents in the unit			
Understand the importance of good hand hygiene to prevent infections			
Be oriented to the infection prevention policy of the unit			
Be familiar with the daily routine of the unit (eg, ward rounds, visiting policy)			
Be familiar with the multidisciplinary team looking after my baby			
Be familiar with the use and purpose of headphones			
Be familiar with the IFDC mobile App			
Be comfortable with presenting on ward rounds and have an active role in discussing a plan of care for my baby			
Be informed about the parent education sessions			
Know how to proceed if I have a complaint or problem			

Notes:



2. Expressing your breast milk

Watch Small Wonders
films 4 and 7
Read chapters 9 and 14
of IFDC App

Understanding what is really important to do after delivery to establish lactation	Familiar with the task, able to explain the process	Able to perform with staff's coaching / support	Performs independently under staff's supervision
I have an expressing kit with a miniboo and know how to do breast massage and hand expression			
I know how to use a breast pump including how to clean it after use			
I know how to wash, rinse, dry my milk collection kit			
I can label, store and transport my milk and have the cool bag			
I understand the importance of expressing 8-10 times in 24 hours including at night between 2-4 am			
I understand how to document /follow /assess my lactation and milk volumes using the App if helpful			

Notes:



3. Caring for your baby

Watch Small Wonders
film 6
Read chapters 3, 4 and
12 of IFDC App

If you are involved in your baby's care as much as possible this will help you all to be ready for home sooner	Familiar with the task, able to explain the process	Able to perform with staff's coaching / support	Performs independently under staff's supervision
I can provide mouth care/positive oral touch			
I can provide skin/eye care			
I can change my baby's nappy/top and tail			
I can take my baby's temperature and know what to do if it is not within the normal range			
I can assist with applying oxygen saturation probe and leads			
I feel comfortable taking my baby in and out of the incubator/cot			
I can make my baby's bed/nest			
I can dress/undress my baby			
I can give my baby a wrapped bath			



4. Feeding journey

Watch Small Wonders
film 7
Read chapters 9 and 14
of IFDC App

Being involved with your baby's feeds and encouraging him/her to suck will help your baby feed and go home sooner	Familiar with the task, able to explain the process	Able to perform with staff's coaching / support	Performs independently under staff's supervision
I know how to check milk with the nurse, draw up, warm the milk and hold the syringe			
I know how to test my baby's aspirate with the pH paper and show it to my baby's nurse before feeding			
I am aware of feeding readiness cues and signs that my baby is hungry			
I know how to support my baby during tube feeding with skin to skin, positioning and non-nutritive sucking			
I know how to position my baby at the breast and recognise effective attachment and signs of milk transfer			
I know how to use the NGT top up chart and how to work out with the nurse how much top up to give			
I understand when my baby is satisfied and how often he or she needs to feed			
I know how to safely prepare formula milk			
I know how to support my baby to bottle feed if that is my feeding choice			



5. Getting to know your baby

Watch Small Wonders
films 5 and 6
Read chapters 12 and
13 of IFDC App

Understanding basics of developmental care can help you with bonding <i>Age appropriate core measures for trauma informed care in the NICU, Mary Coughlin (2017)</i>	Familiar with the task, able to explain the process	Able to perform with staff's coaching / support	Performs independently under staff's supervision
I understand my baby's cues and their coping strategies.			
I understand my baby's sensory development (touch, body awareness, movement, taste, smell, hearing and vision)			
I understand the benefits of skin to skin cuddles and how to do it and record for memories on the App			
I understand the importance of sleep.			
I can support my baby's motor development and position him in his bed.			
I understand signs of pain and stress and how I can support my baby			

Notes:



6. Medication and immunisation

Watch Small Wonders
films 8 and 9
Read chapters 11 of
IFDC App

Medications and Immunisations	Familiar with the task, able to explain the process	Able to perform with staff's coaching / support	Performs independently under staff's supervision
I am aware of the medications my baby is receiving and what they are for			
I can mix human milk fortifier and add it to my breast milk as per guideline			
I know how to mix human milk fortifier and give it to my baby as a concentrate if that is what he/she is having			
I understand and I am able to administer all discharge medications			
I have my 2-week supply of medications and know how to get more in the community			
I have consented for my baby to have a BCG vaccine			
I understand my baby's immunisation program and when they are due			



7. Making progress: Getting ready for transfer and/or home

Watch Small Wonders
 films 8 and 9
 Read chapters 15 of
 IFDC App

Things to do early so you are ready for your baby to come home	Completed	Date / Parent Signature
I have registered my baby's birth		
I have registered with a GP in my local area		
I have my 'Red Book' - Child Health Record Book		
I have completed my shopping and preparation of the nursery depending on my baby's needs		
My baby is in special care		
My baby has been moved to a cot		
My baby has come off the monitors and heated mattress		
I have completed my Basic Life Support training and know about the importance of safe sleep		



8. Ready for Home

Discharge Checklist	Completed	Date / Parent Signature
I have been given a copy of my baby's discharge summary		
I am aware of how to access breastfeeding support in the community		
I am aware of post discharge support and how to access it		
I understand how the follow up program works		
My baby has had a hearing test		
My baby has had an eye check		
My baby is up to date with blood spot tests		
My baby has had a final physical check, weight and head circumference		
I have been given a letter for formula milk to use at home (if that is my feeding choice)		

Appendix

Integrated Family Delivered Care and mobile application

We understand and believe that even the best medical care cannot replace your presence and the love you can provide to your baby.

The overarching goal of family integrated care is to support parents in becoming equal members of the neonatal team and participate in providing active care for their baby.

With the help of the **IFDC mobile app**, rolling education programme and competency-based training parents can be more involved in their baby's care whilst on the neonatal unit. The IFDC app will give you the opportunity to learn more about neonatal care.

The app is free to download using the below QR code or by searching IFDC in the app store or play store on your smart phone.

Our **IFDC App** and educational material has been designed to support you through your time on the neonatal unit with veteran parents. We hope that with this material we can help you to prepare and engage in this journey, and understand what is happening to your baby. For more resources you can check our website: www.imperial-familyintegratedcare.com



**Integrated
Family Delivered
Neonatal Care**

Expert in your baby's care

Educate Engage Empower Enable

Acknowledgments

With grateful thanks to parents and staff in North West London Perinatal Network

for working together to develop the

Steps to Home

With special thanks for support from

North West London Perinatal Network Parent Representative Group

North West London Perinatal Network Discharge Special Interest Group

North West London Perinatal Network Board and Management Team

Integrated Family Delivered Care Project ICHNT

