



Chapter 15. Discharge planning and post-discharge support

Parent educational material for app

Imperial Neonatal Service, Imperial College Healthcare NHS Trust

Discharge planning and post-discharge support

1.1 Introduction

In this chapter you can learn more about the process of getting your Baby ready to go home and the preparations required for this. The chapter will aim towards building your confidence in your role as your Baby moves closer and closer to discharge.

This journey does not stop at the time of discharge – you and your Baby will continue to have support and close follow up once at home.



Aims for this chapter

We want you as a parent to know and achieve:

- feeling confident and competent when your Baby is ready to go home
- an understanding of the preparations necessary for going home
- an understanding of the on-going care, support and follow up after discharge
- how to access specialist services for your Baby, especially if your Baby continues to have significant health issues such as chronic lung disease

1.2 Registering birth and GP

Our discharge liaison nurses will help you understand the preparation required for your Baby to come home.

One of the main things is to register your Baby's birth. Birth registration needs to be done within 42 days of your Baby being born and this will enable you to access all the necessary resources for your Baby. The birth registration should be done at the local register office where your Baby was born. You may need to make an appointment to do this, which can take up to three weeks.

For further details please see the link: <https://www.gov.uk/register-birth/overview>. Other countries may have different birth registration policies; please check with your local neonatal discharge liaison team.

After registration of birth you need to register with your GP so that you can access the necessary health resources for your Baby. The neonatal team will make contact with your health visitor within the first week of your Baby being born and will maintain regular contact to update them with your Baby's progress. Nearer the time of discharge, either you or one of the nurses in the discharge liaison team will be able to contact your health visitor who will continue to monitor your Baby as required at home or in a local centre.

Your health visitor will supply you with a 'Red Book', which is essentially a handheld health record for your Baby. Here your Baby's growth, vaccinations and interactions with the health services will be recorded in writing. The Red Book will need to be presented at all consultations. It is used nationally and it is good to take it with you when you travel.



The health visitor will visit you at home once your Baby is discharged. In some cases, especially if your Baby has significant medical problems, they may visit you before or even visit you and your Baby in the neonatal unit. This varies from borough to borough. The health visitor will be your first contact in the community for non-urgent problems and will discuss resources and pathways with you.

1.3 Resuscitation training

Basic life support (BLS) training will be provided by the neonatal nurses and is delivered one-to-one as well as in small group training sessions. You will be taught basic life support on a mannequin.



Please see this video for BLS by Bliss: 'What to do if your baby stops breathing – a guide for parents':
<https://www.bliss.org.uk/parents/going-home/settling-in-at-home/resuscitation-video>

Other guidance provided to you is safe sleep and sudden infant death syndrome (SIDS) guidance. Babies should only be sleeping on their back and never on their front or tummy during their first year.

Guidance will also be provided on what to do if your baby is choking and important issues such as maintaining temperature, especially in babies who are born preterm.

Pathways of help if your Baby is unwell:

1. In an emergency or if your baby needs BLS, call 999 and ask for an ambulance.
2. If your child is unwell and you are concerned, call your GP for an emergency appointment.
3. If you are concerned and you cannot see your GP, you can attend your local A&E department with paediatric services.
4. If you have concerns that are not urgent, you can contact your health visitor or the neonatal discharge nurse.

1.4 Infection prevention and vaccination

Childhood vaccinations are an important aspect of healthcare all over the world. In the UK we provide a national schedule of vaccination which is followed by all neonatal units and healthcare providers.



You can find the latest UK immunisation schedule here below and in your Red Book:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/533863/PHE_2016_Routine_Childhood_Immunisation_Schedule_SUMMER2016.pdf

BCG tuberculosis (TB) vaccine

The first immunisation in the schedule is the BCG. This is usually given shortly before discharge. A BCG vaccination information leaflet will be provided to you prior to vaccination.

