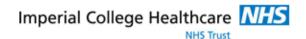




Chapter 5. Working together as a team

Parent educational material for app

Imperial Neonatal Service, Imperial College Healthcare NHS Trust





# 1. Working together as a team

Having a baby in the neonatal intensive care unit (NICU) can be stressful, but we need you to play a valuable role in your Baby's care. It is helpful for you to get to know who is who and how the multidisciplinary team in the NICU works, so that you can find the best way work with us effectively as an equal team member. Your input is essential and we need you to be at your

Baby's bedside as much as possible so together we can provide the best neonatal care for your Baby.

We believe that even the best medical care cannot replace your presence and the love you will provide to your Baby.

Our project logo emphasises this – we would like to educate, engage, empower and enable you to be the expert in your Baby's care.

The multidisciplinary team is a group of professionals working on the neonatal unit helping to look after your Baby. You can find our photo board in both units which can help you to identify the different team members working with you.



Expert in your baby's care

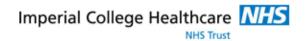
Educate Engage Empower Enable

There is also a board with the name of the attending consultant medical team and nurse in charge for the day.

## Aims for this chapter

We want you as a parent to:

- understand the roles of the different professionals in the neonatal unit and how they work together
- understand your roles and responsibilities in your Baby's care
- learn how to present your Baby's progress at the ward round
- achieve our goals to educate, engage, empower and enable you to be expert in your Baby's care
- be aware where can you find more support.





# 1.1 Background to communications – values and outcomes

Your central role in looking after your Baby in the neonatal unit is supported by good communication with the team. To begin with, this will mean you having plenty of opportunities to ask questions. Over time, you will have your own observations of your Baby to share with the team. At any time, information about your family circumstances that you share will help us support you and think together about your Baby's needs as you prepare for the time when you take them home with you.

The Royal College of Paediatrics and Child Health monitors the standards of care provided by neonatal units in the National Neonatal Audit Program. Early and regular communication with parents is recognised as an essential standard of good neonatal care.

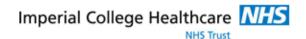
You can expect that a senior member of the neonatal team will speak with you within 24 hours of your Baby being admitted to the unit.

Throughout your Baby's stay, staff will take time to explain to you how your Baby is being cared for and to answer any questions you may have. There is a lot of specialist medical terminology used in a neonatal unit, which will initially be incomprehensible to most people. You can expect the team to put medical terms into everyday language for you – just ask if someone uses a term you don't understand. The chapters and the glossary of terms in this app can also help you to understand neonatal care.

Many little conversations every day will happen by the cotside, including informal chats with your Baby's nurse of the day, ward rounds where the team comes together at the cotside to plan your Baby's daily care, and sit-down conversations with you in privacy when you and the team wish to discuss your Baby's care in more detail.

If English is not your first language, the team can organise an interpreter for regular updates or for more complex discussions.

Communication along with all other aspects of your Baby's care is recorded in your Baby's confidential medical records.





## 1.2 Members of the neonatal multidisciplinary team

### Attending neonatologist consultant

The attending consultant leads the neonatal team and will coordinate and direct your Baby's care. There is a weekly rotation in the consultant team to provide continuous cover in the unit. You will meet them on their daily ward rounds, and at the cotside during the day. You can ask the attending consultant to have a sit-down update if you need a longer conversation about your Baby's progress and treatment plan.

### Consultants in other specialties

We work closely with consultants in other specialties such as cardiologists, ophthalmologists, neurologists and paediatric surgeons. The medical team will involve them in your Baby's care as indicated.

#### Medical team

The doctors are available 24/7 in the neonatal unit and they coordinate your Baby's care. You can talk to them during the daily ward round or at any time if you have questions. The specialist registrars and senior house officers carry out many of the day-to-day medical tasks under the consultant's lead and you will see them throughout the day on the unit. They can answer questions you have about the baby's treatment or refer you to the consultant if needed.

#### **Neonatal nurses**

The nurses provide most of the day-to-day care for your Baby and work in shifts. Your Baby will have a dedicated bedside nurse all the time, who will work with you closely and be your first contact with the team.

