Newborn Infants & the Special Care Baby Unit was written especially to support you as parents of babies who have been admitted to the Special Care Baby Unit. It will give you an understanding of the equipment used and the procedures and treatments your baby will undergo during this eventful time.
Important Notice
Breastfeeding is best for your baby, as it is perfectly suited to nourish infants and protect them from illnesses such as ear infections, stomach upsets, diabetes, eczema and obesity. It is important that, in preparation for and during breastfeeding, you eat a healthy, balanced diet. Combined breast and bottlefeeding in the first weeks of life may reduce the supply of your own breastmilk, and reversing the decision not to breastfeed is difficult. The social and financial implications of using an infant milk should be considered. Improper use of an infant milk or inappropriate foods or feeding methods may present a health hazard. If you use an infant milk, you should follow manufacturer’s instructions for use carefully – failure to follow the instructions may make your baby ill. Always consult your doctor, midwife or public health nurse for advice about feeding your baby.

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Foreword
We have prepared this book to help you understand what may happen during your baby’s stay in our unit and for you as parents following discharge home. It is hoped that it will give you an outline of the likely treatment and care that your baby will receive. It will help to familiarise you with new and strange sounding terms used in relation to the medical and nursing care of babies. It is divided into six sections for you to refer to as required: Neonatal care, Equipment, tests and medicines, Caring for your baby, Home time, Development, Follow-up.

If at any point you do not understand your baby’s condition or treatment, please ask the doctors or nurses to explain again as there is a lot of information to take in. We recognise and appreciate that this is a difficult time for parents. We, the staff, will do everything to support you during your baby’s stay in the neonatal unit.
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Introduction

75,000 babies are born in Ireland each year. There are 20 maternity units in the country. Ninety percent of babies are full term and healthy and require routine medical and nursing care only, but 10% of babies will need admission to the neonatal / special care baby unit. Babies requiring admission include preterm babies and term babies who are unwell or need more support, investigations, or medications and babies born with abnormalities.

Reasons why your baby may be admitted to the neonatal unit

Babies are admitted to the neonatal unit for a number of reasons. Many are born preterm and require careful observation and monitoring. Others, such as full-term newborns, may have health problems, such as infection, jaundice, cardiac or surgical problems, that require special treatment.

Preterm birth

Preterm babies are those babies born before 37 weeks gestation. Every year, 5,000 babies are born preterm in Ireland. About 900 of these preterm babies are very immature, born at less than 32 weeks gestation (that is, at least 8 weeks before they are normally due). If your baby is born before 35 weeks gestation, they will usually be admitted to the neonatal unit.

Among preterm babies, approximately:

- 60% are born at 34 to 36 weeks gestation
- 20% are born at 32 to 33 weeks gestation
- 15% are born at 29 to 31 weeks gestation
- 5% are born at less than 28 weeks gestation

Preterm birth occurs for various reasons. Twin or multiple pregnancy is one of the more common causes. Other causes include infection or if a baby is growing slowly – there are various reasons for this, for example, pregnancy-related high blood pressure or problems with the placenta (after-birth). Sometimes the cause is not known.

Mother enjoying her twin babies

Snuggled preterm baby

Term baby

Preterm birth

Preterm babies are those babies born before 37 weeks gestation. Every year, 5,000 babies are born preterm in Ireland. About 900 of these preterm babies are very immature, born at less than 32 weeks gestation (that is, at least 8 weeks before they are normally due). If your baby is born before 35 weeks gestation, they will usually be admitted to the neonatal unit.

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Multiple births: twins, triplets and more

Multiple births (usually twins, occasionally triplets or quads) are a risk factor for preterm birth. About 50% of twins are born preterm. The staff, where possible, will keep your babies near each other. However, sometimes one baby may require a different level of care, for example, one baby may be in intensive care and the other one in special care. It is also possible that one baby will be discharged home before the other.

Neonatal care and the term baby

When term babies are admitted to the neonatal unit it may be for observation following a complicated birth. If all is well after 24 to 48 hours and your baby is alert and feeding well, they can usually be discharged. Other conditions that necessitate admission include rapid breathing after birth, known as transient tachypnoea of the newborn (TTN), jaundice requiring phototherapy, poor feeding, possible infection needing intravenous antibiotics, or if your baby needs support to maintain their body temperature.

Less commonly a baby may have a more serious problem which requires investigation and a specific medical or surgical treatment, for example, heart condition or intestine (bowel / gut) problem.
Coping with your baby in the neonatal unit

First reactions
Entering a neonatal unit can be an upsetting experience. You will see a lot of equipment and will hear unfamiliar noises. This equipment is designed to keep your baby warm, to monitor many of their vital body functions (heart rate, blood pressure, oxygen saturation), and to support their breathing if necessary.

Your baby’s small, fragile appearance can be upsetting. It is common to feel helpless and that your role as a parent has been side-lined. You may feel that you have nothing to contribute and that the doctors and nurses are completely in charge. This is not the case; the staff are there to help your baby and support you to get through this difficult time. Your opinion and point of view remains important and where possible will be included in your baby’s care. Your role as a parent is still a vital part of your baby’s care.

At first the unit may seem impersonal but behind all this technology there is a very caring approach. The staff will explain the functions of each item of equipment surrounding your baby. If you do not understand what is being said to you, please do not hesitate to ask again. There may be a lot of new information for you to take in.

As a parent it is important to be both hopeful and realistic. The staff will encourage you to visit your baby frequently and be involved in their care.

The mixture of shock and worry can seem overwhelming, and you may have fears about your ability to cope. This is all normal. If you have fears it is good to share them with staff as it may help to relieve those fears.

The following may help you to cope:
- Talk about your feelings.
- Talk with staff about your baby.
- Visit your baby as often as you can.
- Take pictures of your baby.
- Become actively involved in your baby’s care.
- Spend time with your other children, family and friends.
- Let family and friends help, for example, by caring for other children at home and cooking meals, etc.
- Take care of yourself – eat properly and get plenty of rest.
- Remember that the doctors and nurses are there to help you in every way that they can – it may help to share your feelings with them.
- Talk with other parents of babies in the neonatal unit.
- Spend time together with your partner or a friend and discuss your feelings together.
- A medical social worker is available to offer you emotional and other support if needed.

“As a parent it is important to be both hopeful and realistic”

Coping with your feelings
Acknowledge your feelings. It is best to put the actual birth to one side and concentrate on helping your baby and yourself.

It helps to keep in close contact with the doctors and nurses. Your baby needs to get to know you and will be comforted by your visits. It is good to spend time talking to and looking at your baby, see section “Getting to know your preterm baby in the neonatal unit”, page 24. The nurses will also be happy to involve you in your baby’s care. As soon as your baby stabilises you will be able to help with feeding, changing nappies, cuddling and comforting your baby. See section “Ways you can comfort and care for your baby in the neonatal unit”, page 31. No matter how sick your baby is, you should not be afraid to get close to them.

“No matter how sick your baby is, you should not be afraid to get close to them”

Mother caring for her baby

Parents cuddle their baby boy

As a parent it is still a vital part of your baby’s care.
Understanding neonatal intensive care

The neonatal unit
The neonatal unit is an area of the hospital that is specially designed for the care of newborn babies. Some neonatal units are divided into different areas, depending on the level of care offered, for example:
- Neonatal Intensive Care Unit (NICU) is for sick babies who are receiving intensive care. In intensive care, one nurse will look after fewer babies than in special care.
- High Dependency Unit (HDU) is an area for babies who may have recently come through intensive care but who still require a high level of care.
- Special Care Baby Unit (SCBU) is for growing babies who are preparing for home. Here you will have increasing contact with your baby and have an opportunity to do more for your baby, such as nappy change, feeding, cuddling and bathing.

How long will my baby be in hospital?
The length of time that your baby needs to stay in the neonatal unit depends on their size, prematurity and medical circumstances. Many babies will have easily treatable conditions and can be discharged back to you after a few hours / days of observation and care. On the other hand, some very preterm babies may require admission for up to 4 months or more.

As a general rule, for preterm babies the discharge time will be approximate to your expected date of delivery, for example, babies of:

- Under 1000g: 100 days (3 months)
- 1000g to 1500g: 60 days (2 months)
- 1500g and over: 20 days (3 weeks)
- Term babies: A few hours or days

These are only estimates. Some babies may stay for longer and others shorter. See section ‘Home time’, page 46 for further information about your baby’s discharge.

Terms related to prematurity
- Preterm / premature: Born before 37 weeks gestational age
- Low birth weight (LBW): Birth weight <2500g (5lb 8oz)
- Very low birth weight (VLBW): Birth weight <1500g (3lb 5oz)
- Extremely low birth weight (ELBW): Birth weight <1000g (2lb 3oz)
- Chronological age: Age based on date of birth
- Gestational age (GA): Age estimated from start of pregnancy (the number of weeks your baby is in the uterus (womb))
- Corrected age (CA) / corrected gestational age (CGA): Age adjusted according to how preterm your baby was born.

The degree of prematurity matters. Generally, the more preterm the baby the more complex the problems. A very preterm baby will need intensive care, whereas babies born around 32 to 33 weeks will generally need high dependency care and babies born at 34 to 35 weeks will require special care.

The preterm baby and ‘corrected age’
Because preterm babies are born before their expected due date, age in days or weeks does not mean the same as it does for a full-term baby. For example, a preterm baby of 8 months cannot be compared with a full-term baby who is 8 months old. For this reason the term ‘corrected age’ is used. ‘Corrected age’ counts a baby’s age from the time they should have been born, rather than the time they were actually born.

For example, if your baby was born at 32 weeks and is now 8 months old by date of birth, your baby’s corrected age is 6 months, i.e. 8 months minus 2 months preterm = 6 months corrected age.

The ‘corrected age’ is used when assessing a baby’s development. The doctors are happy as long as a baby’s developmental milestones are approximate to a baby’s corrected age.

In other situations ‘actual age’ is used, for example, when giving immunisations. These are given according to a baby’s actual age (chronological age) and allowance for prematurity is not necessary.
Neonatal team

The neonatal unit is staffed by personnel who specialise in caring for sick babies and who will give your baby the highest level of care. Staff in the neonatal unit like babies and know how to give them the care they need to get well. They also care about your feelings as parents. They know nothing can replace your love but you can be reassured that your baby will be well cared for, even when you are not there.

The main carers on a neonatal unit are the doctors and nurses. In addition, there are many other health professionals who may be available, such as:

- Radiographer, who takes x-rays.
- Dietitian, who monitors and manages your baby’s nourishment and growth.
- Pharmacist, who looks after the medicines prescribed for your baby.
- Physiotherapist, who helps preterm and unwell term babies learn the correct movement patterns and gives advice on positioning to promote normal movement and muscle development.
- Medical social worker, who can provide support counselling, information on entitlements, practical and legal issues such as guardianship, and assistance in accessing supports in the community. If you wish to meet with a medical social worker, ask a member of staff.
- Clinical engineer, who prepares and maintains medical equipment.
- Hospital chaplain, who is available at your request for spiritual support. There is also a hospital chapel / prayer room for quiet prayer and reflection.
- Audiologist, for hearing screen post discharge

A doctor who specialises in the care of small babies is called a neonatologist. In addition to these doctors who care for your baby on a daily basis, there are also other specialist doctors who may visit the unit or who will be consulted regarding your baby’s care, as required. These include:

- Cardiologist – a heart specialist.
- Geneticist – a specialist in inherited conditions.
- Microbiologist – a specialist in infections.
- Ophthalmologist – an eye specialist.
- Radiologist – a specialist in reviewing x-rays and taking ultrasounds and scans.
- Paediatric surgeon – who performs surgical procedures.

There may also be specialist nurses, for example:

- Advanced neonatal nurse practitioner (ANNP), who has advanced training in the medical needs of your baby.
- Neonatal liaison clinical nurse / midwife specialist (CNS / CMS), who will help you prepare for your baby’s discharge and organise follow-up care post discharge. Your baby may be referred to this nurse / midwife in advance of discharge if they were born very preterm.
- Lactation (breastfeeding) support nurse specialist, who is available to support mothers who are expressing breastmilk or who require extra support when breastfeeding.

These staff may not always be available in your unit but they can usually be consulted if their input is required.

“Staff in the neonatal unit like babies and know how to give them the care they need to get well”
Section 1: Neonatal care

Transferring babies from one hospital to another

On occasion it is necessary to transfer a newborn baby from the hospital they are born in to another hospital. This is because they need additional medical or surgical care at another hospital. Some babies develop bowel complications, which will necessitate their transfer to one of the Dublin Children’s hospitals for surgery. Others may need transfer because of a heart condition. Babies born very preterm in smaller units will be transferred to a larger neonatal unit in order to obtain the full range of intensive care.

The transfer of a small or sick baby from one unit to another is a complex procedure requiring planning, organisation and skilled staff. The babies are placed inside a specialised transport incubator capable of providing full intensive care for the baby during transport. The babies are transported in a specially modified ambulance which is capable of safely securing the incubator while in transit. During transport, the baby is accompanied by a doctor and a nurse. On occasions, where time is very critical and the distance is long, the air-corp services may be employed. The current fleet of helicopters is specially designed to carry an incubator.

We appreciate that transferring to another hospital may be difficult for you. Staff at the new hospital will do their best to make you feel welcome.

If you are unable to be with your baby, every effort will be made to maintain a good communication line between you and those looking after your baby in the other hospital. As soon as your baby improves they will be transferred back to your local hospital.

Transferring babies back to their local hospitals

If your baby was transferred to a large centre for specialised care and treatment, the doctors and nurses in this centre will arrange to send your baby back to your local hospital when the treatment has been provided and your baby is stable and improving. This is beneficial for you and your baby as, when your baby is transferred back, it will be easier for you to visit and to become more involved in their day-to-day care. It also gives you the chance to get to know your local unit, which will provide your baby’s longer-term follow up. This process also permits the larger unit to accept other babies with new critical problems. This rotation of care, now called the Model of Care, is an important part of the overall provision of newborn services in Ireland.

Letting you know what is happening

Irrespective of medical circumstances, we fully appreciate the worry and concern that is caused when your baby is admitted to the neonatal unit. Neonatal staff understand parents’ feelings. We will try to keep you fully informed about your baby’s diagnosis, investigations, treatments and management. If there is anything which you are uncertain about, never hesitate to ask.

The staff will do everything to make your baby better. Some of the treatments are straight-forward, others are more complex and invasive. The staff will inform you about these treatments where possible. Occasionally, however, staff may have to act in an emergency without there being time to contact you.

