



Going home from the neonatal unit – a guide

Bliss
for babies born
premature or sick

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About us

We're Bliss, the leading UK charity for babies born premature or sick. We were founded in 1979 by parents determined to give babies born premature or sick the very best care. Today we're just as committed to giving every baby the best chance of survival and quality of life. If you would like to support our work, visit bliss.org.uk to find out how.

Introduction

This guide is to help you when your baby is ready to leave the neonatal unit. Preparing for your baby to come home from the neonatal unit can feel exciting but it can also be challenging and daunting. These feelings are normal and lots of parents feel this way. This guide will help you to prepare to leave the unit and to start life at home as a new family.

We have more detailed information about the topics covered in this booklet on our website, bliss.org.uk. For more information about the emotional and practical support we provide, visit bliss.org.uk/support



You are not alone. You can read other parents' stories on our website – bliss.org.uk/your-stories

Preparing to go home from the neonatal unit

The staff on the unit will help you to get ready to leave the unit from early on in your stay, and will want you to feel confident in your baby's care. You might be involved in changing nappies and giving feeds, and will be able to have skin-to-skin time with your baby.

Unit staff will work with you to ensure that you feel ready to care for your baby independently. Your baby is coming home because they are well enough to leave the unit, and the staff are confident that you are able to look after them.

Some parents feel like they're not ready to leave the unit, and may be worried about the lack of support. If you don't feel ready to go home or have any other worries, it is important to talk to unit staff.

Questions and worries I have about going home

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Getting organised to go home

Getting organised will help you to be more prepared to look after your baby at home. The staff on the unit will help you to plan, and you can ask them any questions.

If you will be expressing and/or bottle feeding your baby at home, you may want to talk to the unit staff about bringing in the bottles or teats so that your baby can start to get used to them. You can ask the unit staff about when the best time to do this might be.

If you are planning to express milk at home and are not hand expressing, you will also need your own breast pump. If the pump you use in hospital is working well for you, you may want to buy or rent the same type of machine. Your local breastfeeding support service or health visitor may be able to help you to find this.

Staff on the unit may help you to learn to express milk by hand. Your local breastfeeding support service or health visitor will be able to help you with this when you get home.

You may also want to bring in a brightly coloured toy for your baby. Bringing something which smells of home, such as a special blanket, may help your baby to be comforted by familiar objects and smells when they arrive home. Always check with staff before you bring any objects on to the unit.

The staff on the unit or your community neonatal nurse will talk to you about any other equipment that your baby might need, and will answer any questions.



Rooming-in

Before going home, your hospital might offer you the chance to room-in. This means you stay with your baby in a room on or near the unit and care for them overnight for one to two days. Rooming-in aims to give you more confidence in caring for your baby, while having the support of unit staff to help you if needed.

Talk to the unit staff about whether rooming-in is available.

If your baby is going home on oxygen

Some premature or sick babies go home on oxygen. Unit staff will talk to you about this in good time so you can plan your baby's discharge together, receive training to care for your baby's oxygen needs and ask any questions.

We have more detailed information about going home on oxygen on our website.

If your baby is on medication

It is possible that your baby will need medication at home. Unit staff will show you how to give your baby their medication. You should also talk to your pharmacist to explain what medication your baby needs and that you may be coming in regularly.

Travelling by car

It is important to have an appropriate car seat for your baby, even if the only car journey you are going to make is to go home. You may be able to borrow or hire a car seat to take your baby home from hospital by car or taxi. You can ask the staff on the unit if there is a local loan scheme.

Some babies may have a test to check if they fit properly in their car seat before leaving the unit. This is sometimes called a 'car seat challenge'.

We have more information about travelling by car on our website, including information about car seat safety.

If you have twins or multiples

If you have twins or multiples, one baby may be ready to go home before the other/s. Your babies will only be separated if there is likely to be a long period between them being ready to go home. Units will try to ensure that babies come home at the same time if there is only likely to be a few days between them being ready.