They can answer a lot of your questions, show you how to comfort, take care of and feed your Baby and arrange for you to speak to any of the doctors. You should talk with your Baby's nurse each day, so you can coordinate being involved in your Baby's care. Let your nurse know any things you would like to do with your Baby and any concerns you have so they can support you or link you with a specialist in the team.

Share your own observations of your Baby with your nurse as you get to know your Baby as a delightful individual.

Additionally we have a dedicated nurse working on the Integrated Family Delivered Care project. They coordinate the parent education sessions, provide one-to-one training as needed and support you in the discharge planning.

### Nurse in charge

Each shift there is a team leader who organises the day's work of looking after the babies. They are there to support nurses and parents in working together to look after the babies in the unit. Sometimes they will also be looking after a baby. Please feel free to speak to the nurse in





charge if you have a question about your Baby's progress, treatment or care that your Baby's nurse is unable to resolve or if you need extra help.

#### Matron

The matron is in charge of the unit. She leads and manages the nurses and ensures high standards of care. She would be your ultimate resource if you have a concern you have not been able to resolve with nurses on the ward.

#### Dietitian

The dietitian is an expert in babies' growth and nutrition. They join the ward rounds at least once a week and make sure that your Baby is receiving optimal nutrition and growing well. They can explain your Baby's nutritional needs and discuss any questions you have about feeding and growth. They will also be interested in your nutritional needs as you recover from pregnancy and birth and establish a milk supply.

#### Neonatal outreach team

In our team we have senior nurses who will help you prepare for taking your Baby home both practically and in building up your skills and confidence. This also includes preparation of home oxygen if necessary. They provide a community outreach service for vulnerable babies discharged home in our local area. They offer resuscitation training to parents during their stay. They will liaise with your health visitor and other community health and social care professionals as needed.

### **Lactation consultants**

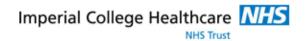
Lactation consultants have specialist training to support you with lactation and breastfeeding. They work closely with the nurses working with your Baby to support you with making milk for your Baby and breastfeeding. All the nurses are trained to support you, but they can also link you with one of these specialists for more detailed, individualised support.

### Speech and language therapist

Speech and language therapists are trained to assess your Baby's ability to feed and swallow, learn to feed and support them to overcome any challenges. They also think about how babies and parents communicate long before speech emerges, and how all those daily playful vocalisations between parent and baby build into a talking child over the first few years of life. They are concerned with keeping the mouth a place of largely pleasant experiences for your Baby, so that when they are able to start to suck feed they feel confident to begin doing so. For example, supporting mouth cares with milk and practicing sucking.

#### **Pharmacist**

The pharmacist checks your Baby's medication, which is prescribed by the medical team, to ensure that they receive the correct and best possible treatment. They can tell you what medicines your Baby is taking and provide information about the benefits and possible side





effects. They can also answer questions about medications that you might be taking, especially related to breastfeeding.

### Physiotherapist and occupational therapist

These therapists are specialists in helping you assess and support your Baby's development. They have a special interest in developmental care. Occupational therapists and physiotherapists assess your Baby's posture, movement and behaviour to help support you with bonding, understanding your Baby's cues and supporting early development. They are also interested in your Baby's environment and may advise on strategies to help support your Baby's sleep/wake cycles whilst they are on the unit.

### **Psychologist**

They are a resource for you in supporting your own coping. Clinical psychologists are available to support the psychosocial and emotional needs of families and can offer you support as required. They work from a strength-based approach, helping you to make sense of the challenging experience of becoming a parent in the neonatal unit, and find ways of looking after yourself so you can focus on getting to know and enjoying your Baby.

You can talk with them about recovering from pregnancy worries and difficulties associated with the birth; developing your relationship with your Baby; supporting each other as parents; and resolving concerns and communication issues with the team.

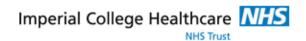
You can book a one to one appointment for yourself or together with your partner. They also run the weekly parent group sessions.

#### Ward clerks

Our ward clerks are the first to meet you at the entrance of the unit at the reception. They will help orientate parents to the unit and can give general information about the neonatal unit. They will be familiar with the rest of the team, and can help you find the right person to speak to. They can help you with any questions or problems like issues with the parent rooms, parking or where local food outlets are. They can also give you information about registering the birth of your baby.