Some treatments require your consent, for example, if your baby needs a blood transfusion, the newborn bloodspot screening test, if they are to be transferred to another hospital for tests or treatment, or if your baby requires laser therapy or vaccinations.

There is a ward round every day. This is an important event. During the round each baby’s condition and progress is assessed and their daily management is decided. After the ward round is usually a good time to find out the latest information about your baby’s progress.

Telephone contact

While your baby is in the neonatal unit contact between you and the hospital, and the hospital and you, is very important. At any time you are free to phone the hospital to get the latest update and information from the nurse caring for your baby. You will be provided with the hospital number or neonatal unit number. It is equally essential that you provide the hospital with a reliable set of phone numbers so that you can be easily contacted.

While your baby is in hospital we ask you to be attentive to your phone at all times as it creates problems for staff if they are trying to contact you and they can’t. If you get a phone call at night don’t think the worst as the hospital may be contacting you for a wide variety of reasons, such as permission for a blood transfusion, or consent for a procedure.

Please understand that the hospital is not permitted to give information about your baby’s clinical condition to anybody other than you, the parents, except with your expressed permission. You may be requested for confirmation of your relationship with the baby when phoning in.

“The philosophy is to provide care for your baby as close to home as possible as much as possible – Right Care, Right Place, Right Time”
Visiting your baby in hospital

Parents are welcome to visit their baby almost always but there are times when you will be requested to leave the unit for a brief period, for example:

- During the daily ward round. This is necessary to protect the privacy and confidentiality of other babies whose conditions are also being discussed.
- When there is an emergency or complicated procedure being performed.
- During shift change, when nurses are giving reports about the babies to the incoming staff.

When visiting your baby we ask you to observe the following important infection control and visiting policies:

Infection control

- **Hand hygiene is essential every time you visit the unit.** Hand-washing is one of the most effective ways of preventing infection and safeguarding your baby. If you are visiting twins or triplets, please wash your hands before handling each baby.
- It is important to wash your hands properly: first roll up your sleeves and remove any watch, rings and bracelets; then wash your hands and lower arms in warm soapy water; rinse your hands and lower arms in clean running water; and dry with a clean towel.
- Alcohol gels and sanitiser can be used instead of hand-washing if your hands are visibly clean.
- For your baby’s safety, anyone who has been exposed to a contagious disease (for example, chicken pox, German measles, tuberculosis) should not visit the neonatal unit.

Brothers and sisters

Your baby's brothers and sisters are not permitted into the neonatal unit. The reason for this is the risk of cross infection. However, they should be part of the whole experience and be kept up-to-date:

- Tell them about their new baby sister / brother.
- Show them a video or photos of the new baby.
- Explain in simple terms the reason why their little brother or sister is in hospital.
- Discuss any concerns they may have about the baby and try to answer their questions at a level that they will understand.
- Encourage them to make drawings or get well cards for the baby, which can then be attached to the incubator or cot.
- They may like to send in a photo of themselves for their baby sister or brother to ‘see’.
- Involve them in planning for the baby’s homecoming.

‘Quiet time’ in the neonatal unit

In-utero (in the womb) babies sleep 80% of the time. It is important to try to mimic this as much as possible if your baby was born early – this helps facilitate your baby’s development.

For specified periods each day, the unit has a ‘quiet time’. The aim is to give babies a chance to rest and sleep by reducing the light intensity and noise levels and by keeping medical procedures to a minimum. During quiet time, lights are turned down, voices are kept low and the medical and nursing staff attempt to provide your baby with uninterrupted rest.
Neonatal intensive care and the preterm baby

A neonatal intensive care unit tries to imitate the conditions that your baby has been used to in the womb. Preterm babies may have trouble keeping their body temperature at the right level. This is because they have almost no fat for insulation, therefore they must have their body temperature controlled and must be kept warm.

To do this, small babies and some larger sick babies are nursed in an incubator. This allows us to keep your baby warm while at the same time provides access for medical and nursing procedures.

Sick babies are nursed without clothing so that their breathing and colour can be closely observed.

Monitors may also be used to measure your baby’s heart rate and oxygen levels.

What preterm babies may look like

The first thing you may notice about your preterm baby is how small and fragile they may be. Missing time in the womb means that they have missed out on some growing time. Their skin may be thin, wrinkled and red. It may look as if it is too big for their body – and it is. This is because your baby has yet to develop another layer of fat under their skin. As your baby gains weight, they will put on fat which will fill out their skin, making them more rounded in appearance and more ‘baby-like’.

Your baby’s ears may look flat. Again as your baby matures and gains weight, they will assume their normal shape. Your baby may appear hypotonic (limp like) because of muscle weakness and may have a flat posture on the mattress. This is in contrast to a full-term baby who tends to adopt a more flexed (curled up) position.

Your baby’s movements may be less well coordinated and may be jerky. You may find that they keep their eyes closed and spend most of their time in a sleep-like state. Even though your baby may be small, they will have a distinctive appearance. Like all babies, your baby will have their own little personality. Because of their small size, the signals may be subtle but are still observable. As you get to know your baby you will recognise their personality and their likes and dislikes.

Your preterm baby in the neonatal unit

Your baby needs as much rest and sleep as possible. Neonatal units work hard to reduce the amount of noise and activity around each baby.

When completely well and weighing about 1800g (4lbs) your baby is usually ready to be transferred from an incubator to a cot.

“Although many babies require intensive care, every attempt is made to provide it in a gentle manner with minimal disturbance”

Your preterm baby’s early developmental progress: step-by-step

This chart outlines your preterm baby’s early developmental progress from birth. Note that your baby’s physiological, motor and state of alertness need to be met first before they are ready to actively socialise with you.

- **Step 1** Physiological and autonomic organisation: Baby’s regulation of heart beat, blood pressure, temperature control and digestive system.

- **Step 2** Motor organisation: Baby has smooth, coordinated movements, muscles gain more tone, become stronger, and posture is improved.

- **Step 3** State organisation: Easier for you to determine baby’s awake / asleep states. Awake times get longer and your baby has more facial expression, eye movements, body movement and reaction to external stimuli.

- **Step 4** Social interaction: Baby can maintain alert state to take interest in and look at faces or objects or react to meaningful sounds.

- **Step 5** Interactive organisation: Baby can interact with the environment without getting unduly stressed or upset, can self-comfort to remain composed for longer.

- **Step 6** Watching, focusing and following: Baby can focus their eyes on your face, watch people nearby, track movement of bright lights.
Equipment in the neonatal unit

Neonatal units are full of equipment that you may not have seen before. It is there to give your baby the best possible chance of survival and a healthy future. Here is a brief description of some of the equipment you may see surrounding your baby.

**Intravenous (IV) lines**
IV stands for intravenous. An IV line is a fine tube threaded into one of your baby’s veins, for example, in the arm, leg or scalp. Parents may feel anxious about an IV line in the scalp but it is placed only on the skin surface. Your baby can be given fluids, nutrition, or medication through these lines.

**Apnoea monitor**
This is a sensor that is attached to your baby to detect and record their breathing rate. If their breathing stops, it sets off an alarm.

**Incubator**
This keeps your baby warm and controls the humidity levels around them by preventing moisture loss from their thin skin. Incubators also protect your baby from a busy neonatal environment.

**Infusion pump**
This is used to control the rate that fluids, feeds and medication are given to your baby. Infusion pumps are sometimes called syringe pumps or syringe drivers.

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**Vital signs monitor**
Vital signs is the term used for the markers that show how well your baby’s major body systems are working. Vital signs include your baby’s:

- Breathing rate
- Heart rate
- Blood pressure
- Temperature
- Oxygen saturation

Babies in intensive care are attached to vital signs monitors 24 hours a day. Small pads may be placed on your baby’s chest to pick up electrical signals given out by the heart and check that it is beating properly. The pads can also detect changes in breathing. Pauses in breathing may trigger an alarm.

**Ventilator**
A ventilator is used to help your baby to breathe. This machine gently pushes air through a tube placed into your baby’s trachea (windpipe) and down into their lungs. Some babies need ventilation for just a day or two, others may need it for longer. The amount of support given by the ventilator will be regularly adjusted to meet your baby’s current needs. Sometimes a special type of ventilation is used, for example:

- High frequency oscillator (HFO): This is when the ventilation rate is faster than conventional ventilation. It is used to help overcome respiratory difficulties in very sick infants.
- Nitric oxide: Nitric oxide is an additional gas supplied through the ventilator. This gas has a unique ability to expand blood vessels in the lungs and thus improve the baby’s breathing.

**Continuous positive airway pressure driver (CPAP)**
CPAP is used to help your baby to breathe. CPAP provides a mixture of air and extra oxygen, which is blown through two small tubes placed in your baby’s nostrils (nasal prongs) or through a mask, which pass down into your baby’s lungs to help keep the air sacs open.

**Nasal prong / low flow oxygen**
This provides a low flow of oxygen, which is blown through nasal prongs to help your baby’s breathing.

**Bag and mask**
If your baby stops breathing, staff may help to re-start their breathing with a procedure called ‘bagging’. A mask attached to a soft plastic bag or a ‘neo puff’ is placed over your baby’s face, and the bag is squeezed several times to gently push air into their lungs and stimulate them to start breathing again.

**Pulse oximeter / saturation monitor**
This measures the amount of oxygen in your baby’s blood using an infra-red light sensor, which is usually attached to your baby’s foot or hand.

**Pauses in breathing**
Pauses in breathing may trigger an alarm.
Conditions that babies in the neonatal unit may have

Apnoea
Sometimes preterm babies take pauses in their breathing and occasionally their breathing may stop. This condition is known as apnoea and is detected with an apnoea monitor.

Bradycardia (slow heartbeat) and tachycardia (fast heartbeat)
The normal newborn’s heart rate is 140 beats per minute. Bradycardia is the term used when the heart is beating slower than normal. Tachycardia is when the heart is beating more rapidly.

Breathing difficulties / respiratory problems
Some babies have breathing problems. There are two main reasons. First, the lungs may not be fully developed, and secondly, the baby may be unwell and very weak.

If your baby’s lungs are not fully developed they can be very stiff. Doctors may use a tube to pass a substance called ‘surfactant’ directly into their lungs. Surfactant helps to make the lungs more spongy and easier to fill with air, making breathing easier.

Some babies with breathing difficulties may require extra support to help them to breathe, for example, a ventilator or CPAP. See section ‘Equipment in the neonatal unit’, page 16.

Tachypnoea
This is a term used to describe when a baby’s breathing is rapid, usually more than 60 times per minute.

Jaundice
Yellow discolouration of the skin and whites of the eyes caused by build up of a substance called bilirubin in the blood. It is predominantly due to immaturity of the liver and resolves as the baby matures.

Chronic lung disease / Broncho-pulmonary dysplasia (BPD)
Babies who need to be ventilated for long periods of time may get chronic lung disease (CLD). Babies with CLD have stiffer lungs and have to work harder to get air into their lungs. They may also become more tired during feeds. Babies with CLD sometimes need additional oxygen support for a while after they go home. CLD may also be referred to as broncho-pulmonary dysplasia (BPD).

Jaundice is treated by exposing your baby’s skin to special lights called phototherapy. For this reason, your baby will be nursed without clothing while undergoing phototherapy. Eye pads are used to protect your baby’s eyes from the bright lights. The lights may cause a mild rash but this passes quickly when phototherapy stops.

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Hernias – inguinal and umbilical
Hernias are common in preterm babies and often disappear on their own. They can affect up to 10% of preterm babies and are more common in boys than girls.

- **Inguinal hernias** appear in the baby’s groin. These are surgically repaired as soon as your baby is well enough to tolerate an anaesthetic.
- **Umbilical hernias** appear behind your baby’s belly-button. These tend to sort themselves out without any treatment. They don’t need surgery.

Meconium aspiration syndrome
This condition develops before or during the time of birth. The baby passes meconium (a specific form of bowel motion encountered only in the newborn infant and consisting of amniotic fluid and cells), which they then inhale into their lungs. It is highly irritant and when inhaled causes lung inflammation. As a result, these babies develop breathing problems requiring oxygen and sometimes ventilation.

Necrotising enterocolitis (NEC)
NEC is a bowel complication that can occur in preterm infants. It varies in degrees of severity. In minor cases the baby gets a slightly swollen abdomen. In more severe cases the baby becomes very unwell. The condition is treated with intravenous fluids and antibiotics. In some cases the baby may require surgery.

Neonatal abstinence syndrome (NAS)
This is a condition in which the baby exhibits withdrawal features. It occurs when a mother has been on narcotics such as methadone during pregnancy. Babies with NAS are irritable, unsettled, restless and cry excessively. They are difficult to feed and require additional nursing. The features may last up to 6 weeks or more. In the early days of the withdrawal the baby may require small doses of oral morphine.

Patent ductus arteriosus (PDA)
This is a vessel that forms a link between the two main arteries in the body – the aorta and pulmonary artery. This link is open before birth and usually closes within a few minutes after the baby is born. In some preterm babies it remains open causing additional pressure on the heart and lungs and requires medical and sometimes surgical management.

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Blood transfusions
Newborns, especially those born preterm, have a small circulating blood volume. Their ability to make blood is limited. Their blood is further reduced by illness or necessary blood tests. If your baby's blood count falls they may need a blood transfusion.

In order to reduce exposure to a minimum, the donor unit of blood is subdivided into 5 small packs called ‘pedipacks’. The designated pedipacks are set aside and are given to your baby as needed throughout their time in the neonatal unit.

Humidification
This is when humidity inside an incubator is used to reduce water loss from the delicate skin of very small preterm babies.

Phototherapy
Phototherapy is used if your baby is jaundiced. It consists of blue lights placed over your baby. See section ‘Jaundice’, page 18.

Therapeutic cooling (TC)
TC is the deliberate cooling of the baby’s body temperature down to 33.5°C. The baby’s normal temperature is 37°C. TC has been found to be an effective treatment in babies who have had an oxygen deficiency in or around the time of birth. The treatment is instituted for a total of 72 hours. At the end of the cooling period the baby is re-warmed and the temperature is brought back to 37°C.

Extra corporeal membrane oxygenation (ECMO)
ECMO is an artificial lung by-pass. It is used when the baby is in respiratory (lung) failure. The machine takes over the work of the baby's lungs. The process keeps the baby stable until the lungs have recovered, which can take up to a week. The treatment is very complex and is usually performed by the ECMO unit in Stockholm, Sweden. When contacted, an experienced team arrive and transport the baby to Stockholm for this treatment. The baby remains in the unit in Stockholm until their lungs have recovered and they are breathing normally. In Ireland, approximately 6 babies require this treatment annually.

