mater mothers

A helpful guide to

Mater Mothers' Hospitals Neonatal Critical Care Unit

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Meet Miracle Max

A friend to all babies born and cared for at Mater.

Welcome

Congratulations on the birth of your baby or babies. We'd like to welcome you to the Neonatal Critical Care Unit (NCCU) at Mater Mothers' Hospitals.

The birth of a new baby is an exciting time, but having a baby that needs admission to a neonatal unit, particularly intensive care, can be challenging.

When you arrive in the unit, the environment and technology may seem daunting. We are here to look after your baby and provide the best possible care and recovery; working together with you. We will provide you with a lot of information and you may hear unfamiliar words, all of which may be overwhelming at first. We are very happy to answer any of your questions or repeat explanations.

We hope that the information in this booklet will help you to better understand the care that your baby is receiving. If you are unsure about anything, please do not hesitate to ask questions or request information to be repeated.

Dr Pita Birch
Neonatologist
Director of Neonatology
Neonatal Critical Care Unit

Lynne Elliott
Nursing and Midwifery Director
Neonatal Critical Care Unit
Maternal Fetal Medicine

About the Neonatal Critical Care Unit (NCCU)

Mater Mothers' Hospitals' NCCU consists of 79 cots separated into intensive care and special care areas. Your baby will be admitted to the area best suited to their needs with the doctors, nurses and other healthcare professionals dedicated to helping your baby while in hospital.

We believe that you, as parents and family, are the most important part of the team caring for your baby. We encourage you to visit, participate and ask questions about your baby's care every step of the journey. It is important for you to be involved in your baby's care wherever possible, as this helps to establish and strengthen your bond with your baby and helps to lay down pathways in their brain for improved neurodevelopmental outcomes. You are the familiar presence in an otherwise new and busy environment.

Please discuss your baby's plan of care with staff so that you can coordinate your visits to maximise your involvement. If you wish to check on your baby when away from the hospital, we welcome phone calls at any time. Throughout your baby's stay we aim to explain all tests and treatments, but if there is anything that you are unsure of, please ask.

If you're feeling unwell, it's best to stay away to protect our little patients' immune systems. The little miracles in our care need your support to get better.

How do I access the nursery to see my baby?

Entry to NCCU can be obtained either via an intercom located beside the main entry doors next to reception on Level 6 of the Mater Mothers' Hospitals, or with your allocated swipe card. The intercom alerts the nurses in the room where your baby is being cared for and is designed to keep your baby safe. It will also alert you in cases where there are procedures occurring in your baby's pod. Please follow the directions for the intercom and wait for your call to be answered. When speaking to staff via the intercom please clearly state the following information:

- your name e.g. "Chris Smith; father or mother of..."
- who you are visiting e.g. baby Smith or Emma Smith
- your baby's cot number e.g. 612.

When you enter the nursery please ensure that other people do not follow you inside.

Who can visit my baby?

Parents and siblings are welcome to visit any time. However, we ask that anyone who is unwell avoids visiting the nursery and that you discuss with your baby's doctor and/or nurse their recommendations about when you can visit again. Premature and sick babies have limited defences to fight infection and it is everyone's responsibility to reduce the risk where possible.

There is a limit of two visitors to each cot at one time (i.e. two parents or one parent with one visitor). Your family and friends must visit with you unless you have included their name on your approved visitor list. If this is the case, they may visit independently. Other children who are not siblings to your baby will not be able to enter the nursery. The parent lounges are for the use of parents and siblings only. Please do not leave young children unattended in the parent lounges. All other visitors can use the waiting room located in the Level 6 foyer.

What can I do if I am concerned or feel like I am not being heard?

Our goal is to include you in the plans for your baby's treatment, and keep you up to date with the results of any tests and your baby's progress. We take your concerns seriously and would like to discuss them with you, or direct you to the people who can best answer your questions. If you do have any concerns or would like to ask a question, please initially speak to the nurse caring for your baby. You should also ask to speak with one of the doctors caring for your baby. If you would like to meet with the specialist (neonatologist) and any other members of the team in a family meeting, please ask and that will be arranged.

If you feel your concerns are not being heard please ask to speak with the:

- team leader on duty
- nurse unit manager of the area your baby is in
- neonatologist/paediatrician caring for your baby
- social worker
- patient representative (phone 07 3163 8303)
- medical and/or nursing directors of NCCU.

These contact details are available in Mater's NCCU Parent Lounge.

If you have immediate concerns and feel that these are not being heard, despite speaking to the above people, you may call 'PACE'. This stands for **P**atient **A**nd **C**arer **E**scalation and can be activated by calling 07 3163 8555. Tell the operator "I am using PACE", your name, ward, bed number (or baby's cot number) and doctor's name if known. A senior member of staff will see or speak with you within 10 minutes from the activation of this call.

What to expect when your baby is in NCCU

When your baby is admitted to NCCU, the multidisciplinary team work quickly to meet the needs of your baby and it may appear very scary and overwhelming. This can be a very busy time, however we aim to explain all procedures and equipment to you, your family and encourage questions.

Initially, all babies admitted to NCCU will be monitored with echocardiogram leads and a probe placed around their hand or foot to monitor heart rate, respiratory rate and oxygen saturation levels. They may also have their temperature and blood pressure taken, some blood tests collected, and be assessed to ensure they are not in pain (using a neonatal specific pain assessment tool).

Your baby may be placed into a number of different cots depending on their size, condition and how many weeks gestation they are. This may include an incubator, open care system, cot with a heated gel mattress or a perspex baby cot. We aim to provide an environment that supports the developmental needs of your baby.