### Students and trainees

All the professions listed above will also be training staff. You may meet medical, nursing and midwifery students. Students will be observing care to begin with and then undertaking specific tasks under the supervision and guidance of qualified staff. If you have any questions or concerns, please ask the nurse in charge.





# 1.3 Parents as caregivers\*

We recognise the importance of involving you as parents in the care of your Baby while in hospital, and encourage you to be an active member of the team, so together we can take care of your Baby. See our developmental timeline for details about how you can be involved in your Baby's care week by week as they are developing.

### Your roles in the neonatal unit:

#### Communicate with our team:

- Keep updated with information about your Baby's condition and progress.
- Take part in decision-making.
- Ask questions and give feedback about your experience.
- Ask for an interpreter if you have difficulties understanding English.

## Learn and develop confidence in performing care-giving skills:

- Reading our curriculum will support your understanding about your Baby's management and progress.
- Attending parent educational sessions will build your confidence.
- Completing the competencies will give you the skills and knowledge to care for your Baby in a family delivered care model.

### Participate in your Baby's care:

- Spend as much time as you can with your Baby.
- Assist with and/or perform their cares: changing nappies, mouth care, feeding, bathing.
- Touching and holding your baby helps you to build a loving relationship with them and helps their brain to develop and grow.
- Sing or read to your baby and watch them while sleeping.
- Have regular, long skin-to-skin cuddles.
- Keep a diary of your journey using the multiple functions in this app. There are many special milestones to remember!

### Respect rules in the neonatal unit

- Treat all staff members and other parents in the NICU with dignity, courtesy and respect.
- · Respect the privacy of other families in the unit.
- Ensure that proper hand hygiene and hand-washing techniques are used before entering the unit and before entering your baby's bed-space.

### Take care of yourself:

- Make sure you eat, drink appropriately and have sufficient rest.
- Seek support for yourself while your Baby is in the hospital.

<sup>\*</sup> Adapted from Mount Sinai Hospital FlCare Programme





## 1.4 Ward rounds and how to present your Baby

#### Please do come to the ward rounds!

You are encouraged to attend the morning ward rounds when the team discusses your Baby's progress and agrees on the plans for the day. You are welcome to ask questions when the team is at your Baby's cotside.

There are twice-daily medical ward rounds in our neonatal units. The ward rounds are consultant or registrar led. Once a week the multidisciplinary team will also join the ward round and discuss the management plan, providing their expert input.

Privacy and confidentiality is important to us. We will ask you to use the headphones when we are discussing other patients in the nursery.

Some parents prefer to let the nurse present their baby first, but as you grow in confidence and knowledge, we believe you are the best person to begin our conversation about your Baby. Remember that if you spend a lot of time with your Baby, you will know them best and you can recognise subtle changes in their condition. Don't worry if you forget some details or don't know something, the nurse looking after your Baby will be there too to support you. They can help you in the presentation and complete any details or nursing issues.

If you plan to present at the ward round, make sure you come to the ward when the round is due to start or let us know if you are running late.

### **Helpful tips:**

- Think about whether or not you would find it helpful to tell the story of your Baby's birth and the early challenges. Some parents find it empowering to see they hold the whole story of their baby and choose to share it with others to inform their care; others find it too emotional. The further you go along, the more the focus will be on the day-to-day and future plans. Do what feels comfortable for you and your partner.
- Talk about how your Baby has been in the last few days and 24 hours in particular.
- How has their breathing been? What support have they needed?
- How are they feeding? Are they comfortable with their feeds? How are you managing expressing?
- Have they seemed comfortable and settled and able to sleep for extended periods?
  What helps them settle after cares or medical treatments that disturb them?
- How are they responding to touch and to everyday cares? Skin-so-skin cuddles?
- What are you feeling confident to do with your Baby and is there any additional support you need in making progress?
- What are you noticing about your Baby as an individual: their emerging personality, likes and dislikes? Share any recent highlights in your Baby's development, or special moments you have enjoyed together.
- You may want to make a note of any questions for the team including any specialists who are present.

