



for babies born too soon,  
too small, too sick

# Bliss Community Health Professionals' Information Guide

Supporting families of premature and sick  
babies following discharge from hospital.

[www.bliss.org.uk](http://www.bliss.org.uk)

# Bliss Community Health Professionals' Information Guide

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## Foreword


The care of preterm and sick newborn babies has developed dramatically over the last two decades. Improved technology and advances in medical and nursing care means that we can now look after babies born very early in pregnancy and babies who are sick at birth.

Parents and other family members who have had a baby or babies in a neonatal unit may have experienced an enormous rollercoaster of emotions and lived through one of the most traumatic periods of their lives.

As hospitals seek to discharge babies into the care of their parents earlier, the role of community health professionals becomes ever more important, as does the increasingly specialist knowledge needed to support these babies and their families at home.

This guide explores both the medical and emotional stages that preterm and sick babies and their families experience. It also provides background information on a wide range of medical conditions, developmental issues and parents' concerns that you may encounter. There are signposts to further reading and other sources of information aimed at strengthening the support available for families in the community.

To prepare this guide, Bliss has worked with the Community Practitioners' and Health Visitors' Association.

A handwritten signature in black ink, appearing to read 'Andy Cole', with a second, less legible signature to its right.

Andy Cole  
Chief Executive

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## Introduction

This guide has been written specifically for health visitors and other community-based health professionals. It gives you up-to-date evidence-based information about the post discharge care needed by babies who have been born preterm or sick. Just as importantly, it highlights the support that you can give to their parents as they prepare for and adjust to family life after hospital.

It will also help you develop a greater understanding of neonatal care and the short and long term issues that affect babies and their families. The guide is designed to complement your own practice and to ensure that community health professionals feel confident and able to give consistent and appropriate advice to parents as part of a co-ordinated healthcare team.

Families whose babies are, or have been, cared for in a neonatal unit can have particular requirements in terms of information and advice. Health visitors are well-placed to provide this and families will value the support you can give them.

Babies' and parents' needs are diverse and vary according to circumstances and the stage they have reached, around the time of birth, while in the neonatal unit, after discharge home, during the first year and subsequently. By focusing on many different aspects of care (clinical, practical and psychosocial) the guide can help you individualise the care you provide, while at the same time contributing to parents' confidence in their own knowledge and skills.

For more information on Bliss resources and services for families and health professionals visit [www.bliss.org.uk](http://www.bliss.org.uk)

# 1

## Overview of preterm and sick newborn babies





# 1. Overview of preterm and sick newborn babies

- It is common for parents of preterm babies to experience feelings of grief, loss, fear and guilt for some time after their baby has been discharged from hospital.
- By building a strong supportive relationship with parents, you can significantly alleviate their distress and anxiety and make a valuable contribution to improving the outcomes for their preterm baby.
- It is important to ensure that their baby's developmental progress is closely monitored, while avoiding assumptions regarding the types of problems he or she might experience.

Survival rates of preterm babies (especially those born before 28 weeks gestation) have improved significantly over the last 30 years. This is due to technological advances in medicine, such as the widespread use of surfactant therapy for respiratory distress syndrome, together with antenatal glucosteroids and new ventilation techniques.

Assumptions should never be made about preterm babies and any problems that they may experience: each baby must be carefully assessed according to their individual health, development and needs. The baby's developmental progress should be closely monitored. The origin of developmental difficulties has been attributed to a delay in neurologic maturation, early cerebral injury, social factors, or reduced early growth<sup>1</sup>.

## Risk factors for preterm labour

A range of factors can contribute to the risk of preterm birth and/or low birthweight. These include both medical and social factors, many of which are interrelated and beyond the control of mothers and their families.

### Medical factors

If a pregnant woman experiences any of the following, she may be at a higher risk of preterm birth and/or having a baby with a low birthweight:

- Anxiety and stress
- Cervical incompetence/short cervical length
- Infections
- Low consumption of fish during early pregnancy
- Multiple pregnancy
- Older mothers
- Preterm rupture of the membranes
- Pre-eclampsia/hypertension
- Previous spontaneous preterm delivery
- Sexually transmitted diseases (including bacterial vaginosis and chlamydia)

- Systemic lupus erythematosus (SLE)
- Type 1 diabetes during pregnancy
- Uncontrolled asthma
- Being underweight
- Eating disorders
- Being younger than 15 years old

## Social factors

If a pregnant woman experiences any of the following, she may be at a higher risk of preterm birth and/or having a baby with a low birthweight:

- Alcohol misuse
- Cigarette smoking
- Intimate partner abuse
- Being a member of a high-risk ethnic group
- Being from a low socioeconomic class
- Substance misuse
- Unmarried or unsupported

## Classification of preterm and low birthweight babies

### By gestation

Preterm baby: born before 37 weeks

Moderately preterm baby: born between 35 and 37 weeks

Very preterm baby: born between 29 and 34 weeks

Extremely preterm baby: born between 24 and 28 weeks

### By weight at birth

Low birthweight baby: weighs less than 2,500g (5.5lbs)

Very low birthweight baby: weighs less than 1,500g (3.0lbs)

Extremely low birthweight baby: weighs less than 1,000g (2.0lbs)

## Impact on the parents

During pregnancy most parents imagine an ideal labour and birth, resulting in a perfect, healthy baby whom they can take home shortly after delivery. However it is common for parents of a baby admitted to a neonatal unit to have experienced a complicated pregnancy, labour and/or birth. The healthy baby they imagined is, in many cases, not the baby they see in the cot or incubator.

Feelings of parental grief, loss, fear and guilt are common, as well as anxiety about their baby's survival and long term future.

Parents can feel helpless, confused and frightened and it is not surprising that research has shown that mothers of preterm babies experience more severe levels of psychological distress in the neonatal period than mothers of term babies<sup>2</sup>.

For couples who have undergone several courses of fertility treatment before becoming pregnant (which can be a stressful and distressing experience in itself), the impact of then having a preterm birth may be particularly devastating. These cumulative difficulties can affect some parents, resulting in increased anxiety about the survival and well-being of their baby or babies.

## Health outcomes

Technological advances mean that the prognosis of very small preterm babies has improved significantly in recent years, and babies born from 29 weeks gestation onwards usually have a high survival rate and develop normally. However, extremely preterm babies born before 28 weeks gestation, or with a very low birthweight (less than 1,500g), may face an increased number of health or developmental challenges.

### Short to medium term outcomes

Apart from short term complications that may occur following birth, studies have shown that very low birthweight or extremely preterm infants can be at risk of:

- Poor health
- Slower growth
- Developmental disabilities
- Increased likelihood of cerebral palsy
- Visual problems
- Hearing problems
- Motor delay and poor motor skills
- Specific difficulties in areas of learning and academic achievement
- Difficulties with visuomotor integration
- Poor language skills

## Long term outcomes for extremely preterm babies

### EPICure 1

The first EPICure study started in 1995 to follow the survival, long term development and health status of a cohort of babies born before 25 weeks gestation. Results have since been published with regards to their outcomes at six and ten years of age. At six years of age the data revealed that 22 per cent had severe disabilities, 24 per cent had moderate disabilities, 32 per cent had mild disabilities, 41 per cent had some cognitive impairment and 22 per cent had no problems.

Physical disabilities include mild to severe forms of cerebral palsy, blindness and deafness. Twenty per cent of babies that survived have some form of cerebral palsy, although only half of these have a severe or moderate form. The study also showed that the most common medical problems were related to respiratory disease.

### EPICure 2

The way doctors and nurses look after preterm babies has changed considerably since the original EPICure study began in 1995, and more babies seem to be surviving now compared to then. A second study was undertaken during 2006 – collecting information on all babies born in England between the gestational ages of 22 weeks and 26 weeks and six days. A small section of the cord attached to the placenta was also looked at under a microscope to check for evidence of infection or inflammation occurring in the womb before the baby was born.

Using survival information from the 2006 study and outcome data from the 1995 study, the chances of survival without serious disabilities in England today have been roughly estimated as<sup>3</sup>:

- 23 weeks - 11 per cent
- 24 weeks - 24 per cent
- 25 weeks - 40 per cent

## Chris and Nicola's story

Chris and Nicola Robson from Lockerbie were terrified when their baby, Millie, was born at 24 weeks in 2005, weighing just 750g. Millie was whisked away to intensive care where she stayed for eight weeks. During this time she suffered three cerebral haemorrhages, had a total of eight blood transfusions and was suspected to have an infection in her intestine. Nicola and Chris found it difficult to cope, not knowing what each day would bring.



Nicola couldn't stay on the unit at the hospital where Millie was transferred to and found it practically and emotionally stressful having to travel so far every day to visit her.

***"The whole experience was exhausting. At the time I just focussed on my little girl getting well and I was thankful we were in a great hospital with amazing staff. I asked questions when I had them and they were always answered, which helped me through each day,"*** says Nicola.

***"Looking back I wonder how we got through but it has made us stronger. The hardest part at times was when I had to go back to work and could not be with my wife and daughter. We came through some really dark days to have a brilliant little girl now,"*** says Chris.

Millie is now five years old and a very happy, healthy little girl with no side effects from her prematurity. She is full of life and is a fantastic daughter and big sister. Chris and Nicola feel very fortunate that their life has turned out this way.



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## Useful information

[www.epicure.ac.uk](http://www.epicure.ac.uk)

# 2

## Understanding the parents' perspective





## 2. Understanding the parents' perspective

- Meeting parents before their baby goes home from the unit is crucial in helping to build their trust and confidence in you.
- You can also play an important role in encouraging parents to be actively involved in their baby's care as soon their baby is stable enough.
- Acknowledging that this is an emotional and difficult time for parents, listening to what they have to say and encouraging them to express their feelings will help them come to terms with what has happened to their baby.

The birth of a preterm or sick baby can affect parents in different ways depending on the circumstances of the birth and the family situation. Over the last decade, the different pressures experienced by parents whose baby is admitted onto a neonatal unit have been widely documented. The birth of an extremely preterm or extremely low birthweight baby is now recognised to be a particularly stressful event for parents and other members of the family.

While the majority of babies require only special care, any form of neonatal care is likely to appear frightening to parents. Grief, anxiety, guilt, feelings of failure and helplessness can impinge on the early parent-child relationship and may have long-lasting effects on the parents' perceptions of their child's health, many of whom worry about their baby's survival and the possibility of their child having a long term disability.<sup>1, 2</sup>

### What their baby may look like

If the baby was born very preterm, parents are likely to be shocked by their tiny size and appearance. It is also likely that they will see various tubes and equipment attached to their little bodies.

The earlier a baby is born, the less mature their lungs will be, so very preterm babies may be dependent on a ventilator to help with their breathing. The different types of equipment will seem alarming to parents until they become more familiar with what it is for and how it works.

### Common characteristics of preterm babies may include:

- Very thin, transparent, waxy skin through which the fine network of underlying veins is easily seen.
- A covering of fine body hair (lanugo), which normally disappears after 38 weeks gestation.
- Very little subcutaneous fat, hair or external ear cartilage.
- Jaundice.
- Reduction in spontaneous activity and tone.
- In males, the scrotum may have few rugae, and the testes may be undescended.
- In females, the labia majora do not yet cover the labia minora.

### Encouraging the parents' relationship with their baby

Parents should always be encouraged to spend time with their baby, talking to them and touching him or her whenever possible, with most units providing a 24-hour open door policy for parents and siblings.

Many units have also introduced a daily 'quiet time' during which handling of the babies by medical staff is actively discouraged and light and noise is kept to a minimum. Although covers may be placed over the cots or incubators, this is a good opportunity to support new parents who are unsure about using comforting touch and/or keen to spend time with their baby undisturbed.

The best way to improve a parent's self-esteem and care-giving competence is to encourage regular and frequent visits to their baby on the neonatal unit and the earliest possible involvement in their practical and emotional cares, such as holding, cuddling, feeding, bathing and nappy changing.

These activities improve the parent's ability to bond with their baby, and benefit the baby by allowing him/her to get to know their parents' voices, touch and smells. Practical and emotional involvement in the baby's cares has also been found to increase the incidence and duration of lactation in the mother.<sup>3</sup>

It is also important to consider the different pressures each parent may be under. Fathers in particular may have to look after other family members and go to work as well as being supportive of their partner. It is important that you acknowledge these challenges by encouraging fathers to express how they are feeling, providing relevant stress management techniques for both mothers and fathers, and always addressing both parents when talking about their baby. Parents may find it helpful to seek support through whichever of the following might be available on the unit: a parent support group, a counsellor, or a Bliss support group.

## Liz and Anthony's story

Doctors told Liz, from South London, that Henry (born at 24 weeks) might not make it. Henry suffered a traumatic birth and was bruised and swollen from his head to shoulders. He suffered from cerebral bleeds and it was feared he might have been severely brain damaged. He was monitored in an intensive care unit for eight weeks and then spent a further four weeks in SCBU.

*"It was hard being scared to touch him. I didn't really feel like his mother as all the nurses and doctors were doing a better job caring for him than I could. The only thing I clung to was that I could give him my milk. At first I thought I wouldn't be able to cuddle him but skin-to-skin care helped a lot. As I became more capable at giving Henry his medications it got easier, and he felt more like my son,"* says Liz.



Anthony had a different experience to Liz. After the first week he had to get on with normal life and go back to work while Liz was at the hospital all day, every day. However, he still managed to go to the hospital every evening after work and at the weekends too. He would change Henry's nappy and gave him skin-to-skin care whenever he could. This really helped him bond with his son.

## Coming to terms with the birth

Parents may need help to accept a tiny, sick baby as their own. They may not feel that this is their baby because he or she is not at home and is in the care of other people instead. Family and friends might not know what to say to people who have a baby on the neonatal unit, and this can be difficult for parents to deal with.

### Practical tips

There are many ways you can help parents come to terms with what has happened to their baby:

- ✓ Acknowledging that this is an emotional and difficult time for them.
- ✓ Listening to what they have to say.
- ✓ Encouraging them to express their feelings.
- ✓ Assuring them it is ok to pay attention to their own needs and those of the rest of the family, particularly those of any other children.
- ✓ Reminding them that in the middle of all the stress they have still given birth to a baby.
- ✓ Congratulating them and explaining that it is still all right to celebrate this new member of the family.
- ✓ Encouraging the mother to express her breast milk.
- ✓ Encouraging both parents to touch, stroke and cuddle their baby despite the barriers of equipment such as the incubator.
- ✓ Encouraging them to be actively involved in their baby's care as soon their baby is stable enough.



## The relationship between parents, unit staff and you

It is important to meet parents and begin a relationship with them before the baby goes home. This builds the parents' trust and confidence that support will be available to them at home, once their baby is discharged.

It is also vital to establish early, sensitive and consistent communication with hospital staff, particularly as staff on a neonatal unit are often extremely busy and may not be able to spend as much time talking to parents as they, or the parents, would wish. Parents often find that the stress they are under makes it difficult to retain all the information given to them. Repeating this information to them at a later time, in simple, non-technical language, can help them to understand what is happening to their baby and may help encourage them to ask more questions.

Parents have also said it can be helpful to talk to another health professional, who is not part of the unit, but is knowledgeable about the medical procedures the baby will be receiving and can explain why certain types of equipment are used.

### Practical tips

Meeting parents prior to discharge and establishing good channels of communication with unit staff will help you to:

- ✓ reduce maternal distress
- ✓ provide a feeling of 'normality' which parents may have felt lacking following their baby's preterm birth
- ✓ assist parents in coping with the emotional highs and lows that accompany their baby's treatment and stay on the unit
- ✓ promote babies' health and development
- ✓ help parents who are facing the prospect of an adverse outcome, such as the death of their baby.<sup>4</sup>





## Siblings

Having a brother or sister on a neonatal unit can be a very hard time for the baby's siblings. The children probably know that their parents are experiencing problems but may not be old enough to understand what is going on, or to do anything helpful. Long maternal absences will also be difficult for young children, and the arrival of a new brother or sister can trigger jealousy, whether the baby is at home or in hospital. Often this may be taken out on the parents themselves, in the form of tantrums, aggression or clinging behaviour.

If possible, normal routines such as going to nursery should be continued. The children may be upset that a different member of the family has taken over responsibility for looking after them, but these routines can help the family get through this time of stress.

It is important to advise parents to take the time to explain to their other children what is happening. They should give them reassurance that even though they are busy looking after the new baby they still love them and they are as important as ever.

It is also good for the parents to involve their other children as much as possible in the care of the new baby. How they chose to do this will depend very much on the individual family, but options include taking siblings to the hospital on some visits and encouraging them to make cards and paintings that can be hung near the baby's incubator.

The effort and logistics involved in parents visiting babies in hospital cannot be underestimated, and single parents especially may need help with getting older siblings to and from school. Children should not be taken to the neonatal unit if they have an infectious illness such as chickenpox or a heavy cold, and they should wash their hands thoroughly before entering and on leaving the unit.