Your baby will be weighed and measured at birth and on a regular basis throughout their stay in NCCU. Please ask your nurse for further information about when your baby will be weighed as you are welcome to be present and assist with this.

Helping to prevent infection

We know that the immune system of newborn babies is immature, particularly if they are born premature, so we take infection control very seriously.

This is very important in the protection of your baby. Handwashing is the most effective way to prevent infection. For this reason it is expected that you wash your hands thoroughly as instructed by the healthcare team (and any visitors do too).

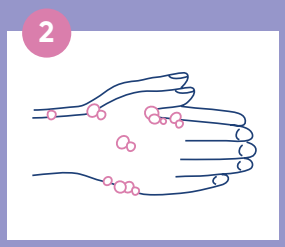
Handwashing is required as you enter the room, when your hands are visibly soiled, before feeding your baby and after nappy changes. It is important that you take all jewellery off and are 'bare below the elbow' while visiting your baby. There is also alcohol based hand spray or gel available at your baby's cot side to use after touching things like mobile phones, breast pumps, chairs and before handling your baby. This spray/gel should also be used prior to leaving your baby's cot space.

Additionally you can help prevent the spread of germs by keeping your baby's cot side clean. Detergent wipes are provided for cleaning mobile phones. We also have recommendations about what is safe in the space around your baby in the cot, incubator, and immediate surroundings. NCCU staff follow these recommendations to help keep your baby and other babies safe from infection. For this reason, baby's toys are not to be placed inside the cot or incubator, but up to two toys can be kept in the area around the cot.

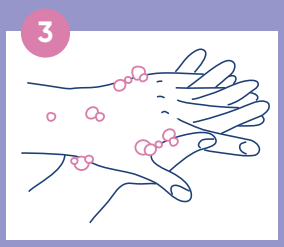
At Mater, it's ok to ask anyone to clean their hands.

How to perform hand hygiene

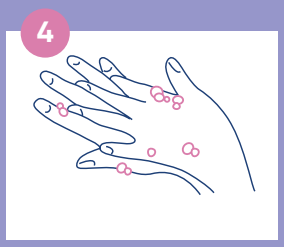
Wet hands and apply 1 pump of soap to hands **or** apply 1 to 2 pumps of alcohol-based gel to palms of dry hands.



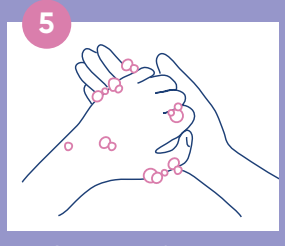
Rub hands together, palm to palm.



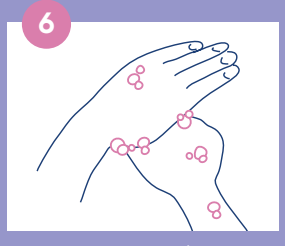
Rub in between and around fingers.



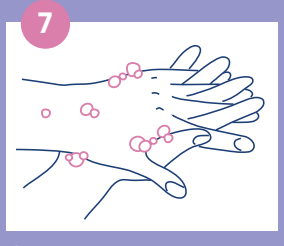
Rub back of each hand with palm of other hand.



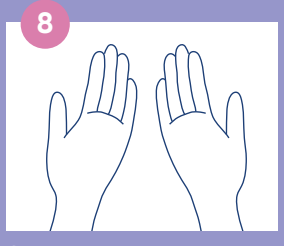
Rub fingertips of each hand in opposite palm.



Rub each thumb clasped in opposite hand.



If using soap and water, rinse hands and pat dry with paper towel. If using alcohol-based gel, rub hands until they are dry.



Once dry, your hands are safe.

Caring for your baby

How to be a partner in the care of your baby

We aim to provide the best environment for your baby to continue to grow and develop. We are particularly focussed on brain development and want to support your baby to mature and thrive. These are some developmental care principles that you may experience while your baby is in NCCU:

- The environment should be a mostly quiet, low noise, low light, clean and safe space for you, your baby, and your family
- Learning opportunities are always available for you and for the healthcare providers looking after you and your baby
- It's our priority to build a relationship with you, so you are comfortable to take the lead with caring for your baby, asking questions, receiving information, are comfortable in the environment and ultimately allowing us to provide the best care possible to your baby. Open communication between the healthcare team and you and your family is crucial
- We strive to individualise the care we give to your baby. That is, tailoring our care to suit the particular needs of your baby, and you; reading your baby's cues and administering care in recognition of your baby's condition at any given time. We encourage you to be present and support your baby during painful procedures using comfort measures and small amounts of your expressed breast milk (EBM) and/or sucrose (see our online brochure *Reducing your baby's pain during invasive tests or procedures*).
- If you wish to learn more about baby cues, our occupational therapists run baby cue sessions every Thursday at 11 am in room 5.3 (located on Level 5, behind the café).

What you can do every day

We encourage you to be present during the ward rounds that occur in the nursery every day. These will usually take place between 8.30 am and 11 am. This can be a good time to find out about the clinical care of your baby. If you would like to meet with the team, including the specialist doctor caring for your baby, we encourage you to speak up and a family meeting can be organised.

Ask questions and request information to be repeated if you are unsure about anything you have been told. Communicate with the nurses, doctors, allied health workers and social workers.

You can also use the communication board at your baby's cot side, for example:

- comment on how long you will be staying with your baby today
- which breastfeeds you will be doing/attempting
- your request for Kangaroo Skin Care
- what you would like to happen overnight when you are not with your baby
- discuss these comments and requests with the nurse caring for your baby.