Endotracheal tube (ET)
A tube is placed into the windpipe (trachea), through the nose or mouth, and delivers oxygen to the lungs from a ventilator.

Intubation
The insertion of an endotracheal tube so that oxygen can be given via a ventilator.

Gastro-oesophageal reflux (GOR)
GOR is the regurgitation / spilling / possetting of stomach contents back up through the tube that connects the stomach to the mouth. This is generally quite harmless and babies will grow out of it as they mature.

Retinopathy of prematurity (ROP)
ROP is a disorder of the retina of the eye which usually only affects babies who are born less than 32 weeks gestation. If your baby is born less than 32 weeks they will have their eyes checked routinely by the Ophthalmologist (an eye specialist). ROP may resolve spontaneously. If it progresses, the eye specialist will treat it with either laser therapy or injections into the eye.

Outcome for ROP is very successful. However, some cases do result in minor vision problems, which may necessitate wearing glasses for short-sightedness, or treatment with minor surgery, an eye patch for ‘crossed eyes’ (strabismus) or ‘lazy eye’ (amblyopia).

Hydrocephalus - shunt reservoir
Hydrocephalus is a condition in which the normal flow of cerebro-spinal fluid (CSF), the fluid around the brain and in the spine, is blocked. The fluid builds up in the brain, which makes it swell. If this fluid does not clear of its own accord or with medication, an operation will be necessary to insert a small tube called a shunt to help to remove the excess fluid as it is produced.

Care is delivered as gently as possible
Doctor listens to baby’s heart
Tests and examinations that babies may undergo in the neonatal unit

Babies brought to the neonatal unit may be very sick and need a high level of medical and nursing care. This means watching and measuring many of their body functions with tests and examinations. Every test or treatment is done for a reason. You will be informed about any major procedures your baby may need.

Weight checks
Babies are weighed regularly, either inside the incubator or on a separate scales. Babies usually lose some weight in the first few days – this is regained within a couple of weeks. Very small, preterm or sick babies may take a little longer to gain weight.

Blood tests
Babies in the neonatal unit often need blood tests to check the level of various substances in the blood. The smallest amount of blood possible is taken using very small needles.

Blood gases
These are small samples of blood which are used to determine the amount of oxygen and carbon dioxide in your baby’s blood and also how acidic or alkaline their blood is.

Electroencephalographs (EEGs)
EEGs are tests that measure the electrical impulses of the brain.

Electrocardiograms (ECG)
ECGs are tests that measure the electrical activity of the heart.

X-rays
X-rays are images of internal structures such as the heart, lungs, intestine (bowel) and bones.

Ultrasonic sound
Ultrasounds are used to scan various organs, including the brain, kidneys, liver, and intestine (bowel).

Magnetic resonance imaging (MRI)
MRI is a specialised scan to obtain greater detail. It is commonly performed to examine a baby’s brain.

Lumbar puncture
This is a procedure for removing cerebrospinal fluid (CSF), the fluid that circulates around the spine and brain. A needle is passed gently into the lumber region (at the base of the spine) – taking a sample of fluid for testing. It is mainly used to check for meningitis.

Medicines babies may be given in the neonatal unit

Sick babies in the neonatal unit often need medicines as part of their treatment.

Some commonly prescribed drugs include antibiotics for infection; agents for sedation and pain relief, drugs to treat lung problems; drugs to maintain blood pressure; and vitamin and mineral supplements for growth and development.

Other drugs that your baby might receive include caffeine to help breathing and prevent a condition called apnoea which is when a baby forgets to breathe; and salt supplements if levels in the blood are low.

Steroids, which are powerful anti-inflammatory drugs, may be used infrequently for conditions such as chronic lung disease.

Most of these medicines are given in liquid form or through an IV line and are not painful.

Newborn babies are vitamin K deficient, therefore it is given to all newborns as a single injection shortly after birth. Vitamin K is necessary for normal blood clotting and to prevent bleeding.
Section 3: Caring for your baby

Getting to know your preterm baby in the neonatal unit

When you first visit your preterm baby in the neonatal unit you may not know what to expect.

Seeing your baby surrounded by tubes, wires and machines may make you feel helpless, but there is a lot you can do.

Watch your baby
Watch your baby, learn how they communicate with you and discover what they like.

Look at the changing expressions on your baby's face; do they look relaxed, comfortable, tired or tense?

Look at your baby's hand movements; notice if they bring their hands up towards their face or mouth or use their feet to kick against their bedding.

In the early days your baby may not like being stroked or touched, as this may be too stressful for them.

Interact with your baby
When your baby is first ready for contact they may only like their hand or foot to be held.

Unlike full-term babies, most preterm babies initially can only take in and respond to one contact / interaction at a time; either touch, voice or being picked up.

If presented with two interactions too soon, for example, voice and face or voice and touch, it can be too much stimulation and can overpower your baby.

Your baby may become upset, for example, they may show a panicked facial expression, appear drowsy, stiffen their arms and legs, display a limp posture, or engage in frantic activity. These responses are exhausting for your baby and should be avoided.

Coping strategies are used by preterm babies to protect themselves from over-stimulation. Coping strategies include active gaze aversion (avoiding eye contact with you), hand-to-mouth manoeuvres to comfort themselves, or bracing their feet against the side of the incubator. See ‘Interpreting your preterm baby’s movements in the neonatal unit’, page 26 and 27.

If your baby shows signs of distress, give them time to recover and rest.

If your baby is constantly fighting off ‘over-stimulation’, it can use up a lot of energy and leave them less able to engage in more social and interactive behaviours with you. As your baby matures they will gradually learn to be less reactive and sensitive to every stimulus, and will be more alert and sociable. Watch out for their signals inviting you to interact.

A simple test to measure your baby’s readiness to respond is to observe their response to a bright light or loud noise:

• If your baby continues to display a startled response to the bright light or loud noise then they are not able to ‘shut-out’ (stop themselves reacting) to noise or light like term babies can. They need to be protected by maintaining reduced lighting and noise levels.

• If your baby is able to ‘shut-out’ they will initially react to the bright light or loud noise, but they will then get used to the stimulation and not react or be affected by it. This is called ‘habituation’.

Behaviours are dependent upon your individual baby. Preterm babies, just like term babies, can present ‘positive approach’ behaviours. Being aware of these behaviours will help you to support and enhance them. For example, when your baby becomes alert on hearing your voice, this may be their signal indicating that they are ready for social interaction. To enhance this, first present a still face and quiet voice, then experiment with more expression and vocal tones. As your baby matures, their alertness or attentiveness to a toy or picture may be another signal of readiness to interact with you. If your baby is happy, continue this interaction. If your baby shows signs of distress, decrease your interaction.

“If your baby shows signs of distress give them time to recover and rest”
Interpreting your preterm baby’s movements in the neonatal unit

“How I comfort myself” – coping behaviour:

• Your baby brings hand to mouth or touches face. May cover ears or eyes.
• Clasps hands together or presses one foot over the other.
• Moves body, lifts or turns head to get comfortable.
• Sucks hand or soother.
• ‘Leg bracing’ - presses feet against bedding or cot.
• Grabs or holds onto something for example, hat, bedding or tubes.
• Rests one hand over the other or tucks hand under head.
• Sleeps quietly or is quietly awake and still.

“Behaviours are dependent upon your individual baby”

You will get to know your baby’s individual personality, learning the signals they give you, learning when to pause, when to comfort, when to stimulate, being aware of your baby’s strengths and sensitivities, and how they communicate with you in their own little way.

If you see these ‘time-out’ signals it is time to:

• Stop what you are doing.
• Let your baby rest or calm them with a comfort hold. See section ‘Comfort Hold’, page 32.
• If you must continue an activity for example, nappy change, restart more slowly and quietly.

“Let me rest now” - ‘time-out’ signals if an activity is becoming too much:

• Your baby will close their eyes or turn away. Eyes may have a glazed expression.
• Breathing will become irregular.
• Your baby may stretch and wriggle.
• Your baby’s body may become limp or stiffen – arms and legs may straighten.
• Your baby may put their hand over their face (palm turned outwards) with fingers opened wide (finger splay).
• Your baby may frown, grimace, yawn, or make hiccupping or grunting sounds.
• Mouth may droop and fall open.
• Your baby may look tired or fall asleep.

“I’m ready to listen and respond” - invitation to interact:

• Your baby has a relaxed open facial expression.
• Breathing is regular and relaxed.
• Your baby is comfortable (arms and legs tucked close to their body).
• Arm and leg movements are smooth.
• Mouth is relaxed and slightly open. Your baby may make sucking movements.
• Eyes are open or may open in response to you.
• Your baby calms when you talk.
• As your baby matures they will become quietly alert and will be able to pay attention for longer periods, turning their head to follow your movements, face or sounds.

Mother watching baby

Hand over face – self-comforting

Leg straightened and stiff – time-out signal

Mouth drooped open – “Let me rest now”
Positioning and handling your baby in the neonatal unit

Why are positioning, movement and handling important?

Preterm babies have less muscle tone and are often hypotonic (floppy) compared with babies born at term. Term babies have a curled up or ‘flexed’ position, while babies born preterm are less flexed and less strong. They tend to allow their arms and legs to fall outward ('frog like' position) and their head to roll to one side. They may find it difficult to move their arms and legs especially now that they must move against gravity and are no longer supported by fluid as they were in the womb. They may also find it difficult to maintain or hold positions and their movements may be jerky and disorganised until they get a little bigger and stronger. Positioning and handling are important for development of movement and to help your baby feel secure.

Preterm babies will not automatically learn to adopt the curled up foetal position and have to be shown.

“Positioning and handling are important for development of movement and to help your baby feel secure”

Positioning preterm babies in supported positions, ones that encourage flexion (curling up) or that copy the foetal position, can help:

- Promote normal muscle development and movement patterns.
- Promote balanced muscle development in order to avoid muscle weakness in some areas and tighter muscles in others.
- Minimise head flattening known as ‘plagiocephaly’. If your baby’s head is not turned and their position changed regularly, their head may develop flattened areas. See section ‘Positional plagiocephaly’, page 51.
- Promote a feeling of calmness and security.
- Reduce stress and energy expenditure.
- Promote more settled and easier breathing and circulation.
- Preserve energy levels as your baby is more comfortable, sleeps and feeds better, and doesn’t use vital energy to calm and settle.
- Promote baby’s awareness of their hands – important for development of fine motor (precise use of hands and fingers) and feeding skills later on.
- Encourage your baby to bring their hands to the middle or midline (in front of their body) – an important early developmental stage and precursor to gross motor (use of the large muscles of the body) and fine motor skill development.
- Promote development of crawling, standing and walking later.

Baby in curled up flexed position

Making a nest in your baby’s incubator

- You can use your own blankets and sheets to make your baby’s nest.
- Small babies like to feel the nest around their body and head.
- The nest should be snug as well as giving your baby room to move their hand near their face or change their position.
- When your baby kicks or pushes their legs, they will feel calmer if their feet touch the nest boundary. The nest is shaped to have a deeper rim at your baby’s feet.
- A ‘cocoon’ can be used to make your baby feel more snug. This is made by placing a light sheet over your baby’s back and tucking it around the nest.
- Your baby’s nurse will do this for your baby.

When your baby is big enough to be in a cot you can usually stop using positioning aides and nesting your baby. Now you can teach your baby to sleep on their back. When your baby is going home and all monitors have been removed you must only sleep your baby on their back to reduce the risk of cot death (Sudden Infant Death Syndrome) unless specifically advised otherwise by the physiotherapist. See section ‘Positioning during sleep time’, page 51.

What is a comfortable position for my baby?

Small babies like to lie either on their tummies or on their side, arms and legs tucked in towards the middle or midline in a supported position.

Nesting

In the womb your baby has boundaries to push and rest against. A ‘nest’ helps your baby find the same boundaries to move against when in an incubator. This helps them feel comfortable and secure and strengthens their bones and muscles.

Cocoon – light sheet tucked around nest to make baby feel snug

Baby nested, back supported, hands to face, feet touching nest

Section 3: Caring for your baby

“Positioning and handling are important for development of movement and to help your baby feel secure”
Positive touch

Preterm and sick babies undergo many medical procedures which can be intensive and unpleasant. You can balance these experiences with some positive touch. Positive touch is a way of communicating love and reassurance to your baby and is also a very rewarding experience for you when you visit your baby in hospital. Babies, no matter how small, do communicate. By looking at your baby you can learn what kind of touch to use and when it is appropriate, safe and pleasurable for your baby. Your baby’s nurse will guide you on how to recognise these behaviours.

A quiet environment is very important so that all your baby has to focus on is your touch and not on responding to a noisy environment.

When touching your baby:

- Wash and warm your hands; babies like warm hands. Rubbing your hands together near your baby will let your baby hear and sense your approaching touch.
- Gently open the incubator doors, talk to your baby to let them know you are nearby.
- Hearing your soothing voice can be a comfort. Wait and look for your baby’s response, it can take a while for preterm babies to react.
- Your first touch may be to put your finger near your baby’s hand – they may just like to feel your touch or they may grasp your finger.

Don’t be. Ask your nurse to help you. In time it will become easier.

 Examples of positions used in the neonatal unit

Supine – baby lying on their back:
This position is more appropriate for babies who are well and in a cot.

- Shoulders are rounded and supported and hands can easily come forward to the face and mouth.
- Legs are bent and the feet have boundaries.
- Preterm babies should be nested (see page 29).

Side-lying:

- Shoulders are gently rounded and relaxed.
- Legs are bent with boundaries for foot support.
- Hands are in the middle and can reach to mouth and face.

Alternate sides to which baby lies.

Prone – baby lying on their tummy:
This position can only be used while a baby is in the neonatal unit. It cannot be used for sleeping at home due to risk of cot death (sudden infant death). When your baby is at home, some tummy time is recommended but only when your baby is awake. See section ‘Tummy time’, page 52. When visiting your baby, get familiar with ‘tummy time’ by placing them on their tummy for short periods of time each day when they are awake.

“Positive touch is a way of communicating love and reassurance to your baby”
Two special forms of positive touch include ‘Comfort hold’ ‘Other comfort measures’ and ‘Kangaroo care’ as described below.

**Comfort hold**

Comfort hold is a form of positive touch. It can help your baby to feel secure and relaxed. It is also used by staff to comfort your baby after a medical procedure. It is nice for your baby to experience this pleasant touch in contrast to medical touching.