## Diversity issues

In a technologically complex and highly intense arena such as the neonatal unit, cultural consideration in provision of care may be overlooked.<sup>5</sup> However, studies have consistently shown that certain ethnicities and races are determinants of low birthweight, preterm delivery and neonatal death.<sup>6</sup> The different practices which shape the way parents from other cultures care for their children may also influence their health beliefs and behaviours; it is important that such differences be sensitively addressed and openly discussed.

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information@bliss.org.uk
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**3**

## The neonatal unit





### 3. The neonatal unit

- Health visitors are always welcome to visit the unit so you can meet the baby, his or her parents, and discuss the infant's progress with the staff.
- It can be difficult for parents to develop a close physical attachment to their baby in a neonatal unit, particularly if the doctors or nurses have to carry out invasive procedures which prevent the parents from having contact with their son or daughter. We recommend spending time with parents and encouraging them to use 'positive touch' as a way of supporting parents to engage with and touch their baby.

One in nine babies born in the UK will spend at least a few days in a neonatal unit which specialises in looking after preterm, small and sick babies. Some babies may have an infection and need intravenous antibiotics, others need extra breathing support or extra monitoring, some may need treatment for jaundice or they may be suffering from other medical complications. Most preterm babies will need neonatal care. Preterm birth can happen for many different reasons, including a multiple pregnancy, pre-eclampsia, an intrauterine infection, preterm rupture of membranes, reduced intrauterine growth or stressful events. The length of a preterm baby's stay in the neonatal unit will vary from days to weeks or months, depending on his or her needs.

#### Neonatal networks and units in the UK

The British Association of Perinatal Medicine (BAPM) *Service Standards for Hospitals Providing Neonatal Care* (2010)<sup>1</sup> sets out the principles for the delivery of neonatal care based on networks, which it believes is valid across the UK.

To improve the delivery of care for both mothers and babies, neonatal units throughout the UK are divided into regional clinical networks.

Their primary aim is to ensure that mothers and babies are cared for in a level of unit appropriate to their needs, as near to their home as possible. Each network is made up of a number of different types of unit, capable of delivering a range of care. All networks have at least one level three or intensive care unit which is the tertiary centre. The BAPM Service Standards has defined the three different types of neonatal units:

**Special care baby units (SCBU)** provide special care for their own local population. They mainly deliver level one care, but will also stabilise any babies that require more high dependency or intensive care before transfer.

**Local neonatal units** provide all levels of care for their local population, but they transfer babies that require complex or long term intensive care.

**Neonatal intensive care units (NICU)** provide the whole range of care for their local population along with additional care for babies and their families referred from the neonatal network.

**England** In 2008, the Department of Health (DH) set up a Neonatal Taskforce to agree a set of measures which would make a significant difference to the quality of neonatal services. The taskforce produced a *Toolkit for High Quality Neonatal Services*, designed to stimulate the action needed to improve services and ensure that the baby and family remain as the focus along the whole pathway of care.<sup>1</sup>

**Scotland** In 2010, a Neonatal Expert Advisory Group was set up in Scotland to take forward the recommendations of the neonatal subgroup of the Maternity Services Action Group. This group has overseen the establishment of three Managed Clinical Networks for Scotland, structured in line with the existing regional planning boundaries.

### Different levels of care

The DH *Toolkit for High Quality Neonatal Services* and the draft *Scottish Service Standards for Neonatal Care* define three levels of neonatal care:

- Level 1 (special care, the least intensive care)
- Level 2 (high dependency)
- Level 3 (intensive care)

In addition to the three key levels of care within neonatal units, there is a fourth level, transitional care.

#### Level 1. Special care – for babies who need:

- continuous monitoring of their breathing or heart rate
- additional oxygen
- tube feeding
- phototherapy
- recovery and convalescence from specialist care.

#### Level 2. High dependency care – for babies:

- who are receiving nasal continuous positive airway pressure (CPAP) but who weigh below 1,000g and do not fulfil any of the categories for intensive care
- receiving parenteral nutrition
- with apnoeic attacks who require stimulation
- needing short term intensive care.

### Level 3. Neonatal intensive care – for babies:

- needing respiratory support (ventilation)
- weighing less than 1,000g and/or who were born at less than 28 weeks gestation and need nasal continuous positive airway pressure
- with severe respiratory disease
- who require surgery.

### Transitional care

This is special care for babies who are being cared for by their mothers in preparation for going home. Mother and baby share a room and this type of care may involve light therapy for jaundice, tube feeding and intravenous antibiotics.

### Recommended nursing ratios:

The DH *Toolkit for High Quality Neonatal Services*, and BAPM recommend the following staffing levels for neonatal care<sup>2</sup>:

- Intensive care: minimum of 1:1 staff to baby ratio
- High dependency: minimum of 1:2 staff to baby ratio
- Special care: minimum of 1:4 staff to baby ratio

### Communication with the neonatal unit staff and parents

Following the admittance of a newborn baby to the neonatal unit staff may inform the child's health visitor about the admission, and also before the baby is about to be discharged.

You are always welcome to visit the unit to see the baby, meet the parents, and to discuss the child's progress with the staff. In most cases, a visit to the unit (including participation in ward rounds) can be arranged over the phone. Establishing a relationship with the neonatal staff and sharing any concerns about the family may be beneficial, as can meeting the parents on the unit and establishing a relationship with them.



## Interdisciplinary communication

It is important that you are aware of all the health professionals that have been involved in the care of the baby including, for example, the paediatrician, dietitian and physiotherapist. You should also establish which health professionals may continue to be involved in the baby's care after the baby leaves the unit and/or need to be informed of the baby's condition and progress.

## Transfer between hospital units

The main purpose of the Managed Clinical Networks is to ensure that appropriate care is available as near to home as possible. If, for example, a baby needing neonatal intensive care is born in a hospital with a special care unit, he or she will be transferred to either the local neonatal or intensive care unit within the network for more specialist care. Where mothers have been identified as presenting a high risk of giving birth to a sick baby, they may be transferred to the hospital within the network with the most appropriate level of specialist obstetric and neonatal care.

Transferring preterm or sick newborn babies over even short distances can be very stressful for the families involved and for the infant. Specialist staff and equipment are used to transfer the baby safely. Transfers in-utero are generally recognised as presenting fewer risks and causing less stress because mother and baby are not separated.

Whatever the reasons for the transfer, it is always a very anxious time for parents. Transfer from an intensive care unit back to their local special care unit in particular brings very high levels of stress due to less intensive levels of care, the difference in regime and the fact that there are fewer staff for each baby. Transfer to a lower level of care or unit will only take place because the baby's condition is sufficiently improving and is often the precursor to a welcome return home.



## Supporting the parenting role

Developing a close physical attachment to a baby in a neonatal unit can be difficult for parents, particularly when the staff are carrying out many invasive procedures which prevent them from having contact with their baby. 'Positive touch' is a technique which can encourage parents to engage with, and touch their baby. The neonatal staff will show parents the ways in which they can support their baby and the choice of the most appropriate level or kind of contact will depend on the baby's condition at the time.

**Positive touch** Positive touch can be used in numerous ways, all of which provide comfort and reassurance to the baby, as well as greatly enhancing parent-baby attachment. This has the dual benefit of helping parents to bond with their baby as well as counteracting some of the discomfort the baby experiences.



**Containment holding** If a baby will be more comfortable left lying in the incubator, staff may suggest that parents let their hands touch their baby by placing one hand on the baby's head, and one on the middle. This 'containment holding' helps the baby feel secure, relaxed and loved.

**Still touch** Still touch can help babies learn to trust contact and avoids the overstimulation which stroking can produce in very fragile babies. Movement can be gradually introduced depending on the baby's response.

**Massage** As the baby grows stronger, massage can be introduced. Baby massage has a variety of health and emotional benefits. It is a skill best taught by a qualified baby massage instructor and how it is administered will vary at different developmental stages.



**Skin-to-skin care** Skin-to-skin care is the term used to describe a baby being placed in contact with a parent's chest, like a young kangaroo in its mother's pouch. This is often the first time parents feel that they are having loving contact with their baby. Skin-to-skin care can help with breast milk production and with establishing breastfeeding when the baby is ready. Research suggests that babies who experience skin-to-skin care have a more regular heart rate and increased oxygen levels as they are calmer. In the longer term it may also help with weight gain and in establishing sleeping patterns.<sup>3,4,5</sup>

### Equipment and procedures in the neonatal unit

A number of invasive techniques may be necessary in the delivery suite immediately after birth for resuscitation or stabilisation of the baby. Nearly all of these babies will need to be admitted to the neonatal unit for a number of reasons, including a variety of short term problems or complications that require the extensive use of specialised equipment.

Although neonatal unit staff usually explain the use of specialised equipment, the unit environment – with its high tech machines, 'alien' procedures and busy staff – is often overwhelming, and in the early days parents may find the constant sound of alarms going off particularly distressing. Parents are frequently concerned that their baby may suffer pain or discomfort when tubes are inserted or, for example, when their baby is on ventilation. They require reassurance that their baby will be comforted, and/or given pain relief if necessary.

Parents may voice the need for further explanations about what has happened in the neonatal unit long after the baby has returned home with them. Any further explanations and reassurance that you can provide will therefore be extremely helpful.

The equipment and procedures used to treat complications on the neonatal unit include:

**Monitoring** Many clinical signs may be monitored in critically ill and convalescing newborn babies. These are some of the routine parameters, many of which are often contained in a single vital signs monitor.

**Heart rate and respiratory rate** The baby's heart and respiratory rates are usually measured from electrodes on the baby's chest. An alarm is triggered if the heart or breathing rate becomes too fast or too slow. During convalescence, babies are often monitored using a simple apnoea alarm which detects breathing movements and is triggered if the baby pauses for too long between breaths.

**Blood pressure** Sick babies may have their blood pressure measured continuously via a catheter inserted into an artery. This gives a constant display of blood pressure and will sound an alarm if it becomes too high or low. Alternatively blood pressure may be measured by a small cuff wrapped around the baby's arm or leg. The cuff will automatically take the baby's blood pressure at regular times and display this on a screen.

**Oxygen and other blood gas levels** Oxygen saturation monitoring (also called pulse oximetry) is commonly used. A small probe is wrapped around a baby's foot or hand, which uses a light sensor to help determine whether a baby needs more or less oxygen. These monitors are very prone to false alarms when the baby moves and they are relatively poor at showing when too much oxygen is being given. For this reason many babies are also monitored with other devices, such as transcutaneous oxygen and carbon dioxide probes or arterial catheters, which measure blood oxygen levels differently so that excess oxygen may also be detected. The definitive measurement of all blood gas parameters, such as oxygen and carbon dioxide, is performed by taking a blood gas sample from an artery.

**Cranial ultrasounds** These are standard investigations performed on the majority of preterm babies, acutely ill babies, newborns displaying abnormal neurological signs following a traumatic delivery or those who suffered birth asphyxia. The aim of the cranial ultrasound scan is to identify any major abnormalities that may influence management and care. The scanning is non-invasive via a jelly-covered probe placed over the anterior fontanelle. Results may show structural abnormalities, haemorrhages, periventricular leucomalacia (following previous hypoxic brain injury) or hydrocephalus.

A series of cranial ultrasounds may be performed according to the findings, level of prematurity of the baby and medical judgement. A CT and/or MRI scan may be arranged following a cranial ultrasound according to the findings.

## Respiratory support

**Oxygen** Oxygen is commonly used in the treatment of babies on the neonatal unit. The baby's oxygen requirements are monitored by pulse oximetry and/or blood sampling. Oxygen can be used while the baby is ventilated or on CPAP (see next page). It can also be administered directly into the incubator for babies who need additional oxygen but do not require ventilatory support, or by nasal cannulae or a face mask. Babies with Chronic Lung Disease (sometimes called bronchopulmonary dysplasia, see the *Glossary* for more information) may

be discharged home with oxygen therapy via nasal cannulae. Very rarely an oxygen hood is used to administer oxygen. This is a clear plastic box that fits over a baby's head and supplies oxygen. It is primarily for babies who can breathe on their own, but need some extra oxygen.

**CPAP (continuous positive airway pressure)** This is a form of non-invasive respiratory support to treat both term and preterm babies with respiratory disease. CPAP delivers a positive pressure applied to the airways of a spontaneously breathing baby throughout the respiratory cycle. Through gentle distension of the lungs it prevents collapse of the alveoli and terminal airways during expiration. Warmed, humidified air/oxygen is delivered via the system (most commonly by nasal prongs and less commonly via face mask, nasal pharyngeal tube or endotracheal tube). CPAP is used to support newborns who can breathe spontaneously but who have mild or moderate respiratory distress syndrome, newborns with apnoeas of prematurity and obstructive apnoeas, and newborns following extubation.

**Extracorporeal membrane oxygenation (ECMO)** ECMO is a complex technique that helps support babies with severe respiratory or cardio-respiratory failure. Venous blood is drained via a cannula to a mechanical circuit containing an artificial membrane lung (where gas exchange takes place) before returning oxygenated blood back to the baby. ECMO allows the lungs to rest and recover without barotrauma or oxygen toxicity.

**Nitric oxide** This is a drug which is delivered as a gas via the ventilator to the lungs of babies with severe problems with the circulation of blood around the lungs. The gas causes the pulmonary blood vessels to dilate, allowing better flow of blood past the lungs and hence better exchange of oxygen and carbon dioxide. Delivery of the gas requires specialised equipment and expertise which is usually only available at specialised neonatal centres.

**Ventilation** In some preterm babies, especially those born before 28 weeks gestation, the brain's respiratory centre has not had time to mature and respiratory support in the neonatal period is essential for their survival. In such cases, a mechanical ventilator delivers a mixture of air and oxygen to the baby's lungs. It can help the baby's own efforts to breathe or, if necessary, take over the breathing function completely. There are several different types of ventilation in use. The most common type gently pushes the air/oxygen mix into the lungs, and then allows time for the air and carbon dioxide to exit. The speed at which this happens can be varied. It can be adjusted to match the baby's own breathing rate (normally between 60 and 80 breaths per minute). Other types of ventilators include jet, oscillatory and flow-interrupter ventilators that can provide 400 to 900 breaths per minute. High frequency oscillatory ventilation may be particularly suitable for babies with serious breathing problems.

As the practice of administering antenatal steroids to mothers threatening to go into preterm labour and giving selected babies exogenous surfactant has increased, the severity of respiratory disease in newborns has been reduced.

## Other equipment and procedures

**Phototherapy** Sometimes bilirubin can build up in the blood of newborn babies because the liver cannot remove it fast enough. Bilirubin is broken down by light, so fluorescent lights (phototherapy) may be placed over the baby's incubator or the baby may be laid on top of a biliblanket that gives out similar light. Babies with jaundice usually receive phototherapy treatment for three to seven days. If bilirubin levels become too high, on rare occasions an exchange blood transfusion may be necessary.

**Infusion devices** These are used to provide accurate administration of intravenous and intra-arterial fluids, such as:

- IV/IA medication by slow infusion rather than bolus injections
- blood products via peripheral cannula over a prescribed period
- total parenteral nutrition.

Lines or catheters are inserted into blood vessels in different parts of the body as appropriate. Some of those that are commonly used include:

- **Umbilical catheters** These are relatively easy to insert in newborns and have been used for sick babies for many years. Umbilical artery catheters (UACs) are threaded to the aorta. Through this, blood can be drawn and blood pressure and gases monitored. Multiple lumen umbilical vein catheters (UVCs) are used to reduce the need for peripheral venous access in extremely preterm and/or very sick babies, and are used to give fluid, blood, nutrients and medications. Once an umbilical catheter is removed, the normal process of closure of these blood vessels occurs to form the umbilicus.
- **Peripherally inserted central lines** A type of central line that is placed into a vein, usually in the arm or leg, to allow intravenous feeding and medication.
- **Surgically inserted central lines** These are inserted after direct cut down; usually done with a Hickman or Broviac catheter into a large vein in the neck or leg.

## Incubators

Placing babies in incubators will help to keep them warm through temperature regulation and may protect them from infections and noise. There are various types of incubators. Some are closed boxes with hand-sized holes in the side and around which air can circulate. These can keep the heat in and help control the humidity around the baby and so prevent loss of too much moisture by evaporation from the skin. Other incubators have open tops and often an overhead heater. These can give easier access to the baby. Some babies will be transferred from an incubator to an open cot with a heated mattress.

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# 4

## Nutrition and feeding issues in the early weeks







## 4. Nutrition and feeding issues in the early weeks

- Preterm babies can be fed on human milk (sometimes fortified), a preterm infant formula, or a combination of these.
- Many mothers feel that providing breast milk is the one thing that they alone can do. It is important for the mother to express eight to ten times in 24-hours and once during the night to mimic a baby's pattern of feeding.
- Provision of expressed breast milk to preterm babies has been associated with low rates of a variety of serious illnesses, for example, necrotizing enterocolitis (NEC), and sepsis, which have a high mortality rate.