Other things to consider:

- Spend time with your baby. Visit, touch, talk, read or sing to your baby quietly—this helps you to establish a bond. The nurses will help you learn about how much, and what type of contact is right for your baby. Cuddle your baby if their condition is stable. In circumstances where it is not possible for you to cuddle your baby, singing and reading to your baby is encouraged. Your baby knows your voices and talking/reading to them has shown to have great benefits for their brain development (neurodevelopment). Developmental touch or 'hand hugs' can also be beneficial to contain and comfort your baby. The nurses will explain and demonstrate this for you
- Learn to recognise your baby's behavioural cues, in partnership with the healthcare team. Your baby may qualify for assessment by the developmental care team in their regular rounds and individualised care plans created in partnership with you
- Plan and help in care activities.

What we suggest you do

- On admission you will be given an information pack that is appropriate for your baby's gestation. Read all the information given to you before you decide what is best for your family. We are here to help and assist you so that you can have the best possible experience of your baby's first days and weeks of life.
- Try to get plenty of rest and sleep, take good care of yourself and try to relax as much as you can. This can be a very stressful time for parents. Communicating with your baby's nurses to help plan your day around your baby's activities can help you to utilise the best time for rest periods.
- Keep a diary. Writing down your experiences, thoughts, questions and observations will help you to cope with the situation and create a record of your baby's progress. Take photos and celebrate your baby's milestones.
- Seek help and comfort from a variety of outside sources and then decide which one is most suitable for you. Some people prefer to internalise their feelings, but it is always better to talk about things before you reach your limit. Community supports are a good resource to access if you feel comfortable. If you would like some help to find the support you need, please ask to see the Mater social workers or pastoral care workers can help you with this. There are facilities on the Mater South Brisbane campus including the Chapel and multi faith rooms available for private prayer and devotions.

What may not be possible

We hope you will have enough information to understand why it is not always possible for you to participate in your baby's care. For example, your baby's condition may not be stable enough for you to cuddle your baby at a certain time.

To understand what is happening, we encourage you to ask questions, try to stay calm, and let us know your feelings. Please discuss any concerns, as well as your plans and wishes with us, or if you need help.

We ask that you are respectful of others present in this busy environment. Disruptive or abusive behaviour is unacceptable and we have zero tolerance for it. People acting in this manner may compromise the safety of the babies and families in our care and they will be asked to leave the hospital.

Breastfeeding

Breast milk and breastfeeding have great benefits for mums and babies. These benefits are particularly important for vulnerable, sick or premature babies. Breast milk is specifically designed for your baby and changes to meet their nutritional requirements. It provides easily digested food and also has unique antibodies and growth factors to help protect and support your baby.

While your baby is unwell and/or premature you may need to express your breast milk if they are unable to feed. If you're intending to breastfeed, start expressing your colostrum (milk from the breasts in the first stages of lactation) soon after birth. It's recommended to express a minimum of eight times each 24 hours (or approximately every three hours) to promote your milk supply. The midwives and nurses on the postnatal floor and in NCCU can help you with this. Breast expressing kits are available from reception on Level 6, for a nominal fee. Initially, your expressed breast milk (EBM) may be fed to your baby via a gastric tube (the tube that is placed in your baby's stomach), but the overall aim is for you to take your baby home fully breast fed. The nurses and lactation consultants are available to mums for support and assistance while you are establishing your milk supply and when breastfeeding your baby, as well as providing information about storage of EBM.

Printed, named stickers for labelling your bottles or bags of EBM are available from the ward clerk at the reception desk, or you can ask the nurse caring for your baby. Please complete these labels by clearly writing EBM, the time and date of each expression and then add your initials before applying the completed label to each bottle or bag of EBM. You may be asked to check containers of EBM before the milk is given to your baby; please read the labels carefully to be sure the details are correct.

After you have finished expressing please wash your equipment in warm soapy water, rinse thoroughly with clean water and allow to air-dry, or dry using clean paper towel. Do not store wet or damp equipment. A large lunch box or plastic airtight container is suitable for use as a washing up dish and storage container. Do not wash your equipment directly in the hand wash basin. Additionally, please clean all the outside surfaces of the breast pump with the detergent wipes provided.

Discharge and follow up care for your baby

As part of your preparation for taking your baby or babies home, NCCU staff will provide education to ensure you feel well prepared. Hands on baby Cardio Pulmonary Resuscitation (CPR) and 'how to manage a choking baby', plus how to sleep your baby safely, will be shared. A pharmacist will provide you with information about medications if your baby requires them once they are discharged from NCCU. A Healthy Hearing screen will be conducted in the days leading up to discharge and documented in your baby's health record. This booklet is a great place to document vaccinations, child health check-ups and track your baby's growth. Your baby's health record is available at any time to familiarise yourself with the contents and is kept at your baby's cot side for the duration of their admission.

Length of stay

Many babies born premature may be ready to go home two to three weeks before their due date, although this will vary from baby to baby. Those that are born extremely premature usually remain in hospital beyond their due date. There are no weight criteria that babies must meet to be able to discharge home but your baby must be breathing without support (the need for low flow oxygen for some baby's is ok), no longer having significant pauses in breathing, feeding well, gaining weight and you must be confident in providing the care your baby requires. For babies who are not premature and who need the care of NCCU at term, the length of stay depends on the condition your baby requires treatment for.

Transfer

Mater Mothers' Hospitals is a tertiary facility for high risk babies, requiring specialist care. If you live closer to, or were booked into another hospital with a neonatal unit, your baby will be transferred to that hospital when appropriate. Having your baby cared for in a hospital closer to home means you will be able to consult with local healthcare professionals who will ultimately be responsible for the long term care of your baby. Additionally, if your baby requires ongoing care for their diagnosed condition, they may be transferred to a specialist ward at the Queensland Children's Hospital (QCH).

