

Going home

The next big step



Bliss

for babies born too soon,
too small, too sick

Going home

The next big step

The right time for you and your baby

Advice

- Sleeping
- Travelling home
- Feeding
- Immunisations
- How are you feeling?

Who can help?

- Community neonatal nurses
- Family care worker
- Health visitor
- Your GP
- Practice nurse

You may have many questions about going home. This booklet looks at the questions commonly asked by parents at the different stages you and your baby may go through. We hope you find this helpful, but do bear in mind that each family is different and not all of this information will apply to you and your baby.

"After weeks on the unit we were itching to get our twins home. Eventually, we were able to and it was so exciting. I had watched so many mums let through the doors of the unit. Now it was our turn. We were so happy."

Louise, mum to Isobel and Imogen, born at 28 weeks

Bliss Family Support Services provide:

- A freephone Helpline for advice and support. Open Monday to Friday, 9am-9pm
- Parents 4 Parents - a peer support service which puts you in touch with other parents of special care babies
- A low cost or free counselling service

Other Bliss publications you might find helpful:

- *Common winter illnesses*
- *Going home on oxygen*
- *Financial advice*
- *Weaning your premature baby*

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Introduction

This guide has been written to help you prepare for bringing your baby home from the unit. It is intended to go with the advice you receive from the staff caring for your baby.

Over the weeks or months that your baby has been on the unit, you will have grown used to a high level of support – always having people around to answer questions and give advice. At home, you will be the main person caring for your baby. So, as well as being a happy time, bringing your baby home can be emotional and worrying too.

But remember – your baby is only coming home because the staff on the unit believe he or she is well enough to leave the hospital and that you are able to look after them.

The right time to go home

How will the hospital staff decide when my baby is ready to go home?

The staff involved in the care of your baby will have kept you up to date with your baby's progress while on the unit. To decide if your baby is ready to go home, they will assess if your baby is able to control their temperature, how well they are feeding and if their cares can be continued outside of the unit, without constant professional support.

If your baby still has certain feeding or breathing difficulties or requires specialist attention, they may well still be able to go home, but only once you have been given enough information on how to look after your baby confidently and follow-up support has been arranged.

It is also very important that you feel it is the right time to bring your baby home too. You may well have questions or concerns, so make sure you discuss them with the staff or discharge team.

Will my baby have to stay in hospital until they reach their due date?

Not always. In your discharge planning meeting, which should take place in what would have been the 33/34 week of pregnancy, you will meet the multi-disciplinary team and they will assess your baby's progress. If your baby is feeding well, gaining weight and has no other problems, they may be well enough to go home before their original due date, with an average of 37 weeks.

Babies may have to stay in hospital longer if they need help with feeding, breathing or have other complications.

What if my baby is on medication or is very small when I am told they can go home? Is this dangerous?

The staff on the unit wouldn't discharge your baby if they thought it was unsafe. Even though some babies may still have ongoing medical issues, these issues will be ones that staff are sure you are able to cope with at home. You will have access to advice and support if you need it, and staff will explain to you all you need to know to become the main carers of your baby when they discharge you.

If your baby is still on medication, you will be given information on why it is needed, how to give it and if it has any side effects. Remember it is very common for premature babies who are being breastfed to be prescribed vitamin and iron supplements.

If your baby is very small or was born very early, they will continue to be closely monitored by a specialist nurse, hospital consultant, dietitian or health visitor.

If your baby has ongoing feeding problems, they will be referred to a feeding specialist by the neonatal team before discharge. If the problems develop after discharge, your GP will arrange a referral if necessary.

I have twins - what if one baby is ready to go home before the other?

When you have twins or triplets, it does sometimes happen that one of the babies will be ready for discharge before the other/s. Of course, this can be very difficult for parents, both on an emotional and practical level, with visiting and caring for two or more babies in different places. Although you may have planned to take your babies home together, many organisations, such as The Twin and Multiple Birth Association (TAMBA), think that it can be beneficial for you and your family to begin caring for one baby whilst the other is receiving further specialist medical care. Your babies will only be separated if there is likely to be a long period between them being ready for discharge; if it's a matter of a few days, it would be reasonable to expect them to come home at the same time.

If one of your babies does need to stay at the unit, staff will support you with

your visiting plans, and your other baby/ babies will be able to visit and room in with you when you need to stay overnight.

Will my baby's development be the same as for a baby of the same corrected age?

Your baby's prematurity will be taken into account when looking at their development. However, this does not necessarily mean that your baby will be at exactly the same stage of development in all areas as babies of the same corrected age. Like term babies, premature babies will have their own individual pace and abilities, which may be faster or slower than other babies.

For certain things, such as immunisations, your baby's age will be worked out according to their actual birth date, not their corrected age.



Preparing to go home

It may be hard to believe that the day your baby will be well enough to come home will ever arrive, when they are so small and sick. But the weeks do go by, and as well as fitting in hospital visits, looking after the family and keeping things running smoothly at home, you now have to get ready for your baby's home-coming. If you get organised in advance, you will be able to spend more time with your baby when they are establishing breastfeeding and need you with them for longer periods. Share your concerns or practical difficulties with the staff on the unit. In any case, the hospital will arrange a meeting with you before your baby goes home.