It is critical for a baby's healthy development that they receive adequate nutrition according to their size and gestation. Ensuring that the baby's nutritional intake meets their requirements for growth is a major concern. Preterm babies have higher nutritional requirements per kilogram of body weight than term babies due to their rapid growth rate. Stores of glycogen and fat are built up over the third trimester of pregnancy, so babies born preterm have limited reserves of energy at birth. This means that a source of nutrition is vital from soon after delivery.

Establishing an adequate intake can be difficult during a sick baby's first few days and weeks as they may be unable to tolerate large volumes of nutrition either into their stomach via tube (enterally) or intravenously (parenterally). Babies' dietary needs vary, depending on their maturity, nutritional and clinical status.<sup>1</sup>

Feeding practices in preterm and very low birth weight babies can vary widely between and within neonatal units, however there are greater moves to guidelines based on clinical evidence.

Feeding and growth often emerge as major areas of concern for parents of preterm babies, both when the baby is in hospital and once he or she has been discharged. This section deals mainly with early feeding and nutritional issues – those encountered in the days and weeks immediately after birth – when many preterm babies will still be in hospital. It also touches on feeding issues that may emerge later (these are dealt with in more detail in Chapter 8, *Helping the family at home*).

## Modes of feeding

Although babies are neurologically and developmentally able to suck and to swallow from early on in gestation, it takes time for preterm babies to effectively coordinate sucking with swallowing and breathing. This co-ordination is mastered between 32 to 36 weeks' gestation. Many preterm babies now leave hospital for home at about 35 weeks gestation when they may still be establishing this co-ordinated feeding pattern. Before a baby is mature enough to suck directly from the breast or a bottle, expressed breast milk or formula milk will need to be given through a tube passed through the nose or the mouth into the stomach (these are called nasogastric or orogastric tube feeds).



### Parenteral nutrition

Beginning very soon after birth the baby will need adequate fluids and nutrition. If these cannot be given by mouth because of the infant's condition, intravenous or parenteral nutrition may be given. It is common for there to be a combination of enteral and parenteral nutrition. Parenteral nutrition may also be indicated:

- to support nutrition in preterm babies who require a slow increase in enteral feeds
- as a sole source of nutrition if the gut cannot be used for any reason.

### Trophic feeds

Trophic feeds are tiny amounts of enteral feed, preferably colostrum or breast milk given via a nasogastric tube following birth as soon as the baby's clinical condition allows. This has been shown to encourage gut development and reduce morbidity, for example, less sepsis and quicker to full enteral feeds.

Before a baby starts to take suck feeds there are a number of things that can help support the development of their feeding skills:

- **Non-nutritive sucking**  
Non-nutritive sucking is practiced by babies in-utero as they suck on their hands and fingers. It is important to encourage this in the neonatal unit when babies are not yet able to suck feed. This encourages them to practice their sucking and can also provide comfort. Non-nutritive sucking during a tube feed can build an association between sucking and having milk in their stomach and lead to a faster transition to full suck feeds. This can be carried out using a pacifier/dummy or by encouraging the baby to suck at the mother's emptied breast after she has expressed milk.
- **Skin-to-skin contact**  
Bringing the baby out of their incubator or cot during feed times and supporting them to be held skin-to-skin can help both with the mother's milk production and in the transition to breastfeeding. A mother can learn to identify feeding readiness cues at feed times and encourage licking and tasting milk near the nipple as early feeding experiences during tube feeding.
- **Mouth cares with milk**  
Using expressed breast milk or formula when doing mouth care can give a baby early positive taste and smell experiences and encourage the transition to oral feeding.



## Types of feeds

### Breast milk

Breastfeeding is the best start for all babies and has some specific additional benefits for the preterm infant. Breast milk is the best food for preterm babies as it provides immunologic, antioxidant and nutritional factors that are absent in formula milk. Provision of expressed breast milk to preterm babies has been associated with low rates of a variety of serious illnesses, for example,

necrotizing enterocolitis (NEC), and sepsis, which have a high mortality rate.<sup>2,3</sup> Increasingly compelling evidence demonstrates that breast milk imparts advantages in cognitive development in preterm babies.<sup>4</sup>

### Donor breast milk

Some units use breast milk that has been expressed and donated by other mothers. Milk donors are screened and the milk is pasteurised so it is safe to give to babies. Donor milk is better tolerated by very sick and preterm babies than formula, and can help to prevent some of the complications that can follow if babies are fed formula early on. The use of donor milk can be used to bridge the gap while a mother's milk supply comes in, and provides a vital support to encouraging breastfeeding. Donor milk should always be obtained from a milk bank operating according to NICE guidelines.<sup>5</sup> Donor milk banks are not present in every neonatal unit, however most will readily transport milk to units requesting it. Donor milk can be used to make up the shortfall if the mother is not producing sufficient milk for her baby and is usually given according to a guideline to ensure that those babies most in need are prioritised.<sup>6</sup>

### Fortifiers

Breast milk may not provide sufficient calcium, phosphorus or protein, trace elements and vitamins for some preterm babies. Studies of infants fed fortified versus unfortified human milk have found that intakes of protein and minerals as well as rates of gain in weight and length are greater in those babies fed fortified human milk.<sup>7</sup> For these reasons, breast milk may need to be mixed with one of several available breast milk fortifiers before feedings. Fortifiers are available only in hospital, however, some babies are discharged on fortifier for a short time and it is provided by the neonatal unit. (See *Bliss Briefings – Discussion paper on the use of breast milk fortifiers in the feeding of preterm infants* for more information).



## Formula milk

If the baby is not being fed on breast milk, specially formulated preterm formulas will be used. Formulas used for term babies are not suitable for preterm babies. If the preterm baby needs more breast milk than is available, and they are not in a high risk group which would benefit from donor milk, the shortfall can be made up with preterm infant formula. If a baby is on any formula at discharge they are usually changed to a post discharge formula designed for preterm babies, to ensure continued catch up growth and replenishment of nutritional status. This formula can be given for three to six months post estimated date of delivery and can be prescribed in the community. Preterm babies may therefore be fed on human milk (sometimes fortified), a preterm infant formula, or a combination of these.

## Supporting the mother to breastfeed

You can support and encourage mothers who are expressing breast milk in a variety of ways:

- ✓ Encouraging mothers to look after their own health and ensure that they take sufficient rest and follow a healthy diet.
- ✓ Providing consistent support and advice. Conflicting advice can undermine confidence - we recommend the Bliss *Breastfeeding your preterm baby* booklet which has the up-to-date evidence based advice for mothers of preterm babies.
- ✓ Providing mothers with or helping them to access the equipment needed to facilitate expressing at home, storing and transporting of their milk.
- ✓ Facilitating contact with a breastfeeding counsellor who can give them practical advice and emotional support.

## Encouraging the expression of breast milk

Mothers who have to express milk at home or in a room, without the presence or stimulation of their baby, may find it difficult to produce enough milk. Research has shown that having a photograph of the baby nearby or holding and smelling a piece of clothing that the baby has worn may prove beneficial in improving the flow of breast milk when using an electric breast pump.<sup>8</sup>

The milk flow may also improve if the baby is close to the mother. Some units are able to provide portable pumps and screens so a mother can express next to her baby at the cot side. It is becoming increasingly recognised that skin-to-skin care can also help to stimulate the mother's breast milk production.<sup>9</sup>

For mothers who have succeeded in lactation using an electric pump, the transition from tube feeds to breastfeeding may nevertheless need support from you and other neonatal staff.<sup>10</sup>

Bliss has produced a booklet *Breastfeeding your preterm baby* (Bliss seventh edition, 2010) which will be helpful for parents.

In view of the many benefits associated with the feeding of breast milk, mothers are encouraged to express breast milk for their preterm babies as soon as they can, within six hours of delivery if possible to ensure colostrum is removed and milk production is initiated. At a time when medical staff can appear to have taken over caring for their baby, many mothers feel that providing breast milk is the one thing that they alone can do. It is important for the mother to express eight to ten times in 24-hours and once during the night to mimic a baby's pattern of feeding and work to produce the volume of milk the baby will need for the future.



## The baby's growth



Early postnatal increases in weight, head circumference and length will be measured and the baby's weight will be plotted on a preterm centile chart to monitor growth velocities. After discharge the frequency of weighing and the measuring of the baby's length is negotiable depending on the baby's progress.

There is no established standard of growth for the first 28 days of life although all babies have an initial weight loss: this can be up to 12 per cent in very immature babies and is usually not a cause for concern. Healthy preterm babies will catch up to their birth weight within one to

three weeks; however, they may not be expected to catch up to grow along their birth centile as the initial weight loss is primarily extracellular water which they are not expected to regain. Weighing procedures may cause stress and anxiety to parents, as growth may initially be very gradual.<sup>11</sup>

It is important, therefore, that you strike the right balance between reassuring parents that their baby is doing well and being alert to any significant growth problems that may need addressing by the appropriate health professionals. Any concerns about growth will be referred to the paediatrician or dietitian.

Issues around growth may also be associated with feeding itself. It is not unusual for preterm babies to have uncoordinated feeding patterns until they have reached term gestational age. Early negative oral experiences, such as intubation and suctioning, increase the potential for aversive feeding behaviours.

It is recommended that a paediatric dietitian and speech and language therapist be part of the neonatal unit team to monitor the baby's progress while they are on the unit and following the baby's discharge. Some units may also use the services of community therapists following discharge.



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**5**

**Multiple Births**





## 5. Multiple births

- A simple thing like offering to weigh the babies at home for the first few weeks, if the visiting community neonatal nurse is not doing so, can significantly relieve pressure on parents, especially for those who have other children as well.
- You may need to gain additional knowledge and skills from a breast feeding counsellor to provide the appropriate support to a mother who wants to breastfeed twins or multiple babies.
- Continuing support and practical suggestions from you, as well as signposting to other support agencies, are essential. Studies have found that mothers of multiples have almost twice the average risk of postnatal depression.

Each year in the UK there are more than 10,000 multiple births. With advanced fertility techniques and mothers delaying pregnancy until later in life along with continual improvements in the care of preterm babies, it is likely that this number will increase. Compared with singleton pregnancies, pregnancies with multiple foetuses are associated with increased risks for both the mother and the babies including preterm labour and birth.<sup>1</sup>

Parents are likely to experience additional strain and stress as the medical needs of siblings, or local capacity issues, often mean that the babies need to be cared for in separate hospitals. Siblings may also be ready for discharge from hospital at different times and hospitals differ on whether a well baby should remain with his or her siblings in hospital until they are all fit to be discharged. Alternatively, the hospital may take into account the parents' preferences regarding this. Following discharge from hospital, caring for more than one baby can be very demanding for parents emotionally, physically, and financially.

### Feeding

#### Breastfeeding

You may need to gain additional knowledge and skills from a breastfeeding counsellor to provide the appropriate support to a mother who wants to breastfeed twins or multiple babies. Mothers can also obtain advice and support from the Twins and Multiple Births Association (Tamba), the Multiple Births Foundation (MBF) and the NCT. The MBF have published a comprehensive guideline on feeding babies from multiple births and also provide other leaflets on breastfeeding for health professionals while Tamba provides useful information for parents.

#### Feeding positions

Mothers may need to experiment with several breastfeeding positions to find the one that suits them the best. If the babies are still tiny, the mother may be able to cradle them both in her lap. She should sit well supported and feel comfortable

with all the necessary equipment close at hand. Alternatively, the mother can tuck the baby's legs under her arms and cradle their heads as they feed. She may find that separate feeds are easier. If breastfeeding is being supplemented with formula, the mother may prefer to breastfeed one baby while the other has a formula feed, and alternate the babies with breast and formula milk.



## Help and support

There is no statutory entitlement to help in the home for families with multiple birth children. The availability of additional help will depend on where the family lives, while social services departments vary in the amount of family support they can offer.

In some areas childcare and education students may be looking for work experience placements with families. Alternatively, if the family can afford it, a nanny or maternity nurse can be employed. If the local health organisation employs nursery nurses, they can also prove invaluable in offering continuing support to mothers.

Parents of twins or multiple babies are not entitled to additional benefits or grants, apart from the normal entitlement of child benefit for all children. Depending on their income, they may, however, be entitled to state benefits. Further information on these can be obtained from the Benefit Enquiry Line on 0800 882 200 or from Maternity Action, or the local Citizens Advice Bureau.

Good quality second-hand equipment (including cots and twin buggies) may be available through local twins clubs sales. Tamba will have details of the nearest twins club and the NCT also run nearly new sales.

## When a twin or triplet dies

The Tamba Bereavement Support Group (BSG) exists to support all parents and carers who have experienced the death of one or more babies from a multiple birth.

## The possibility of depression

Studies have found that mothers of multiples have almost twice the average risk of postnatal depression. Continuing support and practical suggestions from you as well as signposting to other support agencies are essential. Mothers should be informed about support groups and organisations for parents with twins and multiple births, such as Tamba and the MBF, which offer advice, information and the opportunity to meet other parents. Local twins clubs can also offer support and allow parents the time to meet and share experiences.

## Health and development

Twins and multiple babies may develop at a similar rate, for example, identical twins may walk within a few days of each other. It is equally normal, however, for there to be a gap of weeks or even months between the babies reaching particular developmental milestones. Parents are often concerned about discordant physical growth (there tends to be a greater discrepancy in birth weight between identical twins however they often even up as years pass). One baby may be developmentally delayed or may have more serious health problems than the other(s). If there are allergies in the family, such as eczema or hayfever, one baby may inherit one or more of these conditions while the other baby may not.



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# 6

## Bereavement







## 6. Bereavement

- Parents may choose to keep mementoes of their baby's life in recognition of the fact that, for a very important time, this baby was part of their family and always will be. Your acknowledgement that their baby was a real person will help to recognise their role as parents and the place of the baby in their family.
- You have an important role to play in supporting the family beyond the hospital's care. Following the funeral service, when there may be less direct support from family and friends, you will be ideally placed to ask families how they are coping and listen should they wish to speak about it.

There is little anyone can say or do to help ease the pain felt by a parent whose child has died. However, experience has shown that the care which is given to parents in the hospital and in the community, just before and just after a child dies, can have lifelong repercussions. Good care shown to the parents at this time may affect the severity and duration of parental grieving, as well as the ability of parents to resume a normal life. It is important when supporting bereaved families that you take the lead from the family members, and do not assume that you know the best way to help. Everyone will have very different needs, and each individual and family will deal with grief in their own way. Each parent will react differently to the death of a baby.

Mothers will experience all the normal physical and emotional postnatal reactions, which are likely to be especially distressing because their baby has died. In circumstances when a baby has not come home and no one else has seen him or her, it may be particularly important to parents that friends, family and health professionals understand the significance of their loss.

### Recognising differing needs

People from different cultures and religions deal with death and grief in a variety of ways, and many practices and customs need to be supported and respected. This can range from how openly people grieve to specific rituals that must be undertaken within particular timescales. Within one religion, different groups may follow different customs. A professional interpreter (never use children) may be necessary to ensure the health team has a complete picture and is offering appropriate support.

### Understanding grief

#### How long does grief last?

The grief that comes from losing a baby can be much deeper and last longer than most people expect. Parents are likely to 'contain' the experience and carry it with them for the rest of their life. In the first few days, parents may find it difficult to believe that their baby is no longer with them and it may seem as if

they are in a bad dream. The reality will slowly unfold and parents may experience the pain at its worst just when you, and others, think that it should be 'getting better'.

### Emotional impact

The death of a baby is a devastating experience. The effects of grief can be overwhelming and parents, their families and friends can be left feeling dazed, disorientated, isolated and exhausted. They may find it hard to take in information, to make decisions or to imagine how they are going to cope. Often parents feel overwhelmed and frightened by the intensity of their emotional and physical pain – they may feel, hear or see something that they cannot explain and very powerful maternal urges can be common. It can seem as if the pain is never going to stop or change.

As the grieving process progresses, parents, especially mothers, may experience a feeling of failure and often feel guilty – as if they should have been able to stop their tiny baby from dying. Anger is sometimes a reaction at this time and parents may direct this at themselves, loved ones or the health professionals that looked after their baby. Other common emotions include self-blame, particularly as the grief becomes less raw. For example, some parents have said that they felt they had let their baby down when they started crying less. All these feelings are perfectly normal.

### Abnormal grief

The grief process will naturally take its course, but if you are concerned about a parent, or believe that someone may be experiencing abnormal grief (if they appear 'stuck' in their grief, for example), it can be beneficial to talk to them about seeking help. Talking things through with someone who understands may help them to feel less isolated and see that their feelings are entirely appropriate. Sands, the stillbirth and neonatal death charity, is an organisation which can offer parents support when their baby dies during pregnancy or after birth.

