

Going home

The next big step



Bliss

for babies born too soon,
too small, too sick

www.bliss.org.uk

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Milton makes it safe

Milton is very happy to sponsor the Bliss *Going Home* booklet, as we understand just how important the next big step is for all premature and sick babies and their families.

Bringing your baby home from the unit is an exciting time for any family, but it can also be worrying to leave hospital and care for your little one at home. One of the most important stages of your baby's growth is the development of their immune system. Babies are born with a certain amount of immunity, however, for the first 12 months, their natural defences are not fully developed. Premature babies tend to be more vulnerable to infections due to their under-developed immune system. Fortunately, you can help keep your baby protected through good hygiene practices such as sterilising all baby feeding equipment, ensuring your hands are disinfected and maintaining a clean environment.

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This is the beginning of a new partnership for Bliss and Milton. Our goal is the same – to make sure babies are safe and healthy. This new *Going Home* booklet helps go that extra step to continue providing the best care for families.

For more information on the Milton range and tips for keeping your home baby friendly and germ free, visit www.milton-tm.com



Contents

Introduction	3
Karen's story	4
The right time to go home	6
Preparing to go home	8
Transporting your baby home	9
At home	12
Sleeping	15
My baby's health	17
Immunisations	20
Follow-up appointments	20
How you might be feeling	21
Feeding	24
Readmission to hospital	28
Financial advice	29
Conclusion	29
Alasdair and Samantha's story	30

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 they are well enough to leave the hospital and that you are able to look after them.

You may have many questions about going home, both when your baby is still in hospital as well as after they are discharged. This booklet looks at the most frequently asked questions and the different stages that you might go through.

We hope you will find the information in this booklet helpful. Bear in mind that not everything in this booklet will apply to you and your baby.

Karen's story

"My daughter Amy was born prematurely at 31 weeks, on 29 August 2008. She spent her first five weeks in a special care baby unit. When she finally came home the following 1 October, it was the beginning of a whole new set of challenges – for me and the rest of the family.



"Amy's time in SCBU was, in hindsight, a fairly routine experience.

She breathed at birth, and only needed the standard help with feeding and temperature. It was awful to have to leave her behind in the hospital, but the only thing we could do, especially with our then two-year-old son James needing us at home.

"Going home was the beginning of a very worrying time for me; I just wanted to hibernate, really. I would worry that Amy might fall ill and have to be readmitted to hospital. I didn't want to go anywhere. For a while, I was on a very short fuse with people. I felt my family was trying to manage me and my feelings, which were only natural in the extremely difficult situation we were in. All I felt I wanted was their support and to get on with things.

"With time though, I realised that I didn't need to be so over-protective with Amy. When she caught a virus from her brother, she wasn't nearly as ill as James was. It was then that I realised Amy wasn't this tiny, delicate and helpless baby, and that she was actually much stronger than I gave her credit for.

"Simply, it was tough to adapt to how things were. We had a toddler to look after as well, who initially took the situation quite badly. I had been going into hospital from week 19 for ongoing bleeding, and when Amy was born, I had to go into hospital in the middle of the night, without saying goodbye to him. This made him very anxious, and he seemed to always be worried when people went away. If my husband went out, he would always ask: "Is daddy coming back?"

Our relationship was tough, which, with having to care for Amy too, made things very difficult. I was always reassured though that he always said, and still does now, how much he loves his little sister.



"It took us a couple of months to get into some sort of normality. At first, I felt really guilty that James' routine had become less of a priority – Amy was taking so much of my time. This had continued from when Amy was on the unit, where I had to visit at very specific times to breastfeed her. That was probably the hardest time for me during Amy's first few months. Now we were home, I was still having to put her first a lot of the time, which made me feel awful.

"A close friend of mine, who'd had her own daughter at 32 weeks a few months before I had Amy, was a huge support for me. To be able to talk through the problems I was experiencing with someone who really understood made a world of difference. I could literally 'compare notes' with her, and feel that my situation wasn't so different from other people's.

"I started feeling like Amy was less different from other babies once I started taking her to a mother and baby group – unthinkable when we first brought her home. She wasn't the smallest baby anymore; she was a lively, bouncy baby who showed little evidence of the tough beginning she'd had.

"Today, Amy is nine months old, thriving, and settled more into her role as a younger sibling. She's not one for keeping still much just now, so most of the photos we have are quite blurred, but this one is a good one.

"I know now how lucky we have been. Amy has had great outcomes so far, and has gone from strength to strength. The best advice I could give parents going through similar difficulties to ours is: talk to each other, and to others who will understand. It will never be easy, but it will help you feel like you are not alone."



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 they are able to control their temperature, how well they are feeding and if their cares can be carried out 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 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. 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, they 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 preterm babies who are being breastfed to be prescribed vitamin and iron supplements.