Follow-up care

There are several options available for follow-up care after your baby is discharged from NCCU. You will be advised which of these options is appropriate for your baby.

Private paediatrician: Your baby was admitted to NCCU under the care of a private paediatrician, they will provide follow-up care for your baby and advise you of any appointments that you will need to make.

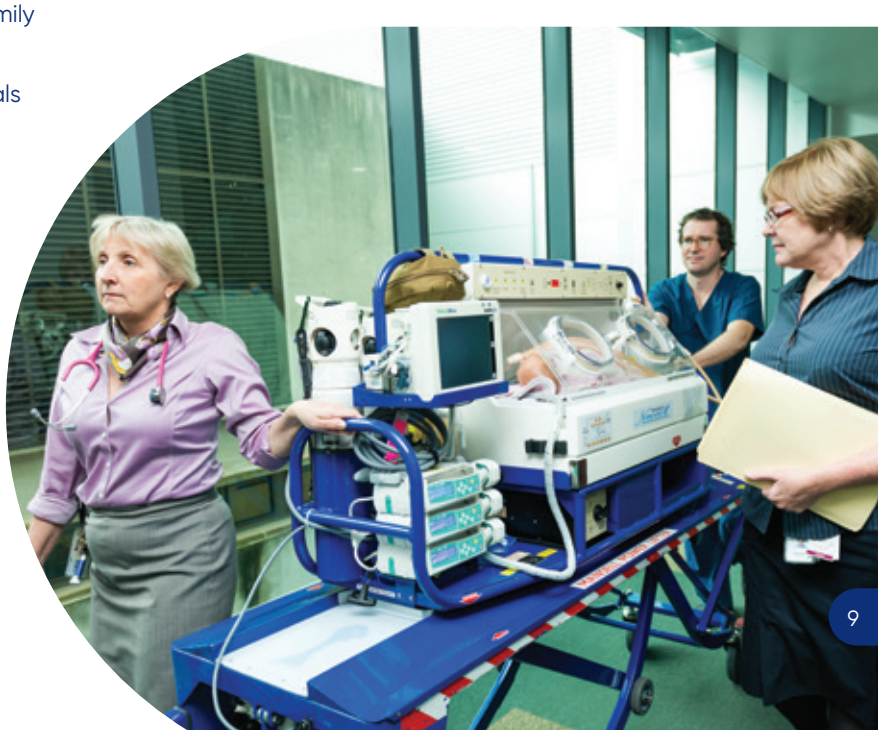
General Paediatric follow up: If you live in the Queensland Children's Hospital (QCH) catchment area and your baby requires paediatric follow up, a referral will be sent to QCH, and an outpatient appointment will be sent to you by mail. If you do not live in the QCH catchment area your baby will have follow up from a general paediatrician at the closest regional hospital. If you have been transferred to Mater from another hospital, either before or after your baby was born, we will attempt to transfer you back to that hospital as soon as it is safe to do so. This gives the hospital closest to you and your baby's home an opportunity to 'get to know' you, your baby and family if any issues arise.

Home care: If you live within Mater Mothers' Hospitals catchment area, a midwife is available to conduct a home visit in the first week post discharge from NCCU. The midwives can assist with any feeding issues and monitor your baby's weight gain.

Short Term Follow-up Clinic (STFC): This is a weekly clinic that provides medical and dietetic/nutrition follow up to babies who require specialist review to manage self-limiting problems, or to assess the results of investigations and/or progress as to whether further referral is needed. The period of follow-up should not extend beyond 12 months. Babies who require long-term paediatric follow-up at QCH may be seen for a 'bridging' appointment in the STFC if an early appointment is not available at the other clinics. This clinic is in Mater's Salmon Building.

Growth and Development Clinic: This provides developmental assessments and an allied health review to feedback to your baby's paediatrician, GP and you. The clinic is designed for those babies who are considered to be at a higher risk of later motor and developmental problems. This includes all babies with a birth weight of less than 1000gms or a gestational age of less than 28 weeks. Additionally, those babies discharged on the home oxygen program, premature babies who have required cooling as part of their care, and babies who participated in research are also assessed. Parents are usually given the date of the first appointment before hospital discharge, with subsequent appointments being made and confirmed at a later stage. This clinic is in Mater's Salmon Building.

Retinopathy of Prematurity (ROP) Clinic: If your baby requires ROP screening in hospital and is not discharged from the ROP team on leaving hospital there is an outpatient clinic run by the team at 9 am on a Wednesday morning in Mater's Salmon Building.



The healthcare team

Our medical, nursing, allied health and support staff work together to ensure the best possible care is provided for your baby. If you have any questions about the team or their roles, please ask.

The roles of the healthcare team

Neonatologist: senior paediatric doctors specially trained in looking after premature and sick babies. They may also be referred to as a consultant and lead the team caring for your baby.

Fellow and Registrars: qualified doctors who are training in neonates/paediatrics as a specialty. There are always doctors present in the neonatal unit at all times.

Residents and Interns: rotational doctors working at Mater.

Nurse Unit Manager (NUM): the senior nursing manager responsible for nursing staff and operations of the unit. We currently have three NUMs across NCCU.

Clinical Nurse Consultant (CNC): a senior nursing role involved in quality improvement and translating research into practice. They look at processes and act as a clinical expert in NCCU.

Clinical Facilitator (CF): part of the education team specialised in neonatal care. They provide support to nursing and medical staff. They also facilitate nursing and medical orientation, graduate nurses' transition into neonatal care and coordinate workshops on a variety of topics.