As well as getting to know your baby, it is important to make sure you are completely confident with providing your baby's care. For example:

- Do you know how to make your baby comfortable and reassured?
- 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 any specialist equipment?
- If you are expressing or bottle feeding, do you know how to sterilise bottles and make up your baby's feeds?

- Have you received resuscitation training?
- Do you know how to monitor and control temperature?
- Are you aware of techniques to prevent cot death?
- Do you have enough information and support to breastfeed?

If you don't feel sure about any aspect of your baby's care, ask staff on the unit – they will be happy to help you.

Rooming in

Before going home, all hospitals should offer the chance to 'room in'. This means you stay in a room on or near the unit and care for your baby overnight for a few days. It is a good idea to use this opportunity if you can. It will give you more confidence in caring for your baby,



while the unit staff are on hand to help you if necessary. It will also help you to find out what you feel you need to know before taking your baby home.

Getting ready

If you will be expressing or bottle feeding your baby at home, it is helpful to bring in the bottles and teats so that your baby can start to get used to them. You may also like to bring in a brightly coloured or musical toy (check whether it's appropriate with the staff first) for your baby's cot and something which smells of home; for example, a special blanket. Once your baby arrives home, they will be comforted by familiar objects and smells.

Telephone

You should have easy access to a telephone. A mobile will do, but a landline is better if your baby has complex needs. If you do not have one, ask staff on the unit for help. They should be able to put you in contact with social services, who may pay to install a phone at your house if your baby needs ongoing specialist care. If you need to have your line repaired, tell your telephone company that repairing the line is urgent, because you need to be in contact with the hospital and emergency services.

"My husband and I were very lucky that we could both room in before Joshua came home. Being in the same room with our son overnight made us feel like a real family before we went home."

Angie, mum to Joshua, born at 30 weeks

Transporting your baby home

Car safety

By UK law, all children up to the age of three must use a car seat. You must always use a suitable rear-facing baby car seat whenever possible, even on the shortest of journeys.

If you do not own a car, it is still advisable to borrow or hire a baby seat when taking your baby home from hospital by car or taxi. There may be a local loan scheme - it's worth asking.



Car seat essentials

- To ride in a car, every baby has to use a car seat.
- It is always best to try putting your baby in the car seat before going home to make sure they are comfortable and safe. Unit staff will be able to advise you.
- Your baby can experience breathing difficulties if the seat does not fit properly.
- You can get 'head hugger' supports to fix into car seats – these are useful if you have a very small baby.
- Practise fitting the seat into your car.
- Only use a rear-facing seat for a newborn baby.
- Never use a seat in the front if a passenger-seat airbag is fitted.
- Do not buy or use a second-hand seat unless you are fully aware of its history.
- No hospital will loan car seats, but social services can provide one.
- It is a good idea to check with the staff on the unit if they think it safe for your baby to travel in a car seat. All babies weighing under 1500g should have a 'car seat challenge' before they leave the unit. This is a test to check if they fit properly in their car seat.

RoSPA car seat guidelines

The Royal Society for the Prevention of Accidents (RoSPA) has issued guidelines on the use of car seats with premature and low birthweight babies. In the USA, research has indicated that this category of babies can have breathing problems if they stay in a car seat for long periods.

Here is a brief summary of RoSPA's guidelines:

- Avoid keeping your baby in the seat for any longer than is necessary.
- Recline the seat as much as possible when in the car (carefully following the manufacturer's instructions).
- Never leave your baby unattended in the car seat.
- Only use the seat in the car.
- Keep car travel to a minimum for the first few months if possible.
- Always ask for advice if you are unsure about any aspect of car safety.

"When we first took Daisy home we were excited and relieved. Then reality sunk in and we were scared and anxious. I found it hard being alone with Daisy for the first few weeks – I wanted to protect her from everything. Slowly I realised she was stronger than we thought, and with the love and support of my partner, family and close friends we got through it."

Gavin, dad to Daisy, born at 30 weeks

At home

Who will help once my baby is at home?

When your baby is discharged from the unit, a group of health professionals will continue to advise you on issues like feeding, growth, immunisation, development, as well as general baby care. Bear in mind that job titles and services may vary from hospital to hospital, and you may not come across all the different types of healthcare workers listed here.

You will be informed about the types of help available to you when you go home with your baby and who to contact for specific issues. Make sure you have a list of useful contact numbers in a handy place.

- **Community neonatal nurse or family care worker**

A number of hospitals have a nurse connected to the unit who makes home visits to families whose baby has recently been discharged from hospital. This specialist nurse will be there to support you and to advise on areas like feeding and ongoing medical needs, such as home oxygen and gastric reflux. The community neonatal nurse or family care worker, such as a health visitor, will be the point of contact between you, the hospital and other members of the healthcare team.



The home care team

If your baby has ongoing medical needs, there may be a home care team from the hospital who will be involved in caring for them on discharge.

