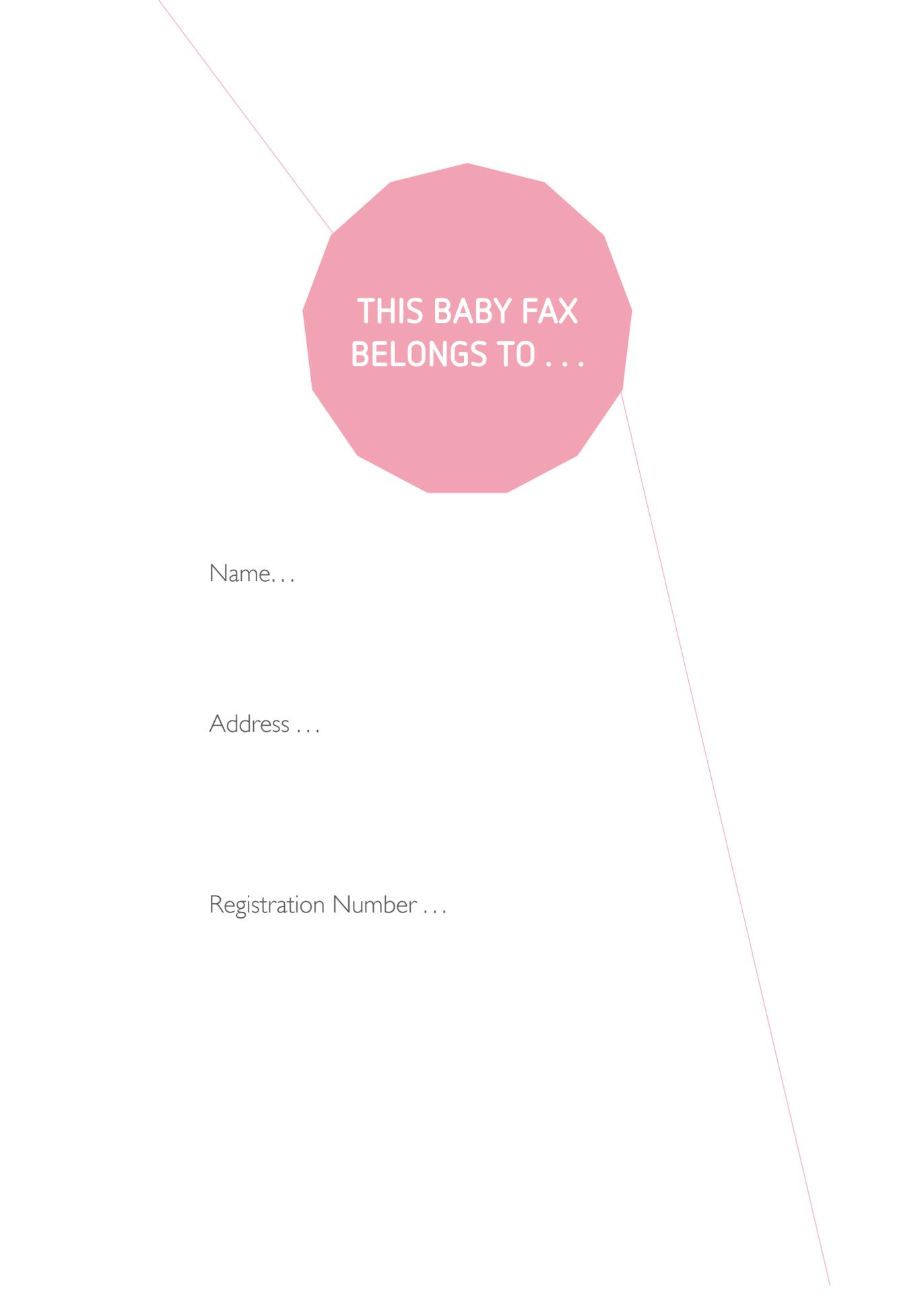


THE COOMBE WOMEN & INFANTS UNIVERSITY HOSPITAL



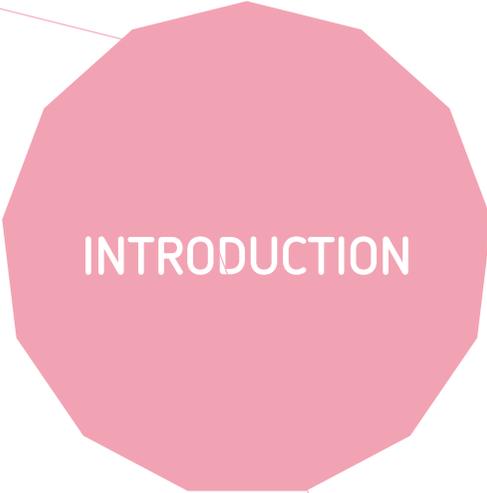


**THIS BABY FAX
BELONGS TO ...**

Name...

Address ...

Registration Number ...



INTRODUCTION

The arrival of a new baby is a very exciting time for a family, but having one or more babies born prematurely, or ill, can be quite overwhelming. It is not unusual for parents to find such a birth experience confusing and stressful. As a parent we know you want to be informed and involved in the care process of your baby.

It is our hope that this baby fax will help you understand your baby's progress and give you confidence to ask questions and get the information you need about how to care for your baby, how to look after your baby at home and where to turn for help.

Not everything described in this baby fax will apply to your baby, it is not intended to replace your regular discussions with nursing and medical staff. If you have any questions please feel free to ask the staff, who will be happy to help.



BABY INFORMATION

Name _____

Due Date _____

Actual Date of Birth _____

Weight _____

I cried for the first time on _____

Mum first held me on _____

Dad first held me on _____

I was breastfed / bottlefed for the first time on _____

I moved to an open cot on _____

I graduated to special care on _____

I went home on _____

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INFORMATION

Patent Ductus Arteriosus
Necrotising Enterocolitis (Nec)
Respiratory Distress Syndrome
Broncho-Pulmonary Dysplasia
Intraventricular Haemorrhage
Periventricular Leucomalacia (Pvl)
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A teal-colored octagonal graphic with a white border, containing the title text. A thin teal line extends from the right side of the octagon across the top of the page.

ABOUT THE NEONATAL CENTRE

The Neonatal Centre of the Coombe Women and Infants University Hospital is comprised of the Intensive Care and High Dependency Unit on the 2nd floor and the Special Care Baby Unit on the 3rd floor.

Babies require admission to the centre for a number of reasons. Whilst many are born prematurely, babies at or near term may also require admission. Every effort is made to minimise the separation of mother and baby and therefore, where possible, babies will be discharged to the post natal wards as soon as their condition allows.

Babies transferred to the Neonatal Intensive Care Unit (NICU) from other hospitals will be transferred back to the referring hospital once their condition is stable. All babies will be treated as an individual. Their privacy, dignity, religious and cultural needs will always be respected.

The length of a baby's stay varies from days to months and depends on each baby's needs. The largest single group of babies in the Neonatal Centre are there because they were born many weeks before their due date. There are many reasons why babies are born prematurely and usually there is nothing that mothers could have done to prevent it.



VISITING THE NEONATAL CENTRE

We welcome you being close to your baby whenever you wish and are happy for you to visit up to 9pm. For the safety and well being of the babies in the Neonatal Centre visiting is restricted to parents only. Unfortunately we do not allow children or other relatives to visit except in exceptional circumstances.

This is required in order to minimise the risk of infection to your baby. A named person may visit following discussion with the clinical manager, but details must be recorded in the baby's chart, and a parent must accompany the visitor at all times.

On arrival to the intensive care unit, please ring the bell once only. Staff may be busy. Occasionally you may be asked to wait for a few minutes, if for example there is an emergency or medical rounds are taking place. This waiting is necessary to protect confidentiality of all babies in the unit.

Only two visitors are allowed in the Neonatal Centre at any one time. Overcoats and jackets must be removed (and placed in lockers provided).

Please do not leave valuables unattended. Mobile phones must be switched off. Use of Spirigel entering and leaving the unit is essential. Hand washing is mandatory before and after visiting a baby on the Neonatal Centre. All visitors must wash their hands and wear aprons provided, before entering the Centre. Any special precaution or instruction as directed by the clinical nurse manager/ staff member must be observed.

Visitors to the Neonatal Centre must leave immediately when requested. Please do not photograph or video other babies or staff in the unit. During your visit you are requested to respect the privacy of the other babies by not straying over to their cots or incubator or asking staff questions about them.

Parents are requested not to visit at staff report times which take place at 07.30hrs – 08.30hrs and 19.30-20.30hrs.