Discharge Coordinator: a nurse who is dedicated to organising and coordinating discharge of your baby from NCCU. If you are referred in from another hospital, the discharge coordinator is able to liaise with other hospitals when it is appropriate to transfer your baby closer to home. They will also arrange follow up appointments if required post-discharge.

Clinical Nurse (CN): a nurse who displays advanced practice in neonatal care. They have the responsibility to be able to coordinate the team and manage a shift as well as oversee the care of babies in their area.

Registered Nurse (RN) and/or Midwife (RM): is a qualified nurse and/or midwife and is accredited by the Nursing and Midwifery Board of Australia supported by the Australian Health Practitioner Regulation Agency (AHPRA). Many nurses/midwives working in NCCU have completed further training in caring for babies.

Enrolled Nurse (EN): a nurse who is qualified by completion of a vocational education training course and is endorsed to give medications. They are also accredited by AHPRA.

Assistant in Nursing (AIN): provide support to the nursing team ensuring essential and operational activities run as smoothly as possible.

Lactation Consultant: a nurse/midwife specialising in the clinical management of breastfeeding, including providing support to breastfeeding women, and assisting them in the initiation and maintenance of their breast milk supply if unable to breastfeed. Lactation consultants hold an International Board Certified Lactation Consultant (IBCLC) qualification.

Dietitian: an expert in diet and nutrition who monitors your baby's growth to ensure your baby is receiving adequate nourishment.

Speech Pathologist: part of the allied health team that focus on the ability of babies to feed and swallow safely. They may also provide follow up with speech development.

Physiotherapist: part of our healthcare team who assist with assessment of baby's respiratory state, observe movement and provide education on baby handling and developmental care.

Occupational Therapist: an allied health professional that looks at how your baby's diagnosis can affect their development and behaviour. They can help you to read your baby's developmental cues.

Pharmacist: reviews and provides advice on medications that your baby may require while in NCCU. They also provide education for medication administration on discharge if required.

Social Worker: provides emotional support and strategies to cope with stress for families and staff in NCCU. They can assist with arrangements for accommodation and discharge.

Pastoral Carer: team members from pastoral services who can provide assistance and compassionate support for families in NCCU.

Specialist Teams: there are a number of paediatric teams who visit from QCH. These may include surgical, cardiac, endocrinology, palliative care, respiratory, plastics, urology, neurology, neurosurgical, ENT (ear, nose and throat), and stomal therapy.

Ward Clerk: an administrative officer who supports the staff and families in the unit.

Common procedures, tests and treatments

During admission to NCCU, your baby might require the following common procedures and/or treatments. Most of these are routine practices and the nursing and medical staff will then discuss any new procedure or treatment with you before it is commenced.

Blood tests

Samples of your baby's blood are taken to monitor your baby's progress and to make adjustments to treatments such as ventilation, oxygen, fluid, antibiotics or other medications. Blood samples may be collected via a heel prick where several drops of blood are taken from your baby's heel or through a catheter inserted into an artery or a vein.

Cranial ultrasound

Uses soundwaves to look at your baby's brain structure. This is a harmless procedure which causes little discomfort to your baby. Refer to *Your baby's head ultrasound* online brochure for further information.

Echocardiogram

An ultrasound study of your baby's heart. Some babies need this to screen for, or diagnose, problems with their heart or major blood vessels. This may also be called an echo or cardiac echo.

Eye examination

An ophthalmologist (eye doctor) will check your baby's eyes to determine if they are at risk of Retinopathy of Prematurity (ROP). A series of examinations are usually required. Eye tests are limited to those babies whose birth weights were less than 1250 g or born at less than 32 weeks gestation, or if specifically requested by your baby's doctor. Nurses specifically trained in this procedure (Retcam nurses) may conduct these tests on your baby. For further information on this particular test please refer to Mater's online brochure *Retinopathy of prematurity.*

Hearing screen

Queensland Health offers all babies an automated hearing screen. A staff member trained in this procedure will obtain consent for this to occur and the test can be done before discharge, or arrangements can be made for it to happen at a later date.

Insertion of a long line

This is a sterile procedure where a soft, long and pliable catheter (called a long line or peripherally inserted central catheter (PICC)) is inserted into a vein that is either in your baby's arm or leg and advanced to a larger vessel nearer the heart. This type of line is used for long term intravenous nutrition (TPN and lipids) or medications such as antibiotics. Staff will monitor your baby closely for potential complications such as bleeding on insertion or infection in the line.

Insertion of an umbilical venous and/or arterial catheter

This is a sterile procedure that involves a trained doctor accessing the umbilical cord to place a thin plastic catheter into a baby's artery and/or vein. During the procedure, your baby will be monitored and contained to make sure they are not in any distress. There are usually three vessels in the umbilical cord; two arteries and one vein. Placing a catheter in the vein can allow for administration of fluids and medications. Placing a catheter in the artery can allow for pain-free blood sampling and blood pressure monitoring.

The positions of the catheters are confirmed by a low radiation x-ray (not harmful to your baby) and often with ultrasound a few days later. While these catheters are in place your baby will need to be nursed where the umbilical cord can be seen to make sure they are secure, which may mean it is not possible to cuddle your baby during this time.

Although these procedures are very commonly performed and usually very safe, there are occasional complications. If the plastic catheter is in an incorrect position these complications are more common and so the catheter may be removed. Uncommonly these can become infected and baby will need to be treated with antibiotics and the catheter removed. Very rarely, a blood clot can form at the tip of the catheter and it will also need to be removed.