The team will usually include a neonatal or community paediatric nurse and other specialists, depending on your baby's needs. Who makes up the team will also depend on the type of services available at that particular hospital.

- **Health visitor**

Every family in the UK is assigned a health visitor when there is a new baby in the family. Yours may have already visited you while your baby was still on the unit. Unless your baby still needs to see a specialist, your health visitor will be your main professional support once you go home. They will be involved in following your baby's development from birth to school age. The health visitor will carry out basic checks for growth, developmental milestones, and may be involved in organising immunisations. Your health visitor is a source of information for promoting health, home safety and parenting skills. Health visitors are available for home visits and at baby clinics.

- **General practitioner (GP)**

This is the local doctor that you should register your baby with. Your

doctor is your first point of contact for any type of health-related problem and can make referrals to other specialised health professionals or, if needed, hospital. It is essential to register your baby with a GP in the catchment area of your home address.

- **Practice nurse**

You may see a nurse at your GP's surgery or if you go to your local health centre. Practice nurses may be involved in your baby's immunisation.

What if I still don't feel confident with my baby by the time they leave hospital?

It is extremely common for parents of special care babies to feel nervous and unsure about being able to cope. The transition from hospital to home is a big step for you, your baby and the whole family. It is often a time of mixed emotions. It takes time, but gradually you will learn what you need to do. You will be able to understand what your baby is saying to you and know exactly what they need and what is best for them.

In the unit, you will have been encouraged to be involved in feeding and handling your baby more and more, with help from staff if you needed it. This is because it is important that you and your baby know each other, so that at home you can feel confident to care for them on your own.

If you find that you continue to not feel confident, remember that help is at hand. You can speak to your health visitor and your community neonatal nurse and explain to them how you are feeling; often some practical, objective advice is all you need. You may also be able to see a counsellor or a psychotherapist through the unit that discharged you. Contact your unit for more information. Alternatively, call the Bliss freephone Helpline on 0500 618140, and an advisor will be able to help you.

How many visitors can I have when my baby first comes home?

Your baby will need to get used to a new environment when they come home from the unit. This is true for you and your partner too. Everyone has to adjust to the new situation and this may take some time. Try to limit how many visitors you have at home until you are feeling settled and comfortable.

Once everyone has had a chance to get used to the new situation and your baby is progressing well, it is important to start getting back into a normal routine, which involves being at home as well as getting out and about a little. You can decide to have more people over to see you at this stage as well, or organise to meet them somewhere else.

It is important to avoid, as far as possible, contact with people who have respiratory viruses or other contagious illnesses to reduce the risks of infection for you and your baby.

For help and advice to stop smoking, try the NHS Smoking Helpline on 0800 169 0 169 or visit www.gosmokefree.co.uk

Smoking at home

It is very important to remember that babies who have been in special care can have fragile lungs and fall ill very easily. If your baby comes home to a house where people smoke regularly, their health can be quite seriously affected, even if they are not in the room where someone is smoking. This is the perfect time for you or others living with you to try and stop smoking, for the sake of your own health, but also that of the baby. Quitting smoking is not easy, and will require a lot of discipline, but it is an effort worth making.

If you are finding it hard to stop smoking completely, try to only smoke outdoors with an outdoor coat on, when your baby is not with you. Wash your hands thoroughly afterwards.

Will smoking increase the risk of cot death?

Smoking does increase the risk of cot death. For every hour of the day that a baby is in a room where people routinely smoke, the risk of cot death increases by 100 per cent. For example, if a baby is exposed for two hours a day, the risk of cot death is doubled. If a baby is exposed for eight hours a day, the risk increases by eight times.

The risk of cot death is also significantly increased for babies who share a bed with a parent who smokes, even if the parent smokes outside.

For more information on cot death, contact the Foundation for the Study of Infant Deaths (FSID) if you are in England and Wales, or the Scottish Cot Death Trust in Scotland.

I've been told not to overheat my baby because of the risk of cot death. What temperature should I keep my house at?

It is important not to overheat your baby, but remember that if your baby was very small or premature, they may find it more difficult to keep warm. A nursery thermometer will help you to monitor the room temperature. Keep the temperature between 18 and 21° Celsius (64–69° Fahrenheit).

Check your baby regularly to ensure they are not too hot or cold. You can do this by feeling the back of their neck or tummy. It is normal for a baby's hands and feet to feel colder than the rest of their body.

You may want to buy a thermometer to monitor your baby's temperature until you feel more confident. This should be a digital thermometer, and you should place this under your baby's armpit. Their temperature should normally be between 36.5 and 37.1° Celsius (97.7–98.7° Fahrenheit).

If your baby is too hot, take some layers off and check again. If your baby is too cold, put a hat on and more layers and give your baby a cuddle. If they seem unwell, if their temperature remains very high or very low, for example, speak to your GP as soon as possible.



Sleeping

What is the best sleeping position for my baby?

You should place your baby on their back at the start of sleep time. If you find your baby has rolled over onto their tummy or the side, place them on their back again.

Eventually, babies learn to roll onto their front and back again. When this happens, you do not need to reposition them.