If you cannot visit, you may wish to keep in touch by phone.

ICU Ph. (01) 408 52 76
HDU Ph. (01) 408 53 23
SCBU Ph. (01) 408 53 43

You will be able to speak to the nurse caring for your baby. In the interest of confidentiality information will only be given to the parents. Investigation results will not be discussed over the phone.

Please ask your relatives and friends not to telephone the Neonatal Centre. Please ensure that staff have up to date contact numbers for both parents.

Laundry

You are welcome to provide your own sheets, blankets and clothes for your baby's use. However, the hospital cannot be held responsible for items that are lost or mislaid.

If you choose to use your own supplies it is essential that you comply with the following to assist in our efforts to prevent infection.

Please take laundry home on a daily basis for washing.

If you are unable to take laundry home daily we would request that hospital supplies be used. If laundry is not taken home after 24 hours it will be sent to hospital laundry at your own risk.

Toys

You are welcome to provide one small toy for your baby. Toys must be washable. Please take home once a week and wash in 60°C wash. Please do not bring balloons or flowers to the neonatal centre.

Religious items

Relics, beads, novenas etc. must be given to the nurse looking after your baby who will place them in a sealed plastic bag prior to placing in incubator or cot. Holy water must be kept in a sealed container at all times. All items are left at your own risk.

Car Parking

The hospital recognises that parents of babies admitted to the neonatal centre may have to spend long periods of time in the hospital, during their baby's stay. To facilitate this, parents visiting a baby admitted to the neonatal centre are provided with "Free Parking" in the visitors car park subject to availability.

To receive this concession, please contact a member of the nursing staff who will stamp your car park ticket (Neonatal centre free parking).

This facility is available to parents only. On your exit from the hospital take the stamped ticket to the security office (located opposite the car park pay station) where a member of the security staff will provide you with a 'Replacement Ticket' allowing you to exit the car park free of charge. If you have comments regarding car parking at the hospital, please contact the General Services Manager on (01) 408 5292 or extension 5292 if phoning from inside the hospital.



THE NEONATAL TEAM

You are an important part of your baby's life in the NICU and a valuable member of your baby's healthcare team. You may feel intimidated by the technology and outnumbered by the NICU staff, but you have a bond with your baby that no other member of the team can match. You will learn how to care for your baby in a context of love that will continue long after the NICU stay is behind you.

You will entrust your baby to many people during his/her hospitalisation. Each person plays an important role in the health care of your baby. The following is the "who's who" of doctors, nurses, support staff and other members of the team you may encounter;

Consultant Neonatologist

A neonatologist is a Consultant who specialises in the diagnosis and treatment of sick newborns.

Non-consultant hospital doctors

The Team of neonatology registrars and senior house officers who provide 24 hour cover for the Department.

Advanced nurse practitioner- Neonatal

A nurse who has completed advanced education and training in the care and treatment of babies and their families. Wears navy uniform

Clinical Midwife / Nurse Specialist

Is a valuable resource in planning your baby's discharge and follow on care. The Clinical Midwife Specialist (CMS) wears a pink tunic.

Clinical Midwife / Nurse Manager

The Clinical Midwife / Nurse Manager is responsible for the running of the shift and co-coordinating your baby's care, liaising with all staff. There is a Clinical Midwife / Nurse Manager (CMM) on every shift and she is available to meet with parents on request. She wears a blue tunic.

The midwifery/ nursing team is led by the Clinical Midwife Manager 3 (CMM3). The CMM 3 is a senior manager with overall responsibility for the nursing team and is available Monday to Friday. She wears a purple uniform.

Staff Midwife/ Nurse

The Staff Midwife/ Nurse is a qualified midwife/ nurse, specialising in neonatal care who will provide direct care to your baby. You will meet many of the staff over the course of your baby's stay.

Health Care Assistant

The health care assistant is an integral part of the neonatal team, assisting nursing staff in the provision of care, and wears a lilac striped tunic.

Hygiene Services Operative

The hygiene services operatives are responsible for hygiene services within the department, and wear black tunics.

Medical Social Worker

The role of the medical social worker is to provide positive holistic intervention to parents at times of crisis as well as support to parents whose baby has been diagnosed with a long term illness.

The Medical Social Worker:

- Provides support and counselling, where necessary, to parents of babies in the Neonatal Centre.
- Provides practical information about entitlements to parents as well as assistance in navigating the welfare system with which they may not be familiar.
- Identifies and provides information about agencies both statutory and voluntary within the community that may be of support to children,
- Advocates on behalf of parents,
- Works as part of the interdisciplinary team in the Neonatal Unit and communicates relevant information to the interdisciplinary team about the parents psycho social situation in order to assist with an appropriate care and discharge plan for the baby.

Other Members of Staff

Other members of the team that you may meet include the clerical staff, radiographers and visiting consultants from other hospitals, chaplains and physiotherapist.



FINDING OUT HOW YOUR BABY IS DOING

The nurse caring for your baby will be able to update you on their progress when you visit or telephone the unit. Information will be given to parents only. You can also ask to talk to the medical staff for an update on your baby's condition when you visit. An appointment can also be made for you to meet the consultant caring for your baby.

The team conducts a ward round twice daily in the morning and again in the evening, after which you can be updated. Should you wish to speak with the team please let the nurse caring for your baby know and appropriate arrangements will be made.

Don't feel shy about voicing your concerns, tell the staff any worries you have about your baby, both for your peace of mind and to maintain good communication with the NICU team.



CARING FOR YOUR BABY

First impressions

If you are shocked when you first walk into the neonatal centre, you are not alone. It is very likely to be different from almost any other place you have been. The room is full of monitors, high tech equipment and the frequent sound of alarms. But all of the staff know that you are under stress and are there to help you as well as your baby. Many of the babies in the neonatal unit are extremely tiny and immature. The equipment that surrounds them is designed to keep them warm, to monitor many of their bodily functions and to support their breathing. Here your baby will be provided with the optimal environment for growth.

What to tell siblings

If you have other children they will want to know where the baby is or when he/ she is coming home. Tell them as simply as you can about "their baby". Be honest and try to answer your children's questions at their level. Remember that for younger children, a baby they cannot see is difficult to imagine. Showing them pictures or videos of the baby can help.



YOUR BABY'S APPEARANCE

Parents often remember little about their baby's appearance following their first visit to the NICU. What they do remember are the machines, tubes and wires. This is understandable as the technology may be intimidating. Try to focus on your baby, not the technology. Rest assured that with each subsequent visit you will notice more details about your baby.

Your tiny baby is fragile. Since the skin is not fully developed, you may be able to see the blood vessels beneath. This gives premature babies a reddish purple skin colour. Their skin may feel "sticky" and can bruise and tear easily.

Most very premature babies also have very soft hair called lanugo, which may cover most of the body. It disappears as the baby grows. Your tiny baby's head may look unusually large for the size of the body, and the arms and legs might look quite long. Very premature babies have very little fat covering their bones. However, as your baby grows and develops more fat, his/her head, arms, and legs should begin to look more 'normal' for their size. It is not unusual for a very premature baby's eyelids to be stuck shut at the time of birth. Don't worry about this, as they will open in time. The ears are also still developing and may well be very close to the head and have little of the material called cartilage that gives the ears their final shape. If the ears are folded or bent, they may stay in a folded position for a while. Don't worry. With time, the ears will develop cartilage which will make them spring back into place when touched. As they sleep, eat, and gain weight, their body shape and skin will begin to look more like that of older babies.

AGE (CORRECTED AND UNCORRECTED)

Uncorrected (or actual) age is the age of a baby from their birth date. For example, a baby born 12 weeks ago is 12 weeks old, even if they were born at 30 weeks gestation.

Corrected age is calculated according to the number of weeks a baby was born before term (40 weeks). So a baby born at 32 weeks' gestation was 8 weeks early. Ten weeks after birth (e.g. 42 weeks actual age), their corrected age would be 2 weeks.

The corrected age is sometimes used by people to compare premature babies to term babies, particularly in areas of development and weight gain. A baby who is 4 weeks old corrected may be compared to a 4 week old term baby.

Bear in mind, however, that your premature baby will not necessarily follow the same progress and development pattern as an 'average' term baby and that currently, there are no charts on weight gain or development used to reflect an 'average' premature baby's progress for comparison.