Primary and secondary course of immunisations

The Department of Health booklet will be provided to you prior to vaccination. Immunisation is a relatively safe procedure and will be initiated at two months of chronological age. It is recommended for extremely premature babies as well to have it at around two months of chronological age. If your Baby is still at the hospital and stable, they will be given the first dose of the primary course of immunisation by the neonatal team after taking consent from you. If your Baby is still unwell or unstable the vaccination will be slightly delayed.

Further doses of immunisations will usually be provided by the practice nurse at your GP practice in the community. All the vaccinations should be recorded in your Red Book.

Respiratory syncytial virus (RSV) immunisation

We run a programme for respiratory syncytial virus (RSV) immunisation to protect premature babies against development of the RSV infection of lung (bronchiolitis), which is a potentially dangerous condition with significant morbidity and mortality rates. The winter period (early November to February) is considered as a high-risk period for this virus along with other types of viruses.

The immunisation is only given to babies who fulfil specific criteria, for example have been discharged home on oxygen or have recently come out of oxygen soon before discharge and are going home in the winter period. You can read more about RSV in the information pack given to you by the neonatal team and via the link below:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213155/03-Respiratory-syncytial-virus-RSV-immunisation-programme.pdf

1.5 Getting ready for home

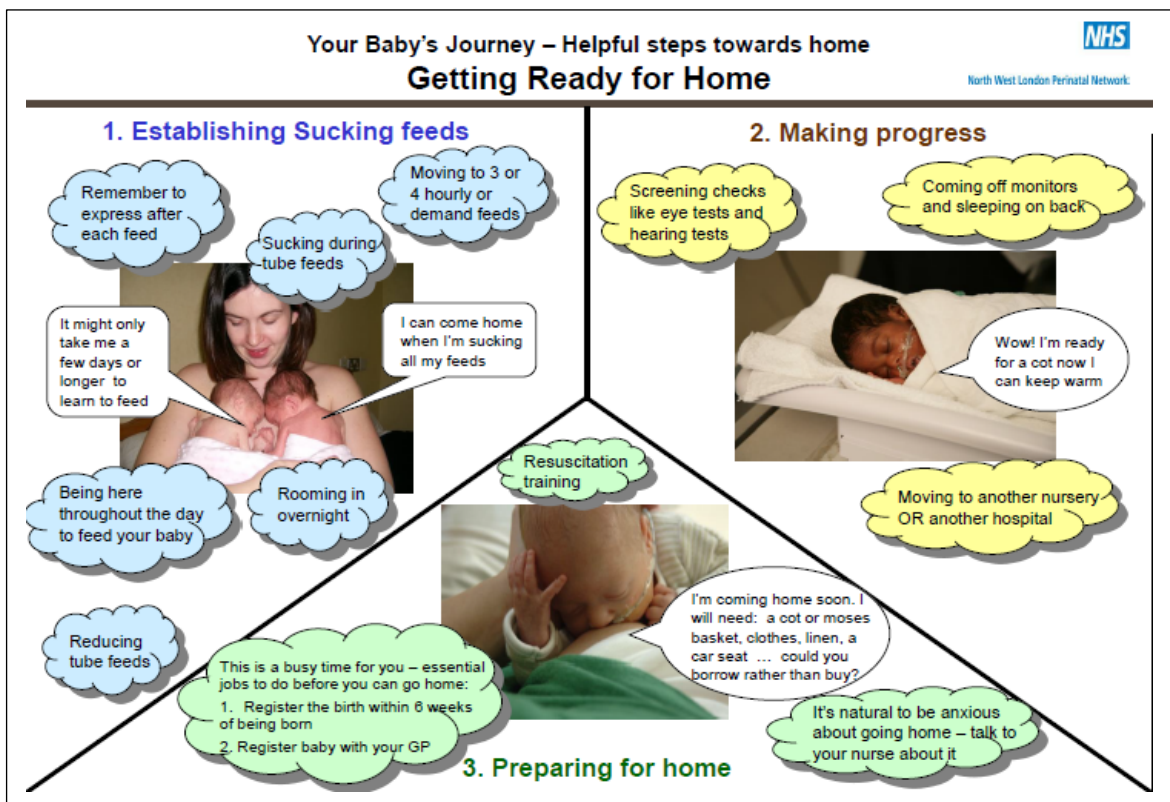
Exciting times! While your Baby is getting ready in the neonatal unit, you need to gradually get ready at home for their arrival.