Babies who have spent time in special care may have become used to being positioned on their front. This may mean they take some time to learn to settle and sleep on their back. Most babies will be introduced to sleeping on their backs two weeks before discharge by the team caring for them on the unit.

It is recommended that babies who are reluctant to sleep on their back are not fed or cuddled to sleep before being placed in their cots.

For more information, see the flyer by the Foundation for the Study of Infant Deaths (FSID) called *Back to sleep*.

Can my baby share a bed with me?

You should avoid this as much as possible. The safest place for your baby to sleep for the first six months is in a cot in the same room as you. If you decide to have your baby in bed with you to comfort or feed them, you must be very



careful not to fall asleep and:

- Make sure your baby cannot fall out of bed
- Use lightweight covers or duvets, not adult weight covers which can make your baby too hot
- When on the mattress, place them away from the pillows.

It is especially dangerous to have your baby fall asleep in bed if you or your partner smokes, have recently drunk alcohol, use drugs or are very tired. It is also dangerous to fall asleep on the sofa or an arm chair with your baby. In any of these cases, put your baby back in the cot before you go to sleep.

What are apnoea monitors?

Apnoea monitors are extremely sensitive alarms which monitor breathing – they will usually be attached to your baby's chest. If a baby stops breathing for longer than 20 seconds, an alarm is triggered.

If your baby has had frequent apnoea attacks (pauses in breathing) in hospital or has come home on oxygen, staff on the unit may recommend you use an apnoea monitor at home.

It's important to remember that false alarms are very common, and the alarm can often be triggered when a baby is in deep sleep and their breathing is shallow. Apnoea monitors vary in price and ability; why not ask the hospital what they would recommend?

If you need to use a monitor, it is important that you also learn how to resuscitate your baby if they stop breathing. Staff on the unit will make sure you are trained before your baby is discharged.

Bliss produces a DVD for parents on resuscitation techniques that is distributed to units all over the country. You can get a copy from your unit, or you can ask your paediatrician if they think it would be helpful for you.

My baby is unsettled and wants to be picked up all the time. What should I do?

Coming home is a big change for your baby. Everything is new and different; noises, temperature, smells and colours. They may need lots of cuddles for reassurance. It can take some time for babies to settle into a new environment.

Remember that premature babies have more active sleep than term babies, so although they may be moving around at night, they may well be sleeping better

than you think. If your baby is unsettled, you can try stroking them to reassure them you are there. This will be easier if you can have a Moses basket next to your bed. You may also want to try leaving a night light on.

Allow your baby time to try and settle on their own. Many babies cry briefly before going to sleep, and it is better not to pick them up or disturb them if they are trying to settle down. Watch out for what your baby likes to do before falling asleep and you will soon be able to read their cues.

Baby massage

Massaging your baby is a great way of bringing you and your baby closer, and is also very good for their health and sense of wellbeing. Massage has been shown to be especially useful for premature and sick babies.

It can help you bond by making your baby feel loved and helping you learn about your baby's needs. You will also both find it very relaxing.

Health benefits can include:

- Better sleep
- Boosting your baby's immune system
- Improving your baby's circulation
- Helping your baby's digestion
- Improving the condition of your baby's skin
- Helping build self-confidence in both you and your baby.

Ask your health visitors if any of your local centres run baby massage groups.

My baby's health

What if my baby comes home on oxygen?

Some babies who need extra help with breathing will go home 'on oxygen'. Being on oxygen means that your baby needs a supply of oxygen to support their breathing. They may need this for a few weeks or longer.

This is quite common, and staff will make sure you have all the information you need about this aspect of your baby's care. You will be told about the levels of oxygen your baby needs, and you will be shown how to tell if your baby needs more.



Oxygen comes in two forms:

- Gas oxygen cylinders (which can be moved around the house)
- Portable oxygen cylinders (which mean you can leave the house with your baby) - these can contain both gas oxygen and liquid oxygen.

If you transport oxygen cylinders in your car, don't forget to tell your car insurance company about it. You are also entitled to a warning sticker for your car alerting people to the fact you have oxygen on board. Ask your car insurance company about it.

See the free Bliss booklet *Going home on oxygen* for more information about taking your baby home on oxygen.

Since coming home my baby sounds snuffly. Could they have caught a cold?

The change in atmosphere and the drier heat you will have at home compared to the unit may make some babies more snuffly. Your home environment will also be a bit dustier than the hospital. Don't worry, particularly if your baby seems well and is able to feed. The snuffling will settle down, but this may take a few weeks. Check your baby's temperature if you think they might be unwell; if it is lower or higher than normal, or if they are struggling to keep warm, ask your GP or health visitor for advice.

How can I protect my baby from the risk of infection?

If your baby was ventilated, needed oxygen or was very premature, they may be more at risk from infections which affect their breathing. It is not possible to completely protect your baby, but there are steps you can take.

If you are worried that your baby is unwell, seek medical advice.

What is RSV?