Lumbar Puncture (LP)

This is performed on babies where there is a risk that an infection has spread to the fluid around baby's brain (meningitis). Usually, results show the baby does not have meningitis, but it is very important to know. It involves placement of a needle in a space between the lumbar spine to collect a sterile sample of cerebral spinal fluid (CSF), which is sent to pathology for testing. The needle is placed below a point where the spinal cord ends so there is very little risk to baby's spinal cord. However, this procedure can very rarely be associated with infection or bleeding at the site.

Newborn Screening Test

Between 48 and 72 hours after your baby's birth, a blood sample is taken and sent to the Queensland Neonatal Screening Laboratory to test for rare but serious medical disorders. This test is performed on all newborns in Queensland whether sick or well. The test will need to be repeated if your baby is very small or sick at the time of the first test, or if the result is abnormal. For further information on this particular test please refer to Mater's brochure *Your Baby's Newborn Screening Test*.

Multi-Resistant Organism (MRO) screening swabs

All babies in NCCU are tested each week for antibiotic resistant germs. The tests involve collecting swabs from your baby's skin surfaces, where these germs normally live. If your baby is found to have one of these germs, special infection control precautions will be required to stop the spread of the germ to other babies. Please refer to Mater's brochure *Isolation. Care of babies requiring isolation in the Neonatal Critical Care Unit*.

X-rays

These are done if your baby has respiratory issues (breathing), bowel problems, to diagnose skeletal issues or to confirm line placement. Very low amounts of radiation are used so it is not harmful to your baby even if multiple x-rays are needed.

Terminology

While your baby is in NCCU you may hear many unfamiliar terms. Some of these terms may include:

Anaemia

A low red blood cell count (haemoglobin) diagnosed with a blood test. This can be due to prematurity or acute blood loss.

Antibiotics

A medication which is given in the treatment of infection or suspected infection. Babies in NCCU mostly have intravenous administration but sometimes it can be oral.

Apgar

A universal scoring tool used at the birth of your baby, looking at your baby's breathing efforts, muscle tone, colour, heart rate and reflex response. It is scored at one and five minutes with a maximum score of ten.

Apnoea

A temporary pause in your baby's breathing. Apnoea is very common in premature babies. Babies born before 35 weeks gestation are monitored for apnoea, and some need treatment. The most common treatments are caffeine and with respiratory support such as CPAP or Hi-Flow Nasal Cannula (see below).

Bagging (bag and mask ventilation)

A doctor or nurse/midwife uses a special hand held apparatus for a short interval to help your baby breathe.

BGL

Refers to the measurement of blood glucose (sugar) level.

Bilirubin

Is the yellow compound that results from the breakdown of haemoglobin in the red blood cells in the body. Because the liver is still maturing in the first few days of life, sometimes bilirubin is not efficiently broken down and can cause jaundice. It is more common in premature babies and the levels of bilirubin in your baby's blood will be monitored with a blood test if indicated.

Blood culture or 'culture'

Blood, urine or other body fluid sent to a pathology lab to look for infection. This result can take up to 48 hours.

Blood transfusion

Premature or very sick babies may require one or more blood transfusions. Before the first transfusion is given, your baby will have a blood test to determine their blood type and it is matched with appropriate blood that has been treated for neonatal use. We will seek your consent before giving your baby a transfusion, unless your baby urgently needs this, in which case we will inform you after the transfusion. Although you may wish to donate your own blood for your baby, it is not recommended due to the risk of reactions from relative's blood. For further information, please refer to our online brochure *Babies requiring a blood transfusion* and if you have any further questions please ask your nurse/midwife or doctor.

Bradycardia

A slowing of your baby's heart rate to less than 100 beats per minute. Babies may correct this slowed heart rate themselves, or some stimulation may be required. Bradycardia often occurs with apnoea.

Breast pump

An electric pump used to express breast milk.

Caffeine

A drug given to premature babies to reduce apnoea and bradycardia.

Cares

Your baby's cares are performed based on their needs and include activities such as taking a temperature, cleaning baby's mouth and eyes, changing their nappy, changing position and attending to any prongs, tubes or drips. Cares are done regularly based on baby's cues or within specific time frames. These are important times for you to be involved in your baby's care as well. We encourage you to be present during your baby's cares.

Chest tube/drain

A small tube or catheter that is placed in your baby's chest into the pleural cavity (space between the ribs and lungs) under sterile conditions. It is used as a treatment for pneumothorax (air in the pleural cavity) or in surgical procedures to create a negative pressure allowing the lung to expand or to drain excess fluids post-operatively.

Corrected age

A term used in babies born premature in order to consider developmental expectations. It is based on the baby's due date and how old baby would be if born on their due date at 40 weeks rather than premature. For example, if a baby is born at 28 weeks gestation and is now two weeks old, their corrected age is 30 weeks (age is added to gestation). If they are 13 weeks old, they have passed their due date and their corrected age is one week (age is now subtracted from gestation).

CPAP

Continuous Positive Airway Pressure is a method of helping your baby to breathe. CPAP is usually delivered into your baby's nose via soft silicone prongs. We mostly use 'bubble CPAP' which your baby breathes against a set number of centimetres of water to help keep the alveoli (tiny sacs in the lungs) open.

Desaturation

A fall in the blood oxygen level that often occurs with an apnoea or bradycardia. Babies are continually monitored for this and the desaturation can be corrected quickly by nursing staff if baby does not self-correct. It is often abbreviated to 'desat'.

EBM

Expressed breast milk.

Endotracheal tube (ETT)

A thin plastic tube that is placed via your baby's mouth or nose into their trachea (windpipe) to enable a breathing machine called a ventilator to support your baby's breathing.