Term**A baby that spent at least 37 weeks in the womb**

Premature	Born before 37 weeks in the womb
Moderately Premature	Born between 35 and 37 weeks in the womb
Very Premature	Born between 29 to 34 weeks in the womb
Extremely Premature	Born between 24 and 28 weeks in the womb. Note: Babies born at less than 24 weeks will be extremely low birth weight and are less well developed. However a small, but significant, percentage of babies born even this early will survive
Low Birth Weight	Born weighing less than 2,500g (5lbs)
Very Low Birth Weight	Born weighing less than 1,500g (3lbs)
Extremely Low Birth Weight	Born weighing less than 1,000g (2lbs)



INFECTION

Neonates are immunologically immature and as a result they are at increased risk of infection. The more immature the infant the greater the risk. Neonatal infection can be acquired in utero, through the placenta, through the birth canal during delivery (intrapartum) or postnatally from contact with an infected mother or from contact with health care practitioners and the hospital environment. Premature and sick infants are also more likely to require invasive procedures (eg, endotracheal intubation to help your baby breathe with a ventilator, prolonged IV access until your baby is on feeds), this further predispose them to infection. Hand washing is by far the most effective way to minimise the risk of infection to your baby, to minimize this risk staff and parents are expected to wash their hands on entering the Department of Paediatrics and Newborn Medicine and again before and after contact with your baby or any item in your baby's environment. Spirigel may also be used on clean hands but must be allowed to dry.

To further minimise the risks of infection we restrict visiting to parents, grandparents and siblings once a week. We also advise parents of the importance of personal hygiene prior to Kangaroo care (daily shower and change of clothes) paying particular attention to the areas where skin to skin contact will occur namely the hands and the chest.

Where staff do suspect an infection because your baby is less active and sleeping a lot, or there are changes in physiological parameters, for example, temperature, heart rate or oxygenation levels, your baby will have a number of tests which might include blood tests and x-rays and may start on antibiotics.



KANGAROO CARE.

Neonatal Units may be technological marvels but when it comes to tender loving care nothing beats the real thing.

It is well established that Kangaroo Care is one of the most important, nurturing gifts you can give your baby, from both Mum and Dad. Kangaroo Care is the process of initiating skin-skin contact between you and your baby. Fathers, with a blanket draped over your baby's back, place him upon the bare chest; mothers between your breasts. This has several benefits, including establishing an everlasting bond between child and parent through touch and smell. The process can help regulate your baby's heart and breathing rates and help them gain weight. It can also help calm him, serve as a catalyst for deeper sleep, and regulate baby's temperature.

For some new parents, the thought of handling such a small baby may seem frighteningly impossible. Will I be too rough with him? You won't. Starting with gentle contact through the Kangaroo Care method will allow parents to become increasingly comfortable with handling their newborn before it's time to leave the hospital and the real journey begins.

The staff looking after your baby will discuss with you when the time is right for you and your baby to begin Kangaroo care.

EXPRESSING BREAST MILK FOR YOUR BABY

All babies benefit from breast milk. The nutrients in breast milk are in the perfect proportions for your baby.

It is important to commence expressing as early as possible in order to establish your breast milk supply. Staff in the unit and on the postnatal ward will discuss this with you as soon as possible. You will receive information leaflets and advice on expressing for your baby. There is also a weekly class that you will be encouraged to attend as it offers encouragement and support for mothers expressing milk for their babies. The clinical midwife specialist is available on a daily basis to assist with any problems. A pumping record is included in this booklet. This can be a helpful tool in establishing your supply, and identifying any issues which can be discussed with staff.

Before you begin expressing for the first time it is important that you discuss the following with the staff caring for you and your baby:

Hand Hygiene

Cleaning and caring for your expressing kit and pump

Expressing technique: frequency, duration, transport, storage of your milk.

Building and maintaining supply

There are 2 breastfeeding rooms in the unit, one in the special care area and another in the high dependency area. Pumps are available for use in the unit. Individual pumping kits will be provided.

However for home use, pumps can be rented from:

Lactina Breast Pump (Blue) rental €75 per month

Symphony Breast Pump (yellow) rental €95 per month

Ameda (Elite) Breast Pump (Turquoise) rental €95 per month

Symphony and Lactina Breast pumps may be hired from

Medicare, Glencormack Business Park, Kilmacanogue.

Tel: 012014900 (Next working day delivery of pumps to mothers nationwide from Medicare)

Mon – Fri: 9am – 5.30pm Sat: 9am – 4.30pm

Price's Medical Hall, 26 Clare Street, Dublin 2.

Tel: 01 6761899

Mon – Fri: 8am – 7pm Sat: 9am – 6pm

Ameda (Elite) Breast Pumps may be hired from Moore's Pharmacy, Cork Street, Dublin 8.

Tel: 01 4542981

Mon – Fri: 9am – 7pm Sat: 9am – 6pm

Credit Card required

THIS IS A BREAST PUMP



PUMPING LOG

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PUMPING LOG

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PUMPING LOG

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Total _____



THE NICU ENVIRONMENT

All of the equipment can be distracting and eye catching. The displays are designed to be easily seen and grab attention. Try not to be overwhelmed when you see your baby surrounded by equipment. Keep focused on him/her as much as possible. Remember the staff constantly check the monitors so you can spend time watching your baby.

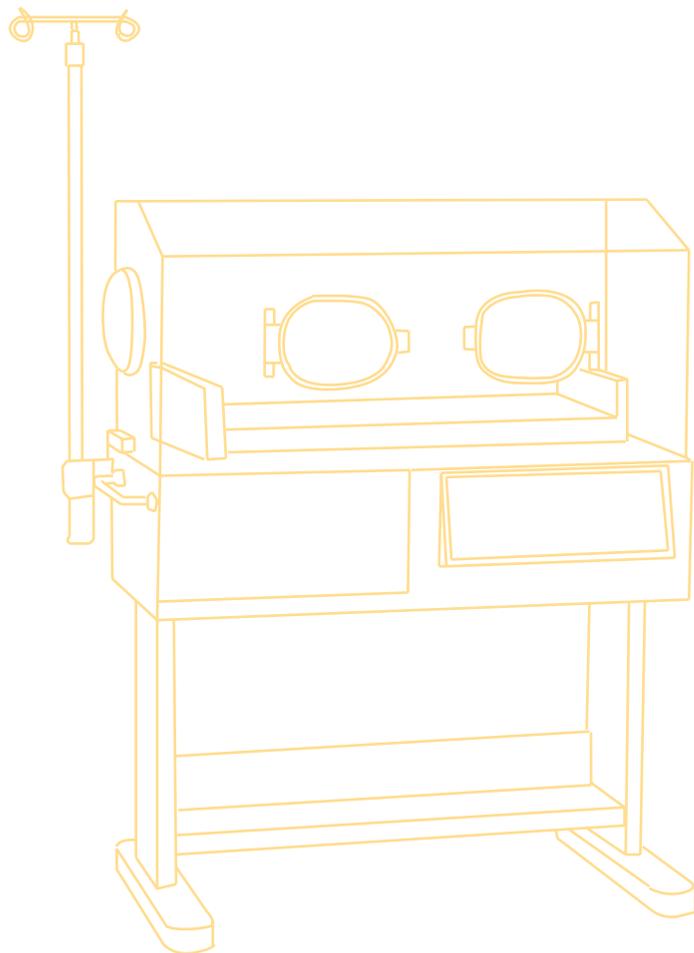
Incubators

A basic need for your baby is to keep warm. Placing a premature or vulnerable baby inside an incubator will help do this. Some incubators are closed units with hand-sized holes in the side and mechanisms to circulate air inside. Being in a closed unit not only keeps the heat in, but also helps to control the humidity around the baby. This prevents the baby from losing too much moisture by evaporation from his or her fine skin.

Other incubators have open tops and often have an overhead heater. These can give staff greater access to the baby.

The temperature inside the incubator can be regulated in two ways. It can be set manually with the controls or set to automatically respond to information about the baby's temperature that is picked up by a small sensor on his or her skin. If the sensor falls off, or does not pick up the baby's temperature, this will trigger an alarm so that a nurse can make sure the incubator does not become too warm.

THIS IS AN INCUBATOR



Vital signs monitors

Small pads may be placed on the baby's chest with leads running to a monitor. These pick up the electrical signals given out by the baby's heart and constantly check that it is beating properly. The pads can also detect changes during breathing, and pauses in breathing may trigger an alarm.

Blood oxygen monitors

This probe is normally strapped gently to the baby's foot or hand. This shines light through the skin and monitors the amount of oxygen in your baby's blood.

Ventilation

Some sick or premature babies may need help with their breathing. In order to facilitate this a thin plastic tube will be gently placed via the nose or mouth into the baby's trachea or wind pipe. This tube is then connected to a ventilator, which will deliver a controlled mixture of air, oxygen, and pressure with each breath, and a certain number of breaths per minute.