**How to do ‘comfort hold’**
- Cup your warm still hand around your baby’s head and/or feet.
- Gently rest your other hand around their shoulders or hold their arms across their chest.
- Do not use light feathery stroking movements as preterm and sick babies may find this ticklish and irritating.
- It helps to breathe slowly and deeply with a feeling of relaxation in your hands.
- Continue to comfort hold until your baby feels settled.
- To finish comfort hold, slowly remove one hand, and if your baby remains settled, remove your other hand and quietly close the incubator doors.

**Other comfort measures**

During medical procedures, or if your baby looks unsettled, other comfort measures may also be used, for example:
- A soothing voice.
- Offering your finger to grasp.
- Offering a soother or your clean finger to suck.
- For pain relief babies may also be given a sucrose (sugar) solution and a soother to suck.

**When is a good time to comfort hold my baby?**
- When your baby would enjoy a gentle touch.
- During and after medical / nursing procedures and care-giving.
- For pain relief.
- When your baby looks unsettled.

Some procedures, such as taking a blood sample, can be done while your baby is feeding – this may help to comfort your baby.

**Kangaroo care (KC)**

Kangaroo care is another form of ‘positive touch’. Kangaroo care involves holding your baby ‘skin-to-skin’, in a ‘kangaroo style’ position, on your chest. Preterm babies can rest and sleep very well in this position, they can also be tube-fed. Even stable babies on respiratory support (ventilator / CPAP) can enjoy kangaroo care. Ask your nurse when your baby is ready for kangaroo care.

**Benefits of kangaroo care for you and your baby include:**
- Helps bonding, attachment and positive interaction between you and your baby.
- Helps build up your sense of wellbeing and self confidence as a parent, and reduces stress and fatigue.
- Helps stimulate and increases breastmilk supply and helps prepare mothers for breastfeeding.
- Helps steady your baby’s heart beat and breathing and helps maintain their body temperature and keep them warm.
- Helps conserve your baby’s energy, increase time sleeping and improve neuro-behavioural responses.
- Helps improve weight gain, feeding and promote an earlier discharge from hospital.

“**Kangaroo care helps bonding, attachment and positive interaction between you and your baby**”

**How to do kangaroo care**

You may feel nervous at first. Don’t worry; your baby’s nurse will always be there to help you.

- Plan a suitable time with your baby’s nurse, for example, when the unit is quiet; when your baby is out of the incubator, for example, when being weighed or their cot is being changed; or when your baby is due a feed. Kangaroo care is generally not initiated just after feeds as delicate babies may be uncomfortable being moved on a full stomach; however your baby can be fed during kangaroo care.
Nurse helps to place baby on mother’s chest

• All kangaroo care is beneficial for your baby, but for greatest benefit, an hour or so is suggested.
• Wear a light comfortable front opening top, for example, pyjama top or shirt. Stable babies with less tubes and leads can be tuck inside your top or T-shirt.
• Have a drink of water nearby.
• You may like to use your own soft blanket to keep your baby warm if needed.
• Very small babies may need extra warmth from a hat.
• Turn your chair inwards to create a private space.
• Wash your hands.
• Greet and touch your baby to let them know you are there.
• Lean into the incubator and cup one hand under your baby's head and your other hand around their hips. Gently lift your baby onto your chest, rest their head against your breastbone and support their back and bottom with your hands. You can also lift your baby out of the incubator on their nest.
• While you are becoming comfortable with kangaroo care your nurse or partner may take your baby out of the incubator and help to position your baby on your chest.

There may be times when kangaroo care is not possible or practical, for example:
• If your baby needs high humidity inside an incubator.
• If your baby has umbilical IV lines in their tummy.
• If your baby is receiving a type of ventilation called high frequency oscillation.
• If your baby is receiving phototherapy to treat jaundice.

Supporting your baby during practical care procedures

Mouth-care
One of the first care-giving activities you may take part in is cleaning your baby's mouth; you can do this when your baby looks awake and comfortable. During a feed may be a good time. Sometimes breastmilk is used to clean your baby's mouth because of its antibacterial properties. If breastmilk is not to hand, use sterile water.
To clean your baby's mouth:
• You need a cotton bud swab and tube feeding tube. See section ‘How will my baby be fed?’, page 42.
• If using a blanket, wrap it around your baby with the top lying just below their ear.
• Ask the nurse to check your baby's position. Their chin should be level.
• If your baby shows an interest in sucking you can change their position to reach your breast.
• Alternate the side to which you position your baby's head each time you do kangaroo care.
• Both mum and dad can take it in turns to do kangaroo care.

When tube-feeding your baby

• Sit comfortably with your back supported. Turn your chair inwards to create a private space.
• Hold your baby in a supported position, see section ‘Positioning and handling your baby in the neonatal unit’, page 28.
• You can hold your baby next to your breast with one arm and you or your partner can hold the syringe. Your baby may take a few little sucks at their mother's nipple – this helps to prepare your baby for breastfeeding. Holding your baby close to the breast will release hormones and help to stimulate your milk supply. Expressing milk after being with your baby will also help your milk supply.
• Your baby may also be fed in a supported position in the crook of your arm or resting on a padded blanket on top of your bent knees.
• Watch your baby's behaviour. If you notice that they start to wriggle or look uncomfortable, lower the syringe to slow down the flow of milk and give them a chance to relax.
• If your baby is asleep and being given a tube-feed in the incubator, you can lightly rest your hand over their shoulder or bottom. This lets them know you are there.
Non-nutritive sucking (NNS)

NNS is a natural sucking behaviour for babies. NNS is the behaviour which babies enjoy such as sucking a soother or your finger, rather than when your baby is sucking to take in food. NNS has a special role in the care of preterm babies and other babies who have difficulty feeding normally and need to be tube-fed.

- NNS helps to make tube-feeding more pleasurable and helps associate sucking with feed time.
- NNS helps build up pleasurable oral experiences, it also helps stimulate digestion and is a comfort for your baby during difficult procedures.
- When your baby shows an interest in sucking, you may notice that they may suck on the breathing tube in their mouth or on soothers that fit around the breathing tube.

“Non-nutritive sucking (NNS) helps to make tube-feeding more pleasurable and helps associate sucking with feed time”

- During NNS your baby may like to taste some breastmilk dipped on the soother or a cotton swab, and mothers are often encouraged to offer their breast to their baby to suckle (see photo, page 40). This is good for your baby and it helps mother’s milk supply. If you have a good flow of milk you may need to express some of your milk before putting your baby to your breast.
- Sometimes a soother is used to satisfy your baby’s sucking needs. Staff will guide you to choose a soother according to your baby’s size. If a soother is too small for your baby it can cause them to suck in their cheeks.
- NNS in the neonatal unit does not affect your baby’s ability to breastfeed.

Nappy change

Changing your baby’s nappy may seem awkward with all the wires and tubes, but don’t be discouraged.

- Start by watching the nurse change your baby’s nappy, you can get involved when you feel comfortable to do so. Even if only observing you can participate through comfort holding your baby. See section ‘Comfort hold’, page 32.
- Before opening the nappy, slide a clean nappy in under your baby’s bottom to avoid soiling the bedclothes. Have some wet warm cotton wool and Vaseline (or equivalent) nearby on a tissue.
- Open the tabs on the soiled nappy and use this nappy to gently wipe down your baby’s bottom, and then leave it tucked in.
- Hold your baby’s feet sole to sole, gently bending their knees. Avoid lifting up your baby’s legs to raise their bottom as this can put pressure on their tummy.
- Small babies may find nappy changing tiring or upsetting, so take your time and if necessary use a ‘comfort hold’ to calm your baby. Alternatively, if your baby looks uncomfortable, stop, gently cross your baby’s arms over their chest or wrap a small sheet around their arms and shoulders. When your baby is calm, continue the nappy change.

It isn’t always necessary to change your baby’s nappy before feeds. If your baby is awake and hungry, they may become impatient and restless during the nappy change and then may not be relaxed during the feed that follows. Conserve their energy by letting them feed first.

If your baby slows down during their feed, it may help to change their nappy (as described above). This gives your baby a chance to rest. They may then have energy to resume feeding or if not, the feed may be finished using a feeding tube.

Note that babies feeding breastmilk often dirty their nappy during feeds.

Non-nutritive sucking with mother during tube-feed

Nurse’s soothing touch as baby, 27 wks, sucks his tiny soother

Baby’s feet held sole-to-sole and knees bent during nappy change
Bathing
Bath-time is another opportunity to engage with your baby. Plan with your baby’s nurse to know when might be a good time for a bath, perhaps before a feed, or when the unit is quiet. Bathing classes are provided, ask your nurse for details.

If your baby is in an incubator:
- Your baby may be given a little ‘bed bath’ or a ‘top and tail’.
- Your nurse will show you how to gently clean your baby’s face, cleaning each eye separately, ears, neck, body, arms, legs and all the creases.

If your baby is in a cot:
- Your nurse will show you how to bathe your baby in water. With practice you will become more comfortable doing this yourself. The nurse will always be nearby if you need any support.
- Fill the bath with enough warm water to cover your baby’s tummy, and allow them to float.
- Use your elbow to test the temperature of the water. It should feel warm, rather than lukewarm or hot.
- Your baby will feel relaxed if you ease them into the bath by letting their feet touch the end of the bath first and by tucking in their arms and legs.
- To make your baby feel more secure, allow your baby to touch the end of the bath when they stretch out their legs.
- For small babies, bathing can be a tiring activity. Your small baby may feel more relaxed during their bath if wrapped in a light sheet; this helps them to feel snug and helps to keep their arms and legs tucked in. As you and your small baby become used to bathing, wrapping won’t be necessary.

- You may like to use your own towels, sponge and face cloth.
- You may like to take photos or a little video clip of your baby’s first bath.
- To protect the natural oils in your baby’s skin, it is usually enough to bath your baby once a week.
Good nutrition is important for growth and development. As a parent of a preterm or ill baby you may wonder when, what and how your baby will be fed?

This section sets out to help answer these questions.

When will my baby be fed?

This will depend on several factors but we aim to start milk feeds as soon as possible. If we expect your baby to take a little time to establish feeds, they may be given fluids with extra nutrients (parenteral nutrition) through an intravenous (IV) line until they are able to progress to adequate milk feeds.

What will my baby be fed?

Breastmilk is the feed of choice for babies, including those born preterm, with a low birth weight or those who are sick. Mothers are encouraged to provide breastmilk for their baby as this has many benefits (see below). If breastmilk is not available formula milk will be used instead.

The value of breastmilk

- Breastmilk is the most natural and easily tolerated feed for babies.
- Breastmilk contains an ideal source of nutrients and other ingredients to support your baby’s growth, development and long-term health.
- Breastmilk is not just food – it also helps protect against infections, helps digestion and promotes brain development.
- Many mothers tell us that providing their baby with breastmilk is a comfort during this time as it is something only they can do for their baby.

If you have any questions about breastfeeding or expressing breastmilk for your baby, do not hesitate to discuss them with your baby’s nurse.

If you are undecided about how you will feed your baby, we hope you will consider the benefits of breastmilk. Even if you only provide breastmilk for the early feedings, or during your baby’s hospital stay, it will be of benefit. Staff in the neonatal unit value breastmilk and will be happy to assist you in any way possible.

Expressing breastmilk

- If your baby is not able to breastfeed at your breast, you will need to express (pump) your milk so that it can be given through a feeding tube instead.
- It is important to express your milk right from the start, ideally within the first 6 hours.
- In the early days you will need to express at least 8 to 12 times a day, including during the night, in order to stimulate your milk supply.
- When your supply is established, you will need to continue to express your milk regularly – 6 to 8 times daily, including at least once during the night – to help keep up your supply. This will also ensure a good supply when your baby is ready to feed at your breast.
- Breastmilk can be expressed by hand in the early days. However, for longer term expressing, we recommend using a suitable breast pump. Staff in the neonatal unit will be able to advise you. Most units have a breastfeeding / lactation room and breast pump for your use while visiting your baby. You will also need to organise a suitable breast pump for use at home.
- Expressed breastmilk needs to be handled and stored properly. Ask staff for details and note the following guidelines:
  - Always store in a sterile container.
  - Refrigerate milk as soon as possible after pumping.
  - If you express your breastmilk at home, make sure you keep it cold during transport to the hospital.
  - Store milk as advised by your local hospital.

- It can require a lot of effort to express milk but please don’t be discouraged. This milk is very precious for your baby and staff are available to help and support you – just ask.
- If your baby was born preterm, a breastmilk fortifier (BMF) which contains extra energy, protein, vitamins and minerals, may be added to your expressed breastmilk to help your baby’s growth.

Parents share the enjoyment of feeding their twin daughters breastmilk
When can I expect my baby to breastfeed or bottlefeed?

- Preterm babies do not begin to safely coordinate sucking, swallowing and breathing until about 32 to 33 weeks corrected age. Before this time, your baby may appear alert and looking to be fed, but cannot safely swallow milk, and will receive feeds through a feeding tube instead.
- If your baby is not ready for oral feeds, non-nutritive sucking (NNS) is encouraged to help your baby enjoy pleasurable oral experiences. See section ‘Non-nutritive sucking’, page 36.
- Oral feeds will be increased gradually based on your own baby’s ability, perhaps starting with a small oral feed just once a day, and gradually increasing the amount until your baby no longer needs any tube-feeds. Oral feeding requires more effort than tube-feeding and so the transition can take a little time.
- If your baby is not able for an oral feed, they can be fed using a feeding tube instead. We do not expect your baby to fully manage full oral feeds until about 35 weeks corrected age, and this may be delayed if your baby was very sick or fragile.
- It does not take much to change your baby’s oral feeding ability. Setbacks such as infection, or the need for extra oxygen, can affect how well your baby feeds at any given time.

Your baby’s environment is also important. Over-stimulation, such as noise and over-handling, can affect their feeding ability. Try to feed your baby in as quiet, calm and soothing an environment as possible for both of you.

Formula milk

- If breastmilk is not available, infant formula milk will be used instead.
- If your baby was born preterm, they may be given formula milk that is specially designed for preterm babies, with extra energy and other nutrients. This will be decided by your baby’s doctor, nurse or dietitian.
- When your baby no longer needs a special formula, they can change to a standard infant formula milk until they are at least 12 months old (corrected age).

How will my baby be fed?