### When a twin or triplet dies

To his or her parents, any baby who dies is an irreplaceable individual, and the parents will have to deal with their own grief as well as continuing to meet the needs of the surviving twin or triplets. It is important that you provide support and practical advice, such as encouraging the mother to continue breastfeeding the surviving baby or babies.

### When a parent dies

When one of the parents dies, the surviving parent will have to deal with his or her own reactions, as well as continuing to meet the needs of the child or children. Support from you, their family, and friends will be essential at this time. Bereavement support and one-parent organisations can be useful. There are also support groups for fathers who are bringing up children alone.

## Palliative care and end of life care

### Palliative care

Palliative care aims to keep babies comfortable and control symptoms. Families are also offered continuing support, even after the baby has died. Aspects such as pain relief, comfort measures and support for the family are always offered.

Parents should be able to choose where their baby receives palliative care. This might be in the hospital, preferably in a quiet, private area. They might want to take their baby home and get help caring for him or her from visiting nurses.

If parents live in an area with a children's hospice, this might be another place their baby can receive palliative care. A hospice offers more home-like surroundings than a hospital. People working in a hospice are very skilled at caring for children with life-limiting conditions and they can offer each family a lot of support too, both now and in the future.

### End of life care

The outcomes for preterm babies, especially those born very early, can be uncertain from the start. It is very important, whatever the prognosis, that parents are encouraged to be involved in their baby's care. Research has shown that those parents who became involved in their baby's care and lost their baby were more able to come to terms with their loss than those parents who were less involved.

You can help by ensuring that neonatal staff provide honest and comprehensive information to parents about the condition and treatment of their baby, that carers and families are in full agreement about the management of the baby, and that – if appropriate – parents are supported in providing nursing care for their baby.

### Making memories

Memories are precious for parents and so are the moments that they had with their baby. Parents may choose to keep mementoes of their baby's life in different ways, in recognition of the fact that, for a very important time, this baby was part of their family and always will be.

Most neonatal units will take a photo of the baby (with the parents' permission) for parents to bring home with them or take away at a later date. Parents may also be given a memento card with a foot print or a hand print and a lock of hair. However, it is important to remember that these things may not be appropriate for all religions and cultures and it is important not to assume that what is right for one family will be appropriate for all.

Some neonatal units give parents a 'journey box' when their baby is admitted so that parents have a place to keep special reminders. Many parents gather

keepsakes of their baby's time in hospital, starting when they are first born or admitted. These significant objects can become very important to parents and may become an important part of the memories they return to in the future.

Here are some items that parents often keep:



- a hospital bracelet or cot card
- the baby's name tag and bonnet
- photographs of them, their baby and family together
- a hat or special clothing
- handprints or footprints
- cardiac monitor sticker or syringe
- cards and letters from family and friends
- a diary, poems or notes that they jotted down.

## Health concerns

It is important to try to encourage parents (and mothers in particular) to look after themselves physically after the birth.

It may take mothers longer to recover from the birth than would be expected. They may be prone to lots of viral infections such as colds or feel physically exhausted. Sleep may be difficult for a while. It is important to make sure that the mother has attended her six-week postnatal check.

Parents may not feel like eating or drinking but need to do so. After any bereavement, loss of appetite and weight loss are not unusual; however, if it is excessive, encourage the parent to talk to their GP. It is important that they get their general physical health back to normal – as they will be able to cope with the emotional aspects better if they are physically stronger.

Many bereaved parents find it very difficult to leave the house, and may dread the idea of seeing others' babies, or having to explain to an acquaintance where their baby is. However those that do go out generally say that it makes them feel better. If appropriate, encourage parents to try to get a bit of exercise, perhaps a short walk in the fresh air.

A bereaved mother's breasts may still fill with milk. Although milk production can be suppressed by medication many women decide not to take this. Breast engorgement can be painful, if so, encourage them to ask a midwife for advice.

Finally, it is not an unusual phenomenon for bereaved parents, particularly mothers, to become obsessed with their own, their partner's or their other children's health. Again, this reaction usually fades with time. If it does not, then they need to talk to their doctor.

## Practical information

Information can be very helpful to bereaved families. The many practical considerations surrounding a death can be extremely difficult for grieving

relatives and close family friends to take in and retain. Help and guidance through this process can be invaluable.

### Registering a neonatal death

If a baby is born alive and then dies, the death can be registered by both parents or by just one parent, whether or not they are married. If the baby's birth has not yet been registered, this can be done at the same time. If neither parent can register the death, another relative, someone else who was present at the death, or a member of the hospital staff can register.

### Funerals

If a baby was stillborn after 24 completed weeks of pregnancy, or was born alive at any stage of pregnancy and then died, he or she must, by law, be formally buried or cremated. A baby who was born dead before 24 weeks can also have a funeral but this is not required by law. Many hospitals in England, Wales and Scotland offer to arrange and pay for a funeral for a baby. Alternatively parents can arrange the funeral themselves. Parents may choose to have their baby dressed in a particular outfit or wrapped in a special shawl. They may also want to ask the funeral director to put special items into their baby's coffin, such as a soft toy, a letter or a poem. Some parents keep an identical outfit, a shawl, a toy, a letter or a poem as a memento. However, if a baby is going to be cremated, the crematorium staff may remove some items from the coffin before the cremation. Any items that are removed should be returned to the parents.

### Post-mortems

A post mortem examination of the baby's body and of the placenta (afterbirth) may help discover why a baby died. It may confirm any problems that were identified by earlier tests and investigations, and help to assess the risk of the same thing happening in a future pregnancy. A post-mortem examination on a baby cannot be carried out, and the baby's organs cannot be kept, without the parent's knowledge and consent (called authorisation in Scotland). It can be difficult for parents to decide whether to have a post-mortem and there are those who wish for their baby to be left in peace. Some refuse post-mortem for religious reasons, while others agree, in spite of religious teaching, because they need to find out why their baby died. If parents don't want their baby to have a full post-mortem examination, they can ask for a partial post-mortem, an external examination of the baby, blood tests, or just an examination of the placenta.

If a post-mortem is to be undertaken the parents need to understand that there may be some delay before their baby's funeral can take place (the time required varies considerably around the UK). The funeral can be held as soon as the post-mortem examination is completed. There is no need to wait for the post-mortem results. Before the post-mortem, some parents dress or wrap their baby in a special shawl, or place a small cuddly toy with him or her. The staff should ensure that these items stay with the baby and are returned with him or her.

Many parents find waiting for the post-mortem results very stressful. The results are usually discussed with parents at the hospital, and although some

people find it hard to go back to the place where their baby died, it is important to encourage them to attend this meeting. Parents will normally be given a summary of the post-mortem results, while the full report will be sent to the mother's GP. If parents want their own full copy, the mother can write to the hospital to ask for one. If a genetic abnormality has been found, the consultant will offer the parents an appointment with a genetic counsellor. Many parents have high expectations of the post-mortem and hope that the results will provide some clues as to why their baby died. However, in some cases doctors can find no reason for the baby's death.

## Follow-up support

You have an important role to play in supporting the family beyond the hospital's care. Following the funeral service, when there may be less direct support from family and friends, you will be ideally placed to ask families how they are coping and be able to listen should they wish to speak about it. It is also important to recognise when other intervention is needed, such as counselling, referral to support groups or medication. Some hospitals have bereavement support counsellors attached to them, or parents can be referred to the Bliss counselling service. There is also usually a bereavement follow-up appointment with a neonatologist, and it is important to encourage parents to attend this.

### Financial support

Many bereaved families face unexpected financial strain, and it is important that they find out about all the rights and benefits that they may be entitled to. Maternity and paternity benefits are complicated, administered by several government agencies, in some cases by employers and are subject to frequent changes.

### Other parents and staff on the neonatal unit

The death of a baby who is still in the neonatal unit may have a profound impact on the staff and parents of other babies on the unit who may need either formal or informal support. It is important to make the time to listen to staff and the parents (as they may not have anyone else to talk to) and offer support rather than just going ahead and doing something.

## Sudden infant death: 'Back to sleep' campaign

Sudden infant death syndrome (SIDS) continues to be the most common cause of unexplained deaths of babies in western countries. Prematurity and/or low birthweight are known risk factors for SIDS, but after surviving the anxious time when their baby was in the neonatal unit, the sudden death of their baby later can be particularly hard for parents to deal with. Acknowledgement of the death and the provision of practical support to the family as soon as possible after the baby has died are essential. Guidelines for community health professionals who are involved with the family of a baby who has died suddenly and unexpectedly are available from the Foundation for the Study of Infant Deaths (FSID).

## Other family members

### Fathers

When a baby dies at birth, there will inevitably be concerns about the medical condition of the mother. Fathers can often get forgotten, even though they may have just as much to cope with – such as their own grief as well as worries surrounding their partner. It is not unusual for men and women to grieve differently, and even in today's society, some men may find it difficult to express their emotions and feelings openly. To some this may look like indifference to the death of the baby, but many men need time and space to grieve. This may happen after the funeral, if there is one, or possibly many weeks later. It is important that you ask the father directly how he is feeling, and ensure that his own grief and concerns are acknowledged. It may be helpful to talk to him on his own if he fears that what he says will distress his partner.

### Sibling issues

Children also grieve, experiencing similar feelings to adults such as shock, confusion, anger and guilt, and it is generally helpful if parents can prepare their other children if the new baby sibling is not expected to live. Parents can find it extremely difficult to explain to their other children why their brother or sister has died. During this time they will be supporting the child through their grief, as well as their own. Children do not need protecting from their feelings, but support in coping with them. You can help parents to create an appropriate environment for children to express themselves, either in hospital or at home, where they can talk naturally about the baby who has died and how they feel. Do not be afraid to encourage children to show their emotions, likewise let them cry. At some stage most children blame themselves for the death of their baby brother or sister, so explaining the death in terms of 'it was nobody's fault' is very important. A recent study found that the most important things in dealing with a child's grief included:

- recognising and acknowledging their grief
- including the child in family rituals
- keeping the memory of the baby alive in the family.

### Babies and toddlers

Babies and toddlers may be deeply affected by their parents' emotions and will react to those around them. They may show distress through weight loss, disturbed sleep patterns or crying for no obvious reason. Twins are especially affected by the loss of their 'other half'. If possible, they should have lots of physical closeness, holding and cuddles from their parents.

### Schoolchildren

Older children may experience feelings such as shock and disbelief. They may not show their feelings openly, and an apparent lack of sadness may lead adults to believe they are not affected by the death. Normal signs of grief in children include behaviour changes such as becoming withdrawn, bed-wetting, lack of concentration, bullying, being aggressive and refusing to go to school.



## Anniversaries

Parents may find family birthdays and special occasions, the anniversary of the baby's birth and death, New Year and other important religious dates particularly painful. Parents may also experience difficulties in celebrating surviving twin or multiples' birthdays. If a new baby's birthday is close to the anniversary of another baby's death, parents may experience many conflicting feelings: confused thoughts, tears of joy and sadness or difficulties in separating the two events. These may be significant milestones experienced by the parents of which you should try to be aware.

## Future pregnancies

Planning for, or having another pregnancy can be a difficult and emotional time for parents. There may be possible difficulties with the relationship and/or with sexual relations, and real fears about the health of any future babies. Supporting the parents through subsequent pregnancies and births is particularly important during what can be a terrifying time. This includes encouraging parents to discuss all concerns with an obstetrician, and in some cases providing advice around access to genetic counselling or fertility counselling.

## Useful information

Sands, the stillbirth and neonatal death charity  
[www.uk-sands.org.uk](http://www.uk-sands.org.uk)

NICE guidelines on antenatal and postnatal mental health  
[www.nice.org.uk/cg45](http://www.nice.org.uk/cg45)

7

Going home





## 7. Going home

- Planning to take their baby home can cause parents profound anxiety as well as great relief.
- Meeting you before their baby is discharged, and knowing that you are familiar with their situation and can provide help and advice, gives parents tremendous reassurance.
- The baby's discharge date will be assessed by staff, and will only be confirmed when they are satisfied that the baby no longer needs medical treatment and/or monitoring, or that the care required is such that it can be provided within the home.

During their baby's journey through neonatal care, parents will grow used to receiving a high level of support in the unit and having health professionals available to answer questions. To ensure a smooth transition for the baby from unit to home, it is also essential to give parents sufficient time to prepare for the break from the relative safety of the neonatal unit.

**“The staff were excellent and kept us well informed. I came to look on the intensive care unit staff as my own family, and was actually upset when Ellen got transferred to my local SCBU even though she was doing really well.”**

Sarah, mother of Ellen May, 24 weeks

### Areas of concern for parents

Although parents are usually advised early on that the time of discharge from hospital is around the baby's expected date of birth, babies can often be ready earlier if they progress well.

Parents whose baby or babies are discharged unexpectedly, or before their due date, are denied this period of adjustment and often feel emotionally, psychologically and practically unprepared for the new challenges at home.<sup>1</sup>

You can offer a range of practical advice and emotional support in this situation. Issues which cause concern for parents<sup>2</sup> and need to be addressed both pre and post discharge include:

- feeding and growth
- feeling different from other families
- identifying and coping with health problems or emergencies
- risk of infection
- administering medications and/or managing side effects
- temperature control
- developmental progress and uncertainty about the future pathways of help and access to advice once they are at home with their baby
- postnatal depression
- social isolation.



### When can the baby go home?

In order to determine the baby's discharge date, the baby's overall progress is assessed, taking into account factors such as the stability of the baby's temperature and whether or not this can successfully be maintained at home, the baby's feeding patterns and the necessity for any special medical treatments.

As one of the key criteria for discharging preterm babies is their ability to maintain temperature, the baby will need to make the transition from incubator to open cot before going home.<sup>3</sup>

Some babies who are feeding well, gaining weight and have no other problems will be discharged a few weeks before their due date. Weight is not a useful criterion for determining readiness for discharge. Others babies, who have special needs such as feeding problems or oxygen requirements will need to stay in hospital until their condition is stable.

Before a baby with special requirements, such as tube feeding or breathing support, is allowed to go home, the family will need sufficient training to deal with these requirements with confidence. This should include basic resuscitation training.

Some hospitals offer parents of preterm babies a rooming-in period that allows them a brief stay in a hospital room with the baby so they can gain some experience in taking care of all of the baby's needs before discharge.

## Emma and Michael's story

After baby Oliver was born at 28 weeks gestation he suffered a pulmonary haemorrhage, a bleed on the brain, and developed hydrocephalus and severe gastroesophageal reflux.

Eleven weeks after their son was born, Emma and Michael spent an anxious Friday afternoon at the unit waiting for test results to see if they could finally take their little boy home. Oliver was discharged with numerous medicines and special feeding requirements, and taking him home was a daunting experience. Both Emma and Michael required essential support from their family and health visitor.

"I have to be honest: if they'd have asked me that day if we wanted to stay a little bit longer I might have said yes. It felt like a huge step to take on our own. That first weekend home was mixed with extreme happiness and extreme anxiety," says Emma.





## Discharge planning

Discharge procedures and handover to the neonatal community outreach team, where there is one available, will vary from unit to unit, so these should be checked with the local unit. If there is a community nurse or family care worker attached to the neonatal unit it is likely that they will coordinate the discharge. Before a baby is discharged the neonatal unit staff will also discuss with the parents the practical side of caring for the baby.

You will have valuable information to share and should be welcomed by neonatal units at any discharge planning meeting. This meeting affords you a clearer insight into any current concerns of staff or parents and any potential problems that may arise.

Some babies may have one of a wide range of life-limiting or threatening conditions. The necessary community services should be identified and a care plan put in place involving the neonatal unit outreach team. You will need to ensure a degree of co-ordination between services as well as support for the parents.

Before discharge, if the baby is on medication, families will be shown how to administer it to the baby, given full details about what the medication is for and informed about possible side effects. After discharge, if you are concerned about growth, you may need to refer the baby to the neonatal nurse, hospital consultant or dietitian as appropriate.

## Management of long term problems

Some babies may have medical problems that continue for months or years. For example, babies who have spent a long time on a ventilator often become wheezy when they have a cold or virus that affects their chests. Others may have problems with their sight, or movement difficulties. Plans for follow-up and who has medical responsibility for the management of these should be identified.

## Continuing medical needs

Oxygen therapy does not require a hospital environment, and major benefits accrue from discharging stable infants while they are still receiving supplemental oxygen. The primary benefit is the promotion of the baby's normal development and parent-baby attachment, which is best achieved in the environment of the home. The risk of nosocomial infection is eliminated, although counselling against exposure to viruses from ill relatives and friends at home must be given.