Visiting and caring for two or more babies in different places can be emotionally and practically difficult. You may want to contact Twins Trust for support with twins or multiples. Visit [twinstrust.org](https://www.twinstrust.org)

Preparing for discharge

Some units will have a discharge checklist for you to fill in before you leave the unit. Some of the things on this list may sound daunting. The staff on the unit will want you to feel prepared and will be happy to help if you are unsure about anything.

The discharge checklist may include things like:

- Do you know how to reassure your baby and make them comfortable?
- Do you know how to give your baby a bath?
- Have you been shown how to give your baby medication?
- Have you been shown how to use and order any specialist equipment, such as a nasogastric tube (NG tube) and home oxygen?
- If you are breastfeeding, do you have enough information and support and know where to go for help?
- If you are expressing and bottle feeding, or formula feeding, do you know how to sterilise bottles and make up feeds?
- Have you had resuscitation training?
- Do you know how to check your baby's body temperature?
- Do you know safer sleep guidelines to reduce the risk of sudden infant death syndrome (SIDS)?
- Do you know how to recognise if your baby is ill and what to do if they become ill?

After coming home from the neonatal unit

Follow-up appointments

Once your baby has left the unit, you may need to attend follow-up appointments to check your baby's health and development.

You will have been given a red book, where information about your baby is recorded. It will be helpful to bring this to these appointments.

Many parents feel anxious about attending appointments. You may want to write down a list of questions before each appointment. You may also want to take someone with you to help you remember what was said, or to talk to about how you are feeling.

Having visitors

When you get home, friends and family are likely to want to visit. You may want to limit visitors for a time so that you have time together as a new family, and to reduce the risk of visitors passing infections to your baby.

When you leave the neonatal unit, it is important to avoid contact with adults and children who have cold or flu-like symptoms or stomach upsets. This will reduce the risk of infection.

It is very important that you do not allow anyone to smoke in the same house as your baby.

You may be nervous about visitors who want to hold or touch your baby. You could try and explain the situation to them before they arrive. They will understand and want to support you.

Going out and about

Unit staff may advise you to be cautious when going outside with your baby if they are at an increased risk of infection. They may also advise you to stay away from people with cold and flu-like symptoms, and encourage you to wash your hands thoroughly. We have more information about common infectious illnesses on our website.

Just like other parents out and about with a young baby, you may see people who want to congratulate you. You may receive insensitive comments from people who may not know the right thing to say. It is okay to not engage in conversations which make you feel frustrated or distressed. It is up to you to decide how much or little you tell others.

Sleeping

When you get home, you may have some concerns about how often your baby will sleep, and how to get them into a routine. You will also want to ensure your baby sleeps safely.

Premature babies often have lighter and more active sleep than babies born at full-term, and this means that they can have more frequent sleep difficulties. This can include restlessness and breathing problems at night, like pauses in breathing during sleep (sleep apnoea). If your baby seems unsettled, you can try stroking them to reassure them you are there.

Babies born premature have a higher risk of sudden infant death syndrome (SIDS). SIDS is sometimes called 'cot death'. SIDS is the sudden and unexpected death of a baby where no cause is found. Although premature babies have a higher risk, all babies can be affected by SIDS. By following safer sleep advice you can reduce the risk. Most neonatal units will advise on safer sleeping as part of your discharge plan.

The Lullaby Trust have more information and a video on safer sleeping for premature babies and SIDS on their website. Visit [lullabytrust.org.uk](https://www.lullabytrust.org.uk)

We also have some more information on our website about sleep.



Feeding your baby at home

You may have questions about how to support your baby's feeding.

Every baby is different, and should be fed according to their own needs. Your baby will demonstrate signs that they are ready for a feed, such as moving their eyes rapidly, putting their fingers into their mouth, making sucking motions or becoming restless. These are called feeding cues.