- Babies who are able to feed orally (by mouth) are encouraged to breastfeed. If you do not offer breastfeeds, your baby will be offered bottlefeeds instead. Breast and bottlefeeds are referred to as ‘oral feeds’.
- Some preterm or ill babies may not be mature or strong enough to breast or bottlefeed and may need extra help in the form of ‘tube-feeds’. If your baby requires help with feeding, a soft, narrow tube is passed through their nose or mouth and down into their stomach. This is called a feeding tube and can be used to give milk feeds, other fluids and medications. If the tube passes through a nostril in the nose it is referred to as a ‘naso-gastric’ (NG) tube. If the tube passes through the mouth it is referred to as an ‘oro-gastric’ (OG) tube. Your baby’s nurse will check that the feeding tube is in the right position. Over time babies gradually progress from tube-feeds to oral feeds. See section ‘Tube-feeding’, page 35 for further information.
- All feeding into the gut, whether by breast, bottle or tube, is referred to as ‘enteral nutrition’ or ‘enteral feeds’.
Feeding your baby

- Feeding should be a relaxed, unhurried and positive experience for both you and your baby.
- Try to put your baby to your breast to feed as often as they tolerate – check with your baby's nurse.
- Breastfeeding is natural but that does not mean it is instantly easy or instinctive. It is important to take one step at a time and let staff know if you need any support.
- During feeds check that your baby's tongue is on the floor of their mouth and that they are sucking and swallowing correctly.
- Each feed should take no longer than about 30 minutes to give. Extra time may be required to change or wind your baby afterwards.
- Once your baby is taking full feeds they will usually feed every 3 hours although, by time of discharge, they may have worked up to 4 hourly feeds.
- The volume and timing of feeds may vary. When your baby is established on oral feeds they generally will feed to appetite, this is fine once they do feed well and regularly.
- As your baby grows, there is often a gradual increase in the volume of each feed as the number of feeds reduces.
- Hold premature babies upright after feeds for at least 10-15 minutes to prevent spills (reflux). If your baby has difficulty feeding by mouth, they may be referred to a speech and language therapist.
- Further information about feeding your baby is available from your neonatal unit.

Monitoring your baby's nutritional progress

Your baby's nutritional intake and growth will be monitored closely. Adjustments may be made to their feeds as necessary.

Growth

- Growth measurements are plotted onto growth charts, which compare your baby's growth with the expected growth for a baby of the same age.
- Growth is plotted, taking account of how preterm a baby was, that is, using 'corrected age'. Corrected age is used up to 2 years of age. After that, ‘actual age’ / ‘chronological age’ is generally used.

See page 7 for ‘The preterm baby and “corrected age”’.

Weight checks

- Babies are weighed naked, therefore, if your baby is weighed on a cold scales, use a blanket or towel to keep them warm – the weight of the towel or blanket will be subtracted from your baby's weight.
- During weighing, placing your baby on their side may help them to relax.
Home time

Your baby’s discharge from hospital

The timing of your baby’s discharge will depend on your individual baby. The arrangements for discharge will be coordinated by the neonatal staff or by the neonatal liaison nurse/midwife specialist (neonatal discharge planning coordinator).

Preparation for discharge

It is perfectly normal for you to be nervous about taking your baby home. The best way to prepare is to visit and care for your baby as much as you can during their hospital stay. The hospital staff will help you to prepare for when your baby goes home.

The following will help you to plan for your baby’s discharge:

• Practice baby care. We want you to be comfortable with all aspects of your baby’s care at home including feeding, positioning, bathing and changing their nappy. It is good to practice these skills throughout your baby’s hospital stay. Try to arrange your visits to coincide with your baby’s care giving.

• Classes are available that provide information and demonstrations on baby care – please attend in preparation for discharge.

• If your baby is breastfed organise a comfortable chair and pillow. Also link up with local breastfeeding support groups. Ask your local health centre for details.

• If your baby is bottlefed organise a supply of feeding equipment for home, for example, bottles, teats and equipment for sterilising bottles, warming feeds, etc. Ask your nurse for advice on suitable bottles and teats for your baby before buying them. Sometimes different teats and bottles may help your baby to feed more effectively.

• Preterm babies may take longer to feed because the muscles in their mouth are not as strong as term babies. Medium flow teats are often recommended because the milk flows more quickly so less energy is required for your preterm baby to feed.

• It is a good idea to bring in your own sterilised bottles from home as soon as your baby has started to bottlefeed. This will enable your baby to get used to these bottles before they go home.

• If you feed your baby formula milk, you will also need to buy a supply of this and learn how to prepare bottlefeeds safely. Information is available in the neonatal unit and at baby care classes organised at your local hospital. Staff will give you details about your baby’s feeds for home.

• Organise a supply of clothing, nappies and other things that your baby will need at home.

• Make contact with your general practitioner (GP) and local public health nurse (PHN) prior to your baby’s discharge and link with them after you go home.

• Learn about ‘baby resuscitation’. To relieve anxiety and empower parents, a booklet and practical demonstration (using a mannequin) on baby CPR (cardio pulmonary resuscitation) is taught to parents of preterm, ventilated or critically ill babies, prior to discharge.

Criteria for discharge

Your baby will usually be discharged when the following criteria are met:

• Age at least 35 weeks corrected age.

• Weight about 1.8 kg (4 lbs).

• Stable temperature.

• Regular breathing without assistance. If your baby required oxygen support to breathe, they should be at least 48–72 hours off it and not requiring monitoring before being discharged. If your baby requires oxygen support at home, staff in the neonatal unit will prepare you for this and will organise the services needed.

• Feeding well – this means that your baby is not dependent on IV fluids or tube-feeds, and is able to complete feeds within about 20 to 30 minutes for 1 to 2 days.

• Gaining weight well.

• Not receiving medications that require hospital management.

• No recent major changes in medications or oxygen administration.

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• No recent major changes in medications or oxygen administration.
Going home

- Obtain an appropriate car seat and ensure it is fitted correctly.
- Other staff may meet with you before your baby’s discharge to discuss relevant issues, for example, the medical social worker, physiotherapist, dietitian and pharmacist.
- It is useful to make note of your baby’s weight at discharge. Ask your nurse for a copy of your baby’s growth chart showing their recent growth measurements, especially if weight gain is a concern.

Further information for home time is provided in a range of information leaflets available in the neonatal unit and from other sources, see section ‘Useful contacts and sources of further information’, page 79.

“Your baby should never be left alone in the car even for a short period”

Follow-up appointments

- Staff will explain follow-up schedules with you and will organise appointments for the baby clinic (out-patients), hearing and vision tests and a brain scan (MRI) if necessary.
- Staff will notify your local public health nurse (PHN) that your baby has been discharged and they will visit you and your baby at home. You can also make contact with your local PHN directly, see section ‘Follow-up care and hospital check-ups’, page 72.

Your baby should be visible at all times either directly or through the rear view mirror. If you place the car seat in the front passenger seat, it is essential that you disengage the air bag and place the car seat rear-facing. If you place the car seat in back seat, it is also essential to disengage any air bags and place the car seat rear-facing for newborn babies. If possible an adult should sit and supervise your baby if your baby is in the back seat. Your baby should never be left alone in the car even for a short period. Car seats should only be used for transport. Ask staff in the neonatal unit or your public health nurse for more information.

“Take one day at a time”

Home environment

- Your house does not need to be as warm as the neonatal unit. Keep the room your baby is in at around 18°C (range 16 - 20°C (62 - 68°F)). Babies do not need hot rooms to sleep in. If you are comfortably warm that should be sufficient.
- Maintain a smoke free zone around your baby. Smoking is a powerful risk factor for sudden infant death syndrome (SIDS / cot death). Children exposed to smoke in the air or on their clothes also have a higher risk of developing asthma and respiratory problems such as bronchitis and pneumonia. It is best that no one smokes in your house or anywhere near your baby.
- During the first few days at home, limit visitors and phone calls no matter how well meaning they are. They will only put extra stress and strain on you, be honest if now is not a good time – turn your phone off or turn on the answering machine.
- Try to limit how much your baby is handled by your visitors no matter how nice they are – it is disruptive for your baby and increases their risk of infection.
- Do not over-dress your baby. Take off your baby’s hat and extra clothes when you are indoors.

Tips for reducing the risk of infection in the home

- Hand washing is extremely important in the fight against infection. Insist everyone washes their hands, including visitors.
- Don’t expose your baby to visitors with cold or flu symptoms.
- If you have cold or flu symptoms yourself do not over handle your baby and avoid kissing or sneezing over them.
- If you sneeze use a disposable tissue to catch the sneeze and dispose of it, then wash / sanitise your hands. The cold virus spreads through droplets produced when you sneeze. A hand sanitiser is useful when you are out and about.

Your baby at home

The first few days at home with a preterm baby may be tinged with a mixture of excitement and anxiety. It is great to have your baby safely home with you after the long wait but you may find yourself arriving home and wondering – what do I do now?

You may begin to question yourself about many things – ‘Will I be able to look after my baby properly?’, ‘What if they cry and cry and I don’t know what is wrong with them?’, ‘Are they getting enough milk?’, ‘Are they getting enough sleep?’

Take one day at a time. Remember that you can call the hospital at any time if you are worried or concerned. You can also make contact with your PHN or GP. If your baby has a known heart problem and is being followed up in Our Lady’s Children’s Hospital, Crumlin and becomes suddenly unwell, take your baby to the accident and emergency department in Crumlin or your nearest accident and emergency department.

Your baby at home

Parents with nurse taking their baby girl home. She was born at 32 wks, now 37 wks.
Going out with your baby

- Wait a couple of days before taking your baby out and about – your baby needs time to adjust to each new environment.
- When you do venture out, start small – a short walk, a stroll in the park, a trip to the local shop.
- Wait half an hour or so after a feed before travelling by car or bus, to reduce the chance of your baby bringing up (spilling) some of the feed.
- Bring extra clothing.

Baby’s cot and blankets

- Position your baby’s cot away from radiators, windows and outer doors.
- Use a clean firm mattress that fits the cot correctly.
- Make up the cot with enough thin layers of bedding to keep your baby warm.
- If you need an extra top on while indoors your baby might need an extra layer. If a blanket is folded consider it two layers.
- Use aerated / cellular blankets and cotton sheets, that allow air to pass through.
- Before you go home check with your baby’s nurse as to how many layers you need to prepare and handle feeds safely.
- If your baby is born from October to March you may need to be extra careful of viral flu like infections.
- Avoid plane journeys before 6 months of age or during the flu season.
- Ask staff in the neonatal unit or your public health nurse (PHN) for more information.

Positioning during sleep time

- Always position your baby to sleep on their back, face up, face free from blankets.
- Vary your baby’s head position when sleeping, that is, swap their head between facing to the left or right side.
- Always place your baby’s feet to the foot of the cot, basket or pram, so that they cannot wriggle down under the covers and risk covering their face.
- Keep covers below shoulder level so that they cannot slip over your baby’s head.
- Never fall asleep in bed with your baby if they were born prematurely or had a low birth weight less than 2.5kg or 5.5lb.
- Don’t fall asleep in bed with your baby if you or your partner smoke or have taken alcohol, drugs or medication that makes you sleep more heavily.
- The safest place for your baby to sleep at night is in a cot in your room.
- Never fall asleep with your baby on a sofa, armchair or beanbag.
- Ask staff in the neonatal unit or your public health nurse (PHN) for more information.

Positional plagiocephaly

Positional plagiocephaly refers to flattening of part of a baby’s head. This can occur in preterm and young babies because they have weak neck muscles, poor head control, and their head is soft and pliable.

- Sleeping and lying with their head always turned to one side can cause flattening or misshaping of the head (plagiocephaly) and maybe even tightening of the neck muscles. This does not affect brain development but can cause changes in the physical appearance of the shape of the head.

“Never fall asleep with your baby on a sofa or beanbag”

Tips to help prevent positional plagiocephaly:

- In the neonatal unit babies’ positions are changed regularly and their heads are turned for them.
- If your baby’s bed is near a wall they tend to turn away from it which may lead to positional plagiocephaly. Change your baby’s sleep position from top to bottom of the cot, or use a brightly coloured card, mirror or mobile to encourage your baby to turn to the opposite side.
- Alternate the side to which your baby turns their head each time you are lying them down.
- Do not place any pillows, rolls or props into the cot or under the head while your baby is sleeping – these are not advised and increase the risk of cot death.
- As your baby grows they will turn their head towards a stimulus, for example, a brightly coloured toy / light / your voice. Use this to help encourage them to look to either side.
- It is important to support your baby’s head when you pick them up or carry them. As your baby grows and their head control improves and neck muscles get stronger, they will need less support from you to hold their head up. Carrying your baby over your shoulder or facing them away from you, for example, in the ‘crook’ of your arm, allows visual stimulation to encourage them to look around and hold their head upright themselves.

Always use disposable tissues to wipe your baby’s runny nose.
If your baby has sticky eyes use cotton wool and cooled boiled water to clean.
Ask the nursing staff to teach you.
Clean toys, work surfaces and highchairs regularly, as germs can live up to 48 hours on these areas.
If you have other children who attend crèche or school, ensure that they do not over handle your premature baby. Ask the school to keep you informed of any outbreaks of childhood illnesses.
From October to March you need to be extra careful of viral flu like infections.
Avoid plane journeys before 6 months of age or during the flu season.
Ask staff for further information.
Section 4: Home time

- Until your baby develops the strength to hold their head in the middle (from about 6 to 8 weeks corrected age), it is not advisable to leave them in car seats or any other seats for more than 20 to 30 minutes at a time, and for no more than one hour a day in total. Prolonged periods in a sitting position where their head falls to one side can cause or worsen a plagiocephaly. Do not let your baby nap in a car seat or bouncer seat, as this again encourages their head to fall to their favoured side.

- When your baby is awake and supervised it is very important they spend time on their tummy every day to strengthen their neck and shoulder muscles. Do not put your baby to sleep on their tummy. See section ‘Tummy time’, below.

- If your baby develops a positional plagiocephaly, your baby’s physiotherapist can advise on a repositioning programme to help your baby’s head shape normalise.

Tummy time

Tummy time is very important for your baby to develop head control and shoulder and upper body strength. It is important that your baby gets to spend time on their tummy when they are awake. From the early days this can be done when your baby is placed lying on your chest or on your lap. Try not leave it later than 4 weeks corrected age to start short periods of tummy time unless advised to do so by your doctor, as sometimes it is more difficult introduce it at a later stage. When they get a little bigger and stronger and have longer alert periods you can start to use a mat on the floor (usually from about 8 weeks corrected age). As a rough estimate by the time babies are about 3 months corrected age they should be comfortable on their tummies on a mat for 10 to 15 minute periods a few times a day.

Baby should be supervised at all times when on their tummy. Remember babies should always sleep on their backs with their feet to the foot of the cot, see section ‘Positioning during sleep time’ page 51.

Tips and tricks to help with ‘tummy time’ on the floor

- Have some toys that are ‘tummy time only’, for example, mirror books or a small ball, a little flat drum or mini piano toy are nice as your baby gets older.