If your baby is very small, they will continue to be closely monitored by a specialist nurse, hospital consultant, dietician 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 level and on a practical one, with visiting and caring for two or more babies in different places, sometimes several miles away from each other. You must remember though that cots are constantly needed in a unit, and so it's important to free up a place for a newborn, if one of your babies is ready to go home. 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 and weaning onto solids, your baby's age will be worked out according to their actual birth date, not their corrected age.

"After 10 weeks on the unit, we were itching to get our twins home. Everything was ready for them. We would wait every morning for the doctor's round to ask if that day would be the day. Eventually, on 30

January, we took them home. It was so exciting. I had watched so many mothers let through the doors of the unit with their baby. Now it was our turn. We were so happy."



Louisa Hill, mother of Isobel and Imogen, born at 28 weeks

Preparing to go home

It may be hard to believe that the day your baby will be well enough to come home will ever come when they are so small and sick. But the weeks do go by, and it may be hard to fit in hospital visits, look after the family and keep things running smoothly at home, as well as getting ready for the baby's home-coming. If you get organised in plenty of time, 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 happy with the practical aspects of their 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?

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 they are appropriate with the staff) 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.

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. Some hospitals may be able to loan you a seat, or there may be a local loan scheme – it's worth asking.



Car seat essentials

- It is always best to try 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.
- 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.
- 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. Some babies will 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 and Kirstie Cloke, parents of 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 who have had a baby recently 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.

The community neonatal nurse or family care worker will be the point of contact between you, the hospital and other members of the healthcare team.

- **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 you were still in 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 health 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 there for any type of health-related problem and to make referrals to other specialised health professionals. 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?

You would be a very unusual parent if you didn't 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.

The homecare team

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

The team will usually include a neonatal or paediatric community 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.

If you find that you continue to not feel confident, remember that help is at hand. You can speak to your health visitor 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 them to get 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, involving 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 out.

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.

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 their 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 and when your baby is not with you.

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 to three 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. See page 33 for details.

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

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 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, or don't warm up if cold, 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 back sleeping 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, not adult weight covers which can make your baby too hot.

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. 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.

Your baby's paediatrician should advise you if your baby needs a monitor. Apnoea monitors vary in price and efficacy; the hospital should be able to hire or lend you a suitable one. If you prefer to buy one, ask what kind the hospital 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, 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

Baby massage is a great way of bringing you close to your baby, and is also very good for your baby's 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.

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 months 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 three forms:

- oxygen cylinders (which can be moved around the house)
- oxygen concentrators (which are installed in one place within your home)
- portable oxygen cylinders (which mean you can leave the house with your baby).

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.

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.

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.

To reduce the risk of getting RSV, follow the advice given in the box below. Treatment will vary depending on how

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.

badly your baby is affected, but usually they will need plenty of fluid and calpol for a fever.

See the free Bliss booklet *RSV* for more information. A new Bliss information booklet on winter diseases will also be available from September 2009.

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.

What is 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.

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 mothers 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 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 try to reorganise some of them (if 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 1 kg or before 31 weeks, they should attend an official follow-up appointment when they are two years old to assess their development. 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.

How you might be feeling

For many parents, having a premature or sick baby can be very stressful and frightening. While your baby is 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 10am to 10pm 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. See page 33 for details.

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 mothers during the first week after birth and quickly goes. PND is not easily defined. It is very common for all mothers 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 mothers 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 Helpline on 0500 618140, or see the useful organisations on page 32.

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.

See the free Bliss booklet *Facts for Fathers* for more information on what you can do to help your partner.



How can I look after my other children while my baby is in hospital?

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.

Read Karen's story on page 4, which also deals the specific issues of having an older child, as well as a sick or premature baby.

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, 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.

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! Look out particularly 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 mother 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 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, call the Bliss Helpline on 0500 618140, or see the useful organisations at the back of the booklet.

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 dietician.

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 Helpline on 0500 618140.

Remember that it is entirely up to you whether you breastfeed or not, and if you do, for how long you breastfeed your baby. Research has shown that a mother's breast milk is the best source of nutrition for a premature or sick baby.

Formula milk

If your baby is on formula, they may go home with a special kind, 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.



"I continued to breastfeed Marc long after we were 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 Ebrey, mother of Marc, born at 24 weeks

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 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 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 (as indicated on page 26), 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 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 dietician, 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.



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.

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 dietician, they will also be able to advise you.

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

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

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.

nurses and doctors per baby as the neonatal intensive care unit; this is a standard, so you shouldn't worry about this. Some parents may feel anxious if they are used to a larger number of people caring for their baby.

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.

All babies and mothers 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, Maternal Health

Grant, 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 families* for further information.

Conclusion

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.

Enjoy!



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, 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 will be two years old in July 2009. She has a very mild form of cerebral palsy, but it is quite likely that, as she gets older, this won't have a big effect on her ability to walk.

"It's been wonderful to see her developing more into the lively, determined little girl she is today. It would seem she has reached her

'terrible twos' early; at nursery, she is known for being a little bit mischievous, taking other children's food and toys when she decides she wants them!