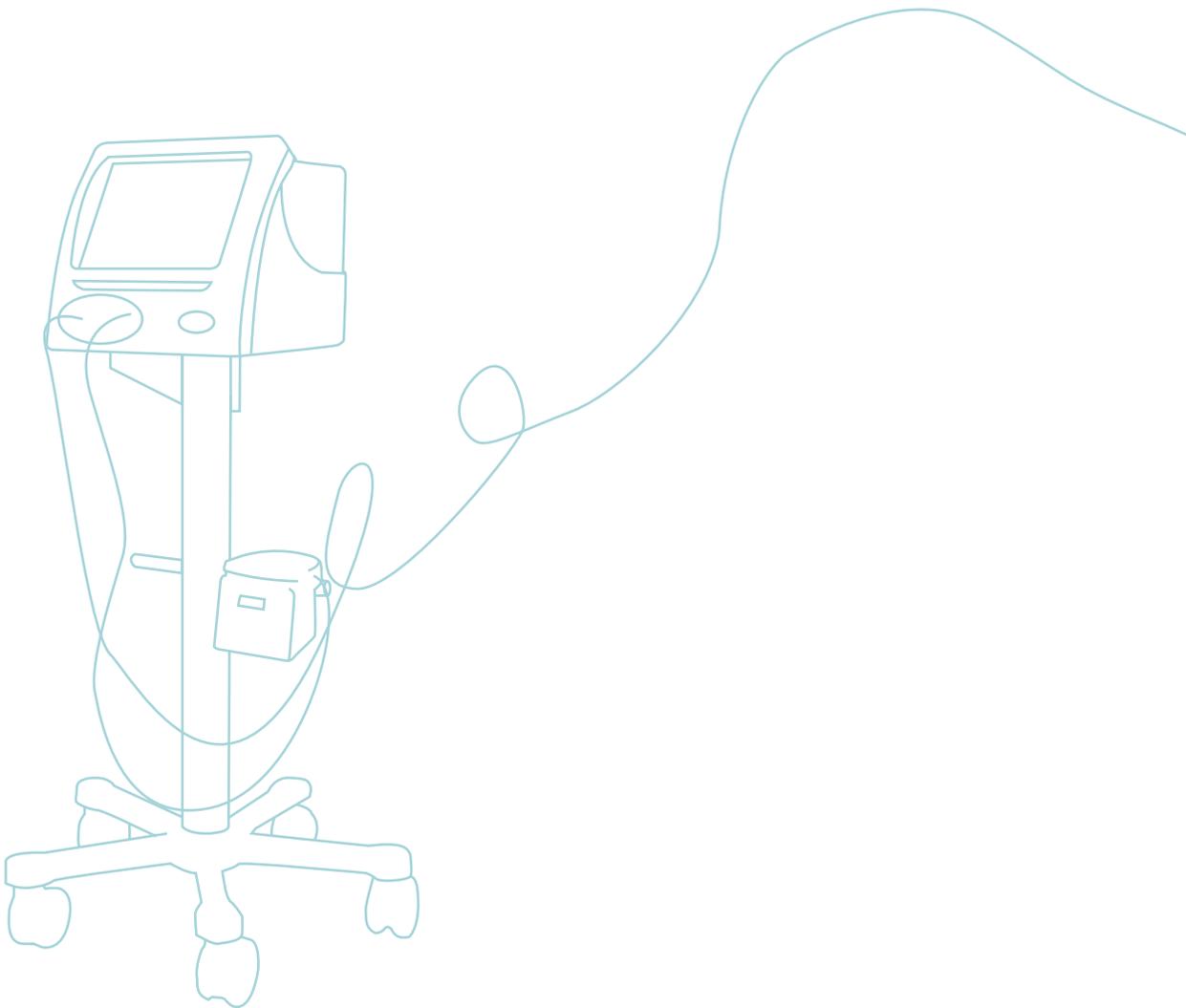
As your baby weans, or needs less assistance from the ventilator, the NICU staff will reduce the amount of pressure supplied with each breath and the number of breaths per minute. The weaning process can be slow, like many elements of care in the NICU. In some cases where lung disease is worse, your baby may be placed on a high frequency oscillator which can send a high number of very gentle breaths per minute into the lungs.

The first time a baby is taken off a ventilator, he or she may breathe well for a bit and then become tired. If this occurs doctors will replace the ventilator and try again later. Gradually the periods off the ventilator should increase. If your baby develops an infection he or she may have difficulty breathing and might need to go back on the ventilator until the infection is cleared.

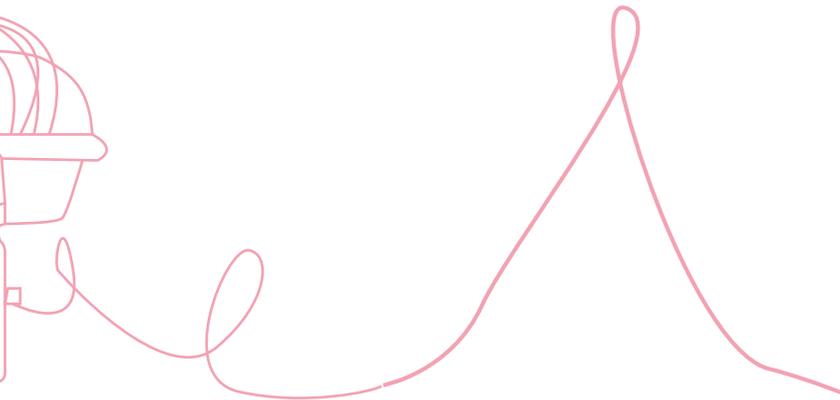
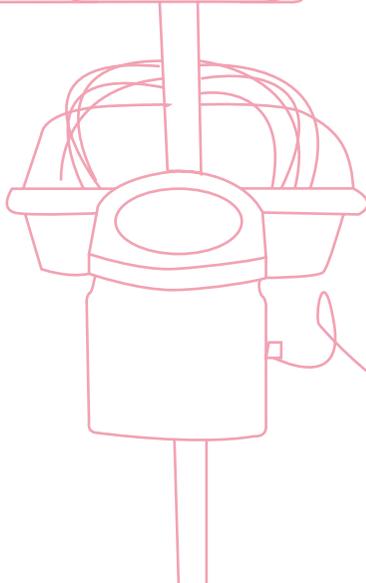
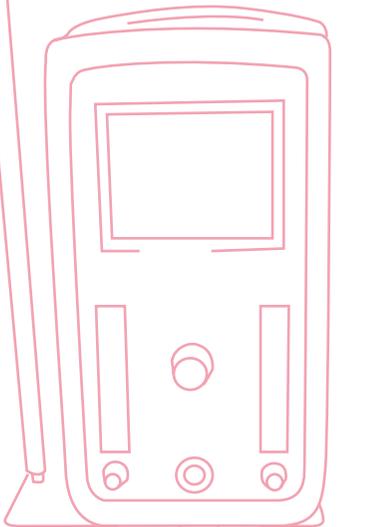
Continuous Positive Airway Pressure (CPAP).

Some babies need a little help with their breathing, but do not need a ventilator. They can be helped with Continuous Positive Airway Pressure (CPAP). This is when air flows through two fine tubes placed in the baby's nose. This slightly raises the pressure and helps to keep the baby's lungs inflated.