- If your baby is unhappy or unfamiliar with being on their tummy, they may not tolerate it for very long at the start. It is a good idea, providing they are not in pain or hungry, to apply the ‘3 cry rule’ to tummy time.

3 cry rule

1. If your baby cries or shows signs that they want to change position – firstly distract with a toy / mirror / rattle etc.

2. If your baby cries a second time, distract again with another toy or move to face in a different direction but keep them positioned on their tummy.

3. If your baby cries a third time, pick up your baby, but if they have not completed about 10 minutes of tummy time try it again when they have settled. Start again using the 3 cry rule. This will help to lengthen their tolerance for floor time.

Safe sleep

Tummy time when your baby is small

- Place your baby on your chest or lap.
- Place their arms forward so they can lean through them.
- Stroke the back of their neck gently and talk or sing to them to encourage them to lift their head while pushing through their arms (like a baby push up).
- When your baby is showing signs of lifting their head and holding it upright for short periods, and when they are having longer alert awake periods, introduce ‘floor time’ on a play mat or sheet on the ground.
- Sometimes play mats are daunting for a small baby because they are often quite brightly coloured and ‘busy’. Encourage a gentle transition to time on a play mat by placing 1 to 2 toys (for example, red ball / rattle / coloured block) on a white sheet placed over the mat on the floor – this is especially good for babies that may have some visual immaturity.

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Establishing a routine for your baby

A well-organised daily routine is beneficial for your baby. Babies need routine to make sense out of their world and to feel in control.

Preterm babies have specific needs

- Preterm babies mature at a different pace to term babies.
- They are often more sensitive to noise and handling than a term baby for the first few weeks or months. Your baby may not like to sleep in a noisy room as, unlike a full-term baby, they may be unable to block out the excess stimulation that is caused by the noise and may need you to do it for them.
- They like to be held and fed in a certain way and played with at certain times.
- For some months, preterm babies may not be able to cope with as much stimulation and interaction with their world as term babies do.

Preterm babies may have a hard time becoming wide awake and paying attention to the things around them but, as their nervous system develops, your baby’s sleeping and waking patterns become more regular like those of full-term babies.

Preterm babies’ behaviour can be unpredictable, for example:

- They tend not to follow a consistent pattern of behaviour as term babies do.
- They may wake suddenly crying, from a deep sleep.
- They may be feeding quite calmly one minute, and they may fall asleep with no warning or drowsy period in between.
- They may go from feeding happily to a crying fit for no obvious reason.

This unpredictable behaviour can make it harder for parents to cope with or know what to do, but this is normal for preterm babies until their biological systems settle down.

A term baby’s behaviour generally follows a more logical progression, for example, they will typically go from a quiet sleep where they move very little, to alert sleep where they are more active and coming close to waking up, to being awake but dozy, to being fully awake and alert.

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“A well-organised daily routine is very beneficial for your baby”

Knowing when your baby is ready for play, rest and feeds

Preterm babies need more periods of rest and time for recovery than healthy term babies do. They are very good at communicating these needs through non-verbal gestures and behaviour. You will already be familiar with these gestures from the times you were observing your baby while in the neonatal unit. See section ‘Getting to know your preterm baby in the Neonatal Unit’, page 24.

Recognising your baby’s social interactive needs at home

You will rediscover and understand your baby’s needs again by simply watching them and interpreting their behaviour. They will tell you when it is okay to play and when it is too stressful for them. They will signal when they want to feed, socialise and sleep.

“By heeding your baby’s signals you are giving them back some sense of control.”

When your baby is tired and has had enough:

- They will shut their eyes or look away.
- They may grimace.
- Their arms and legs may stretch out and stiffen.
- Their breathing will become uneven.
- They may throw their head back and extend their trunk.
- They may yawn, grunt or hiccup.

When you observe these behaviours your baby is asking you to:

- Stop playing with them.
- Give them a break.
- Hold them quietly or let them lie down to rest.

Signals for ‘time-out’

When you observe these signals it is time to take a break from the play session and let your baby rest. By heeding your baby’s signals and by responding appropriately you are giving back some of your baby’s sense of control over their environment which in turn will boost their self-worth and self-confidence.

It is very important that you don’t tire or over stimulate your baby. Babies need to channel their energies into behaviours that will promote their neurological and physical development and their learning, for example, by following the movement of a bright light or dangling toy, opening their hands from time-to-time, smiling in response to an adult, making non-crying noises such as cooing or gurgling, and being able to ignore certain sounds that would have previously caused them to startle.

When your baby wants to play / socialise:

- Their eyes will open widely.
- They will show eye contact.
- They will increase facial and limb movements.
- They may respond by blinking, or by moving their legs or arms.
- They may mimic gestures that you make such as tongue protrusion (sticking out their tongue), pursing their lips (pouting), opening their mouth.
- Their breathing will be regular and their limbs will be relaxed and supple.

When your baby is hungry:

- Watch for mouthing movements.
- Listen for their ‘hunger cry’.

When your baby is hungry:

- They will shut their eyes or look away.
- They may grimace.
- Their arms and legs may stretch out and stiffen.
- Their breathing will become uneven.
- They may throw their head back and extend their trunk.
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Feeding and growth at home

Following your baby’s discharge from the neonatal unit, two common concerns are often about feeding and growth. Your baby’s feeding and growth will be reviewed by your public health nurse (PHN) and as an outpatient at the hospital baby clinic.

Feeding your baby at home

- We hope you will continue to breastfeed your baby. If your baby was fed breastmilk using a bottle in the neonatal unit, it is possible to transition them to breastfeeding if you have maintained your breastmilk supply. Contact your local health centre for details of breastfeeding support services in your area. If you do not have enough breastmilk or you choose not to fully breastfeed your baby, you can still continue to express breastmilk for as many feeds as possible and give formula milk for the remainder.
- Babies must usually be feeding well before they will be discharged. In practical terms babies should be able to complete a feed within approximately 20 to 30 minutes. We expect this to continue at home.
- If your baby was born preterm, they may feed more often or take bigger feeds relative to their size compared with term babies. This is because babies who are born preterm often need extra nutrition in order for their growth to ‘catch up’.
- Follow the advice of staff in the neonatal unit regarding supplements that may be recommended at home, for example, vitamin and iron drops.
- If your baby is feeding a special formula milk or fortifier, check at the baby clinic how long this is required.

Breastfeeding at home

- Babies should receive only breastmilk or formula milk as their main milk drink until they are at least 1 year old (corrected age).
- If your baby is fed infant formula, it must be prepared safely. Information about preparing bottlefeeds is available from the neonatal unit and your local health centre.
- If you are giving your baby bottlefeeds, it is usually not necessary to warm feeds above room temperature. If you wish to warm feeds, stand the sealed bottle of milk in a container of warm (not hot) water to avoid the risk of scalds for up to 15 minutes until the milk feels lukewarm, not hot. Drip some milk onto your wrist to check. Make sure that the water does not come above the rim of the bottle or it could leak into the bottle and contaminate the feed. Do not warm feeds in a microwave oven as this can lead to ‘hotspots’ in the milk which could scald your baby.
- Keep your baby in a supported, elevated position during feeds, see section ‘Positioning’, page 44. Babies are prone to bringing up (spilling) a little milk, therefore avoid pressure on their tummy and handling after feeds.
- Some babies swallow air during feeds, which may then become trapped and cause upset. Try to help your baby to avoid swallowing air during feeds and if they are unable to pass wind, help by sitting them upright with back supported on your lap or to your shoulder and gently rub their back.
- It is important to make sure that your baby is drinking enough milk feeds. If your baby is gaining weight well and having lots of wet nappies, it usually suggests that they are drinking enough milk. Your baby should have about 5 to 8 very wet nappies every day – one for every feed. Your PHN can weigh and measure your baby regularly to check that they are growing well. See section ‘Feeding time – when your baby is ready for oral feeds’, page 44 for further information about feeding your baby.
- The exact age for starting spoon feeds will depend on your individual baby and their readiness, but is usually some time between 5 to 8 months actual age for preterm babies, and by 6 months for term babies. Information about starting spoon feeds is available from your local hospital or health centre.

Growth

Attention needs to be paid to your baby’s growth and this requires regular checks with your public health nurse (PHN) at your local health centre, or at the hospital baby clinic.

- Growth is monitored by measuring your baby’s weight, length and head circumference.
- Usually we expect your baby to gain 150-200g (5-7ozs) or more per week.
- We usually expect preterm babies to show some ‘catch-up growth’. ‘Catch-up growth’ refers to growth at a rate that is faster than the average so that a baby ‘catches up’ and reaches the appropriate size for their actual age.
- Avoid comparing your baby to other babies. Instead look at the rate at which your child is growing rather than how big they are.
- If your baby does not gain weight well, or you are concerned about your baby’s growth, contact your PHN or GP.

Anaemia of prematurity

Anaemia of prematurity can be a problem in the first weeks after discharge.

- Anaemia can cause your baby to appear pale and tire easily.
- If anaemia is present or suspected you will be asked to bring your baby to the baby clinic for weekly blood tests until it resolves.
- Occasionally some babies need a top-up blood transfusion if their haemoglobin (Hb) levels have dropped. Haemoglobin carries oxygen in the blood and a low level is a marker for anaemia.
- Iron is essential for haemoglobin. Most preterm babies will need to take iron supplements during their first year.
Recognising when your baby is sick and what to do


At the most simple level any baby who is out of sorts should be considered sick. If your concerns about your baby persist, it is likely that something is wrong and your baby needs to see a doctor. Babies get sick more quickly than older children or adults. If you think your baby is ill trust your instincts.

It is important to respond to a crying baby. Try to understand why your baby is crying – this will become easier as you get to know your baby. It is important to respond to a crying baby.

Why do babies cry?

All babies cry, especially when they are very young.

- Crying is a baby’s verbal form of communication.
- Babies cry for a variety of reasons – some important, some trivial.
- When a baby cries they need to be checked out.

Try to understand why your baby is crying – this will become easier as you get to know your baby. It is important to respond to a crying baby.

Reasons why babies cry

- Discomfort
- Trapped wind
- Hunger or thirst
- Having a wet or dirty nappy
- Feeling too hot or too cold
- Being over-tired or over-stimulated
- Feeling lonely or bored or in need of a cuddle / social contact
- Illness – this is a less common reason, however, a number of medical considerations need to be excluded. Check for fever and infection and refer to the check list ‘signs that your baby is unwell’.
- If you suspect that your baby is ill, contact your GP, PHN or local hospital.

Taking your baby’s temperature

It is a good idea to learn how to take your baby’s temperature. The most accurate way is by using a digital thermometer, available from most pharmacies. To measure, place the thermometer under your baby’s armpit. Ensure it is well placed within the folds of skin. The average normal body temperature is 36.6 – 37.1°C (97.9 – 98.8°F).

Check that the crying is not due to any of the reasons listed above. If your baby is difficult to settle it can cause anxiety and exhaustion, especially if the crying is difficult to interpret and there is no obvious cause.

Babies are never, ever manipulative. They only cry when they want help. They are not trying to control you or be assertive, they simply want to be looked after. You cannot spoil a small baby. Your baby will only ask for what is needed.

Your baby should not be left to cry. Long periods of unattended crying may increase your baby’s sense of isolation. Sometimes after going through the checklist your baby may continue to cry. If things get a bit fraught, or if you are finding it hard to cope, seek some support. It may help to just take some time-out – ask a relative or friend to mind your baby for a while and get out for a walk, swim or any activity that you enjoy. Even a short break will be beneficial.

If the crying continues or sounds unusual, or if you are concerned that your baby is ill or not growing well, contact your GP, PHN or local hospital.

Calming a crying preterm baby

There are many ways to calm a term baby such as back-patting, rocking, singing, distraction with toys or making faces. However, these techniques do not seem to work as well with a crying preterm baby, even when they are well and strong enough to be at home.

A gentle approach seems to work best. The usual baby-soothing combination of movement, sound and sight can be too much for a preterm baby and may cause them to cry more. Preterm babies can be overwhelmed and upset by cheery faces talking up close to them, being bounced up and down, or being sung to, rocked and patted all at the same time. The reason they respond like this is that they are still finding it difficult to handle more than one thing happening to them at the one time.

Sitting still and holding your baby close to you in a peaceful quiet surrounding can help settle them. Try to be flexible, what works one day might not work the next.
Your baby’s development

Preterm babies are born before their natural gestation period of 40 weeks, unlike term babies. Being born early means that they have not had the opportunity for full brain development before birth. Consequently, in the early months after birth their milestones may be a little behind when compared to babies born full term. You must make allowances for this.

Their early birth, a period in long term intensive care, an ongoing health problem or a disability are all factors that may slow down a baby’s progress. However, this gap narrows over time and most preterm babies do catch up. Babies usually catch up with their peers sometime before 2 years of age and sometimes later. This will depend upon how preterm they were and their medical history.

“Parents should take an active role in helping their baby’s growth and development”

Parents should take an active role in helping their baby’s growth and development. Creating a warm and loving home environment with appropriate developmental stimulation has a great influence on the outcome of many problems. In the early days, when playing with your baby, use their behaviours to guide you in terms of the type of play / social interaction and in terms of how long you can spend playing with them without over tiring them. Judge appropriate and inappropriate stimulation by observing your baby’s behavioural cues and responses during these social interactive play periods. See section ‘Getting to know your preterm baby in the neonatal unit’, page 24 and section ‘Knowing when baby is ready for play, rest and feeds’, page 54.

It is hard not to make comparisons with other children who were born term, or when reading developmental books. However, when monitoring your baby’s development it is important to bear in mind two key facts:

• Your baby’s corrected age during the first two years of life.
• That most preterm babies do ‘catch up’, but in their own time.

Preterm babies need more time

Preterm babies need more time and care than the term baby. Parents frequently report that the big difference is the additional time and patience needed in relation to their feeding and getting them settled between feeds.

Your baby’s development may be a little behind because of their prematurity. However, you will find that they will get more alert and responsive over time. It is exciting when you notice when they start to follow your movement with their eyes and start to do something new.

As your baby grows older they will become more alert. They will spend more time awake. While their level of eye contact and facial expression will be limited initially, your baby will still need to be looked at and spoken to in order to be able to fulfil their emotional needs and promote their social development.

Growth

Growth is a very important aspect of your preterm baby’s development and will need to be monitored carefully. This will require regular weight checks with your PHN or at your local health centre. See section ‘Feeding and growth at home’, page 56 for more details.

Sensory development

Sensation is the process by which we receive information through the senses. Two important senses are vision and hearing. The other senses are touch, smell, taste and proprioception (sense of the orientation of one’s limbs in space for example, legs, arms).