Full blood count (FBC)

A blood test analysed in a pathology laboratory to give information about your baby's red blood cell count, haemoglobin, white cell count, platelet count, and can determine if there is any indication of infection.

Gastric tube (NG or OG)

A soft tube that is inserted through your baby's nose (NG) or mouth (OG) into the stomach. It is taped to the baby's face and allows breast milk or formula to be fed to those babies unable to suck their feeds. It can also be used to give medication and retrieve air from the stomach if your baby is on respiratory support and has excess gas in their stomach.

Gestation

The length of a pregnancy from two weeks before conception until birth. For mothers who were having regular monthly periods, this is usually the interval from the start of the last menstrual period. The gestation of a normal pregnancy is about 40 weeks.

Graseby monitor

A monitor to detect if your baby has pauses in their breathing.

Grunting

A noise that can be heard when a baby breathes out. Babies grunt as a coping mechanism to help them breathe.

Haemoglobin

The component of red blood cells that has the capacity to bind to and carry oxygen around the body.

Heart rate

The number of times your baby's heart beats in one minute.

Heel prick/lance

A procedure where a small device is used to 'prick' the heel of your baby to take a blood sample. Comfort strategies can be used before and during this to minimise pain.

Humidified Hi-Flow Nasal Cannula

High flow is another form of breathing support where humidified air (or blended with oxygen) is delivered to your baby via soft silicone nasal prongs.

Hyperglycaemia

High blood glucose (sugar).

Hypoglycaemia

Low blood glucose (sugar).

Intravenous (IV)

Into a vein. The term IV is often used when a cannula is placed into a vein to administer medications or fluids.

Incubator

A clear, enclosed perspex cot that provides heat and humidity. It is most useful in the admission of very low birth weight (VLBW) premature babies. Sometimes it can be used for babies who need to be nursed unclothed during the treatment of jaundice.

Jaundice

A yellow colouring of your baby's skin that is caused by a build-up of bilirubin (a breakdown product of haemoglobin) in the blood. Many babies become jaundiced.

Kangaroo care

Skin-to-skin cuddling with a parent or sibling (if appropriate) to increase opportunity for bonding with families. There are many benefits including keeping baby warm, stabilised heart rate and breathing rate, increased milk production for mothers and increased rates of successful breastfeeding.

Lipids

An intravenous fluid providing fats, good 'fatty oils' and vitamins to your baby to help with nutrition and growth in babies that are unable to have any or only a little milk.

Meconium

A tarry, black stool (poo) passed by your baby in their first week of life.

Nasal flaring

Babies flare their nostrils to try to increase their capacity to breath—normally occurs when babies are having trouble breathing.

Necrotising enterocolitis (NEC)

A condition where the lining of the bowel is inflamed and can lose blood supply, usually due to infection in the bowel. It can be diagnosed by abdominal x-ray and can be treated with antibiotics or sometimes may need an operation by trained paediatric surgeons.

Patent Ductus Arteriosus (PDA)

A small vessel near the heart is called the ductus arteriosus. It is used by the baby during their time in the mother's uterus; however, it should close after birth. PDA is the term used when this does not occur.

Phototherapy

A white or blue light used to treat jaundice.

Pneumothorax

A collection of air that has leaked from the air sacs and is sitting between the lung and the ribcage.

Premature or preterm

A baby born before 37 weeks gestation.

Retractions

Pulling in of the chest between the ribs or at the sternum when babies are having trouble breathing. May also be referred to as 'work of breathing'.

Seizure

Caused by abnormal brain activity where the body either jerks, stiffens, or baby has sucking like motion of the lips or rolling of the eyes.

Sepsis

An infection usually in the blood.

Surfactant

A detergent-like substance that is normally produced in the lungs and helps make breathing effortless. Premature babies' lungs often do not make enough surfactant at birth, and this causes a type of breathing problem known as Respiratory Distress Syndrome (RDS), or Hyaline Membrane Disease. Some babies recover just with CPAP, but some need to be given artificial surfactant via an ETT.

Tachycardia

A resting heart rate greater than 160 – 180 beats in a minute.

Tachypnoea

A breathing rate above 60 – 80 breaths in a minute.

Total Parenteral Nutrition (TPN)

TPN is a solution that is run through a central line (longline or umbilical venous catheter (UVC)) to deliver the daily nutritional requirements to your baby when they are unable to have milk. It is made up of glucose, electrolytes, minerals and amino acids which are essential for growth and brain development. Your baby can have a combination of TPN and milk as guided by your baby's doctor.

Ventilator

A machine that supports your baby's breathing.

Facilities and services

Accommodation

If you do not live locally to Mater Mothers' Hospitals, we may be able to provide you with assistance in booking accommodation nearby while your baby is in NCCU. We have a dedicated Patient Travel and Accommodation Officer who consults with you and your local hospital to determine whether some of these costs may be subsidised. Please ask your nurse for further information if you are unsure. Closer to discharge, you may be offered the opportunity to stay with your baby (rooming-in) overnight for one night prior to discharge. Rooming-in helps you to become confident in caring for your baby while you are still in a supportive environment. Rooms are available in the postnatal units for this purpose. For further information please refer to Mater's online brochure *Rooming-in*.

Parent's Lounge

We understand that having your baby in hospital is a very stressful time. While providing compassionate care to your baby is our number one priority, we care about your needs too.

Our Parent's Lounge provides a space for you to have a coffee or tea, read a magazine, or talk with one of our volunteers and other parents. It is located within NCCU on Level 6, so you are never far from your baby.