Sending preterm infants home while they are receiving oxygen therapy requires careful planning to ensure success, taking into account a number of patient, family, financial, and home and community factors. This is best carried out in the context of an organised programme of discharge planning and parent education.<sup>4</sup>

If the baby is going home on oxygen, prescriptions will be needed for the oxygen supplies and equipment. Some will be from the family's doctor and some will be given by the hospital. The person coordinating the discharge will organise this for the parents. After discharge, prescriptions can be obtained from the family doctor.

Early discharge of stable preterm babies who still require tube feeds has the potential benefit of uniting families sooner and reducing healthcare and family costs, compared with waiting until babies are on full sucking feeds. Potential disadvantages include the increased burden for the family and the possibility of complications related to tube feeding.<sup>5</sup>

## Immunisation

The immunisation programme for babies born preterm or sick usually starts at eight weeks after birth, as for term babies. **That is, no correction is made for a baby's preterm birth.** Some babies may therefore start the programme while they are still in hospital. Babies with continuing respiratory or cardiac problems may require additional preventative respiratory syncytial virus (RSV) prophylaxis.



## Support at home

Many hospitals now have a community neonatal nurse or family care sister connected to the neonatal unit who makes home visits to families who have had a baby recently discharged from the hospital. This specialist nurse will be there for support with continuing medical needs, such as home oxygen assist, whilst advising on areas such as feeding. Other health professionals involved in the baby's care may include physiotherapists, child development specialists and dietitians. Before discharge the parents will be given information on who will be involved in supporting them and the baby once they go home.



## Identification of vulnerable babies and families

Although all families who have a preterm baby will need continuing help and support, some families are more vulnerable than others. Families who may need extra support include:

- families in temporary accommodation or in poor or multi-occupied housing
- young or single parents with a poor support network such as lack of nearby relatives and friends
- parents whose other children are known to the social services department
- parents who have drug or alcohol problems, mental health problems, a chaotic lifestyle
- households where there is intimate partner abuse or severe financial problems.

Where such families are already known to community health professionals, or if child protection or other concerns are identified once the child is born, local policies or child protection procedures should be followed.

Each area will have its own policies but these would normally involve the sharing of such information with the appropriate hospital staff and social services department, and the holding of a case conference or professionals' meeting before the child is discharged. In some cases, families may need only extra help and support from agencies such as social workers, or housing or benefit advice. In other families, child protection procedures may need to be instigated and the child discharged into care or placed on the child protection register.

## Case study

### FaB (Families and Babies) project, Cheshire & Mersey neonatal network

This summary outlines how the coordination of services between hospital and community professionals can make a real difference to parents.

A number of families from Arrowse Park had expressed feelings of loss, loneliness and isolation four to six months after their infants' discharge (fit and well) from the neonatal unit, and subsequently from the neonatal community team. The parents reported feeling alone, unsupported and depressed, and a series of follow up meetings with parents made it clear that something needed to be done to improve the range of support options available. Unit staff made contact with the Wirral Children Centres' lead, who agreed that they had a sufficient number of skilled support workers, to help the families based within each children's centre.

An opt-out referral system was implemented, with referrals made by the neonatal staff for all infants admitted to the unit (with the family's consent) to the Children's Centre local to the family. A dedicated support worker was based on the unit one afternoon a week to promote access and ensure high visibility of the scheme to both parents and staff. The support workers became invaluable members of the team, providing sign posting services, financial advice and psychological support.

Summary of key outcomes:

- 49.1 per cent of families contacted support workers on the unit
- 37.2 per cent of families registered with their local children's centre
- 15.2 per cent received direct support
- 30 per cent received benefit advice
- 18.6 per cent received emotional support
- 11.8 per cent were signposted to other services
- 100 per cent family satisfaction rate
- only 1.6 per cent of families declined support.

## Checklist before discharge

Before the baby is discharged you may wish to check the following with the neonatal unit staff and/or the parents:

### Bathing and feeding:

- ✓ Do the parents know how to bathe their baby?
- ✓ Is breastfeeding, if appropriate, fully established?
- ✓ Has breastfeeding help been sought from the local National Childbirth Trust or other breastfeeding support organisations?
- ✓ If the mother wishes to express breast milk, does she have access to a breast pump?
- ✓ Do the parents know how to sterilise bottles and make up the baby's feeds, if appropriate?
- ✓ Does the mother have access to special milk formula, if required?

### Information provision:

- ✓ Has the family received their baby's red book and is it completed?
- ✓ Have the parents been offered the Bliss *Parent Pack* which includes the booklet *Going Home: The Next Big Step* (Bliss fifth edition, 2010)?
- ✓ Have they have been given relevant leaflets on sudden infant death syndrome and cot death prevention?

### Medicines:

- ✓ Are medications and/or equipment organised and available for discharge?
- ✓ Have the parents been shown how to draw up and give any medication the baby needs?
- ✓ Has the baby's immunisation programme commenced? When are further immunisations due?

### Equipment:

- ✓ Have the parents been shown how to use any specialist equipment they may need?
- ✓ Is a correctly fitted car seat available if the baby is going home by car?
- ✓ Do the parents have a suitable cot for the baby to sleep in?
- ✓ Are the parents aware of the 'back to sleep' position?

### Follow up care

- ✓ Have the parents been given a follow-up appointment and what is the date of this?
- ✓ Who is giving the family continuing support at home?
- ✓ Who should you contact at the neonatal unit in the event of a problem?
- ✓ Who has medical responsibility for the management of long-term problems?



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8

Helping the family at home





## 8. Helping the family at home

- Continuing support from you once the family have taken their baby home is essential.
- The daily care for a preterm baby may well be more challenging and stressful for the parents than that of a term baby.
- You can play a vital role in helping parents gain the skills and confidence necessary to care for their baby, particularly if there are issues around feeding.

As well as dealing with any feeding difficulties, special nutritional requirements and medication, the parents' uncertainties about the future may continue after the neonatal period as the child grows and confronts new health challenges.

In addition to common sensory-neural disabilities, preterm and low birthweight babies have a higher risk of slight delays in motor and verbal development, behavioural and emotional problems and minor learning disabilities about which parents will need advice.<sup>1</sup>

### Adjusting to life in the home environment

Parents need to be aware that coming home is as big a change for their baby as it is for them. Everything is new and different – colours, noises, temperature and smells – and it can take some time for babies to settle into a new environment. It is useful to remind parents that they are the familiar factor in their baby's life and that frequent cuddles will provide reassurance and a sense of stability for both the baby and them.





## Temperature regulation

By the time the baby is discharged, he or she should be able to maintain a sufficient body temperature as well as any term baby. Parents may worry about the room temperature being much cooler than the neonatal unit, but, as with all babies, being too hot can be dangerous and the best temperature for the baby at home is around 18°C (65°F). A balanced approach should be taken towards lowering room temperature as the baby cannot cope with an immediate change from the neonatal unit temperature of 26°-28°C. During changes in the weather from hot to cold, or vice versa, parents should be advised to add or remove a layer of clothing or a blanket as necessary.

## Medication

Many babies will go home on medication. The paediatrician will review this at the follow-up appointments and may change the medicines the baby is taking and the dosage required. It is important that parents give their family doctor advance warning of the new medicines needed for the baby.

For example, some medication lasts just seven days and if they live in a rural area, they will need to plan ordering the prescriptions and ensuring that the chemist can provide these on time and regularly. Some medications are not licensed for use in babies and, in these cases, GPs may initially be unwilling to re-prescribe so this may need to be done at the hospital. Dispensing from retail pharmacists may also be problematic as different strength preparations may be used and this may cause confusion with parents.

## Noise and light

The baby will already be accustomed to a noisy and bright environment from being in the neonatal unit and, again, a normal home environment can be maintained during the day as with any baby.

## Follow-up appointments

The number of appointments can vary from one every couple of months to more than one a week. Travelling long distances to and from the hospital can prove very time-consuming and tiring for parents, and stressful for the baby too. If parents are having trouble managing the number of appointments they have to attend, you may be able to rearrange some of the appointments with the various clinics.

## Going out and about

Parents need to keep a happy medium between going out with their baby, avoiding infection, and not becoming isolated at home. Exposing the baby to extremely hot or cold weather should be avoided; otherwise the baby should go out appropriately dressed for the weather – as any other baby would be dressed. However, while the baby is still vulnerable to infection or has respiratory problems, it may be wise to avoid places where these may be a risk such

as public transport, child health clinics and large mother and baby groups, especially from October to March during the respiratory syncytial virus season (RSV - see page 92). Some hospitals have support groups connected to the neonatal unit which can be a useful source of emotional support. However some parents prefer that their preterm babies are treated as normal and wish to join in activities with parents of term babies. If travelling by car, using a suitable car seat for the baby's size, which is correctly fitted is essential.

### Child seats

There are laws concerning appropriate child seats. The only legal and safe way for a baby to travel is in a properly secured backward facing baby seat or in a carrycot (not a Moses basket) with the cover on. It must be properly secured with special straps. The Royal Society for the Prevention of Accidents (ROSPA) has a useful website with more information on car safety.

### Car parking

There are moves towards extending the availability of the disabled parking permit (blue badge scheme) to parents of children under two years old whose medical needs require the transport of bulky essential medical equipment. Parents should be made aware of this and assisted with an application to their local authority if required.

### Parent support

Some parents are sensitive about the size of their baby compared to term babies – they may be subjected to thoughtless remarks by other parents about this. If appropriate, arrangements should be made for parents to attend child health clinics either just before they open or after they are officially closed, or for the baby to be weighed at home for the first few weeks or so, and separate appointments made for immunisations to be completed, if necessary. Parents can also be put in touch with other parents who have had preterm babies.



Bliss has a network of parents who provide support for other parents with similar experiences as well as many branches up and down the country. In Northern Ireland, TinyLife provides a range of support services for families with a preterm or sick baby including: hospital and home-based support service, baby massage, breast pump loan service and parent support groups. Contact TinyLife on 028 9081 505 or the Bliss Family Support Helpline, on freephone 0500 618140.

## Sleep

The government advises that babies (including those born preterm) should lie on their back to sleep, with their feet at the bottom of the cot to reduce the risk of sudden infant death. As babies are sometimes placed on their front or side while in the neonatal unit, parents may need particular reassurance from you that the 'back to sleep' position is the safest sleeping position for their baby now they are at home. However, in a few cases there may be medical indications for different positions for sleep, for example, raising the bed to a 30 degree angle and sleeping left lateral where there is significant gastro-oesophageal reflux; and, if there are any airway/respiratory difficulties associated with congenital abnormalities, other alternative sleeping positions may be required.

## Recommend that the baby sleeps in the cot

Parents who have been separated from their babies for some weeks or months may want to be particularly close to them and wish to take them into their bed to sleep. Although it is helpful to have the baby sleeping in their parents' room (although this is only recommended till six months) they should be advised that co-sleeping is not recommended for babies born before 37 weeks gestation because of the increased risk of sudden infant death, and that they should never let their baby sleep on the sofa or on a cushion.

Parents should also be advised that preterm babies may be more active and noisier in sleep than term babies, and although the baby is moving at night, they may well be sleeping. If the baby is unsettled, parents should try still holding or stroking him or her to reassure the baby that they are there. This will be easier if they can position the Moses basket or cot next to their bed. They may also want to try playing soft music or leaving a night light on.

## Feeding and feeding issues

Some preterm babies are discharged from the neonatal unit before becoming fully skilled at feeding. It is very important for you to help parents gain the skills and confidence necessary to care for their babies at home. To feed successfully, the baby must coordinate sucking, breathing and swallowing throughout a feed. As babies mature, they suck for longer bursts, with less time between these bursts, and they also increase the strength of their sucking. To maintain engagement in feeding requires a mature arousal system, the energy required to perform the activity and the ability to direct and sustain attention to feeding.

## Feeding

### Breastfeeding

With support, many babies now leave the neonatal unit fully breastfed. Once home they may be strong enough to receive all their nutrition directly from the breast but it is important that a mother continues to fully empty the breast after each feed until the baby reaches term gestational age. Preterm babies may still have slightly weaker sucks and not fully drain the breast at each feed. By expressing a mother can make sure she continues to maximise her breast milk supply as the baby gets stronger. If the baby has received breast milk from a bottle and is discharged before being able to suckle well at the breast, he or she may need help adapting to full breastfeeding when home. Sometimes a nipple shield can help a baby to attach to the breast with stronger suction. If using a shield it is important to express from the breast after each feed to maintain milk supply.

### Milk formulas

When breast milk is unavailable, or to treat specific digestive problems, many neonatal units now use formula milks specialised for preterm babies. These feeds will be commenced on the neonatal unit and the baby will be provided with some to take home. They are available on prescription in the community. As not all local pharmacies will keep these formulas in stock, it is important to encourage parents to re-order their prescriptions appropriately. Babies requiring specialised milks will usually have follow-up appointments with neonatologists, paediatricians or dietitians who will advise when to change to standard milk formula.

### Bottle feeding

Babies who still have immature co-ordination of sucking,<sup>1</sup> swallowing and breathing may still have oxygen desaturation, fatigue and early cessation of feeding. In addition, as babies become tired during feeding, their coordination can diminish. Unlike the flow of milk from a breast, which is stimulated in response to the baby's sucking, milk flows from a bottle as soon as it is tipped up in the baby's mouth. Parents can help support a baby's co-ordination with bottle feeding by being taught to spot the subtle signs of immature co-ordination and disengagement, such as long pauses in taking a breath, slower sucking, a raised eyebrow, blinking and drooling. They can then provide a break in feeding early – before the baby becomes distressed. Parents should be taught that it is critical not to interrupt pauses for breathing and to resist the temptation to jiggle the teat to stimulate sucking if bottle feeding, as this can cause feeding distress. If the infant is falling asleep, feeding should cease and the baby allowed to rest.<sup>2</sup> Bottle fed preterm babies may feed better if fed in an elevated side lying position as they would if breastfed, they may also feed better if fed with a slower flow teat that enables them to control the flow of milk and co-ordinate swallowing and breathing more easily.<sup>3</sup>

### Bottles and teats

There is a wide range of bottles and teats available on the market. The neonatal unit staff usually discuss with the parents which type of bottle and teat will be most appropriate for their baby, and they should also ensure that the baby is able to feed well using them before the baby goes home.

### Feeding issues

Continuing to maintain a sufficient milk supply can be difficult when a mother and baby have been separated for extended periods of time and a mother has been expressing for a prolonged period. Community health professionals or other medical staff may need to offer support to mothers who have successfully initiated lactation and are making the transition to fully breastfeeding. A baby's growth needs to be monitored. Expressing and storage of breast milk should be continued so that if the baby is not yet taking enough from the breast, the mother can feed the baby a bit more of her own milk from a bottle.

As with any mother breastfeeding their baby, some mothers may experience breastfeeding problems after their baby has been discharged from the neonatal unit. Apart from problems with positioning and attaching, other breastfeeding problems may include mastitis and nipple thrush. Candidiasis infection (thrush), in particular, is often a cause of breastfeeding failure and should be suspected if the mother complains of shooting pains in her breast or redness or soreness of the areola and nipples. Both mother and baby should be treated even if the baby shows no sign of oral thrush.



## Anna's story

"Our twin girls Amelie Hope and Isabel Faith were delivered eight weeks early by caesarean section. Both babies were immediately taken to intensive care and Amelie had to be transferred to another unit for life-saving surgery. Exhausted from the operation, Amelie needed to be ventilated for five days.



This was the lowest point for me and felt like a major backwards step, but finally a call came from the hospital to say she was breathing on her own. She was transferred back to be by her twin sister's side. After 38 days in the unit the decision was made to take Isabel home. Amelie, however was still struggling to feed and nurses discovered that scar tissue from the operation had caused her throat to narrow. SCBU taught me to tube feed Amelie and eventually I was able to take her home, 54 days after birth and one day before she should have been born. When you have a child in the unit you are very focused on when you will be able to bring your baby home.

**I found bringing home a child with ongoing special feeding needs terrifying and felt overwhelmed by the number of hospital appointments, therapists, health visitors and GP visits all giving conflicting advice.**

It has taken me a year to come to terms with Amelie's condition and those precious early weeks I felt I had missed out on. I now realise that I got to meet my girls early. Two of us went in and four of us came out. The best outcome I could have hoped for.

Their first birthday was a turning point for me, to look to the future and stop looking back, but always to remember how far we've come and how much we've all achieved."

## Common feeding problems

There are a number of common problems to take into account with preterm babies:

- Possetting / regurgitation
- Feeding while oxygen dependent
- The issue of nutritional interventions
- Iron deficiency
- Constipation.

### Possetting / regurgitation

Both these terms may be used to describe the non-forceful return of milk, but differ in degree. Possetting describes the small amounts of milk, which often accompany the return of swallowed air or 'wind', and is unimportant. Regurgitation is used to describe larger, more frequent losses and may indicate the presence of gastro-oesophageal reflux. Projectile vomiting may indicate a more significant problem and should be medically reviewed.