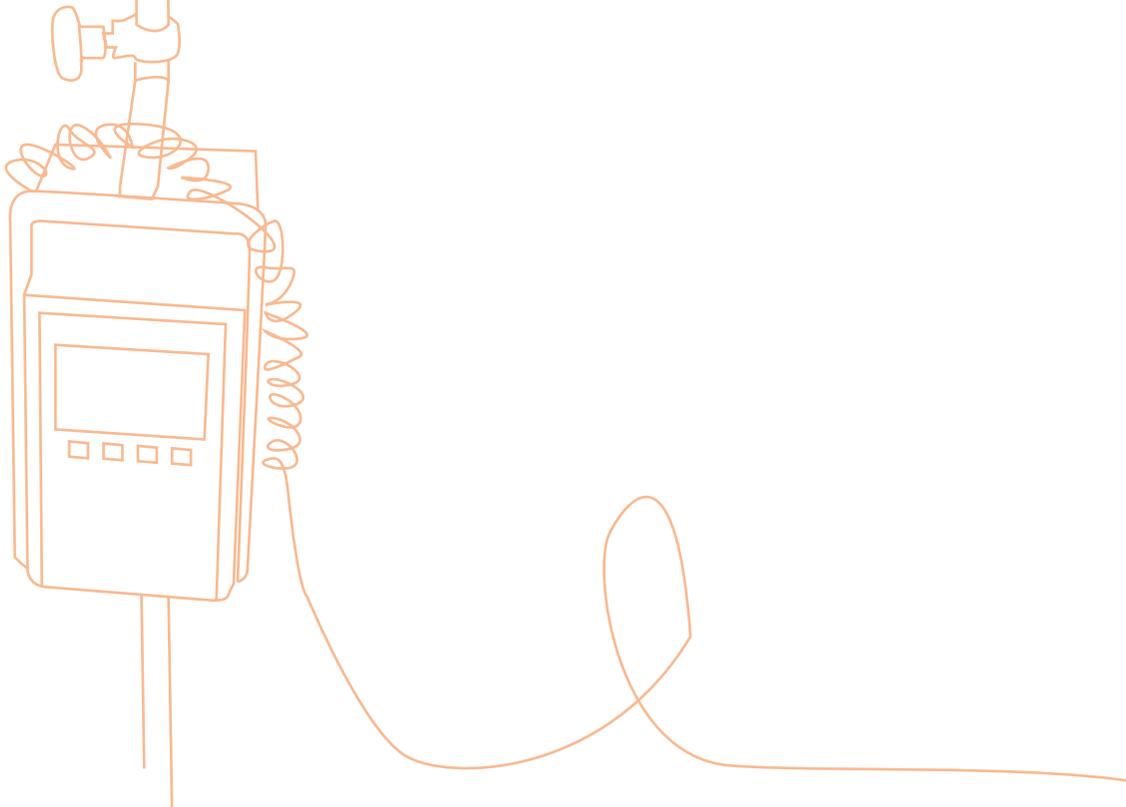
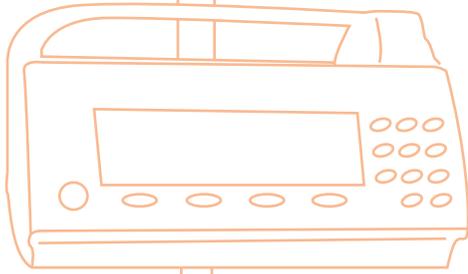
THIS IS A VENTILATOR

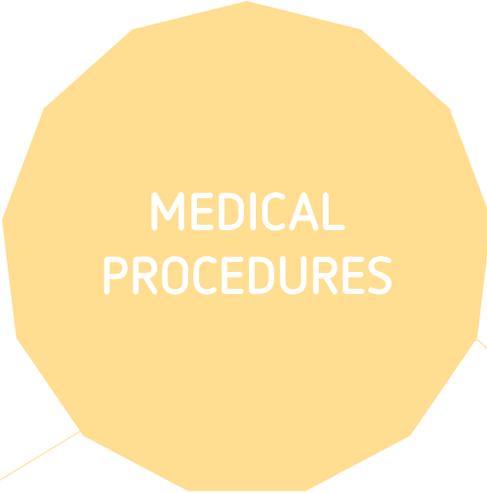


THIS IS A CPAP MACHINE



THIS IS AN
INFUSION PUMP





MEDICAL PROCEDURES

Almost all babies on the unit will need some tests and procedures. The hospital staff are required to ensure that you understand why these procedures are needed throughout your baby's stay and, wherever possible, you should be aware of what is happening to your baby and be involved in decision making. Many of these tests and procedures can cause short-term mild discomfort but not long-term risk. Staff will discuss this with you and give you the relevant information.

Consent or permission

Medical staff have a responsibility to you as a parent to ensure you are clear about what tests and treatment may be given to your baby. As many procedures are considered 'low risk' (that is they do not carry a risk of harm to your baby, but not doing them might harm your baby, such as routine blood test), you will not be formally asked for consent. Also, it may not be possible to obtain informed consent for everything that is done, as any emergency procedures will have to be dealt with immediately. You should feel free, however, to ask about any test or procedure that may or may not be carried out with or without your consent. If your baby requires transfer to another hospital for a procedure or treatment, this will be discussed with you and written consent will be sought.

Pain Relief

Preterm and critically ill infants admitted to neonatal intensive care undergo repeated skin-breaking procedures that are necessary for their survival. There is a vast body of research available, and International guidelines, which we use in our efforts to alleviate your baby's pain and discomfort.

Oral Sucrose is recommended extensively for minor procedural pain relief in preterm and term infants. Sucrose works best when given in conjunction with sucking in which case we give your baby a soother (if available) or his thumb to suck. Supporting him in a comfortable position is also helpful. If necessary your baby may have repeated doses of sucrose, within safety recommendations. If your baby is unable to have sucrose, we support him in a comfortable position and offer him a soother.

Intravenous (IV) lines (Drips)

Most babies on a neonatal unit have fine tubes (called drips or cannulae) inserted into a tiny blood vessel, usually in a hand, foot, arm or leg. These are usually either to provide fluid or as a route for giving important medication, such as antibiotics. Very occasionally, these can break the delicate blood vessels, or become blocked. If so, fluids can leak into the surrounding tissues causing swelling. On rare occasions this may damage the skin leaving a scar.

PICC Lines

A very fine 'line' is passed into one of the baby's large veins. Staff will always watch these carefully and remove them if there are concerns. A long line can also be used for injecting medication, such as antibiotics. These lines may be left in site for several days/ weeks

Arterial Lines

Doctors / ANP may place a larger tube into an artery to allow them to take blood samples. The artery they choose may be in the arm, leg or umbilical cord.

Umbilical catheters

Fine tubes can be inserted into blood vessels in the tummy button. They are mostly used in the first days after birth. The one in the artery is mostly used for measuring blood pressure and blood sampling. The one in the vein is used to administer fluids and medication.

Blood tests and transfusions

Blood is much more than a red fluid that carries oxygen around the body. It is packed with living cells and looking at these cells can give clues about a baby's overall health. Blood also acts as the body's transport system, moving nutrients, waste products and chemical messages around. Blood samples can give useful information about what is going on inside a baby.

Most samples are taken by pricking the skin to get blood from the back of the hand or the heel. These pricks leave tiny scars but do not affect the growth of the hand or the foot.

Sugar levels - Blood needs to contain enough sugar to distribute energy to all the body's organs. Doctors want to know that the baby is managing to control the amount of sugar in his or her blood, and may give the baby supplements through one of the intravenous tubes. Babies born to diabetic mothers, or babies that had a very low birthweight, may have problems maintaining blood sugars levels and need extra monitoring.

Gases – As well as carrying oxygen from lungs to organs, blood transports carbon dioxide from organs to lungs. Measuring the amount of these gases along with levels of acid can give clues about how well the baby is breathing, as well as indicating whether organs like the kidneys are meeting your baby's needs.

Platelets – these fragments in blood play a part in preventing excessive bleeding. They are often reduced in number in premature babies. If levels are very low, doctors may transfuse some platelets.

Haemoglobin- this is the chemical that blood uses to transport oxygen. If babies have too few red blood cells and are anaemic, the amount of oxygen carried to the body organs may be below what the baby actually needs. If your baby is anaemic, he or she may need one or more blood transfusions.

White blood cells – these cells play a big role in fighting infections. If levels in your baby's blood are very low, doctors can give drugs to help your baby produce more and therefore be in a better position to fight off infections.

Eye tests

Premature babies are at increased risk of having problems with their eyes. If your baby weighed less than 1,500g at birth or was born at less than 31 weeks, an eye specialist (an ophthalmologist) will check for a condition called retinopathy of prematurity (ROP). This can be a serious condition and occasionally needs to be treated. Premature babies are also at higher risk of other eye problems, in particular squints and long or short sightedness, occasionally needing glasses.

Head Ultrasound scan

This looks at the structure of a newborn baby's brain and can show whether there is any bleeding or other problems. Doctors will always discuss results of any scans they do.

Immunisation

It is standard practice to start routine immunisation eight weeks after birth, even if your baby is still in hospital. You will have an opportunity to talk about this with staff and they will ask for consent to do this.

Lumbar puncture

If there is evidence of a severe infection, doctors may want to investigate and take a sample of fluid that surrounds the spinal cord. This fluid flows down from the brain, so analysing it should show if the infection is present in this vital part of the nervous system.

A small needle is used, and a doctor will insert this between two bones low in the baby's back. While many important nerves run through the spine, they will not be damaged because these nerves are all higher than the level where this needle is placed.

MRI scan

MRI scans can give very useful pictures of the baby's organs without harming him or her. If your baby has an MRI scan, he or she will be placed in a special incubator that keeps him or her safe and warm while they are transported to one of the paediatric hospitals. The baby may need to be in a stable condition for this investigation to occur.