RSV (Respiratory syncytial virus) affects around two-thirds of all babies and children. It causes cold-like symptoms and can cause breathing difficulties if the lungs are affected. Most babies and children show symptoms between October and March. Often parents won't know that the colds or sniffles their children suffer from during this period are caused by this particular virus.

If your baby was born prematurely, with a heart condition, or is prone to getting lung infections, they could be at greater risk of becoming more seriously ill if they were to come into contact with RSV.

See the free Bliss booklet *Common winter illnesses* for more information.

Check if your baby is becoming unwell

- Are they more fretful than usual?
- Do they have a raised or low temperature?
- Are they not interested or reluctant to feed?
- Have they been vomiting (if this has not been a problem before)?
- Has there been a change in stools – more frequent, watery or 'explosive' than usual?
- Are they less aware of you (not as responsive, not waking up as easily, more 'floppy', breathing more rapidly and noisily)?
- Do they have blotchy skin or a rash that doesn't become much lighter when a glass tumbler is pressed against it? Are they pausing for a few seconds between breaths and paler than usual? These two options could possibly be serious, and you should get medical advice urgently.

Make sure you have details of the nearest A&E with children's services.

Reducing the risk of infection

- Avoid places where there are large groups of young children.
- Avoid crowded public places.
- Avoid large air-conditioned buildings; for example, shopping centres.
- Ensure everyone coming into contact with your baby washes their hands thoroughly with soap and warm water.
- Reduce contact if someone has a cold or fever.

Reflux

Many babies bring up some milk after a feed or a breastfeed. However, this is not a problem unless it is painful or distressing for your baby, or if they aren't gaining weight. If either of these happens to your baby, they may have reflux. This is similar to heartburn and symptoms can include gagging, choking and tummy pain.

Babies usually grow out of reflux during their first year, and health professionals can give you advice about the way your baby is feeding.

Reflux is often worse when a baby is lying flat on their back, so it can help if you keep your baby's head gently raised during the day. The most important time

is after a feed; at this time you should hold your baby upright for as long as you can. Changing your baby's nappy before a feed rather than afterwards also helps.

If your baby suffers from reflux during the night, try making the head end of the cot slightly higher by standing it on something stable (a couple of books perhaps), so that your baby's head is slightly raised. However, you must not put anything directly under your baby's head, and never use a pillow with a baby under 12 months old.

Vitamin supplements

Many premature babies are discharged from hospital taking vitamins and iron. This is because babies store up vitamins in the last month of pregnancy, so babies born before 36 weeks may have missed out on this.

You will be advised by your GP or health visitor on how long your baby should continue taking vitamins, but it is usually until the baby is weaned and taking a balanced diet of solid food.

Immunisations

We all have antibodies in our blood. These are proteins produced by the body to fight infections. Term babies do not produce antibodies, but get them from their mums towards the end of the pregnancy. So babies born early will receive fewer antibodies, and as a result will be more at risk of infection. It is very important that they receive their vaccines according to the recommended NHS guidelines, which is at eight weeks

of age counting from their birth date, not their due date.

Babies who are born very early or who are very poorly may still be in hospital when they are eight weeks old, and can start their immunisations before they go home.

If you have any specific worries about immunisations, talk to staff on the unit or to your GP and health visitor once you go home.

Follow-up appointments

Once your baby has left the unit, you may need to attend follow-up appointments for various aspects of your child's health and development. Some people find it very helpful to write down the advice given to them in their baby's red book.

Sometimes, follow-up appointments can mount up and you may have more than one in a week. They can take up a lot of time and be very tiring, especially if you have to travel long distances to and from the hospital. If you are having trouble managing the number of appointments you have to attend, ask your health visitor to reorganise some of them, if it is possible, so that the timings are more manageable.

Your baby's development

Normal development in babies and young children varies tremendously. If your baby was born very prematurely, it is possible they will reach major milestones later than term babies born at the same time. This is because they are in fact much younger, having been born prematurely.



However, in some areas, premature babies may develop more quickly than term babies. Your baby's development will be monitored by a paediatrician or neonatal consultant who is used to dealing with premature babies, so they will take this into account.

Many hospitals now have developmental follow-up programmes, and you may be asked to bring your baby for regular developmental assessments. These should reassure you that your baby is doing well and address any concerns you have about your baby's development. You may also be given advice about developmental activities beneficial to your baby's development.

If your baby was born weighing less than 1kg or before 31 weeks, you should attend an official follow-up appointment to assess their development when they are two years old. This is a standard process, and it is important that you attend it.

If you have particular concerns about your baby's development, you should discuss them with the health professionals still caring for them.

Don't forget that the term 'normal' covers a very wide range of scenarios.

Readmission to hospital

Your baby may need to be readmitted to hospital after they come home. This is not unusual for babies born premature or sick. This may be a worrying and





upsetting time for your family, but remember to be positive, and that your baby has already overcome many difficulties.

Babies who need to go back to hospital will be admitted to the children's ward, not the neonatal unit. There are very rare exceptions to this. One reason could be if it was only a very short time since your baby was discharged.