The discharge coordinators and nurses will talk to you about when you should start thinking about getting ready at home. This will usually be at about 32 or 33 corrected weeks of gestation.

You should get ready in advance with all the equipment at home that you might need to look after your Baby after discharge. This will include a car seat, Moses basket or cot, clothes, nappies, feeding equipment such as bottles and breast pump, sterilising equipment. Ask the nurses for a checklist of necessary items.



One of the main prerequisites for your Baby to come home is that they are able to maintain their temperature with normal baby clothes on and stay in an open cot without any additional heat source. Another important aspect is your Baby should be able to demonstrate a steady gain of weight with oral or other desired mode of feeding.



Generally babies who are born preterm are discharged before their due date at around 35 to 36 weeks of gestational age. However, this depends on the clinical situation and the intensity of care the baby has received.

You will be shown how to prepare and give any medications that your Baby may need. This is usually vitamins and iron on discharge. You can read about medications used after discharge and their preparations in **Chapter 11 'Medication and drug chart'**.

If your Baby goes home on supplemental preterm formula milk, the neonatal team will provide a letter requesting that the GP gives a prescription for the preterm formula. The preterm formula is not available over the counter unlike term formula. This is a special formula and pharmacies need 48 hours to order it. Generally your Baby will remain on this formula until three months after the due date. The dietitian can be contacted for advice.

Some babies remain on breast milk fortifier (BMF) after discharge to support their optimal growth. You need to be trained on how to prepare fortified expressed milk for your Baby and you can read about this in **Chapter 11**. The dietitian will liaise with you regularly and will advise you on the amount of BMF to give and when to wean off depending on your Baby's growth.

You will be able to room in with your Baby before going home, usually for two nights where you will have them with you in our family room and you are providing all their care like at home. This will help the safe transition to home, and enables you to become more confident in their care. You will need to have had BLS training to use our rooming-in facilities. Sometimes we are able to offer you rooming-in facilities earlier during discharge planning when your Baby is establishing suck feeding, so you can be near to the unit continuously.

It is important to arrange extra support from your family and friends to help with the household or look after your other children to allow you bonding time with your Baby. Childcare and family support is really important for you to organise early, especially if you are thinking of going back to work soon.

You can use the 'Steps to Homebooklet' developed by the Imperial and North West London Perinatal Network for the discharge preparation.

www.imperial-familyintegratedcare.com



You can find important information on the Bliss website below including the 'Going home, the next big step' booklet:

<http://www.bliss.org.uk/going-home-with-your-baby>



1.6 Home oxygen

Babies with severe chronic lung disease may require oxygen at home. The neonatal team will assess this nearer the time for home. If your Baby is still dependent on oxygen near to your due date then arranging home oxygen might be useful to enable you to leave the hospital.

Once it is agreed that the home oxygen is necessary, we will start preparation and support and teach you these skills. A sleep study will be performed to identify the correct amount of oxygen needed.

Your consultant and discharge coordinator will discuss all the details of this with you and you will be provided with a booklet on home oxygen.



Oxygen requirement will be stabilised prior to discharge and then the oxygen will be ordered. The oxygen will be delivered to your home and this will be in a number of large cylinders and also some small portable cylinders. To increase your mobility, small oxygen cylinders will be provided for you to travel with your Baby after they come home.

The discharge coordinator will visit your home to do a risk assessment and will arrange a training programme for you to make sure that you are confident in the care of your Baby and the oxygen. A referral will be made to the community team for further support. Once you are at home you will be supported by the discharge coordinator and the children's community nurses will visit you weekly to monitor your Baby's progress.

Further assessments will be done for your Baby including whether they will need RSV immunisation and the necessary specialist appointments in the chronic lung disease clinic. Your Baby will be seen regularly by the consultant running the chronic lung disease clinic, and oxygen will be slowly weaned over the course of the first year.