### Feeding oxygen-dependent babies

Oxygen-dependent babies tend to have a higher calorie requirement due to the additional work of breathing, but find taking in sufficient calories more difficult due to feeding difficulties. They are frequently slower and more difficult to feed, taking smaller volumes due to increased respiratory effort causing more problems with co-ordination. While it is common for all babies that were born preterm to take small amounts, this is even more the case with oxygen-dependent babies.

### Nutritional interventions

Studies suggest that 'normal' preterm babies benefit from nutritional intervention after hospital discharge. Clear cut recommendations are difficult because babies' nutritional needs vary.<sup>4</sup> Any required supplements, such as vitamin drops, will be decided upon by the hospital team before discharge.

### Iron deficiency

Preterm babies have higher iron requirements due to their rapid growth and relatively low iron stores at birth. Any necessary iron supplementation will be decided upon by the hospital team before discharge.

### Constipation

If a baby gets constipated and does not pass stools regularly it can cause discomfort and a lack of appetite that will affect how well they feed.

## Weaning on to solid food

The gastrointestinal system of premature babies develops from the time they are first given enteral feeds, which can be as early as 14 weeks before their due date. Because of this, their gut function matures more rapidly than that of a term baby. Possibly for this reason (and for others), they do not appear to be at increased risk

of gastrointestinal problems or allergy associated with weaning. This, combined with the need to ensure that weaning does not occur too late (which might create problems with accepting a good variety of foods), has led to recommendations to wean between 5 and 8 months (actual, **not** corrected age).<sup>5</sup> Around this time babies should start to show readiness cues for introducing solid foods; parents can be helped to look for appropriate cues.<sup>6</sup> Parents will find the publication *Weaning your preterm baby* (Bliss sixth edition, 2010) helpful.

## Touch and massage

Many cultures have used massage as part of caring for their babies for hundreds of years, and in recent years baby massage has become very popular with western parents with term babies. Although a critical review of the literature on massage in 2000 concluded that there was no strong evidence that massage for preterm babies was of benefit for developmental outcomes,<sup>7</sup> many parents have expressed satisfaction when taught massage for their babies. For those who may have been separated from their babies for weeks or months, baby massage may facilitate parent/baby interaction and attachment.

The potential benefits of massage include:

- helping the parents learn about their baby's needs
- relaxing baby and parents
- helping boost and build self-confidence in baby and parents
- promoting better sleep in the baby
- helping to relieve the baby's colic, wind and constipation.

Massage groups are often held in health centres or in Sure Start (Children's Centres) areas and private classes may also be available for parents who can afford to pay. Alternatively, community health professionals or parents can contact Bliss Family Support for more information.

## Bathing

Parents will normally be taught how to bath their baby before leaving the neonatal unit. They may find it easiest to use a baby bath with a slip mat. The room where the baby is bathed should be at a warm, stable temperature. As with other young babies, daily bathing is not necessary, especially as the baby's skin may be fragile and/or dry. Baby massage, using appropriate natural organic oils, can benefit both babies and parents; just after bathing can be a good time to do this if they are in the quiet alert state.





## Using oxygen at home

Oxygen is supplied in cylinders (which contain gas or liquid) or concentrators. The oxygen company will supply the family with the most suitable equipment to the prescription or Home Oxygen Order Form (HOOF) they receive. There are several oxygen companies covering different regions of the country and the local company will provide training and a 24-hour backup service for the parents and carers. In addition to backup for the equipment, it is essential that families have access to 24-hour medical care, especially when their baby is ill.<sup>8</sup> Oxygen concentrators work by taking room air through a series of filters to remove particulate matter (including bacteria) and nitrogen. The resultant oxygen is stored in a reservoir before use. This is delivered through the oxygen tube to a flow meter and then through the oxygen tubes and nasal cannula to the baby. The rest of the air is returned to the room. Usually, two outlets are sufficient: one in the main living room area and another in the baby's bedroom. Portable oxygen cylinders are essential so that the family can take the baby out of the home from time to time, and the newer cylinders made of aluminium are much lighter than the traditional steel ones.<sup>9</sup> If parents have a concentrator, they will also need a cylinder as a backup in case of mechanical failure. Arrangements are made to refund the electrical costs via the supplier.



## Storage, cleaning and delivery

The oxygen company will advise parents about the safest way to store and clean the oxygen equipment. The neonatal unit nurses will have shown the parents how to manage the oxygen tubes and nasal cannula and they need to check these regularly throughout the day to ensure that there is a free flow of oxygen through the tubes and nasal cannula to the baby. If the nasal cannula becomes blocked, this will need replacing so spare parts should be available. All companies arrange for the cylinders to be delivered to the home. It is also a good idea for parents to stock up so that they will not run out over a weekend or bank holiday.

It is essential that:

- ✓ The parents' gas and electricity suppliers and household and car insurers are advised in writing that they are carrying and storing oxygen in the house and car.
- ✓ The fire brigade is also to be notified of the presence of oxygen in the home as a precaution in the event of a fire. Most fire and rescue services offer a free home fire risk check and will also install a free smoke alarm.
- ✓ If living in rented accommodation or local authority housing, parents should advise the property owner or council that they will be having oxygen in the house.
- ✓ The household and car insurer are told in writing that the parents will be carrying and storing oxygen in the house and car as it may affect future claims if they have not mentioned this. It is useful to have something in writing confirming that they have noted this information on the policy.

## Leaving the house with a baby on oxygen

Life can be quite isolating if the baby is on home oxygen and it helps if the person who is coordinating the discharge of the baby can arrange to provide portable oxygen cylinders for the parents. Having the portable oxygen will mean that the family can leave the house and lead a more active life. The pram will need a sturdy tray or basket underneath. Portable oxygen cylinders cannot be hung over pram handles, as the weight of the cylinder will pull it over. As an alternative, parents can carry the cylinder in a rucksack, ensuring that it is wrapped securely in a towel to prevent damage to any of the connections. Remind parents to check the level of oxygen in the cylinder before they leave the house to ensure they have enough for the outing. For more information on travelling outside of the family's local area, in the UK or abroad please see the Bliss booklet, *Going home on oxygen* (Bliss fourth edition, 2010).

### Weaning from home oxygen

No uniform standards are used in weaning infants from home oxygen. There is no evidence that gradual or abrupt methods are preferable. The paediatrician will monitor the baby's progress so he or she is not on oxygen for longer than necessary. It may be that the baby needs oxygen for just a few months or it may be that oxygen is needed for longer than a year. This will depend on the baby's individual progress and needs. Most commonly, prolonged pulse oximetry is used to determine when it is appropriate to wean infants from supplemental oxygen, using target saturation values similar to those used during oxygen supplementation. Weaning is likely to be influenced by other factors, including associated medical problems (for example, pulmonary hypertension), somatic growth and sometimes, the weather.



### Gastrostomy and stoma

Babies who experience persistent feeding problems may need a gastrostomy. The decision to adopt this treatment is taken after consultation with the appropriate health professionals. Some babies who have required bowel surgery may have a temporary or permanent stoma. Specialist support will have been arranged prior to discharge.

### Gastro-oesophageal reflux (GOR)

Gastro-oesophageal reflux (GOR) describes the effortless or involuntary passage of the gastric contents back into the oesophagus and, at times, into the mouth. It occurs when the sphincter muscle between the oesophagus and the stomach is weak; and is common in many babies who gradually grow out of it as they get bigger and stronger. GOR is the most common cause of vomiting in all babies, but causes effortless rather than projectile vomiting. Preterm babies may have a particular problem because they have weaker muscle tone. GOR becomes a problem when it causes symptoms of discomfort, irritability, significant vomiting and poor weight gain or weight loss. This is known as GOR Disease (GORD).

Those infants with Chronic Lung Disease or neurologically impaired children are at higher risk for having symptomatic GORD.

## Complications of GOR

GOR is a multi-factorial disorder that may cause many clinical problems in preterm babies. These include failure to thrive as result of caloric deprivation, apnoea, desaturation, bradycardia, stridor, oesophagitis with irritability and excessive crying, and a variety of upper respiratory problems caused by repeated pulmonary aspiration of gastric contents. Not all babies with GOR vomit, and significant GOR may occur in the absence of emesis.

## Management of GOR

### Positioning

Positioning techniques, feeding routines and medications should be used by parents to treat GOR only after assessment and advice from a medical team. Although studies have found the prone position reduces GOR, this position is not recommended because of the risk of sudden infant death. The baby should be kept as upright as possible after feeding by being held upright or kept at a 30 degree angle by propping up the bed head. Seated positions, where the baby tends to assume a slumped position, should be avoided, as this increases intra-abdominal pressure and worsens reflux. A left lateral position may be indicated to help reduce reflux.

### Feeding

Thickening agents may be added to infant formula to increase feed viscosity and decrease regurgitation and vomiting as advised by a doctor. As the baby gets older, overfeeding should be avoided and smaller feeds of increased frequency may be recommended.

### Medication

Prescription-only products may be added to formula or to water for breastfed babies. In cases of severe GOR or oesophagitis, H2 antagonists or proton pump inhibitors may be used.

## Respiratory Syncytial Virus (RSV)

Coughs, cold and stuffy noses affect everyone of all ages throughout the year. However, preterm babies can be at higher risk of becoming more seriously ill following a respiratory infection such as bronchiolitis or pneumonia. Approximately 80 per cent of these bronchiolitis infections are attributable to RSV.<sup>10</sup> Although late preterm babies (those born within 33-35 weeks gestational age) usually appear healthy and fine to most people – including healthcare professionals – it is important to remember that their lungs are still under-developed and they may be at risk of developing complications from an RSV infection.

### RSV – quick facts

- RSV is a very common virus which causes cold-like symptoms, but can lead to breathing difficulties if the lungs become infected.<sup>11</sup>
- Around 20,000 infants in the UK are admitted to hospital every year with RSV.<sup>12</sup>
- RSV epidemics are predictable as they occur every winter.<sup>12</sup>
- RSV is the leading cause of viral death in infants younger than one year<sup>13</sup> and can be particularly serious in preterm babies.<sup>10</sup>

### What to look out for

As health visitors, you are best placed to advise parents about RSV and the need to protect their babies, especially during the winter season (October to March).<sup>14</sup> Parents can help to lessen the chance of their baby becoming infected with RSV by:

- ensuring that all people who come into contact with their baby take extra care to wash and dry hands
- reducing their baby's exposure to crowds and public transport
- cleaning toys, highchairs and worktops regularly
- discouraging other adults and children with cold-like symptoms from handling or cuddling their baby
- keeping the baby away from tobacco smoke.



## Risk factors

If a baby is born at less than 35 weeks gestational age he/she will have an immature immune system and can therefore be more susceptible to serious complications from RSV infection than a term baby.<sup>15</sup> However, prematurity is only one of a number of risk factors for severe RSV infection – other factors to consider include:<sup>16,17</sup>

- low birth weight
- pre-school aged siblings in the family
- male gender
- birth preceding or during the early part of the RSV season (October – March)
- smoking in the home.

## RSV clinics

If you identify a preterm or vulnerable baby who may be at risk of complications from RSV, you can contact your local hospital or community nurse to refer them to the nearest RSV clinic, where they can access follow-up care with a paediatric nurse. See the Bliss booklet, *Common winter illness* (second edition, 2010).

## Bronchiolitis

Bronchiolitis is an acute inflammatory respiratory illness of children that can occur in the first two years of life. It is the most common serious respiratory disease of infancy, with 90 per cent of affected children aged one to nine months. In about 80 per cent of cases, bronchiolitis is caused by the respiratory syncytial virus – although other viruses, such as the adenovirus, influenza viruses, and rhinoviruses, can also produce the condition. The peak age incidence for bronchiolitis is between two and five months. It usually occurs in winter epidemics lasting two to five months. Mild cases can be nursed at home, but certain high-risk patients, such as children born preterm, children with underlying cardiac or pulmonary disease and very young patients may have significant morbidity and mortality. In all these cases, hospitalisation should be seriously considered. Signs of respiratory distress occur in severe cases, in which case the child will be admitted to hospital.

Oxygen may be given to the baby if necessary. Feeding may be given via nasogastric tube or intravenous fluids if there is difficulty with feeds. As bronchiolitis is a viral infection, no medicines – such as antibiotics or bronchodilators – have been shown to treat the infection effectively. Bronchiolitis gets worse before it gets better and the child will continue to cough for many days, even weeks after the acute illness. Most infants recover from the acute infection within two weeks, but as many as half will have recurrent episodes of cough and wheeze over the next three to five years. Some may develop asthma. The infection is thought to be caught through direct contact with nasal secretions on the hands of infected children and adults so everyone in the household should wash their hands frequently and thoroughly, especially if they have a cold.

### Symptoms of bronchiolitis

Usually the baby first develops symptoms of a cold, such as a runny nose, a cough and sometimes a mild fever, for three to four days (other members of the household may have a cold usually by day three or four). These symptoms are followed by a more severe cough, the onset of rapid breathing, chest retractions and expiratory wheezing. In severe cases the child may become cyanosed and have difficulty in breathing. The Bliss booklet, *Common winter illnesses* (second edition, 2010) contains useful information for parents on when to call a doctor.

### Apnoea monitor

Research has shown that monitors do not prevent sudden infant death and may increase the anxiety of the parents. However, some parents prefer to have one, particularly if their baby has repeated apnoeic attacks. Some hospitals are able to loan monitors. Parents who are worried about apnoeic attacks should discuss this with the neonatal unit staff who will advise as to whether or not an apnoea monitor is necessary.

### Growth issues

Postnatal growth restriction appears to be inevitable during the initial hospital stay, with preterm babies weighing significantly less than expected at hospital discharge.<sup>18</sup> While some babies will display little catch-up growth after discharge and will remain small throughout infancy and childhood,<sup>19</sup> others will catch up and will eventually fall within the expected range for their age group.

The ideal rate of growth is unclear. Randomised controlled trials have shown that babies given breast milk had long term health advantages such as lower average blood pressure and lower risk factors for heart disease. In addition there is some evidence that avoiding rapid catch up growth may be beneficial in terms of long term health.

It is important to remember that perceived poor growth is a major area of concern for many parents of preterm babies. You will therefore need to strike the right balance between reassuring parents that their infant is doing well and being alert to any significant growth problems that may need addressing by the appropriate health professionals.

Preterm babies who develop bronchopulmonary dysplasia (BPD) show impaired growth during early infancy compared with term and preterm infants babies who do not. The impaired growth sometimes extends over the first few years of life. Different explanations for the slow growth in infants with BPD have been proposed, such as the increased work required to breathe, early use of corticosteroids, intrauterine growth restriction, early postnatal growth restriction and feeding problems related to inadequate intake of food or high metabolic rate.





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9

## Encouraging healthy family relationships





## 9. Encouraging healthy family relationships

- Mothers of babies born preterm or sick are at a higher risk of postnatal depression than mothers of term babies.
- Maternal depression has been identified as the strongest predictor of paternal depression during the period immediately after the baby's birth; symptoms for men usually start later after the birth than for women and can persist for up to a year.<sup>8</sup>
- It is therefore vital that you interact with fathers and acknowledge the father's role in the family in order to enhance and contribute to the health and well-being of the child.

### Jason's story

Jason is the father of Charlie, born at 29 weeks weighing 3lb 7oz.

"One of the most difficult things I had to do was tell my daughter Jessica that her mum was staying in hospital, and I did not know when she was coming home. The injustice of parents having to travel for hours to see their child is, in my view, inhumane. While I was in the unit I spoke with another dad who travelled two hours each way to see his daughter every night. Being a mechanic, he had to attend work to earn money so he came every night after finishing at the garage and then drove home again."



### New challenges

Parenting is challenging, even under ideal circumstances. The quality of parenting and the home environment are crucial factors in any child's health and development. These factors are even more important in the outcome of the preterm or sick baby, but studies have shown that parental anxiety and stress levels are higher and depression is not uncommon in these households.<sup>1</sup>

The birth of a preterm or sick baby represents a well-documented emotional crisis for the parents and the family. Even when the baby is home, parents may need help in coming to terms with what has happened and parents of preterm babies with or without disabilities may question their reactions.<sup>2</sup>

They may feel that they should be grateful that their baby is alive and at home, but instead still feel anger or grief at what has happened. Parents of preterm babies react differently to stressful events such as illness, surgery, behaviour problems and perceived developmental difficulties. These events may resurrect the feelings

of helplessness, frustration and fears for the future of their child that they felt while the baby was in the neonatal unit. These recurring reactions are defined as 'chronic sorrow'.<sup>3</sup>

You will need to acknowledge that this is an emotional and difficult time for the parents and may need to give them 'permission' to express these feelings as normal, without feeling guilty about them. Contact with other parents of preterm babies who share the same difficulties, and, if necessary, some professional counselling may benefit and help support the parents.