We encourage parents to utilise the kitchenette services within the Parent's Lounge for your meals when visiting your baby. Mater has a number of coffee shops and other food outlets located around the South Brisbane campus, as well as other eateries at South Bank and along Annerley Road.

Interpreter

An interpreter service is available for families where English is not their first language and understanding may be compromised. Please ask a nurse/midwife if an interpreter is required.

Parking

Parking is available in Mater's Hancock Street Car Park (P1) and Mater Hill car parks (P4), and you will be required to pre-pay for parking prior to exiting. There are a variety of multi-day parking passes. Please see a parking attendant at the service centres at Hancock Street Car Park (P1) level 1 or Mater Hill West (4) on level 4. You may be eligible for subsidised parking—please ask your baby's nurse for more information.

Transport

There is a taxi rank located on Raymond Terrace outside the Salmon Building. Ride sharing services are also welcome to come through the boom gate at Mater Mothers' Hospitals to pick you up.

The Mater Hill Busway station is situated off Stanley Street near Mater Private Hospital Brisbane. The nearest train station is situated in South Bank at the top of Grey Street. Please refer to Translink's resources to map your journey.

Flower deliveries

Unfortunately, flowers are not able to be taken into your baby's room; however, they can be left at the reception desk for collection when you are leaving NCCU.

Hints and tips from parents

Take videos and photos with perspective. You will want to look back on these to remember how small your baby was.

Chloe, mother of twins Florence and Lucy (born 34 weeks)

Spend a short period of time away from NCCU every day doing a self-care activity. It's important to look after yourself as well during this time.

Hayley, mother of twins Leonardo and Giovanni (born 27 weeks)

Don't put pressure on yourself or your baby to get to their next milestone. It will all happen in good time so take each day at a time. Follow the lead of your baby and they will let you know when they are ready.

Melanie, mother of Charlotte (born 35 weeks)

Accept offers of help from friends and family. And if you need some support, don't be afraid to ask!

Kate, mother of Joseph (born 25 weeks)

Contact information

Our nurses are available around the clock. Please feel free to call through to our reception team or directly to your baby's cot at any time, day or night, for updates on their progress.

Reception	**07 3163 1932**
Cots 601 to 602	**07 3163 1940**
Cot 603	**07 3163 5198**
Cots 604 to 609	**07 3163 5634** or **07 3163 5635**
Cots 610 to 617	**07 3163 1928** or **07 3163 5633**
Cots 618 to 625	**07 3163 1929** or **07 3163 5637**
Cots 626 to 631	**07 3163 5647** or **07 3163 5648**
Cots 632 to 637	**07 3163 1933** or **07 3163 5646**
Cots 638 to 639	**07 3163 5651**
Cots 640 to 647	**07 3163 1937** or **07 3163 5643**
Cots 648 to 655	**07 3163 1787** or **07 3163 5642**
Cots 656 to 663	**07 3163 1939** or **07 3163 5641**
Cots 664 to 671	**07 3163 1936** or **07 3163 5640**
Cots 672 to 679	**07 3163 5639** or **07 3163 5644**

Patient and Carer Escalation (PACE)*

We value your baby's safety above all else. We expect that your healthcare team can address any concerns or worries you may have about your baby's care and immediate safety. Families or carers have a right to further escalate their concerns and we encourage you to raise any concerns as early as possible. If you have serious or immediate concerns about your baby's health, please follow the steps outlined below:

Step 1: Speak to your nurse or doctor, who will listen and respond to your concerns. If you are unsatisfied with the response and are still concerned, move to step 2.

Step 2: Ask to speak to the nursing team leader or nursing unit manager. If you are unsatisfied with the response, and are still concerned, move to step 3.

Step 3: Activate a PACE. Dial 555 from the bedside phone or call 07 3163 8555. Tell the operator "I am using PACE", your name, your baby's name, ward, cot number and doctors name, if known. A senior member of staff will see you within 10 minutes.

*PACE is the equivalent to Ryan's Rule as used by Queensland Health.

Patient Representative

Available to patients who wish to voice complaints or provide valuable feedback about our service. Please call 07 3163 8303.

Consumer engagement

Mater has an engaged community of consumers who partner with us to provide valuable feedback. We would love for you to be a part of this community. Please email **consumers@mater.org.au** to find out more.

matermothers.org.au

For additional patient information, select Mater Mothers' Hospital's **Neonatal Critical Care Unit**.

Research

Mater Mothers' Hospitals strongly support research to improve the care of and outcome for babies born seriously ill and premature.

We strive to provide the gold standard of evidence-based practice and diminish the gap for translating research into practice. You may be asked to allow your baby to be involved in research projects. The decision to participate in any trials or research is of course up to you, but we appreciate your careful consideration of these projects at such a stressful and difficult time.

Mission

We serve together to bring God's mercy to our communities through compassionate, transforming, healing ministries.

Values

We honour and promote the dignity of human life and of all creation

We act with compassion and integrity

We strive for excellence.

Mater Mothers' Hospitals

Raymond Terrace
South Brisbane, Qld 4101

07 3163 1932

07 3163 3980

Mater acknowledges consumer consultation in the development of this patient information.

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mater mothers

mater | Little Miracles

We know that sometimes the biggest miracles come in the smallest packages.

That's why every baby born and cared for at Mater—including yours—is affectionately known as one of our 'Mater little miracles'. That's more than 10 000 Mater little miracles born into the world every year.

Mater Little Miracles raises money year-round to support babies in our Neonatal Critical Care Unit who are born premature, seriously ill, or are simply too small to go home straight away. Funds raised go towards giving these babies the best possible start to life; by investing in life-saving research, care and equipment.

To learn more about Mater Little Miracles visit materlittlemiracles.org.au