The company supplying oxygen will replenish the cylinders according to usage. You will liaise with the company directly for extra cylinders and nasal prongs. The company's home oxygen engineer will teach you how to attach, use and remove the oxygen flow metre. Oxygen is a combustible gas and it is very important to be compliant with safety regulations and keep the oxygen sources away from a naked flame.

Our team will provide all necessary information and training for you, but if you want to read more in advance, you can find important details on the Bliss website:

<http://www.bliss.org.uk/going-home-on-oxygen>

1.7 Neonatal follow up after discharge

For babies who need more attention, the discharge coordinator will arrange a visit to your home to check on you and your Baby together with the health visitor within a week following discharge. A handover will be given to the health visitor and a follow up plan made. This may include weekly weighing if your Baby is less than 2.5kg at discharge or there are concerns about growth.



The discharge coordinator will also provide telephone support for non-urgent matters in working hours. In special cases the dieticians also provide telephone support in monitoring your Baby's growth; you can also leave a message with them to call back in normal working hours.

Your Baby will be followed up in the neonatal outpatient clinics by the neonatal consultants or registrars. In every clinic there is support provided by the dieticians, speech therapists and physiotherapists and they can be called if your Baby needs extra support.

We also have specialist services such as paediatric neurology, cardiology and genetics where babies with specific problems are followed up by our specialists working at Imperial College Healthcare NHS Trust.

Babies with home oxygen will be followed up in the chronic lung disease clinic and the weaning of the oxygen will be planned there. You will work closely with our nurses; this includes performing sleep studies in your home and the results will be used for the weaning process.

The neonatal speech and language therapist team conducts a separate feeding clinic together with the psychologist and dietician for babies who need monitoring of their feeds and breastfeeding support for their mothers.

Some babies with retinopathy of prematurity (ROP) may require eye checks after discharge home as follow up assessment. This is done in the waiting room area outside our neonatal units, usually on set days. You will be given a date and time to bring your Baby to the neonatal unit for this eye check. You have to arrive earlier to allow for eye drops to be given to your Baby to dilate the pupils. The ophthalmologist will review each baby and plan appropriate follow up or treatment.

We follow up babies for up to two years. At a final appointment we perform a neurodevelopmental clinic appointment at two years of corrected age for comprehensive neurodevelopmental assessment of babies who were born extremely preterm or were critically ill.

1.8 Next Steps group

The Next Steps group is a post-discharge support service provided by the Imperial neonatal team together with allied health professionals. The group meets every other week in the outpatient clinic on a Tuesday afternoon to discuss topics and issues after discharge and the first year. There is a rolling programme of topics and sessions, which are run by speech and language therapists, physiotherapists, dieticians, the psychology team and the discharge coordinator nurses.



NEXT STEPS GROUP

The opportunity to come join Imperial Neonatal Staff and veteran parents as you gain confidence in the next stage of your family's journey after your neonatal care

Every other Tuesday 12.15pm for a 12.30-1.30pm Group

Topics include:

Sleep and Soothing	Tummy Time	Linking in with your local team	Wearing
Early communication	Transitions	Play and Development in the first year	

Sign up with Robyn or Maryam, Neonatal Discharge Co-ordinators

Telephone:
020 3313 1121 (QCCH)
020 3312 1283 (St Mary's)

Held in Children's Outpatients at Hammersmith Hospital

A leaflet for this will be provided to you and you can sign up for this with your email and receive updates about the programme.

Key messages and reflection:

After this chapter you should be able to:

- feel confident and competent to take your Baby home
- make sure your home will be prepared
- feel supported and know who to ask if you have concerns
- understand the follow up and supporting system after discharge.

Further learning in this topic

If you wish to know more:

- ask our neonatal team at any time
- ask for one-to-one support from one of our Integrated Family Delivered Care Project nurses
- use this app or your Parent Binder to record notes and questions
- attend small group teaching in topic **Discharge planning**

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