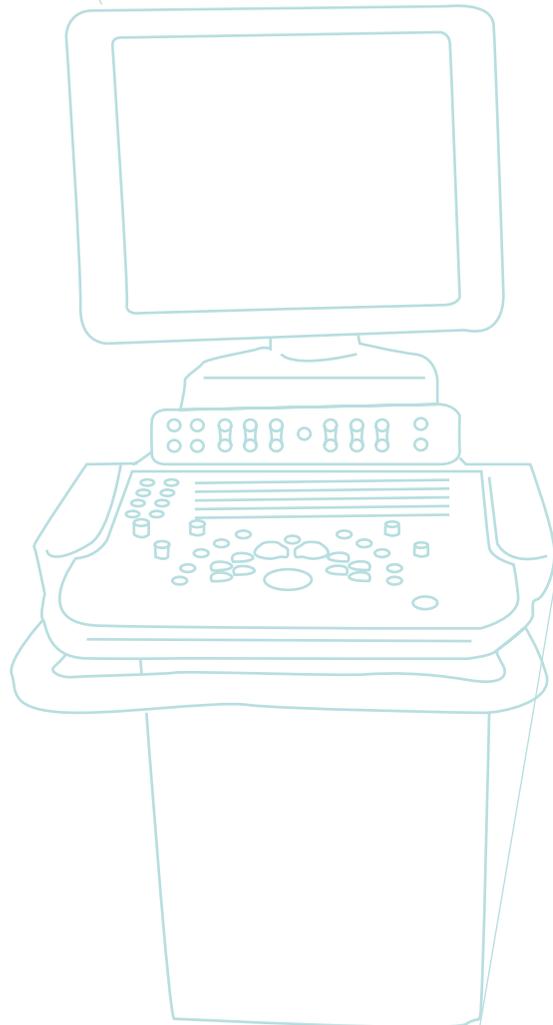
Phototherapy for jaundice

Blood cells only live in the body for a few days or weeks. They are constantly broken down and new ones are formed. When these cells are broken down, a chemical called bilirubin is released into the blood stream. Sometimes levels of bilirubin build up in the blood of newborn babies because their liver cannot remove it fast enough. This is often the case for premature babies and those with liver problems.

If bilirubin builds up to very high levels in the blood for the baby's level of maturity, it carries the risk of causing brain damage. Bilirubin is broken down by blue light, so premature babies are often placed under a blue light or laid on top of a biliblanket that gives out similar light. This is called phototherapy.

If bilirubin levels get too high, doctors may perform an exchange transfusion, replacing the baby's blood with fresh bilirubin-free blood.

THIS IS AN
ULTRA SOUND
MACHINE





NUTRITION

When, what and how your baby will be fed are very important questions for you. Initially most preterm or ill babies are not strong enough to breast feed or suck milk from a bottle and will need special methods of feeding. One such method is to pass a soft narrow tube through either the mouth or nose directly into the stomach to allow feeds to be given. Small amounts of milk are initially given and the volume is increased gradually according to tolerance.

Starting breast or bottle feeds

Babies born before 32 weeks gestation do not have the ability to safely suck, swallow and breathe. While your baby may appear alert and anxious to suck, he/she cannot safely swallow the feed and so tube feeding is necessary. The use of a soother is recommended at this stage.

Breast or bottle feeds may be introduced when the baby reaches 32-33 weeks gestation, and demonstrates that he/she can safely suck, swallow and breathe. The number of oral feeds given each day is gradually increased according to the baby's ability to suck. Some babies may tire easily after the effort of oral feeding. The nurse looking after your baby will recognise if your baby is getting tired and will adjust the frequency of oral feeds accordingly.

As soon as your baby is well enough you will be able to feed him/her yourself. Whilst we encourage all mothers to breastfeed or express breast milk we recognise that this is not always possible. Even under the best of circumstances not all mothers and babies succeed at breastfeeding. It's normal to feel upset if this happens. Even if you expressed for only a few days your baby will experience some long lasting health benefits. Give yourself credit for your hard work.

Don't let anyone make you feel guilty that you didn't try long enough or hard enough. Recognise that you made the best decision for you and your baby under difficult circumstances.

Formula milks specially designed for preterm babies are used in the unit if you do not wish, or are unable to, breastfeed.

Total Parental Nutrition (TPN)

TPN is a mixture of protein, fat and vitamins which is specially made to meet your baby's nutritional needs, and will help him/her grow when your baby cannot take full milk feeds. TPN is given through an intravenous line.



RATE OF WEIGHT GAIN

Weighing your baby is important for monitoring his or her growth. Your infant's weight will be measured in grammes; because a gramme is a smaller unit than an ounce, it gives a more precise measurement than pounds and ounces and it makes it easier to recognise small changes in your infant's weight. Your baby's birth weight reflects the amount of growth and development that occurred whilst the baby was in the womb. The relationship between your baby's birth weight and gestational age indicates how well he or she grew before birth and whether he or she is small, appropriate or large for gestational age. Babies in the NICU are weighed daily or every other day, depending on their condition. After birth, all infants lose weight. This is a normal process. Term infants may lose up to 10% of their birthweight, pre-term babies may lose up to 15% of their birth weight.

Term infants usually only lose weight for the first few days of life. Smaller or sicker babies tend to lose the most weight. At first your baby may not gain weight regularly. Their weight may increase some days, stay the same on others and occasionally go down.

Even when your baby does begin to gain weight regularly there will be occasional days of no gain or even a slight loss. This is normal. Remember each baby is unique and will establish their own weight gain pattern.



GRADUATING FROM INTENSIVE CARE

In the NICU you may have been mostly an observer, watching staff care for your baby. Once your baby graduates to HDU/SCBU there is a greater focus on parent involvement. Learning to care for your baby becomes the focal point of your visits. Because growing babies need lots of undisturbed sleep, feeding time is usually the best time for interaction. You will need to know your baby's schedule to participate in care. Ask the nurse caring for your baby about feeding and bath times. Nurses will gladly save a feed or bath for parents or rearrange the feeding schedule to fit your visiting times. The nursing staff may suggest you begin to visit more frequently now. Unless complications occur, your baby's condition will change much less than in the NICU. Now the staff will focus on your baby's progress and your plans for actively participating in care.

If you were transferred to our hospital during your pregnancy or the baby was transferred here after delivery, the baby will be transferred back to your referring hospital once his or her condition has stabilised. Staff looking after your baby will keep you informed and updated regarding the arrangements.



GOING HOME



BRINGING YOUR BABY HOME

Joy, fear, anxiety, anticipation, apprehension, relief, if you are feeling any or all of these you must be getting ready for home. Having a variety of emotions as you prepare to take your baby home is normal. For the past number of days, weeks or even months highly trained doctors, nurses and other health professionals have been monitoring your baby's every breath. Soon, all of your baby's care will be up to you.

Remember all parents are nervous taking their baby home. It is also important to remember the staff will not let your baby home unless you and your baby are ready. But remember also that there is no better place for your baby than home with you.

There are 3 main criteria your baby must meet prior to discharge:

Be able to maintain normal temperature in a cot

Be gaining weight appropriately on all breast or bottle feeds

Be feeding on all breast/ bottle feeds



BEFORE MY BABY IS DISCHARGED

As the day of discharge gets closer there are some things you can do to prepare yourself, your home and your family for baby's arrival.

Get to know your baby and feel comfortable caring for him/her. Become involved in your baby's care in the hospital, learn ways to comfort and settle your baby.

One of the most important aspects of taking your baby home is that you can feed your baby. You may have spent the past weeks or months pumping breast milk for your baby rather than actually breastfeeding. Or your baby may have been taking formula through a tube.

You may have noticed how each drop of breast milk or formula is measured. The whole idea of having to provide all the nourishment for your baby may suddenly seem like a huge responsibility. Rest assured all parents worry whether their baby is getting enough to eat and whether or not their baby is growing properly. For parents of premature or ill infants this worry can be overwhelming.

Remember your baby will not be discharged until he/she is feeding regularly and growing steadily. Also keep in mind that you are very capable of feeding your baby and taking care of all of his/her needs. You and your baby will work together as a team. You will soon get to know your baby's feeding habits. Often your baby's appetite will go up and down during the day, some babies are hungrier in the morning and others are hungrier at night.

Your baby should have a certain volume of feed over a 24 hour period. The staff will tell you how much your baby should have. Before your baby leaves the hospital decide how you will feed him/her at home. Use the combination of breast milk, formula, bottle-feeding and breastfeeding that works best for you and your baby.