A children's ward is a very different environment to the neonatal unit. Children's wards don't have as many nurses and doctors per baby as the neonatal intensive care unit; this is a standard, so you shouldn't worry. Some parents may feel anxious if they are used to a larger number of people caring for their baby.

A few things to remember

- A different staff team means new people to get used to.
- A small number of hospitals don't have a children's ward. If this the case, your baby may be admitted to a different hospital from the one they were discharged from.
- You will be able to stay with your baby on the children's ward, even if it is only on a camp-bed.
- You will be expected to carry on being very involved in looking after your baby, as you were already at home.

Feeding

If you are breastfeeding your baby at home, you will have probably started expressing and/or breastfeeding while your baby was still in the unit. However, you may have some questions about it now you don't have unit staff on hand to help you.

How will I know my baby is getting enough breast milk when I am at home?

Premature babies who are getting enough to eat have six to eight wet nappies every 24 hours, consisting of pale urine that does not have a strong smell, and regular bowel movements. All babies have different stools; however, in general, these should be soft, yellow and seedy-looking.

Remember, it is entirely up to you whether to breastfeed or not and – if you do – how long you breastfeed your baby for.

Research has shown that a mum's breast milk is the best source of nutrients for a premature or sick baby.

Your baby will seem content and happy after a breastfeed and grow steadily, at their own pace.

For any specific questions, you should consult your health visitor or a health professional in your trust.

How will I know my baby is hungry?

The key is listening to your baby. If they give you a hunger cue, feed them. If you offer the breast and your baby starts to feed, they must be hungry!

You should particularly look out for:

- Rooting
- Hand to mouth movements
- Sucking movements
- Sucking on fingers and hand
- Opening of the mouth in response to touch.

Watch your baby closely while they feed, so you can be sure they are swallowing and sucking well. You may have to remind them to keep sucking and swallowing by stimulating them gently.

Do I still need to express my milk after my baby goes home?

This will depend on your milk supply and how well your baby is feeding. It is very helpful to continue pumping until your baby is able to breastfeed well, as it will help you maintain your milk production. Some babies may find it easier to develop a good sucking rhythm when



their mum has a good milk production. If your baby is growing well, you can try feeding them 'on cue' when they feel hungry, and feed them as much as they want. However, you should aim to reduce the number of times you express slowly, down to once every two or three days.

What should I do if my baby does not want a feed?

- Be patient and keep trying
- Be sure your baby is positioned well
- Offer a cup or a bottle as a last resort
- Continue to express and give the milk to your baby.

What if I am not producing enough milk?

Any breast milk is better than none, so don't worry if your baby is also taking some formula. If you need to increase your milk supply ask your health visitor for advice or call the Bliss freephone Helpline on 0500 618140.

Bottle feeding

Many bottle-fed babies go home using a special discharge preterm formula. This will be prescribed by your doctor while your baby is still in hospital. Most babies continue on this until they are six months old (counting from their birth date). A baby shouldn't stay on this special formula after six months, unless a doctor recommends it. After this time, babies should be fed using a standard whey based formula (first milk). Organic milk should not be used, as it doesn't contain the best blend of fats. Vegan parents should be guided by a dietitian.

Establishing a breast milk supply after discharge

It is possible to stimulate a breast milk supply at any time, but it takes time and perseverance. For more guidance, call the Bliss freephone Helpline 0500 618140.

Formula milk

If your baby is on formula, they may go home with a special kind of milk, designed for premature or sick babies. You should continue using this formula until advised by a health professional. Formula milk made up at home looks thinner and whiter compared to the milk

you get in the hospital. This is because hospital-prepared bottles have been heat-treated, and this makes them look different.

Make sure you follow the instructions carefully when you use the powdered milk at home. You should continue using the same formula milk used in the unit when you get home, unless your health visitor or GP have advised you otherwise.

You and your baby will have got used to the routine on the unit, so it may seem strange when you first take your baby home and give them their first feed.

Is my baby getting enough to eat and gaining enough weight?

In the first few weeks, you may find your baby feeds irregularly; some babies may demand to be fed more often than they had been on the unit. This is to be expected while you and your baby work out the best pattern for you at home. Every baby is different, and they should be fed according to their own needs.

If you offer feeds frequently and make sure your baby takes as much as they want at each feed, your baby should stop feeding when they have had enough.

If you think your baby is feeding too much or too little, discuss it with one of the health professionals supporting you, like your health visitor or your GP.

You can be sure your baby is getting enough milk if they have plenty of wet

“I continued to breastfeed Marc long after we came home. Breastfeeding made me feel like I was continuing the great care and attention he got while in hospital. It was a great way for me to bond with him too – it had been hard to really be a mum on the unit. I was anxious about his health and felt that breastfeeding was best for him and for me.”

Julie, mum to Marc, born at 24 weeks

nappies, are growing/gaining weight and are alert and awake for some of the time.

My baby is feeding every two to three hours. Is this normal?

If your baby is under four months and is growing well, you shouldn't worry. It is very common for babies to feed more frequently when they first go home. If your baby isn't gaining weight, ask your health visitor or GP for advice. If feeds start lasting significantly longer than normal, you should also seek advice.