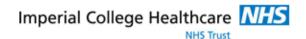




## This proforma may help you summarise the most important information:

How to present my Baby on the Ward round*		
Baby's name		Date today
Birth weight:	Current weight:	↓↑ grams
Gestation at birth:	Corrected gestation:	Days old
Medical history during your Baby's birth and stay: any specific problems or events Your Baby's bedside nurse can help to put this list together		
Current medical care:		
Breathing support any recent changes:		
Feeding update: what is your Baby eating and how often		
How are you getting on making milk for your Baby and how are they doing with sucking and feeding:		
Medications:		
Involvement in your Baby's care: Explain what you are doing for your Baby including skin to skin update		
Anything you think the medical team today should know about today: Share any details/recent changes/observations about your Baby you feel are important		
Questions/concerns		

\* Adapted from Mount Sinai Hospital FlCare Programme





## 1.5 If I need more support

We are here to help and support you in your journey so please feel free to ask! There are several options if you need any help:

### Bedside nurse and neonatal team:

Your Baby has a dedicated bedside nurse all the time; they will work with you closely and be your first contact with the team. You can begin by speaking with your Baby's dedicated nurse. You can also speak with the nurse in charge, or the medical team. We welcome your feedback.

## Family delivered care project nurse

We have a dedicated nurse working on the Integrated Family Delivered Care project. They coordinate the parent education sessions, provide one-to-one training as needed and support you in the discharge planning. If you prefer, you can approach them with your question/concern.

## Psychology team

We have clinical psychologists; feel free to talk to them any time. They support the psychosocial and emotional needs of families and can offer support as required. Meet them on the ward, at parent group or call them on 020 3313 2472 to arrange an appointment.

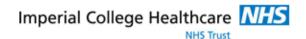
### Parent group

The weekly parent group is a chance to come together with other parents, a nurse and psychologist to talk about life on the neonatal unit, and ask questions large and small about having a baby in hospital.

You can share any concerns that you have not had the opportunity to raise or resolve on the ward. Feedback forms are available for you to give us written feedback about any aspects of care that you have found supportive or ways in which you think we could improve our service to better meet your Baby's and family's needs. After you leave the unit, you may be invited to other forums to feedback your experiences and help us continue to develop our service.

## Pastoral and religious support

A multi-faith chapel and mosque are available in both hospitals. We will be happy to contact a chaplain or leader of your faith on your behalf if you require spiritual, emotional and pastoral support or advice. Whatever your need, just ask the nurse or ward clerk to make the arrangements for you.





## **Imperial Health Charity**

This project is founded by Imperial Health Charity; an independent charity raising funds for projects, research, equipment and training at Charing Cross, Hammersmith, Queen Charlotte's & Chelsea, St Mary's and The Western Eye hospitals. They have awarded more than £12 million to 300 healthcare projects to date, and in the autumn of 2015 committed a further £20 million to the hospitals of Imperial College Healthcare NHS Trust over the next three years for a series of major projects. From giving grants for pioneering research to brightening wards with stunning works of art, Imperial Health Charity is passionate about improving patient care and supporting staff development at the Trust's five hospitals.

See our donation link on the App or this website if you want to support the IFDC programme. https://www.imperialcharity.org.uk/donate/donate-to-a-hospital-or-ward

### **Winnicott Foundation**

The Winnicott Foundation is our dedicated independent registered charity. It was founded in 1985 by parents and doctors who wanted to do more for premature and sick babies than the NHS was able to do. They are a small but much loved charity, dedicated to improving the care of premature and sick babies and their families within the neonatal units of St Mary's Hospital and Queen Charlotte's and Chelsea Hospital, which cares for 1,000 babies born in and around London each and every year. They work very closely with the nursing and medical staff to meet the long-term and day to day needs of the babies, families and neonatal units.