You can be sure that your baby is feeding well if they:

- Are mostly settled and calm between feeds.
- Have plenty of wet and dirty nappies.
- Are growing and gaining weight.

Steady weight gain is a good way of showing that your baby is feeding and growing well. But all babies will gain weight at a different rate.

If you think your baby is feeding too much or too little, talk to your health visitor, GP or another healthcare professional. We have more information about feeding on our website.

Family life

Having a premature or sick baby often has an impact on the whole family. If you already have children, you may find it hard to balance looking after your other children and a new baby. You may want to ask family and friends to help, for example by taking children to school or nursery.

Children can be affected if they have a sibling born premature or sick. They may find it hard to adjust if you have had to spend long periods of time away from home. They also may need help to understand why you need to spend time looking after your new baby.

We have four other children at home and trying to keep things as normal as possible for them, as well as trying to be there for the twins, was really hard. I felt guilty if I was at the hospital with the twins and guilty if I was at home with our other children.

Talia, mum to Joe and Ashley

Try and be open with them about what is happening. You could aim for them to be involved and help out as much as they can.



Support when you get home

When your baby is discharged from the neonatal unit, a number of healthcare professionals will continue to advise you on feeding, growth, vaccinations and development, as well as general care.

Job titles and services may be different in different places, so you may not come across all healthcare professionals listed here. You might also find that some of these services are known by different names.

If you are not sure about the medical support you will get, talk to the unit staff. They will be happy to help.

General practitioner (GP)

A general practitioner (GP) is your family doctor. They are the first person to see if you have any concerns about your or your baby's health. Your GP can also make referrals to other health professionals.

Health visitor

Your health visitor will carry out health checks for growth and development. They can provide information about your baby's health, home safety and parenting.

Community neonatal team

Some hospitals have teams of nurses who will support you at home.

Your baby is likely to be supported in this way if they have ongoing needs, such as home oxygen. If this team is involved in your baby's care, you are likely to meet with them before you leave the unit.

Practice nurse

You may see a nurse at your GP's surgery or health centre. Practice nurses are often responsible for your baby's vaccinations.

Support from your family and friends

Family and friends can be an important source of support when you come home. Often they may want to help, but may not know what to say.

It might be helpful to think about what kind of support you might need. You can ask for help with practical tasks, such as cooking meals or helping with laundry or food shopping.

Having lived off hospital or microwave meals, my husband and I wanted home cooked food. It was a saviour when family offered to bring round food in exchange for a cuddle.

Megan, mum to Fergus

When you get home, family members and friends may ask questions and want to know more about your baby's health. If this feels overwhelming, you may want to ask one family member or friend to update other family members or friends with any news or information.

Support with your finances

Having a baby born premature or sick can have a financial impact. Going to and from hospital can be expensive and it may be more difficult to pay your bills. A social worker at the neonatal unit may be able to provide advice.

We have more information about how having a premature or sick baby can affect your finances and what support is available on our website.



If your baby becomes unwell

After leaving the neonatal unit, you may be worried about your baby becoming unwell. This is something many parents experience, especially when they have become used to the support of the unit staff. Many parents worry that they won't be able to notice the signs that their baby is becoming unwell.

Babies who are born premature or sick may have weaker immune systems than babies who are not born needing neonatal care. It is important to be prepared if your baby is at higher risk.

Some babies may be more snuffly when they come home from the unit, or you may hear a quiet sniffing sound. This may be because of the change in atmosphere and temperature, and more dust at home. The snuffling will settle down, but this may take a few weeks.

You know your baby best. If you think something isn't right, always check with a healthcare professional. No question is too small and it's always best to ask if you are unsure.

If you are concerned about any changes in your baby's behaviour, you should see your GP or call 111 for help over the phone.

Call 999 immediately if you think your baby might be seriously unwell.