What if my baby is feeding badly – not very often, small amounts and hardly gaining weight?

The amount of weight you would expect them to gain is between four to seven ounces a week, but this is only a general guide, and different babies will gain weight at different paces. If your baby

is under the care of a dietitian, they will advise you about a healthy weight gain for your baby.

The community neonatal nurse or health visitor will normally weigh your baby once a week for the first few weeks at home, and help you with any worries or concerns you may have.

My baby has not had a dirty nappy for a few days. What should I do?

Every baby's bowel habits are different and many things can cause them to change; for example:

- A change in feeding routine
- Changing from breast to formula milk
- A change in type of formula milk
- Slight dehydration due to hot weather.

If your baby seems well and is feeding, don't worry. However, if you are still concerned and your baby is not feeding well, vomiting or their tummy is swollen, seek advice.

Colic and wind

Babies who have spent time in special care seem to suffer from winding problems more than term babies. Baby massage is particularly good for giving relief from colic and wind (see page 17 for more information).



As well as massage, the following could help, but you should also ask advice from a health professional:

- Ensure your baby is sitting upright during feeds (if they are old enough) and not gulping too much air.
- Try a medium-flow teat rather than a slow-flow or 'newborn' teat.
- Give your baby a warm bath.
- Hold them and rock them gently.
- Give them colic drops or gripe water.

While colic is particularly common in the first few months, it rarely lasts very long and causes no long-term problems.

Weaning

Weaning is the introduction of the first solid foods to a baby who has only ever been fed on breast or formula milk. Weaning takes place when your baby has reached a point when milk no longer supplies all the nutrition they need to grow. It is also important to teach your baby about eating and accepting a wide range of foods at this stage.

If you are worried about how your baby is feeding, talk to your community neonatal nurse, health visitor or GP. If your baby is under the care of a dietitian, they will also be able to advise you.

See the free Bliss booklet *Weaning your premature baby* for more information.

Financial advice

You are entitled to Child Benefit as soon as your baby is born. If you are not already claiming, contact your local Citizens Advice Bureau for information on how to make a claim and backdate it to when your baby was born. Go to www.citizensadvice.org.uk for more information.

All babies and mums are entitled to free prescriptions and dental treatment until the baby is 12 months old (from their actual birth date, not their due date).

If you are claiming Income Support or Income-based Jobseeker's Allowance, there may be other benefits you are entitled to, such as the Sure Start Maternity Grant, Family Fund, Community Care Grants, free vitamins and milk tokens. You may also be entitled to Carer's Allowance and Disability Living Allowance; for example, if your baby has gone home on oxygen.

See the free Bliss booklet *Financial advice* for further information.



How you might be feeling

For many parents, having a premature or sick baby is very stressful and frightening. While your baby was in the unit, you used a lot of energy just to keep going and stay strong. So when you bring your baby home, the full impact of what has been happening over the last few weeks or months may suddenly catch up with you. You may feel very tearful or simply exhausted as your body starts to relax.

The weeks leading up to your baby's first birthday can also be an emotional time for some parents. Memories of your baby's birth – particularly if it was very traumatic – may come rushing back and take you by surprise. All these feelings are perfectly normal and understandable.

Different members of the family will have experienced the situation in very different ways too, so you will all have to adjust to the new situation, particularly if there are other children in the family.

If you feel overwhelmed, there are many people who can help. Talk to your GP or health visitor, who will be able to tell you how to access counselling if you feel you need it.

Bliss also offers a range of services to support parents at this trying time:

- The Bliss freephone Helpline is open from 9am to 9pm, Monday to Friday, for advice and support.

- The Bliss counselling service offers parents up to six sessions with a qualified counsellor free of charge.
- The Parents 4 Parents network puts you in telephone contact with other parents who have been through similar experiences, for advice and support.
- Bliss' local support groups provide a relaxed and friendly atmosphere somewhere near your home to share what you have been through with other parents.
- Call the freephone Helpline on 0500 618140 for more information on all of these services, or email enquiries@bliss.org.uk
- If you have twins or triplets, there are organisations which can offer specific help and support. The Multiple Births Foundation gives useful guidance on coping with more than one baby. Also, The Twins and Multiple Births Association (TAMBA) has a Support Group which provides a network of contacts.

How do I know if I have postnatal depression?

Postnatal depression (PND) is different to the 'baby blues', which affects at least half of all new mums during the first week after birth and quickly goes. PND is not easily defined. It is very common for all mums of newborns to be tired, lack confidence and energy, as well as having a certain level of anxiety and guilt.

However, PND is usually a combination of many symptoms over a longer period of time. Sometimes the chance to talk to someone who understands can really help. This is particularly the case for mums of premature and sick babies, who have experienced, and are possibly still experiencing, a huge rollercoaster of emotions.

The sooner PND is diagnosed, the sooner it can be treated. Don't be afraid to ask for help if you feel overwhelmed. There are many organisations which can help, and your midwife, health visitor or GP can advise you on local support.

For more information, call the Bliss freephone Helpline on 0500 618140.

My partner has postnatal depression – what can I do to help?