Breastfeeding

Fully breastfeeding a baby in the NICU can be challenging. Before your baby goes home we recommend you spend a day or two with your baby around the clock to help ensure that you can breastfeed successfully at home.

Bottle Feeding

Feed your baby as often as possible using the same type of bottle you will use at home. Discuss this with the nurses caring for your baby. They will be able to advise you on the bottle best suited to your baby's needs. We recommend that you bring in the bottle and begin using it prior to discharge. The staff will tell you the type and amount of formula to feed your baby. Some babies leave the hospital on regular formulas others need a special formula that has more calories or specific nutrients. Before your baby comes home you will want to make sure that you have enough formula for about 2 weeks.

You might also want to invest in an inexpensive bottle warmer; they heat the bottle to just the right temperature. Do not put the bottle in the microwave as the heating can be uneven. Make sure that you prepare the formula exactly as recommended. Give a new bottle of fresh formula at each feed.

Learn to bath your baby. Don't be shy about asking to bath your baby. It is important that you feel confident before going home. The more you do it the easier it becomes.

Be familiar with any other treatment that your baby may need. Attend classes that are provided in the Unit. Feel free to attend more than once. Resuscitation demonstration is held generally once a week in a group session. Arrangements can be made at other times to facilitate parents.

Parent Education and Pre Discharge classes are held in conjunction with the resuscitation class. Several topics of baby care and follow up are discussed at this class. It is a good idea to bring a notebook. Prior to the class you may have questions you would like answered and it is a good idea to jot these down.

Topics covered include:

Safe Sleeping for your baby

Making up bottles, feeding, sterilising of equipment

Protecting your baby against RSV

Vaccination schedule

Follow up for your baby

Post Discharge Parents Support Group

There is also a weekly breastfeeding support class for mums who are expressing milk for their babies. All aspects of breastfeeding are discussed at this class.

You may want to stay overnight with your baby in the days prior to going home. This can be discussed with the nursing staff to choose the most appropriate time.

List of Requirements for baby at home:

Car seat

Pram or buggy

Moses basket / crib

Baby bath or small basin

Blankets

Sheets

Towels

Clothes, vests, babygro, cardigans, hat, socks

Sterilising unit

Bottles

Teats

Nappies

Changing mat

Post Discharge Follow up

You may have several appointments for your baby after going home. Follow up is individualised to each baby and these will be discussed with you before going home. If you are unsure, please ask.

IF YOUR BABY NEEDS MEDICATION

Many babies go home on some medications. You will learn to give your baby the medications before you leave the hospital.

Write down all the instructions and make sure you know:

How often to give the medication

If it should be given before, during or after feeds

How much to give

How to give it

If the medication needs to be refrigerated or mixed

What to do if the baby vomits or spits up the medication

What to do if you miss a dose

If there are any side effects you should watch for

When to stop giving the medication

Whether the dose needs to increase as the baby grows

If your baby needs more than one medication, whether they can be given together, or if you need to wait between doses.

The staff caring for your baby will demonstrate how to give any medications and the pharmacist will prepare a medication schedule for you. To avoid confusion, ensure that you are absolutely comfortable about doses and how to give the medications. Mistakes can be made so practice, practice, practice.



CAR SEAT SAFETY

If your baby was born prematurely or is small, the following information will help you transport your child safely. If your baby weighs less than 7 pounds it is advisable to use a head support cushion with the standard baby car seat. When buying a baby seat check weight, capacity and whether it has an integral harness and quick release button.

Always:

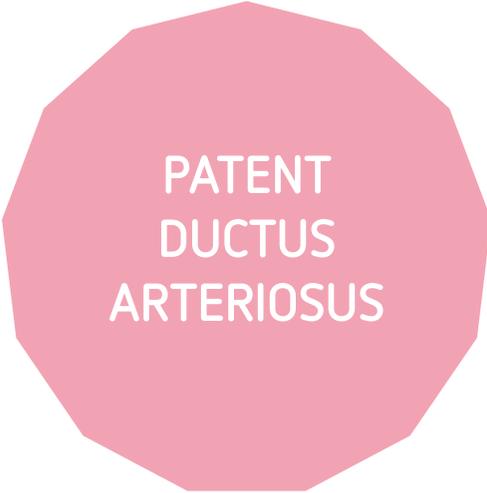
- Use the car seat on every trip, however short.
- Make sure the seat is fitted according to the manufacturer's instructions.
- Make sure the straps are holding your baby securely. You should be able to get only two fingers between the strap and your baby.
- Make sure all passengers and heavy packages are strapped in. In a crash another passenger or heavy package could be thrown on top of your baby and cause serious injuries.
- Protect your baby from direct sunlight by using a child sunscreen or roller blind
- Use the rear seats for your baby seat if your car is fitted with front air bags. Inflated air bags are dangerous for babies.
- As your baby gets older change the seat to suit the baby's size and weight.

Never:

- Buy a second hand car seat - it could have been in an accident.
- Put a belt around yourself and the baby - your weight would crush the baby.
- Carry your baby on your knee either in the front or rear seat - it is dangerous and illegal.
- Leave your baby alone in the car -even for a short time.



INFORMATION



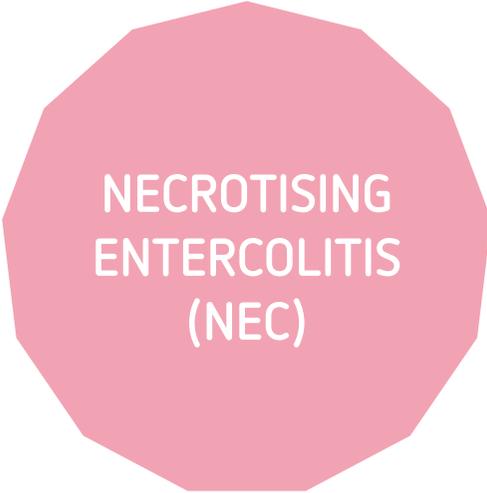
PATENT DUCTUS ARTERIOSUS

When your baby was in the womb, the blood circulating through their heart and lungs followed a path known as fetal circulation. This path allows blood to bypass the baby's lungs. Soon after birth the structures of the heart that allow the blood to bypass the lungs normally begin to close. But in some newborns, especially those born preterm, a structure called the ductus arteriosus remains open after birth or reopens in the weeks following birth. This is referred to as a Patent, (meaning open) Ductus Arteriosus.

The signs of a PDA depend on the size of the ductus and the amount of blood moving through it. A small ductus may cause few if any problems and require no treatment. Signs of a large ductus include a murmur, enlarged heart and worsening respiratory problems.

If untreated a large ductus will place a strain on your baby's heart because it must work harder to circulate blood. Extra blood flow to the lungs may cause fluid to leak into the lung tissue and this is called pulmonary oedema. This may increase your baby's work of breathing, making it more difficult to wean off the ventilator. Your baby may also have difficulty gaining weight.

Treatment of a PDA usually depends on its size and the degree of difficulty it is causing your baby. Medical treatment includes reducing the amount of fluid given to your baby and the use of medication to close the ductus. If medical treatment is unsuccessful in closing the ductus, or can't be used because of other medical problems, surgical closure will be needed. Surgery for a PDA is done under general anaesthetic in one of the paediatric hospitals. The surgeon will make an incision on the left side of your baby's chest wall under the arm, and then places a suture or clip around the ductus and ties it off. Your baby may require a chest tube or drain for one to two days after surgery to drain air from the chest cavity until it begins to heal.



NECROTISING ENTERCOLITIS (NEC)

Necrotising Enterocolitis is a problem affecting the bowel that occurs when the blood supply to the baby's bowel is decreased or interrupted. Hypoxia (lack of oxygen to the tissues) causes damage or death to cells of the bowel wall. Bacteria that are normally present in the bowel may invade the wall of the bowel causing further damage. Bowel damage may be minimal or extensive depending on the severity of the disease. In severe cases the wall of the bowel may perforate leading to peritonitis (infection of the abdominal cavity).

Necrotising Enterocolitis is a disease that most often affects premature infants, however some term or close to term infants may also get NEC. The reason babies develop NEC is not completely understood.

Infants with NEC may show a variety of signs, some of them quite subtle. Early signs may present as feeding problems, abdominal distension or swelling, an increase in the amount of milk left in the stomach when the time comes for the next feed, presence of bile (green coloured liquid) in the stomach or vomit, and blood in the stools. More general signs include lethargy, apnoea, bradycardia and temperature instability.