Babies’ sensory development can be observed when they:

• Begin to focus their gaze.
• Turn their head towards a diffuse light source or shiny object.
• Blink defensively when something comes towards them.
• Follow or track the movement of a bright or a dangling toy moved slowly in their line of vision.
• Are startled by sudden noises.
• Turn their head towards a source of a sound.

As your baby grows older:

• They can almost see as well as an adult.
• Their visual memory is good – they can find things.
• They know and respond immediately to their own name.
• They recognise familiar sounds and voices.
• They listen to general conversation with interest.

As sight is important, all babies who have weighed less than 1500g, as well as babies who have had retinopathy of prematurity (ROP), will be requested to attend the Ophthalmologist (eye specialist) regularly for routine eye check-ups. The most common problems include a mild to moderate squint or a disability are all factors that may slow down a baby’s progress. However, this gap narrows over time and most preterm babies do catch up. Babies usually catch up with their peers sometime before 2 years of age and sometimes later. This will depend upon how preterm they were and their medical history.

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When learning new skills, some preterm babies will need additional encouragement as they can be less adventurous than term babies. They can be more hesitant when attempting new tasks, such as trying to roll over or sit. If your baby’s progress seems a little slow the physiotherapist at the hospital can give you guidance on how to bring your baby along more quickly.

Key areas of development that your baby may need help with will their growth and motor (physical) skills but more predictably their cognitive (mental) and language skills.

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Hearing problems are more likely if your baby was born very preterm because their hearing systems are still maturing at 24 to 26 weeks. Other risk factors include a bleed in the brain (intraventricular haemorrhage – IVH), shortage of oxygen at birth, severe jaundice, infection and a birth weight of less than 1500g. Babies who were born less than 1500g are screened by an audiologist (hearing specialist) during the first month when discharged. Hearing difficulties can make it harder for a child not only to listen to language but also to speak clearly. If they cannot hear properly, children may appear disobedient, or behave aggressively or disruptively out of sheer frustration. Therefore, it is vital to detect any hearing difficulties as early as possible.

Language development

Language development is the development of communication skills:

- Receptive speech – what your child understands.
- Expressive speech – the words your child produces / says.
- Articulation – your child’s pronunciation of these words.

Preterm babies are often late to talk. We now know that 30% of preterm toddlers will have difficulty with language at 24 months corrected age. If they have a language problem it is more often a difficulty with expression (speech) than a difficulty with understanding (receptive) what has been said to them.

These children usually have a normal cognitive development (see below) with a specific speech delay. Therefore, it is very important to talk to your baby even if you think that they are too young to understand. Babies love gentle playful games. Eye contact at this stage is your baby’s main mode of interaction. In the early days, babies have little interest in toys and respond best to close contact and social interaction with other human beings. The human voice is what babies want to hear. They learn the sounds of language by listening to their parents and imitating what they hear.

When communicating with your baby, ensure that they can fully see your face, watch your lips move and observe your facial expressions. You will quickly notice your baby mimicking your facial changes. Through tone of voice, facial expression and eye contact your baby becomes secure and self-confident.

“To develop language and communication, show your baby new things everyday”

To develop language and communication, show your baby new things everyday

- When out for a walk talk to your baby about what is happening around them – point out interesting things that you can see and hear in the environment.
- Talk about what you are doing as you bathe, feed and dress your baby.
- Encourage your baby to make vowel-like sounds and consonant – vowel sounds such as ‘ma’, ‘da’, ‘ba’.
- Make time to read to your baby everyday – use picture books for babies.
- Sing nursery rhymes for rhythm and action words.

Babies enjoy:

- Supplying the finishing words to each nursery rhyme sentence – for example, ‘Baa Baa Black Sheep’.
- Repetitive activities such as ‘peek-a-boo’, ‘incy wincy spider’, ‘clap handles’.
- Mimicking animal sounds for example, dog says ‘woof, woof’, cat says ‘meow’, pig says ‘oink, oink’, cow says ‘moo’.
- As your baby reaches two years or earlier ask them to identify objects in a picture book by asking ‘what’s this?’ When they can talk ask them to name objects highlighted by you.
- Make a scrapbook of favourite things by cutting out pictures. Group them into categories such as things to eat, things to take to the beach, fruit, tools, transport, things to play with.
- Expand vocabulary, for example, name body parts and identify what you do with them: ‘This is my nose. I can smell flowers and perfume’.
- Place familiar items in a box – as your child explores and removes each item ask them to tell you what it is called and how to use it, for example, ‘This is my brush. I use it to brush my hair’.
- Simplify your language – if your child is using two-word phrases, try to do the same at regular intervals throughout the day, for example, ‘Daddy gone’, ‘Daddy car’, ‘Mammy shop’, ‘Mammy work’, ‘more water’.
- Give your baby choices to increase their vocabulary, for example, ‘Do you want water or milk?’
Assessing your child's language development

Keep an eye on the way your toddler is communicating with you, whether they are trying to imitate words or whether they are succeeding with any.

By one year corrected age your child should be able to:

• Babble using increasing intonation as if having a conversation.
• Understand simple instructions associated with a gesture such as ‘come to daddy’, ‘clap hands’, and ‘wave bye- bye’.
• Hand objects to adults when asked.

By two years corrected age your child should be able to:

• Respond to simple instructions, for example, ‘please give me the ball’.
• Should be starting to imitate 2 word utterances, for example, ‘Daddy shop’, ‘all gone’.
• Start to use 2 to 3 multiple word sentences, for example, ‘Daddy gone car’.

If your child is making no effort to communicate or babble by two years corrected age you should seek professional advice and arrange to see a speech and language therapist. Your local early intervention service or health centre will be able to help you. A hearing test may need to be performed to rule out hearing loss.

Cognitive / intellectual development

Cognitive or intellectual development is the development of the mind.

Cognitive development is about your baby’s ability to learn about their environment and to solve problems. It involves the use of memory, language, reasoning and thinking. The toys that help a baby’s cognitive development initially are toys that produce cause and effect, i.e. when a baby handles them they do something, for example, rattles, toys that light up and play music, mobiles that chime and sparkle.

To develop your baby’s cognitive skills during their first two years:

• Place toys around them to reach out to, touch and explore.
• Hang rattles and toys over their cot or use a play mobile on the floor to encourage your baby to reach and grab.
• Provide stacking pots and blocks – build a tower of blocks for your baby to topple.
• Look at picture books together.
• Talk about everyday things especially when out and about.
• Provide simple musical instruments, for example, xylophone or wooden spoon and saucepan.
• Provide boxes / beakers for your baby to put things into and take things out of.
• Provide suction toys on table tops.
• Introduce nursery rhymes to promote memory and listening skills, for example, ‘this little piggy’ and ‘pat-a-cake’.
• Let your baby watch a toy / ball being hidden and encourage them to retrieve it.

To build up your baby’s cognitive skills from around two years corrected age, engage them in a variety of more complete activities such as:

• Shape activities, for example, form boards to place shapes or posting boxes for posting shapes (see photo page 73).
• Pegboard activities, for example, placing pegs into holes / peg jigsaws on a form board.
• 2 to 4 piece jigsaws to develop object assembly skills, building up to more complex jigsaw puzzles as they grow older.
• Opportunities for creative / make-believe play, for example, simple puppets, tea sets, doll play, toy telephone.
• Opportunities to play with construction toys, for example, duplo / lego.
• Reproducing simple brick constructions built by you for example, tower, row of blocks, a bridge.
• Language-related cognitive activities should be introduced at around two years of age depending on your child’s language skills, for example, ask your child to:
• Match and distinguish pictures.
• Match colours, for example, present different coloured blocks such as lego to match and group by colour.
• Play games introducing prepositions, for example, ‘on’, ‘in’, ‘under’, ‘behind’, ‘between’, etc.
• Compare objects to show opposites, for example, fast - slow, wet - dry.
• Distinguish between sizes, for example, big and little, long and short.
• Weigh objects to see if they are heavy or light.
• Sort shapes and objects in your home by size, eg. square objects (table), circular objects (ball).
• Discuss objects by use, for example, chair for sitting, ball for bouncing, cup for drinking.
Fine motor development

Fine motor skills involve precise use of the hands and fingers, for example, pointing, drawing, using a spoon to feed, writing, stringing beads, doing up shoelaces. These skills can be developed by encouraging:

- Drawing activities, for example, using crayons for spontaneous scribbling.
- Building blocks for creative building.
- Hammering activities, for example, hammer and peg toys.
- Opening / closing lids on bottles.
- Playing with construction toys, for example, duplo / lego.
- Sticker book activities.
- Opportunities for messy play, for example, with sand, water, and paints.
- Play-dough activities, for example, rolling dough into big balls using palms of hands, into small balls using only the fingertips, or making things, for example, snake, people, snail and house.
- Using a large plastic tweezers to lift small objects into a container, for example, peas, cereal.
- Posting coins (supervised) into a piggy bank.
- Lacing macaroni / cereal onto string.

Supervise your child at all times – take particular care when they are handling small objects.

Gross motor development

Gross motor skills involve the use of the large muscles in the body and include walking, running, jumping, climbing and hopping.

To enhance your baby’s gross motor development provide:

- Supervised play time with freedom to kick and reach for hanging mobile toys.
- Tummy time on play mat to facilitate head and neck control. See section ‘Tummy time’, page 52.
- Opportunities to sit unaided, to crawl and cruise around furniture to aid independent walking – a pull along toy or trolley of blocks will help.
- Toys to ride and climb on and space to run and play.
- Use of climbing frames and play ground activities to aid coordination strength and fitness.
- Ball play – for rolling, throwing, catching and kicking to promote coordination skills.
- Play with discarded cardboard boxes to push, crawl through, pull, get into.
- Play with large pillows to jump on / roll about.

Attention and memory skills

- Produce one or two toys to play with at a time. This will decrease distractibility and the tendency to flit from toy to toy without attending appropriately to one toy.
- Make sure you have your child’s attention and engagement when you are giving them instructions on how to use a toy or puzzle board.
- If your child isn’t attentive, gently hold their head up to gain eye contact with you and repeat the instruction.
- Repeat a simple nursery rhyme daily until your child can say it with you.
- Read a simple story and have your child repeat the story back to you.
- Review events of the day with your child at bedtime.
- Play the memory game with a fun deck of cards starting with 3 pairs and building up gradually to more pairs as your child improves.
- Play a memory game with objects, for example, place 4 objects on a tray, let your child look at these for 1 minute, cover the tray, remove an object, uncover the tray and ask what is missing.

Most importantly, don’t over stimulate your child as you will make fun and learning a chore instead of enjoyment.

Section 5: Development

Example of fine motor / cognitive play

Supervise your child at all times – take particular care when they are handling small objects.

Twin sisters at interactive play

Ball play to promote coordination skills

Ball play / gross motor task

Play with cardboard box

Example of fine motor / cognitive play

Climbing coordination

Sliding
General developmental checklist

Age appropriate activities to help promote your baby’s overall development

1 month corrected age

- Hold and cuddle your baby.
- Make plenty of eye contact.
- Talk to and smile at your baby.
- Face your baby when talking to them.
- Let your baby observe you when awake.
- Provide nappy-free periods to kick freely – help your baby to gently move their legs by moving them in a ‘cycling’ motion.
- Encourage focusing / coordination by hanging rattles / toys over their cot.
- Massage your baby’s body / limbs during / after bathing.
- Stroke the back of your baby’s hands to encourage them to open their fingers and thumb.
- Carry your baby in a curled up posture, keeping their hands forward.
- Encourage your baby to hold their head in the middle.
- Avoid placing your baby in car seats or bouncers for extended periods of time. Do not use car seats for naps / sleep.
- Use side-lying position for playtime. This is a lovely position that encourages hands to midline and shoulder and hip strength.
- Let your baby play on their tummy on your lap or chest daily, see section ‘Tummy time’, page 52.
- Encourage your baby to turn their head to both sides.
- Help your baby to bring their hands and shoulders forward and to tuck their chin in.

3 months corrected age

At this stage your baby is usually beginning to distinguish faces and respond to plain toys with contrasting colours (especially primary colours, for example, red or black on white), for example a face painted on a paper plate, or a small mirror placed close by.

- Provide periods of activity on a play mat on the floor.
- Use a rolled towel under your baby’s chest (as demonstrated by your physiotherapist) to help your baby get better at tummy time. See photo page 53.

This is a crucial time in developing tolerance to tummy time. If your baby is reluctant to go on their tummy apply the 3 cry rule, see section ‘Tummy time’, page 52.

- Place your baby on their back on the mat – encourage them to reach their hands to the middle of their chest by giving them toys to reach for or play games like ‘clap handleys’ etc.
- Encourage your baby to reach for and look at their knees and feet.
- Encourage your baby to roll from their tummy to their back and vice versa – your physiotherapist can show you exercises for this.

- Provide suitable toys to play with on the mat. Suitable toys at this stage include small rattles, books with contrasting pictures, small balls that would fit into your baby’s hands.
- Do not use a seat (other than a car seat) for your baby until they are strong enough to hold their head in the midline position easily and to turn it to both sides. When sitting, ensure that your baby’s shoulders are forward so their hands can easily reach for toys in front of them or they can place their hands together or to their mouths. See photo page 70.
- It is normal and part of your baby’s development that they explore toys with their mouths – ensure toys are safe and clean for them to do so.
- Support your baby around their middle while sitting on your lap and encourage them to reach for toys.
- Introduce action rhymes, for example ‘clap handleys’.
- Encourage interaction and play with other adults and children.

Older child lying on back in mid-line

- Encourage your baby to bring their hands to their mouth and to reach their hands to the middle.

If you have difficulty with any of these positions your baby’s physiotherapist will be happy to demonstrate to you.

Be watchful that your baby does not develop a preference to turn their head in one direction only - see section ‘Positional plagiocephaly’, page 51.