You can relieve stresses upon both parents by communicating with the neonatal unit, answering questions, interfacing with the GP and social services if necessary, assisting with hospital appointments and offering emotional support.

## The parents' relationship

As discussed in Chapter 4, *Understanding the parents' perspectives*, several studies confirm that the birth of a preterm baby is considered to be a crisis for both parents. The way in which each parent copes with this experience will be different, and no one way is 'normal' or 'right'. The stress, fatigue and fear that are likely to accompany having a baby who needs hospital care may, in itself, place significant and considerable strain upon a relationship. The stress of caring for and adjusting to any new baby may also cause or intensify discord between parents.

When a preterm baby goes home it is likely that the father will have returned to work. He may be unable to spend more than a few days at home, especially if he has had to take time off while the baby was in hospital. In most families with a new baby, it is likely that the mother will be the main caregiver, and in families with preterm or sick babies, the overall stress of mothers has been found to be higher than that of fathers.

Sexual problems may occur in both mother and father following the traumas of the birth and these may cause additional discord within the parental relationship.

Although the birth of a preterm or sick baby is a stressful event for parents, and anxiety and stress levels are higher than in parents whose babies do not require hospitalisation, it has been found that most parents seem to have recovered well by the time the child has reached the age of two.<sup>4</sup>



## The father's role in the family

Cultural expectations of fathers, and their participation in the care of children, have evolved over the past 20 years. Research has demonstrated that fathers have assumed more child care responsibilities and that the number of hours spent with children are converging for men and women. Research has confirmed that fathers make different, but equally important, contributions to a child's growth and development with respect to emotional health and cognitive development.<sup>5</sup> However, fathers sometimes feel ignored or marginalised, and their contributions unacknowledged. This may either discourage fathers, who may already be unsure about their new

role, from becoming more involved, or alienate fathers who have strong feelings about being involved, leading to feelings of exclusion.<sup>6</sup> It is therefore vital that you interact with fathers and acknowledge the father's role in the family in order to enhance their contribution to the health and well-being of their child.

## Siblings

These times can be very difficult for older brothers and sisters. They may know that their parents are struggling but they may not be old enough to understand the situation and its implications. Reassurance is essential and, as with term babies, appropriate involvement with the new baby is extremely important. Parental stress and the high levels of care required for a baby with continuing medical complications bring challenges to family relationships and these inevitably impact on siblings.



## The next pregnancy



The risk factors for preterm labour and low birthweight babies are discussed in Chapter 1, *Preterm and sick newborn babies: the overview*. Depending on the cause of the preterm birth, parents may benefit from advice on how to prevent a subsequent preterm birth. For example, if smoking was a factor, advice on smoking cessation should be made available. If other factors such as cervical incompetence or pre-eclampsia/hypertension are involved, antenatal staff will normally closely monitor any subsequent pregnancy and appropriate treatment and advice will be offered.

## Mothers returning to work

The arrival of a preterm or sick baby inevitably has a big impact on any previously laid plans for a mother to return to work. The birth may have meant a sudden departure from the workplace and, depending on the situation, possible short term medical complications for the mother too. With many families dependent on two salaries, and other families consisting of single parents, the pressure on the mother to return to work can be intense. Many parents express worries about putting their child in the care of others when their baby has had such a frightening and fragile start to life. This may be coupled with concerns about continuing medical complications, developmental issues or simply a sense that their baby is exceedingly vulnerable. The actual return to work can be difficult too, particularly if the original departure was sudden. As well as the obvious concerns about their baby, the mother may also be struggling to come to terms with the events of the previous weeks and months. No allowances are made for mothers in terms of maternity benefit or leave when a baby is born preterm and this may add to the pressure on the family if the mother has no choice or flexibility in when she has to return to work. Depending on where they live, the family may be eligible to access Sure Start services.

## Postnatal depression

Postnatal depression is a serious disorder that has been found to affect up to 20 per cent of women six weeks after childbirth.<sup>7</sup> For most parents, the birth of their preterm baby can be a time of great anxiety and stress and many parents will feel depressed, angry and isolated. Not surprisingly, therefore, postnatal depression is found to be greater in mothers of preterm babies (and also in mothers of twins and more). As discussed in Chapter 10, *The preterm child's health and development*, this may affect the growth and development of the baby.

### Layla's story

Layla is the mother of Daisy, who was born at 24 weeks weighing 1lb 7oz.

"I don't honestly think I was really aware of the scale of what we went through until a couple of months after getting Daisy home. I started having the most horrible nightmares and started sleepwalking and screaming, seeing Daisy like she was when she was really poorly.



**My health visitor was excellent and between her and my doctor I was diagnosed with post traumatic stress disorder. It took a number of months, and counselling sessions, to deal with what we had been through and what we had seen on our journey.**

I did not go back to work as I didn't think it was the right thing for Daisy. I still find it really hard to leave her with anyone. I have only let grandparents babysit a couple of times and only in our house. I don't know when I will be less protective but I will get there. It's just about taking it one step at a time."



## Post traumatic stress disorder (PTSD)

The capacity of parents to adjust to a preterm birth (with the baby not corresponding to expectations, separation, invasive treatment and anxiety) has been considered to be a critical factor in many recent studies. Preterm birth may cause considerable stress for parents and result in post traumatic stress disorder symptoms such as invasive memories, attempts to avoid or ignore certain specific experiences and emotional vigilance which may have implications with regard to the transition to parenthood.<sup>8</sup> It is important therefore for community health professionals to acknowledge that post traumatic reactions can occur after a birth and that supportive care and psychological help may be needed.<sup>9</sup>

## Postnatal depression in men

Depression among new fathers, who have to adjust to new gender roles and parental responsibilities, has received little attention. However, there is some evidence that men experience depression after the birth of a child, and that paternal depression is linked to maternal depression. During the first year after the baby's birth, the incidence of paternal depression has been found to range from 1.2 per cent to 25.5 per cent in community samples, and from 24 per cent to 50 per cent among men whose partners were experiencing postnatal depression.<sup>10</sup> Maternal depression has been identified as the strongest predictor of paternal depression during the period immediately after the baby's birth with depression levels tending to be mild to moderate. Symptoms for men usually start later after the birth than for women and can persist for up to a year.<sup>11</sup> It is important therefore for you to consider whether or not both parents may be suffering from depression.



## Things to look out for

### Predictors for postnatal depression

Significant predictors for postnatal depression in mothers of preterm babies include:

- Prenatal depression
- Poor social and family support
- Life stress
- Low socio-economic status
- Low self-esteem
- Childcare stress
- Prenatal anxiety
- Poor relationship with partner
- Difficult temperament of the baby
- Unplanned or unwanted pregnancy

### Recognising depression

The signs and symptoms of depression include:

- Crying
- Anxiety
- Panic attacks
- Sleeplessness or early waking
- Excessive fatigue
- Feeling unable to cope
- Indifference to the baby
- Frequent concerns about the baby
- Memory loss
- Feelings of unreality
- Loss of self-esteem
- Loss of, or excessive appetite
- Inability to concentrate
- Antagonism towards partner

## Assessment of postnatal depression

Routine assessments, for example, using the Edinburgh Postnatal Depression Scale (EPDS, a screening tool developed specifically for health visitors), are carried out by community health professionals in many organisations. It may be particularly appropriate for you to offer 'listening visits', as a first line intervention for women with preterm babies found to be depressed or felt at risk of depression. In addition to any tool you should also use your own intuition, clinical knowledge and experience, along with keen observation to pick up cases of postnatal depression. This is done by observing the interaction between mother and baby, discussing the mother's own well-being, listening to what the mother is saying and observing her mood.<sup>12</sup> A study to improve the early detection and treatment of postnatal depression has found that a substantial number of women were identified for the first time as likely to be suffering from postnatal depression 12 months after giving birth.<sup>13</sup> The authors concluded that community health professionals should screen for postnatal depression throughout the period of their contact with mothers, not solely in the period immediately after giving birth. This conclusion may be particularly appropriate for mothers with preterm babies.

## Intimate partner abuse

Intimate partner abuse (formerly known as domestic violence) is reported by up to one in four women in Britain. It encompasses physical, sexual, emotional and psychological abuse. The psychological and social consequences of intimate partner abuse include alcohol and drug dependence, suicide attempts, depression and post traumatic stress disorder. Intimate partner abuse is also associated with preterm birth and low birthweight, and it has been found that a pregnancy within the past 12 months doubled the risk of physical violence.<sup>14</sup> You should be aware, therefore, that some women who have had preterm babies may be vulnerable to intimate partner abuse and should provide appropriate support and advice to them.

## Child protection issues

As discussed in Chapter 7, *Going home*, although all families who have a preterm baby will need continuing help and support, some families are more vulnerable than others. In particular, higher rates of child abuse and neglect have been reported among preterm babies, and, childhood neglect is also significantly associated with delayed cognitive development and head growth.

You will already be aware of other factors that may indicate child abuse and neglect, and each organisation will have its own child protection guidelines and referrals systems for you to follow.



### How community health professionals can improve outcomes

Your role is vital in assisting healthy family relationships and for giving the preterm or sick baby the best possible chance of a healthy future. You can relieve stresses upon both parents, communicate with the neonatal unit, answer questions, interface with the GP and social services if necessary, assist with hospital appointments and offer emotional support when it may be very much needed. Valuable insights can be obtained by reading the parent stories on the Bliss website [www.bliss.org.uk/parentstories](http://www.bliss.org.uk/parentstories)

Bliss has an active parent forum within its website in which parents may share experiences and discuss feelings with others in a similar situation.

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# 10

## The preterm child's health and development





## 10. The preterm child's health and development

- It is important to remember that parents with very low birthweight babies or with 'small for gestational age' babies may feel under intense pressure to ensure that their baby gains weight.
- Repeated weighing of children with faltering growth or the use of the negative descriptive term 'failure to thrive' can contribute to anxiety and depression in the baby's parents.
- Regular, supportive visits from health visitors have been shown to reduce maternal distress and are believed to promote the baby's healthy development.

Following discharge from the neonatal unit, the preterm baby's health and development needs to be closely monitored. Providing continued support to parents and validation of their parenting skills is important. Parental support and intervention programmes – such as those that you can provide – have been shown to reduce maternal distress and are believed to promote the baby's healthy development.

Postnatal influences such as poor nutrition, a challenging home environment and adverse social factors may contribute to poorer outcomes for the child, particularly in relation to cognitive development and language skills.<sup>1</sup> You can alleviate and/or reduce these negative influences by making use of all the resources available.

### Weight gain and growth

#### Pressures on parents

While it is important to monitor the preterm baby's weight gain and growth, you should be aware that parents with very low birthweight babies or with 'small for gestational age' babies may feel under intense pressure to ensure that their baby gains weight. Repeated weighing of children with faltering growth or the use of the negative descriptive term 'failure to thrive' can contribute to anxiety and depression in the baby's parents. In studies, women have reported that they felt a sense of failure when their baby was not gaining weight and their feelings of inadequacy increased when the emphasis was placed on weekly weighs rather than on time spent discussing any underlying difficulties. Some women may also avoid attending clinic sessions in case their child has not put on any weight, or be sensitive to remarks from other parents about their baby being small when attending the child health clinic.<sup>2</sup> Professional judgement must therefore be exercised between monitoring the baby's growth and causing the family undue anxiety.



### Early weight gain and growth

The early growth of a baby born preterm is the result of a complex interplay of nutritional and endocrine factors that is incompletely understood.<sup>3</sup> Growth status is an important index used to monitor the overall health of very low birthweight babies, which is defined as less than 1,500g.<sup>4</sup> Studies suggest that very low birthweight babies grow differently than higher birthweight babies, and reduced neonatal growth continues to be a major problem, especially among the smallest and sickest babies.<sup>5</sup> Poor postnatal growth is associated with neuro-developmental impairment and other developmental difficulties. Reduced neonatal growth of very low birthweight babies may also influence adult growth attainment and have long term implications for adult health.<sup>6</sup>

### Reduced height and/or weight gain

Many parents find the phrase 'failure to thrive' distressing and health professionals are advised to avoid this description. Despite there being no consistent definition for reduced height and/or weight gain, a fall across two centile channels or a fall beneath the second centile on standardised growth charts for at least three months (to exclude weight loss secondary to an acute illness) are well-established criteria for identification of this condition.<sup>7</sup>



### Faltering growth

The term 'faltering growth' has similar recognition criteria to 'failure to thrive' but has less implication of severity or persistence, covering the spectrum of children with a transient problem in weight gain in addition to those with more persistent problems.<sup>8</sup>

### Catch-up growth in height

Catch-up growth has been defined as a height velocity greater than normal after a period of growth inhibition, the effect of which is to raise the child's height towards what he or she would have attained had growth not been inhibited.<sup>9</sup> Between 80 per cent and 90 per cent of 'small for gestational age' infants achieve normal age range stature by the age of four years; those who fail to catch up by this age are destined to remain small. Other factors, when measuring height velocity, should include familial short stature and possible other causes of short stature such as an endocrine disorder, environmental and emotional problems and chronic conditions such as asthma or coeliac disease.

### Centile charts

The UK-WHO growth charts for children up to four years of age were published in 2009 and replaced the previous UK 1990 charts which were based on predominately formula fed babies. The UK-WHO growth charts combine UK90 and WHO data and are based on infants who have been breastfed for at least four months. The suite of documents also include charts specifically designed for plotting growth measurements of preterm and/or low birthweight infants from birth to the age of two years. A leaflet, *Using the new UK-World Health Organization 0-4 years growth charts*, is also available to support you in using the charts. <http://rcpch.hosting.opendev.net/research/uk-who-growth-charts>

### Factors affecting growth

Differences in the growth pattern of very low birthweight breastfed and formula-fed babies are well recognised and have been attributed to differences in nutrient intake. Formula-fed babies will also grow more rapidly than breastfed babies, not only in weight but also in length. However, research indicates that there are some long-term health disadvantages associated with fast growth on formula feeds.<sup>10</sup> Cerebral palsy is frequently associated with poor growth and unique growth patterns.<sup>11</sup>

### Risks facing very preterm babies

Children who are born at 25 completed weeks of gestational age or less are at an increased risk of poor somatic growth, neurological and developmental difficulties and feeding problems. To a lesser extent, respiratory illness is associated with the poorest growth.<sup>12</sup> However, postnatal outcome is also affected by home environment, care giving practices, the effects of poverty, and other significant psychosocial factors.<sup>13</sup> Again, you have a significant role in supporting the baby's healthy development.

## Referrals

When other measures such as feeding advice are unsuccessful, and reduced growth or faltering weight gain has been identified, a referral should be made through the appropriate health professional such as a paediatrician or GP. Referrals may also be made to a speech therapist, dietitian or play therapist, for example. Early identification of poor postnatal growth patterns can be very helpful because they alert clinicians to a timely assessment of neuro-developmental status and thus, if appropriate, initiate early intervention programmes.<sup>14</sup>

### Points to remember

Factors that can negatively affect growth:

- Medical complications such as Chronic Lung Disease and frequent illness.
- A poor home environment or low income. Childhood neglect is also significantly associated with delayed cognitive development and head growth.<sup>15</sup>
- Postnatal depression. Although there is a strong need for caution before making any assumptions, there is some correlation between depression in mothers and faltering growth in their children. Depression in mothers of children with faltering growth during the first two years of life has been found to be significantly greater than in mothers of children who are gaining weight appropriately.<sup>16</sup>
- Male sex. Researchers have found after tracking the physical growth rates of very preterm babies over a 20-year period that male preterm babies lag behind their female counterparts, while the young women not only catch up in weight and height with their normal birthweight counterparts but also exhibit similar rates of obesity.<sup>17</sup>
- Feeding-related difficulties, including gastro-oesophageal reflux and oral motor dysfunction.
- Children with developmental disabilities who are at increased risk for developing feeding-related difficulties.

## Developmental milestones

Unlike commencing weaning or immunisation schedules, the developmental level of preterm babies should be assessed at the correct age for gestation, so a nine-month-old baby born three months preterm should have the developmental milestones of a six-month-old baby. There is, of course, a wide age range within 'normal' development, and some skill development, such as late walking or talking, may run in the family.

For the extremely preterm baby, there is likely to be some global delay. Poor nutrition and iron deficiency anaemia may cause slow development, as can lack of stimulation and neglect. However, failure to obtain a skill by the latter age range after correction for gestational age could suggest abnormal development and the child should be referred to a paediatrician or child development team as necessary. Parents should be advised against baby walkers for their preterm baby, as not only are they a frequent cause of accidental injury but, in the case of preterm babies, baby walkers can also affect muscle development, leading to delay in sitting, crawling and walking.