If you think your partner may be suffering from PND, there is a lot you can do to help. Depressed people tend to be very self-critical, so staying positive and encouraging your partner can be very valuable. Sometimes just listening can help. Often there are no instant solutions, so don't feel you need to come up with any. Simply sharing your feelings can bring you closer together.

You may be finding the situation hard to cope with too and this is quite understandable. There can be huge pressures on dads to keep everything going in the home and at work, particularly.

How can I look after my other children while caring for my new baby?

Newborn babies always take up a lot of their parents' time, and this can be hard for siblings, especially if they are still very young themselves.

However, there is a lot you can do to help your children to adapt to having the new baby at home:

- Try to understand how they might be feeling. Sometimes children 'play up' or go back to 'baby mode' as a means of getting their parents' attention. Try to make sure you have dedicated time each day to spend with them alone.
- Tell them what's happening. Try to explain things honestly and in a simple way, so your children feel involved. You may find this will also help control their behaviour.
- Involve them in caring for the new baby. There will be things your children can help you with, however small they might be. Older children will be able to help you changing nappies, or even sterilising equipment. You can get smaller children to help you get the baby's things together before a trip out, or you can encourage them to do some drawings for the nursery.



Enjoy!

After everything you have been through this is a very special time for all the family. If you can, take advantage of any practical help that is offered, and try to make sure you have time to rest and take care of yourself as well as your very special baby.

Becoming a parent is a learning curve for everyone, whether their baby was premature, sick or healthy and full term. It is an exhausting, emotional and thrilling time for every parent.

Alasdair and Samantha's story

"Our daughter Charlotte was born at 24 weeks gestation in July 2007. After over three months in hospital we were so excited to come home, but really scared at the same time. We'd always had a nurse or a doctor there to help us; now we'd be on our own. We came away with an endless list of follow-up appointments and tests, but it was still the happiest day of our lives.

As the days went on, Charlotte had both good days and bad days. Her eye check-ups had been going well, but her hearing tests had not been so positive. She only has partial hearing in both ears. We used to find it so exhausting to

attend all those appointments, only to be told they were inconclusive or that we had to wait longer.

After the problem with her hearing, Charlotte developed water on the brain, which thankfully she didn't have to have surgery for. She was monitored closely in the build-up to her first Christmas, but the problem slowly took care of itself. We had our first Christmas at home, just the three of us, as a family. It was exhausting, as Charlotte kept us awake to be fed for long periods, but we were determined to enjoy it. While she was in hospital, we kept saying to her: 'Just come home for Christmas, sweetheart'.



She managed that in plenty of time. By Christmas Eve, Charlotte's head circumference was completely normal. Her blood tests were looking good too.

By the time Charlotte turned six months old, on 15 January, she had come so far. Our tiny baby, whom the doctors thought was unlikely to survive the brain infection she had from birth, had proved a remarkable fighter. Looking back at her discharge notes – which make very scary and daunting reading – we felt, and still feel, so proud of her, after all she had to face and overcome against such overwhelming odds.

As the weeks progressed into the new year, Charlotte was becoming more and more responsive, communicating with us, showing much more interest in what was going on around her, and smiling a lot. We were, and are still, so incredibly proud of her.

Charlotte today

Charlotte was four in July 2011. She has a mild form of cerebral palsy and is learning to walk with the help of a walking frame. She is fully expected to walk unaided and walk quite well according to her physiotherapist. It will be a very special day when she takes her first steps by herself.

Charlotte suffers from hearing loss and wears hearing aids. She is being assessed to see whether a cochlea implant may be beneficial in her left ear. In the meantime, she is learning to talk with the help of speech therapy and sign language.

I remember just over a year ago when she said her first 'proper' word. With the prospect of second helpings of jam sponge and custard at nursery she shouted out "more" ahead of her friends. We were more than a bit jealous that she decided to do this at nursery for the first time, but she hasn't stopped since, especially when she wants something that we have! We are so proud.

Although Charlotte has some obstacles to overcome, this has only made her more determined to achieve anything she sets her mind to. The day we turned our back for 30 seconds, to then find her sitting on top of the kitchen table with a massive smile on her face, so proud of her achievement, was a heart stopping moment, but also made us realise that nothing would be unachievable for our special little girl.

Charlotte may have been late with every milestone so far but has never failed to reach one yet. She has taught us both to be patient and that it does not matter how long it takes to reach them, it just makes it all the more special when she does.



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7th Edition, 2012 © Bliss

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Registered charity no. 1002973 Scottish registered charity SC040878



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0500 618140

or visit our parent messageboard
www.blissmessageboard.org.uk

To volunteer your time or to join our local
network of support groups visit

www.bliss.org.uk

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Bliss is a member of Language Line, the telephone interpreting service,
which has access to qualified interpreters in 170 languages.

Bliss is the UK charity working to provide the best possible care and
support for all premature and sick babies and their families. We support
parents, we work directly with doctors and nurses and we campaign to
ensure the needs of babies and their families are always heard.

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Bliss

for babies born too soon,
too small, too sick