Supine lying with supports, hands at midline

Toddler exploring toy through mouthing
6 months corrected age

- Allow plenty of time to play.
- Encourage mobility by placing toys just out of reach – help your baby to roll and crawl.
- Place your child on their hands and knees over your leg while you are on the floor with them – this helps them get used to the crawl position.
- Place your child between your legs or with some firm supportive cushions around them and encourage them to sit. Teach them to reach for toys in the sitting position and to put their arms out to balance themselves and save themselves from falling over.
- Encourage your baby to play in the kneeling position.
- Teach your baby to move safely from sitting to crawling and vice versa.
- Provide bath toys, for example, beakers and funnels – encourage splashing and kicking in the bath.
- Provide swimming and water activities if it is safe for your baby to do so.
- Provide stacking and nesting toys.
- Build brick towers and enjoy toppling them.
- Place suction toys on table tops, for example, toys like a small drum to bang.
- Play peek-a-boo games and hide and seek.
- Roll balls for baby to bring back to you.
- Encourage self feeding and tolerate mess. Give your baby a spoon to hold and play with, even outside of meal times.
- Talk constantly to your baby when they are alert.
- Continue rhymes and action songs.
- Encourage your baby to play in the kneeling position.
- Teach your baby to move safely from sitting to crawling and vice versa.
- Provide bath toys, for example, beakers and funnels – encourage splashing and kicking in the bath.
- Provide swimming and water activities if it is safe for your baby to do so.
- Provide stacking and nesting toys.
- Build brick towers and enjoy toppling them.
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- Play peek-a-boo games and hide and seek.
- Roll balls for baby to bring back to you.
- Encourage self feeding and tolerate mess. Give your baby a spoon to hold and play with, even outside of meal times.
- Talk constantly to your baby when they are alert.
- Continue rhymes and action songs.

From 12 months

- Provide a wheeled push and pull toy to promote confidence in walking.
- Provide pop-up toys, stacking toys / blocks and hammer and peg toys to develop eye-hand coordination.
- Provide balls to roll, kick and throw.
- Encourage creativity skills using thick crayons and paint brushes.
- Encourage play with messy materials, for example, sand, water and play dough, finger and foot paints and crayons.
- Provide bath toys such as beakers, sprinkling toys, ducks and boats.
- Read picture books with simple rhymes and discuss pictures.
- Encourage page turning and ask your child to identify objects in the pictures.
- Play simple games which involve action and taking turns.
- Play ‘let’s pretend’ games to encourage skills of imagination, for example, pretending to be an animal or driving a fire engine or bus.
- Play role-play games, for example, pretending to be a doctor or pirate.

“Place toys on low furniture to encourage baby to stand, reach and begin to walk and cruise”
Follow-up care and check-ups

Now that your baby is well and at home, anxiety may set in regarding their short-term and long-term progress.

Will they be alright? What will their developmental outcome be like? Will they be able to go to a normal school?

A parent's expectation about a baby's development can often be based on comparisons with other children. As parents of a preterm baby you need to know that your baby will take some time to catch up. You will be measuring your baby’s milestones according to their corrected age for up to 2 years.

It must be appreciated that even with adjustment for gestational age some preterm children may exhibit a delay in their development. Some may have a non-specific cause which will hinder their performance.

Check-ups

After your baby goes home your first contact will be with your public health nurse (PHN) who will call to see you and your baby. You will then be requested to attend the baby clinic over the following weeks, where the doctor will check your baby’s overall appearance and in particular their movements, reflexes, sight, hearing and growth.

Your baby’s social development will also be noted, for example, are they interested when you talk to them? Do they follow you with their eyes? Do they smile?

Regular attendance at the baby clinic will become an important feature during your baby's early life. Some babies may attend baby clinic appointments for up to 2 years or more.

Formal assessment of development in addition to baby clinic check-ups

If your baby’s birth weight was less than 1500g or if your baby was born up to 29 weeks gestation they may be requested to attend for a formal developmental assessment at 24 months corrected age. This assessment is performed by a Developmental Psychologist using the Bayley Scales of Infant and Toddler Development (Bayley-111) and is only available in some hospitals.

This assessment examines in detail your child's current level of cognitive (mental skills), language (receptive and expressive communication skills), motor (fine and gross motor skills), behavioural and social / emotional development.

The testing session usually takes about 2 hours to complete. The assessment is reassuring for parents when they see their child developing normally but also facilitates early detection and early intervention when specific problems emerge. It also affords parents the opportunity to observe their child performing developmental activities or tasks appropriate for their age level and offers guidance regarding the type of play / developmental activities that are important for their child's development.

If your child is demonstrating developmental delay in a specific area when assessed, an appropriate intervention may be recommended to prevent further delay. This developmental assessment facilitates the identification of areas of your child's development that appear responsible for a delay such as language development, sensory integration or fine motor / gross motor delay and will target these areas for further assessment.
Recommended infant immunisation schedule

Preterm babies need immunisation like all other babies. The present immunisation programme is administered to preterm babies according to their chronological age, not corrected age.

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<th>Immunisation</th>
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<tbody>
<tr>
<td>Birth</td>
<td>• BCG</td>
</tr>
<tr>
<td>1</td>
<td>• 6 in 1 [Diphtheria, Tetanus, Whooping Cough]</td>
</tr>
<tr>
<td>2 months</td>
<td>• 6 in 1 [Diphtheria, Tetanus, Whooping Cough]</td>
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<td>• Hib (Haemophilus influenzae B), Polio (Inactivated poliomyelitis), Hepatitis B [6-in-1] – 1st dose</td>
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<tr>
<td>2 months</td>
<td>• PCV (pneumococcal vaccine) – 1st dose</td>
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<td>3 months</td>
<td>• 6 in 1 [Diphtheria, Tetanus, Whooping Cough]</td>
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<tr>
<td>3 months</td>
<td>• Hib (Haemophilus influenzae B), Polio (Inactivated poliomyelitis), Hepatitis B [6-in-1] – 2nd dose</td>
</tr>
<tr>
<td>3 months</td>
<td>• Meningococcal C – 1st dose</td>
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<tr>
<td>4 months</td>
<td>• 6 in 1 [Diphtheria, Tetanus, Whooping Cough]</td>
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<tr>
<td>4 months</td>
<td>• Hib (Haemophilus influenzae B), Polio (Inactivated poliomyelitis), Hepatitis B [6-in-1] – 3rd dose</td>
</tr>
<tr>
<td>4 months</td>
<td>• Meningococcal C – 2nd dose</td>
</tr>
<tr>
<td>4 months</td>
<td>• PCV (pneumococcal vaccine) – 2nd dose</td>
</tr>
<tr>
<td>6 months</td>
<td>• Measles, Mumps, Rubella (MMR) – 1st dose</td>
</tr>
<tr>
<td>6 months</td>
<td>• PCV (pneumococcal vaccine) – 3rd dose</td>
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<tr>
<td>13 months</td>
<td>• Meningococcal C – 3rd dose</td>
</tr>
<tr>
<td>13 months</td>
<td>• Hib</td>
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</tbody>
</table>

Immunisation continues into early childhood. Please ensure that your child receives all their immunisations by consulting with your public health nurse (PHN) or school.

**Synagis (palivizumab)**

Synagis is a preventative medication offered to extremely low birth weight babies. Synagis is a substance that helps to protect your baby against respiratory syncytial virus (RSV), which is a very common cause of chest infections in infancy. Synagis is administered by injection on a monthly basis during the winter months from October to March. This will be discussed with you prior to your baby’s discharge and will be given at home by specialist nurses.
Common issues

Belly button (umbilicus) problems
It is very common for the belly button to protrude. This is harmless and will disappear in a matter of months. If your baby’s belly button is red, ask your public health nurse (PHN) or GP to examine it.

Colds
Your baby is as likely to get a cold as any other baby. The symptoms are a runny nose with a cough and there is usually little to worry about as long as your baby remains in good form and continues to feed well. If there is any drowsiness or deterioration in feeding, seek medical advice.

Colic or trapped wind
Preterm babies tend to be windy because they often swallow excess air. When their stomachs become filled with wind, they may experience pain which makes them cry. By and large the louder and more vigorous the cry, the more likely your baby is well. Sick babies tend to moan and whimper rather than cry loudly. It is reassuring if your baby continues to feed well with no vomiting or change in bowel habits. See section ‘Feeding your baby at home’, page 56 for further information about feeding your baby.

Constipation
It is normal for babies to make some straining noises when they dirty their nappy. Stool patterns also vary – some babies can have a dirty nappy once or more each day, others may have one every few days. If your baby is constipated their stools will be hard like pellets and difficult to pass. If so, make sure they are drinking enough fluids (milk feeds) and if they are fed formula milk make sure it is prepared correctly. Contact your PHN if constipation is a problem for your baby.

Cradle cap
This is a scaly, greasy rash that develops on the scalp and eyebrows. It may also make a baby appear spotty. It is usually mild and responds to gently rubbing olive oil or Vaseline (or equivalent) onto the affected area.

Hiccups
Hiccups are normal. Winding the baby may help. Try to get rid of wind if it is preventing your baby from completing a feed. Change the feeding position by holding your baby over your shoulder or in a sitting position on your lap. Then lay your baby on their back or tummy for a few minutes and repeat the process. As long as your baby is well and is gaining weight there is no need for concern if a mouthful of milk is brought up.

Sneezing and snuffles
Sneezing and snuffles are very common. Treatment is not needed unless it interferes with feeding. If necessary the nostrils can be cleared out with twists of cotton wool dipped in tepid water. The moisture will loosen the dry mucus and this will make your baby sneeze.

Sore bottom
This can develop rapidly. Apply a barrier cream such as Vaseline and secure the nappy loosely. If it doesn’t get better quickly you should contact your PHN or GP. It is quite common for thrush infection to develop on your baby’s bottom and this will need anti-thrush cream which will need to be prescribed by your GP. Thrush can also develop on your baby’s mouth.

Spilling some feeds
It is quite normal for babies to bring up (spill) a little milk after a feed. Most babies grow out of this over time. If your baby is well and growing normally, there is no need for concern. Keeping your baby in a good position during and after feeds and helping them to avoid trapped wind can help, see section ‘Feeding your baby at home’, page 56. If your baby starts to vomit large amounts of milk, ask your GP to examine them.

Sticky eyes
This is a common problem. Clean the eye well before feeds with cotton wool and cooled boiling water. Use a separate piece of cotton wool for each eye. If it doesn’t improve within a day or two consult your GP.

Contact your baby’s Public Health Nurse (PHN) or General Practitioner (GP) if you have any concerns about your baby.
Glossary of commonly used medical terms and abbreviations

You may come across the following terms in the course of your baby’s treatment. This list is provided for your reference in understanding the complex vocabulary that may be used during your baby’s hospital stay.

**Apgar score**: Score used when assessing the wellbeing of a baby at birth.

**Apnoea**: Episode when breathing stops for a period of 20 seconds or more.

**Aspiration**: Breathing any foreign substance into the lungs usually milk or meconium. Aspiration is also used to describe when milk is deliberately drawn up from the stomach – this can be done to test if a feeding tube is in the correct position.

**Bayley scales of infant and toddler development (Bayley - 111)**: Developmental assessment scale measuring cognitive, language, motor and behavioural / emotional development.

**Bradyacardia**: A decrease or slowing of the heart rate, usually below 100 beats per minute in babies.

**Breastmilk fortifier (BMF)**: A powder that can be added to breastmilk for preterm babies. BMF contains energy, protein, vitamins and minerals to help growth.

**Cyanosis**: Bluish colour of the skin usually caused by reduced oxygen levels.

**Electroencephalogram (EEG)**: Test that measures the electrical impulses of the brain.

**Electrocardiogram (ECG)**: Test that measures the electrical activity of the heart.

**Enteral feeding**: Feeding into the gut. Can be given through the mouth as ‘oral feeds’, or through a tube as ‘tube-feeds’.

**Expressed breastmilk (EBM)**: Breastmilk which has been expressed (pumped) either by hand or by pump, for babies who are unable to feed at the breast.

**Extubate**: To remove an endotracheal tube.

**Fine motor skills**: Precise use of the hands and fingers.

**Full-term baby**: A baby born from 37 completed weeks gestation.

**Gavage feeding**: Tube-feeding – feed delivered to the stomach via a tube passed through the nose / mouth to the stomach.

**Gestational age**: The number of weeks a baby is in the uterus (womb).

**General practitioner (GP)**: Family doctor.

**Gross motor skills**: Use of the large muscles of the body.

**Heel prick**: Procedure in which a tiny prick is made on the heel in order to get a sample of blood for laboratory analysis.

**Heel prick test**: Term used to refer to the ‘newborn bloodspot screening test’ that babies have at 5 days of age to screen for certain metabolic / genetic medical conditions. This test is also sometimes called a ‘Guthrie Test’ or PKU.

**Hypoxia**: Lack of sufficient oxygen in the blood.

**Incubator**: A specially designed cot with a perspex cover, used to provide warmth for preterm or sick babies.

**Intra uterine growth retardation (IUGR)**: Describes babies who are lighter in weight than would be expected for their age / gestation.

**Intubate**: To insert an endotracheal tube for ventilation.

**Meconium**: Material present in the gut of an unborn baby. It is usually excreted after birth, but may be excreted before the baby is born.

**Neonatology**: Branch of paediatric medicine which deals with newborn babies.

**NICU**: Neonatal intensive care unit.

**Parenteral nutrition (PN)**: Nutrition that is given directly into a vein. PN is used for babies who are unable to receive adequate nutrition from milk feeds.

**Plain film of abdomen (PFA)**: A PFA is an x-ray of the abdomen.

**Public health nurse (PHN)**: PHNs deal with general baby care. Your local PHN is usually accessed via your local health centre.

**Transient tachypnea of the newborn (TTN)**: This is a short period of rapid breathing after birth, usually after a caesarean section. It is only transient and the baby usually makes a quick recovery.

**SCBU**: Special care baby unit.

**Small for gestational age / small for dates (SGA)**: SGA describes a baby who is born smaller than expected for their gestation. For more terms related to prematurity, see page 6.

Useful contacts / sources of further information

**Organisations**
- **Health Service Executive** – www.hse.ie – provides a range of information relating to health.
- **Health Promotion** – www.healthpromotion.ie – provides a range of publications on various topics including hygiene, safety and accident prevention, immunisations, breastfeeding etc.
- **Bliss** is a UK based charity dedicated to improving both the survival and long-term quality of life for babies born too soon, too small or too sick to cope on their own – www.bliss.org.uk – produces a range of resources and publications for parents.
- **Irish Sudden Infant Death Association (ISIDA)** – www.isida.ie
- **Irish Nutrition and Dietetic Institute (INDI)** – www.indi.ie – provides a range of nutrition fact sheets and details of dietitians in private practice.
- **Irish Society of Chartered Physiotherapists (ISCP)** – www.iscp.ie
- **Developmental care website** – www.aboutkidshealth.ca
- **Premature Baby** – www.prematurebaby.ie
- **Your local hospital website**
- **Our Lady’s Children’s Hospital, Crumlin, Dublin 12** – www.olchc.ie
- **Children’s University Hospital, Temple Street, Dublin 1** – www.cuh.ie

Refer to the neonatal unit or your local health centre for further information.

Page 6: Follow-up
Weight conversion chart

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Acknowledgments

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