You may also be worried about your baby developing the symptoms of coronavirus (COVID-19). These include a high temperature, a new continuous cough and change or loss to your sense of taste or smell. Visit our website for more information about COVID-19 and your baby.

How to know if your baby is becoming unwell

Some parents worry about how to recognise the signs that their baby is becoming unwell.

Here are some of the things to look out for:

- Being more fretful than usual. This means they may be restless, crying more than usual, or fussier than usual.
- A high or low temperature.
- Refusing or being reluctant to feed.
- Vomiting more than usual.
- A change in stools - more frequent, watery or 'explosive' than usual.

There are some signs that might show that your baby needs urgent medical attention. These include:

- Blotchy skin or a rash that does not fade if you press the side of a clear glass firmly against the skin.
- Pausing for a few seconds between breaths.
- Being paler than usual.
- Being unresponsive, floppy or not waking up as easily as usual.
- Showing signs of jaundice (yellowing of the skin and whites of eyes).
- Difficulty breathing, for example their breathing being quicker and louder than usual.
- A wheezing, whistling or grunting noise when your baby is breathing out.

If you notice any of these symptoms you should see your GP or call 111 straight away. **Call 999 immediately if you think your baby might be seriously unwell.**

How to check your baby's temperature

To check your baby's temperature, you can place a digital thermometer under their armpit. Your baby's temperature should normally be between 36.5 and 37.1°C (97.7 to 98.7°F).



For more info on how to help your baby avoid common infectious illnesses, visit our website – bliss.org.uk/winter



How you might feel when you go home

Parents might experience a range of unexpected emotions when they are going home from the neonatal unit. While it is an exciting time, you may also have some uncertainty about not having the support of the unit staff. You can speak to the unit staff about any worries you have. They will be happy to help.

We were at home and finally a family, yet we craved being back on the unit with the support, light and the noise. Going home is a very different experience when you've had a long hospital stay. The hospital becomes home and safe.

Sarah, mum to Wilf

Parents often tell us that even though they were excited, being at home can also feel like an isolating and overwhelming experience. Others say they didn't feel as confident as they wanted to be, and missed the support of the neonatal staff. Some parents describe feeling a 'whirlwind' or 'rollercoaster' of different emotions. It is important to remember that there is no right or wrong way to feel, and it is normal to experience lots of different emotions while you adjust to life at home with your baby.



The Bliss Netmums forum is a community of parents with experience of neonatal care. Visit bliss.org.uk/netmums-forum

How can I get support with my mental health?

Having a baby born premature or sick can make you feel sad and low at times. But if these feelings start to impact on your everyday life, you may be experiencing symptoms of depression. Postnatal depression is a type of depression that parents can experience after having a baby, and affects fathers as well as mothers. If you are worried about how you are feeling, are experiencing persistent low mood or other symptoms associated with postnatal depression, you may need some more support. You can talk to your GP, health visitor or community neonatal nurse about how you are feeling.

You may also find it helps to talk about your concerns with a friend, family member or someone else you trust. It can be easy to forget about looking after yourself when you have a baby to look after, but **it is important to reach out if you need help.**

**Reach out to other parents who have had similar experiences.
Spending time with other mums I met on the unit has really helped.
We turn to each other with questions, reassurance and comfort.**

Victoria, mum to Arthur

We have information about where you can get support with your mental health on our website.

We are here to support you

Whatever stage of your journey you're at, Bliss is here to support you and your family.



Visit our website at bliss.org.uk/support



Ask the neonatal staff for other printed information they have from Bliss



Contact our email support service at hello@bliss.org.uk

Notes

You might like to use this space to write down any questions you have, moments you want to remember, or how you are feeling today. You can share this with others, or keep it for yourself to look back on.



Join the family

If your baby is on a neonatal unit because they were born premature or sick, you're not alone. Find practical information, emotional support and a community of families with a neonatal experience at bliss.org.uk

Join the family, search Blisscharity