## Follow-up appointments

Some babies may require frequent follow-up medical appointments, sometimes more than one a week in the early stages. Parents may find this difficult to manage if they live some distance from the hospital. Community health professionals can help by offering to rearrange some of the appointments so that the timings are more manageable. Major disabilities, such as cerebral palsy, are usually discovered by the age of two years. However, follow-up for all preterm babies should be continued at least to pre-school age in order to detect cognitive disabilities such as problems in learning, behaviour and attention span.

## Behavioural and cognitive problems

Very preterm and very low birthweight children not displaying classical neurological signs and in mainstream education may still be vulnerable to problems later in childhood, particularly behavioural, attention and cognitive disorders.

Despite these concerns, however, the great majority of children who are born preterm enter mainstream education. Attention is increasingly being turned to the quality of life of these children and their educational and behavioural status.<sup>18</sup> Studies of these children have shown that as many as 40 per cent may show learning difficulties, often associated with problems of visuospatial perception, minor motor impairments and behavioural difficulties. The origin of these difficulties has been attributed, variously, to a delay in neurologic maturation, early cerebral injury, social factors and poor early growth.<sup>19</sup>

Most children who are born preterm and receive good support from family and health care professionals will enter mainstream education and thrive both physically and mentally. The contribution of good health care, including support from community health professionals, cannot be over-emphasised.

### Educational issues

Some ten to 15 per cent of children born in the United Kingdom with very low birthweight (less than 1,500g) will have major physical impairments that usually require special educational provision, but the majority will enter mainstream school.<sup>20</sup>

### Growth in adolescence

Recent reports of the adolescent growth attainment of very low birthweight babies indicate that some catch-up occurs during childhood; however, they continue to lag behind in growth when compared with normal birthweight children.

## Weaning



Low birthweight preterm babies have special nutritional needs after discharge from the neonatal unit. These additional requirements include energy, protein, long chain polyunsaturated fatty acids, zinc, iron, calcium and selenium. Government guidelines for term babies now advise exclusive breastfeeding for six months before solid foods are introduced. The Department of Health acknowledges that these deadlines are for healthy, term babies and are not appropriate for preterm or sick newborn babies. When a baby is ready to wean will differ according to the degree of prematurity.

From the time preterm babies are first given enteral feeds their gastrointestinal systems develop more rapidly than if they had remained in utero. Due to this their gut function is much more mature at their expected birthday than that of a term baby.

It is advised that weaning should be started in preterm babies between five and eight months (uncorrected age) from birth.<sup>21</sup> Around this time babies should start to show readiness cues for introducing solids food, parents can be helped to look for appropriate cues which are outlined in a recent piece of work, *A consensus statement on weaning preterm infants 2011*, [www.bapm.org/nutrition/guidelines.php](http://www.bapm.org/nutrition/guidelines.php)

Once a decision has been made to start weaning, the normal weaning guidelines for term babies should be followed, including finger feeding when the baby is ready and introducing lumpy foods at six to eight months from birth.

Parents should be discouraged from pushing as much food and milk as possible into the baby to maximise weight gain as this may lead to feeding problems. Small babies may also need to be offered food four to five times a

day, especially those who are still catching up with their growth. Fortification of solid meals with high energy foods and extra fat should be considered. It is vital to monitor growth following the introduction of solids and refer the infant to a dietitian should weight velocity start to slow significantly.<sup>22</sup> The neonatal unit may have a dietitian who is happy to offer advice following the baby's discharge. The above guidance on weaning is supported by the Paediatric Group of the British Dietetics Association. Also see the Bliss booklet *Weaning your preterm baby* (sixth edition, 2010).

### Why weaning is advised between five and eight months:

- Weaning should commence between five and eight months actual (**not** corrected) age.
- Delayed weaning causes problems later with different tasting food and coping with lumps – mainly because the baby has missed out on the critical phases of developing taste from four to six months and establishing the ability to cope with lumps from six to eight months.
- A good variety of foods from the beginning will help ensure nutritional adequacy and help ensure any sensitive periods for accepting new foods are not missed.
- Many behavioural feeding problems can be avoided if preterm babies are on solids by seven months from their birth date at the latest.
- Preterm babies are at no more risk of food allergies than term babies.

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11

## Glossary and Bliss resources





## Glossary

The most common perinatal and neonatal medical conditions are listed alphabetically below.

**Apnoea** Normal respiration rates for infants are 40–60 breaths per minute. All babies, especially preterm babies, may take pauses of five to ten seconds between breaths. True apnoea is a time delay of greater than this, and this is rare in term infants, but not uncommon in those born preterm. These episodes of loss of effective breathing can lead to hypoxia and bradycardia. Minor episodes can be managed by gentle stimulation but more frequent or prolonged episodes may require treatment with respiratory stimulants or in the most severe cases positive pressure ventilation.<sup>1</sup>

**Chronic Lung Disease (CLD)** Chronic Lung Disease (CLD) is a major cause of morbidity and mortality among very low birthweight babies (weighing less than 1,500g). CLD has been reported in between ten per cent and 40 per cent of very low birthweight infants in different studies. It is a major cause of long term pulmonary complications including recurrent respiratory infections, reactive airway disease and abnormal pulmonary function. In addition to respiratory disease, survivors with CLD have an increased risk of cerebral palsy, mental impairment and other less serious motor and cognitive disorders. CLD, in most cases, correlates with the pathologic process known as bronchopulmonary dysplasia (BPD).<sup>2</sup> Risk factors for CLD include:

- Gestational age
- Birthweight for dates
- Mechanical ventilation
- White race
- Pulmonary air leak
- Patent ductus arteriosus
- Septicaemia
- Acute respiratory distress
- Chorioamnionitis

**Jaundice (Hyperbilirubinaemia)** As liver function is initially poor in newborn infants, mild jaundice is common. If necessary, this can be treated by exposure to blue light, which converts bilirubin into substances that can be excreted by the kidney.<sup>3</sup> As preterm babies have more immature red blood cells (and can therefore produce more bilirubin) and have more persistent immaturity of liver function (and are thus less able to clear it) they are more prone to jaundice. Every jaundiced baby needs assessing and, if the bilirubin levels are high or if the baby is not feeding well or is dehydrated or if the jaundice is prolonged (such as lasting for more than two to four weeks), the baby needs to be referred for further investigation.

**Hypoglycaemia** Hypoglycaemia is traditionally defined as a blood glucose level of less than 2.6 mmol/L in the first 24-hours of life, and less than 3.5 mmol/L thereafter. Causes include:

- Intrauterine growth restriction
- Prematurity
- Delayed feeding
- Chronic asphyxia
- Hypothermia
- A diabetic mother
- Adrenal insufficiency
- Exchange transfusion

Early detection and treatment is essential as symptomatic hypoglycaemia may cause cerebral damage. Treatment can include enteral feeds if tolerated, and intravenous dextrose if not. Any symptomatic infant needs urgent assessment and intravenous glucose.<sup>4</sup>

**Hypothermia** All newborn babies are susceptible to becoming too cold but preterm babies and those with intrauterine growth restriction are particularly vulnerable.

This is because preterm and sick babies have:

- a large surface area to body ratio
- reduced or absent fat stores (particularly brown fat)
- limited control of their body temperature
- very permeable skin.

If preterm or low birthweight babies become cold after delivery mortality increases and there is an increased risk of poor growth rate and respiratory distress syndrome. A recommended core temperature<sup>5</sup> for the very preterm infant is 36.7 to 37.3°C. It should be noted that hyperthermia may also be detrimental and maintaining the temperature within the normal range is essential.

**Hypoxia before birth** Effective resuscitation of infants is extremely important to avoid postnatal hypoxia. Serious consequences of hypoxia (before and after birth) include brain injury, seizures, increased incidence of intraventricular haemorrhage, heart failure and metabolic disturbances (such as hypocalcaemia and hypoglycaemia). Conditions that may require resuscitation when the baby is born include:

- Fetal distress
- Antepartum haemorrhage
- Low birthweight (due to prematurity and/or reduced growth)
- Multiple pregnancy
- Serious fetal abnormality
- Prolonged or difficult labour

In many cases there are no identifiable risk factors in infants who have required resuscitation. Skilled resuscitation must therefore be immediately available at all times.

**Infection** Infection is a major cause of neonatal mortality and morbidity. Newborn infants are more susceptible due to their relative immune deficiency.<sup>6</sup> The incidence of infection is more than doubled in babies needing neonatal intensive care and very low birthweight babies. This is because preterm babies often have particularly poor immunity, with less effective cutaneous and mucosal barriers. The number of invasive procedures that they need also increases their risk of infection.<sup>7</sup> Babies are exposed to infection in four ways:

- **Ascending** This is rare if the membranes are intact but has been recognised, particularly in cases of Group B Strep and Staph Aureus.<sup>8</sup> Colonisation is more likely to occur once the membranes are ruptured and the risk increases the longer that this happens prior to birth.
- **Transplacental** Some agents can cross the placental barrier and this has devastating effects on the fetus (for example, rubella).
- **Intrapartum** Vaginal birth can result in contamination of the baby's skin and gut. Another potential source of contamination is water from water birth.<sup>9</sup>
- **Postnatal** All babies are subject to contamination from the environment and the major risk factor is contact from other people.<sup>10</sup>

**Intracranial haemorrhage** This is a relatively common condition in preterm babies. There are several different types of haemorrhage depending on site of origin, with different prognoses. The major types of intracranial haemorrhage are:

- Subdural
- Subarachnoid
- Intraventricular
- Intraparenchymal
- Intracerebellar

Intraventricular haemorrhage (IVH) is the most common type of intracranial haemorrhage, arising particularly in immature babies. Risk factors for IVH include immaturity, respiratory distress syndrome, pneumonia, hypoxia and hypotension. IVH usually occurs in the first week of life but has been noted antenatally. The majority of all cases of IVH are diagnosed on routine ultrasound scans. Ultrasound scans can detect four grades of IVH, with grade IV being the most serious. The prognosis to some extent depends upon the extent of the haemorrhage. Although there is an association between the grade of IVH and adverse neuro-developmental outcome it is not a very accurate predictor and caution should be exercised before giving precise estimates of prognosis. One of the possible consequences of intracranial haemorrhage is cerebral palsy, which would be diagnosed at a much later stage.

**Necrotising enterocolitis (NEC)** Approximately five to ten per cent of very low birthweight infants develop necrotizing enterocolitis (NEC).<sup>11</sup> The cause is considered to be multifactorial, with a variety of predisposing risk factors including prematurity, intrauterine growth restriction, poor gut blood flow as shown on doppler studies, lack of exposure to antenatal steroids, being of African Caribbean origin, patent ductus arteriosus (PDA) and the placement of an umbilical catheter. There is no consistent agreement that these are independent risk factors.<sup>12</sup> During their initial acute illness, infants with NEC often require ventilator support. Some 20 per cent to 50 per cent of babies with NEC require surgical management and suffer more morbidity, such as infection, retinopathy of prematurity (ROP), or bronchopulmonary dysplasia (BPD), which lengthen their hospital stay.<sup>13</sup> Infants with NEC can often experience difficulties with feeding and poor growth and there is a strong association between more severe grades of NEC and poor neurodevelopmental outcome.

**Patent ductus arteriosus (PDA)** The ductus connects the pulmonary artery to the aorta and provides a pulmonary-to-systemic diversion during fetal life. In most term babies the ductus closes functionally within the first three days after birth. In some babies, especially preterm babies, there is delayed closure and in a proportion this may have a significant impact upon the infant. PDA is associated with increased mortality and morbidity in preterm babies<sup>14</sup> and increases the risk of IVH, NEC, Chronic Lung Disease, bronchopulmonary dysplasia and death.<sup>15</sup> There is controversy as to whether and when the ductus should be closed by either pharmacological or surgical methods. The most common medication used to close a PDA is indomethacin, although use is associated with renal, gastrointestinal and cerebral side effects.<sup>16</sup> Surgery is indicated if other treatments are clearly contraindicated and the baby's clinical condition warrants it but there is increasing evidence to suggest that surgery should be avoided unless absolutely essential.<sup>17</sup>

**Reduced growth** Slow growth in early childhood is very common in preterm babies. This is seen more commonly in the extremely preterm or very low birthweight babies and in those who have suffered long term illness. Babies who have been treated with prolonged courses of systemic steroids for chronic lung disease are also more commonly affected.<sup>18</sup>

**Respiratory distress syndrome** Pulmonary immaturity associated with surfactant deficiency leads to diffuse atelectasis and decreased lung compliance. Mechanical ventilation of a newborn with very small lung volumes, a compliant chest and increased incidence of patent ductus arteriosus may lead to barotraumas and volutrauma and initiate or exacerbate more chronic respiratory disease (bronchopulmonary dysplasia).

## Other respiratory disorders

These include:

- the structurally abnormal lung as seen in infants with congenital diaphragmatic hernia and hypoplastic lungs
- acquired respiratory disease such as lung infection and meconium aspiration syndrome.

**Retinopathy of prematurity (ROP)** This is a vasoproliferative retinopathy affecting preterm babies. In severe cases it can lead to partial or total retinal detachment and blindness. It was originally thought to be entirely caused by excessive amounts of oxygen but it is now evident that other factors are also involved including growth restriction, gestational age, use of surfactant and genetic factors.<sup>19</sup> The two major factors in determining severity of ROP are the degree of prematurity and levels of arterial oxygen. All preterm babies with significant risk must be screened within a very closely defined window of postnatal age while on the neonatal unit. Most mild ROP regresses but babies with more severe ROP may need treatment with laser therapy.<sup>20</sup>

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## Bliss

Throughout the UK, 80,000 babies are born prematurely or sick every year. The critical care that these babies receive in the first hours, days and weeks has a direct impact on their health and wellbeing for the rest of their lives.

Our mission is to make sure that more babies born prematurely or sick in the UK survive and that each one has the best quality of life.

Bliss was established in 1979 and is the only UK charity dedicated to working for special care babies and their families.

As well as funding research and training and campaigning for better care, one of the ways we aim to achieve our mission is through supporting families.

### Supporting families

Having a premature or sick baby is often a frightening and overwhelming experience. Bliss provides a range of free advice, support and information to families, helping them to understand what is happening to their baby and offering a way for parents to talk to others who know what they are going through.

#### Our Family Support Team offers:

- a freephone Helpline providing information and support
- Parents4Parents – a service to put people in touch with other parents who have gone through a similar experience
- a comprehensive website containing information and useful contacts, as well as an interactive parent messageboard
- a wide selection of free information, both in print and online
- a network of local support groups
- access to qualified counsellors.

### Funding research and training

Neonatal medicine is full of constant changes and breakthroughs. Bliss supports new developments in care by funding vital clinical research and providing study days for health professionals to improve their skills, as well as helping the spread of good practice throughout the sector.

### Campaigning for better care

The care premature and sick babies receive in the first few days and weeks after birth plays a key role in shaping their future lives. Bliss fights for the needs of the most vulnerable babies and their families to be met. We want the best standards of care to be available, regardless of when and where a baby is born.

**For more information call us on 020 7378 1122 or visit [www.bliss.org.uk](http://www.bliss.org.uk)**

## Key Bliss resources

### *Common winter illnesses*

Coughs, colds and stuffy noses affect us all throughout the year. Nobody is entirely immune, but some are at higher risk than others. For the very young and in particular those born prematurely, with lung problems or with a congenital heart condition, the high season of October to March can prove to be particularly challenging.

This guide to winter illnesses has been written to provide parents with information on some of the more common infections during this period. It outlines the symptoms to look out for, treatments available and tips on how best to prevent illness.



### *Breastfeeding your premature baby*

This booklet is intended to give a greater understanding of breastfeeding a premature baby and complement the medical advice parents receive from those involved in supporting their baby.

Includes: benefits of breast milk, feeding plan, expressing and storing breastmilk and top tips. This booklet is also of interest to health professionals who are supporting parents of premature or sick babies.

## Bliss resources

- *Bliss Family Handbook*
- *Bliss Baby Charter Standards*
- *Bliss Parent Pack*
- *Breastfeeding your premature baby*
- *Comfort holding poster*
- *Common winter illnesses*
- *Financial advice for families*
- *Going home – the next big step*
- *Going home on oxygen*
- *Kangaroo Care poster*
- *Little bliss magazine\*\**
- *Look at me – I'm talking to you!*
- *Multiple births – a parent's guide to neonatal care*
- *Resuscitation DVD – basic life support for babies*
- *RSV (Respiratory Syncytial Virus)\**
- *Skin-to-skin with your premature baby*
- *The next pregnancy\**
- *Ventilation and Chronic Lung Disease – your questions answered\**
- *Weaning your premature baby*

\*download only \*\*subscription only

For publications: parents can order online at [www.bliss.org.uk](http://www.bliss.org.uk)  
or call 020 7378 1122

All publications are free to parents of a premature or sick baby.

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**Family Support Helpline:** Freephone 0500 618140

**RNID typetalk:** 018001 0500 618140

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for babies born too soon,  
too small, too sick

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