Treatment for NEC depends on the severity of your baby signs and symptoms. Feeds will be discontinued, and a tube will be passed through your baby's nose or mouth into the stomach to drain any mucus or swallowed air and allow the bowel to rest. Your baby will receive intravenous fluids and antibiotics in case of infection.

Your baby may require supplemental oxygen or ventilation and additional fluids and medication to maintain blood pressure. Rupture of the bowel wall is a serious complication of NEC. It often requires emergency surgical treatment.



RESPIRATORY DISTRESS SYNDROME

Respiratory distress syndrome is the most common disease of the lungs that affects premature babies. You may hear RDS also described as Hyaline Membrane Disease. The earlier a baby is born the more likely they are to have RDS, and the more severe the disease is likely to be. Physical immaturities of the lungs, coupled with a decreased amount of a substance known as surfactant are the causes of RDS.

The lungs mature at different rates from one baby to another. Some factors that may increase the likelihood of a baby developing RDS are maternal diabetes, being the second born of a set of twins and being male. The use of maternal steroids 48 hours or more before delivery can aid in the production of surfactant and help reduce the severity of RDS.

Premature babies may show signs of RDS moments after delivery or they may develop breathing problems in the first few hours of life. Initially your baby's breathing may be rapid or laboured. You may also notice retractions or pulling in of the skin and muscles between the ribs or just below the rib cage. You may also hear a grunting or moaning sound as the baby breathes out.

Respiratory distress syndrome may worsen over the first 48 hours as some of the breathing sacs (alveoli) collapse. As the lungs start to produce surfactant the lungs stabilise and begin to recover.

Treatment for Respiratory Distress Syndrome has changed significantly since the introduction of a form of surfactant that can be given to baby's after birth. The doctor administers the surfactant into the baby's lungs through a tube placed in the baby's windpipe. The instilled surfactant does not prevent the development of RDS but it does significantly reduce the severity of the disease.



BRONCHO- PULMONARY DYSPLASIA

Broncho - Pulmonary Dysplasia (BPD) is a chronic lung disease occurring primarily in premature babies who have been ventilated for respiratory distress syndrome. BPD develops when air sacs in the lungs are damaged by RDS and hypoxia (too little oxygen reaching the tissues), as well as by waste products that develop when oxygen is broken down in the lungs. This damage leads to development of abnormal alveoli (small air sacs) and scar tissue.

The presence of scar tissue causes small areas of the lungs to collapse and other areas to trap air and expand. The new cell growth also increases mucus production and causes the walls of the breathing tubes to develop spasms or constrictions similar to those seen in asthma.

It is not clear why some babies develop BPD and some do not. Infants who develop BPD often have more severe RDS initially, infection may also play a role. BPD may result in infants weaning slowly off the ventilator.

The goal of BPD treatment is to allow the infants lungs to heal, and new undamaged lung tissue to develop. Treatment includes providing optimal nutrition, with extra calories for growth, avoiding fluid overload and reducing the use of mechanical ventilation and high oxygen concentrations as the baby's condition allows. BPD can take months or occasionally years to heal. Babies who have a significant degree of BPD may require supplemental oxygen at home.



INTRAVENTRICULAR HAEMORRHAGE

Intraventricular Haemorrhage is bleeding into the ventricles or fluid filled spaces within the brain. All of us have two small fluid filled ventricles in the centre of our brains. These ventricles manufacture cerebrospinal fluid. The fluid filled spaces within these ventricles are called the intraventricular space. The areas just outside of those ventricles are the periventricular areas. Adjacent to the outer wall of the ventricle is the germinal matrix, an area of immature nerve cells and tender blood vessels. As the preterm baby matures, the germinal matrix tissues migrate out into the substance of the brain, and the germinal matrix gradually disappears.

The tender blood vessels within the germinal matrix can rupture and bleed causing what is known as a Grade I Intraventricular Haemorrhage. The bleeding, if severe, can lead to bleeding within the ventricle itself and this is a Grade II Intraventricular Haemorrhage. If there is a lot of bleeding the ventricles can become enlarged and swollen by the blood which is a Grade III Intraventricular Haemorrhage. If the bleeding either involves or injures the periventricular tissue it is a Grade IV Intraventricular Haemorrhage.

Babies born prematurely are monitored regularly to check for this condition. Staff will update you on the findings after each cranial ultrasound is performed.

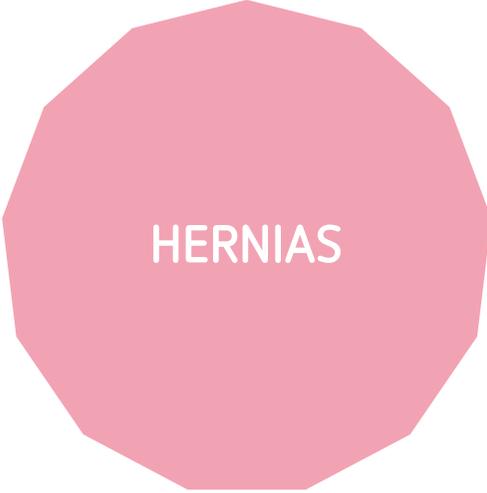


PERIVENTRICULAR LEUCOMALACIA (PVL)

Within our brains are two small fluid filled areas called ventricles. Cerebrospinal fluid is made within these ventricles. Periventricular tissue is just to the right and left sides of the ventricles. The tissue gets its blood supply from the arteries just before they narrow down into capillaries.

If the periventricular tissue does not receive an adequate blood supply the tissue may die. When the tissue dies it leaves fluid in its place, which appears as a cyst.

The cysts represent brain tissue that has died and been replaced by fluid. PVL is the appearance of these cysts on ultrasound, CT or MRI scan of the brain. The brain tissue that has been lost is important to the control of muscle movements in the legs and arms. PVL is often associated with cerebral palsy and other developmental problems.



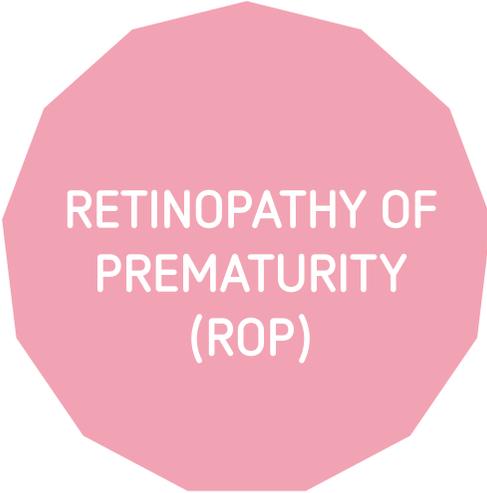
HERNIAS

Preterm infants are at risk for hernias – protusion of a body part, such as a loop of intestine through a muscle weakness or unusual opening inside the body. The most common hernia is called an inguinal hernia. This condition occurs most frequently in boys and usually presents as a bulge in the groin, especially after crying or straining during a bowel movement.

Usually the boys' testicles stay high in the groin, not down in the scrotal sac until about 32 weeks gestation. At that time the testicles descend into the scrotum and the inguinal canal where the testicles were originally closes. But in preterm babies the inguinal canal may not close after the testes descend. This allows part of the intestine to push through this gap in the muscle wall into the scrotum. Sometimes girls get inguinal hernias, which cause a bulge or swelling above the labia.

As long as the hernia can be gently and easily pushed back through the opening, immediate surgical correction is not required. If the hernia becomes trapped in the scrotum, the scrotum will become blue and painful and immediate surgery will be necessary.

Another area where the muscle may not close properly is around the umbilicus. An umbilical hernia causes the umbilicus or belly button area to push outward when the baby cries. As long as there is no marked discoloration, there is no cause for concern. This condition usually corrects itself as your baby grows and the abdominal muscles strengthen and thicken.



RETINOPATHY OF PREMATURITY (ROP)

All babies born before 31 weeks of pregnancy or under 1500 grams have their eyes examined routinely at least once because very small babies are at risk of developing an eye condition, which is mainly caused by prematurity, called Retinopathy of Prematurity (ROP). This eye condition (ROP) affects the developing blood vessels of the retina which lines the inside of the back of the eye. The more prematurely the birth occurs, the greater the risk of ROP occurring.

Examinations start a few weeks after birth and for most babies these are all completed before he/she is discharged. An examination may be necessary after you take your baby home and it is very important that you keep your out-patient eye appointment in Our Lady's Hospital for Sick Children.

ROP is common, usually mild and resolves without treatment. For those babies who develop severe ROP; treatment is necessary and usually successful. Should your baby need treatment the situation will be fully discussed with you. Please do not hesitate to ask if you require any further information.



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