They go above and beyond what the NHS is able to provide, funding:

- Specialist, high-tech life-saving equipment
- Equipment to ensure babies are more comfortable such as gel pillows, cot and incubator covers to reduce the noise within the unit as well as premature baby clothes
- Improving the environment for parents who need to stay with their babies, such as refurbishing the parents accommodation and nursery furniture including the provision of suitable chairs to assist with the skin to skin cuddles and breastfeeding
- Parental support for those in need such as covering travel and food costs for visiting parents
- Staff training to ensure the neonatal units recruit and retain the highest calibre
- Books, welcome and discharge bags for the families

If you would like to support the work of The Winnicott Foundation, please donate here: www.winnicott.org.uk





### **Bliss**

Bliss is a national organisation supporting families of premature and sick babies. They have a free helpline and can provide confidential and free advice on any subject. They also have a lot of supporting material like the Bliss Family Handbook you have received in your admission pack. <a href="https://www.bliss.org.uk">www.bliss.org.uk</a> Free phone helpline: 0500 618140

## 1.6 How to make a complaint

We aim to provide the best care for our patients. However, sometimes things may not go according to plan. If you are not satisfied with the care or treatment you or your Baby has received it is important that we know, so that action can be taken to resolve the problem for you quickly.

### Speak to our team

Often, the quickest and easiest way to resolve a problem or get an answer to any questions you may have is by speaking to the staff caring for your Baby. Staff will always strive to resolve your concerns as soon as they arise. You can share your problem/concern with the nurse looking after your Baby, the medical team or the nurse in charge.

Feel free to speak to our matron if you have a concern you have not been able to resolve with nurses on the ward.

### **Patient Advice and Liaison Service**

Sometimes, you may wish to speak to Patient Advice and Liaison Service (PALS) in confidence if you are unhappy with the action taken or would like support with resolving your concerns.

All hospitals have a Patient Advice and Liaison Service who can support you if you feel you have not been able to resolve a concern with the team, and if needed they can advise you how to make a formal complaint. The PALS team will listen to the concerns of patients, carers or visitors and can help negotiate prompt solutions on your behalf. They can also provide information about other services as we understand that this may be a distressing time for you.

We are keen to receive both positive and negative feedback so that we can learn from this.

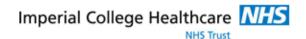
### PALS telephone numbers:

St Mary's Hospital: 020 3312 7777

Hammersmith and Queen Charlotte's & Chelsea Hospitals: 020 3313 0088

Opening Hours: Monday to Friday, 09.30 to 17.00

At busy times, evenings and weekends, your call may be transferred to an answer phone. Please leave a message with your name and number and someone will be in touch as soon as possible.





Walk-in PALS office: There is no PALS walk-in service available on the Hammersmith Hospital site. PALS walk-in service available on the Ground floor of Queen Elizabeth the Queen Mother (QEQM) wing, St Mary's Hospital. Open Monday to Friday, from 10.00 to 16.00

#### PALS address:

For St Mary's Hospital: PALS manager, Nursing directorate, Ground floor, Clarence wing, St Mary's Hospital, London W2 1NY.

For Hammersmith Hospital site: PALS manager, Charing Cross Hospital, Fulham Palace Road, London W6 8RF

Email: pals@imperial.nhs.uk

# Key messages and reflection:

After this chapter you should be able to:

- be familiar with the different members of the neonatal team and their role in your Baby's care
- be able to participate on the ward round and present your Baby's clinical condition
- be aware how to ask for help/further support
- be aware how to report a problem or complaint.

## Further learning in this topic

If you wish to know more:

- ask our neonatal team any time
- ask for one-to-one support from one of our Integrated Family Delivered Care Project nurses
- read Chapter 13 'Coping in the NICU'
- use this app or your Parent Binder to record notes and questions
- Attend small group teaching in topic: Values of family integrated care.

## **Authors**

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Jayanta Banerjee, consultant neonatologist, Imperial College Neonatal Services Rosie Hurlston, clinical psychologist, Imperial College Neonatal Services

## References and resources

Me and My Baby, FlCare programme material, Mount Sinai Hospital, Toronto, Canada

A Guide for Parents and Families of NICU Babies, Sunnybrook Health Sciences Centres, Toronto, Canada

Bliss Family Handbook, BLISS, UK: Information and support for families of premature and sick babies (given out in your welcome pack: please ask the ward clerk if you have not received a copy)