"Just a couple of weeks ago, at just over 21 months, Charlotte managed her first crawl. It was only three or four unsteady moves forward, but she has not stopped since. We write an online diary about Charlotte's development, and we were so excited, we had to share it straight away. We have so longed for this moment; she only started sitting about six months ago.

"It is too easy to become worried every time a premature baby is late with milestones, but it is not about how long it takes to get there – it is crossing the finishing line which is important."



Useful organisations

Benefits

Citizens Advice Bureau (CAB)

Will provide details of your local CAB.

† 020 7833 2181

www.nacab.org.uk

Tax Credits Helpline

Provides advice to families on tax credits.

† 0845 300 3900

www.hmrcgov.uk

Working Families

† 020 7253 7243

www.workingfamilies.org.uk

Bereavement

Child Bereavement Charity

Produces leaflets, books and videos for bereaved families.

Aston House, West Wycombe

High Wycombe HP14 3AG

† 0845 357 1000

www.childbereavement.org.uk

Cruse Bereavement Care

Helpline 0844 477 9400

www.crusebereavementcare.org.uk

SANDS (Stillbirth and Neonatal Death Society)

Telephone support and groups for bereaved families.

Helpline 020 7436 5881

www.uk-sands.org

Breastfeeding: expressing equipment

Express Yourself Mums Ltd

Full range of breastfeeding and expressing equipment including manual and electric pumps, feeding pillows, bras.

Adviceline 0870 389 5576

www.expressyourselfmums.co.uk

Medela UK Ltd

Produce a range of breast pumps and other breastfeeding accessories.

Huntsman Drive, Northbank Industrial Park Irlam, Manchester M44 5EG

† 0870 950 5994

e info@medela.co.uk

www.medela.co.uk

Counselling and advice

The Association for Postnatal Illness (APNI)

Helpline 020 7386 0868

www.apni.org

Birth Trauma Association

Offers support to all women who have had a traumatic birth experience.

www.birthtraumaassociation.org.uk

British Association of Counselling and Psychotherapy

Represents counsellors and psychotherapists and can signpost you to a local therapist.

† 0870 443 5252

www.bacp.co.uk

Cry-sis

Support for families with excessively crying, sleepless and demanding babies.

Helpline 0845 122 669

www.cry-sis.org.uk

Fatherhood Institute

Online information on fatherhood.

† 0845 634 1328

www.fatherhoodinstitute.org

Foundation for the Study of Infant Deaths (FSID)

Information about safe-sleeping and apnoea monitors.

Helpline 020 7233 2090

www.sids.org.uk

NHS Pregnancy Smoking Helpline

† 0800 169 0 169

www.givingupsmoking.co.uk

One Parent Families | Gingerbread

Support for lone parents

225 Kentish Town Road

† 0800 018 5026

www.oneparentfamilies.org.uk

Parentline Plus

Support to anyone parenting a child.

Helpline 0808 800 2222

www.parentlineplus.org.uk

Scottish Cot Death Trust

Helpline 0141 357 3946

wpf Counselling and Psychotherapy

Provides counselling across the UK.

23 Magdalen street, London S1 2EN

† 020 7378 2000

www.wpf.org.uk

Multiple births

Multiple Births Foundation

† 020 8383 3519

e info@multiplebirths.org.uk

Twins and Multiple Births Association (TAMBA)

† 01483 304442

www.tamba.org.uk

Disability and medical problems

Contact a Family

Provides support and advice to families caring for a disabled child or children with specific health conditions.

† 020 7608 8700

Helpline 0808 808 3555

Textphone 0808 808 3556

www.cafamily.org.uk

Scope

Support for cerebral palsy and related disabilities.

† 0808 800 3333

www.scope.org.uk

Safety

Bettacare Ltd

'Tiny Traveller' car seats.

† 01293 851 896

www.bettacare.co.uk

Royal Society for the Prevention of Accidents (RoSPA)

Gives advice on purchasing, fitting and using car seats for children.

† 0121 248 2000

www.rospa.co.uk

Celebration fund

To set up a Bliss celebration fund for your child call 020 7378 5740 or go to www.bliss.org.uk/sunshinefunds

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* download only ** subscription only

Parents: order online at www.bliss.org.uk or call 020 7378 1122
All publications are free to parents of a premature or sick baby

Health professionals: order online or call 01933 318503

Bliss, 9 Holyrood Street, London SE1 2EL
† 020 7378 1122 f 020 7403 0673 e enquiries@bliss.org.uk

Bliss parent messageboard: visit www.bliss.org.uk and follow the link.

Family Support Helpline: Freephone 0500 618140

RNID typetalk 018001 0500 618140

Blisstext text messaging service. Text 'your name' to 07800 00 8100 for details.



Family Support Helpline

Freephone 0500 618140

RNID typetalk 018001 0500 618140

Blisstext Text 'your name' to 07800 00 810.

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