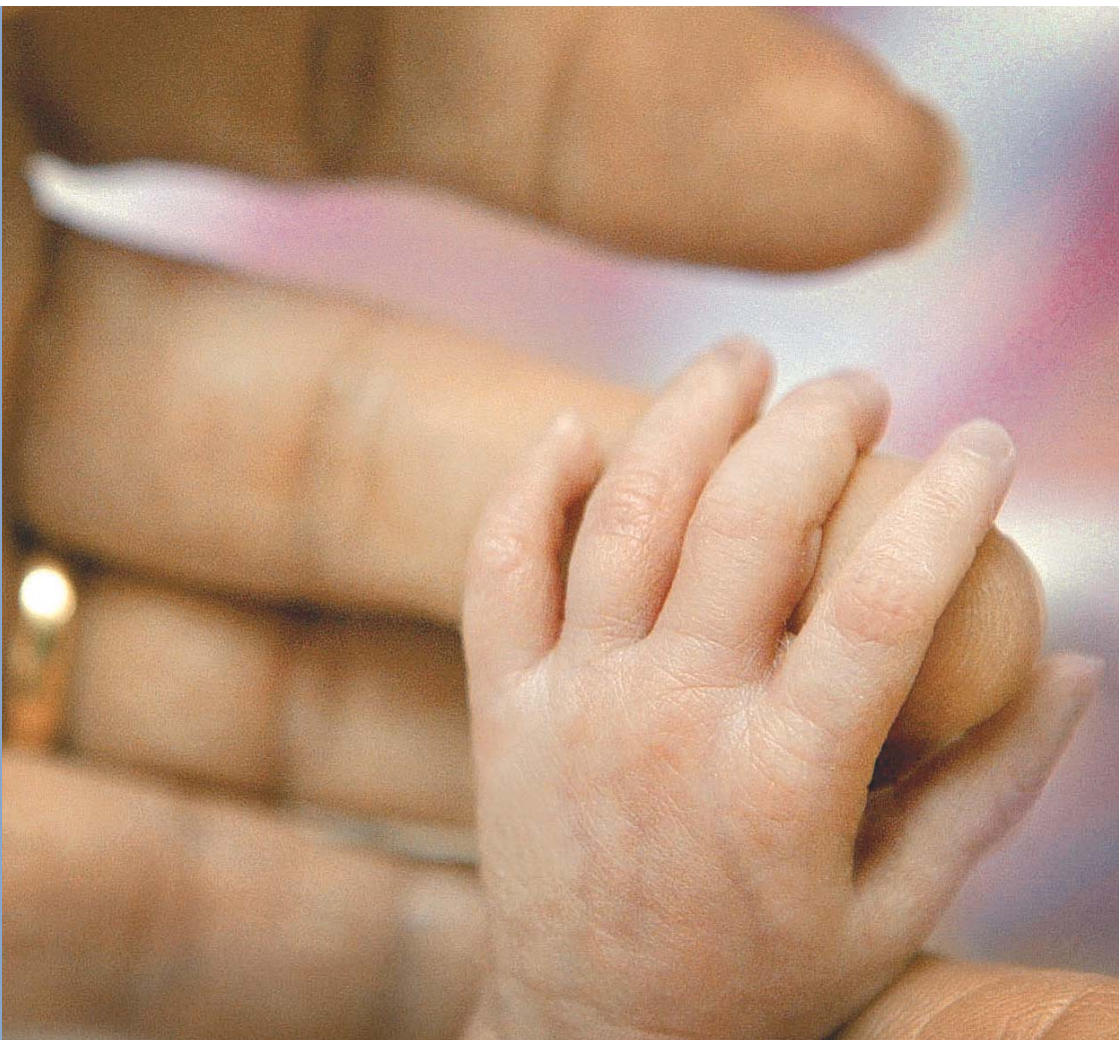


Caring for your very premature baby





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The neonatal intensive care unit

The neonatal intensive care unit (NICU) is sometimes busy and confusing, with lots of activity, staff, families and visitors.

Infants are often surrounded by a great deal of 'high-tech' machinery, including a ventilator to assist with breathing, monitoring equipment, syringe pumps, and blue lights to treat jaundice. Sensors are used to monitor the baby's temperature, automatically adjusting the incubator temperature to keep the baby warm. Other sensors monitor heart rate and breathing. Blood oxygen levels are measured using a small red light taped to the baby's hand or foot.

NICU staff aim to provide infants with the best possible care to keep them safe from infection and to help them grow and develop.



First appearances

When admitted to the NICU, your baby will be looked after by a team of specialist medical and nursing staff. Your baby will be connected to a monitor, respiratory support and syringe pumps. Intravenous (IV) lines will be placed into your baby's arm or leg and perhaps into the umbilical cord.

At first glance, your baby may appear very small and frail. Because they have little body fat, premature babies are often thin and have see-through skin.

Very premature babies lose heat and moisture easily. To help maintain their temperature, these infants are nursed under a radiant heater or in an incubator with high humidity added.

Differing growth patterns, general health and genetic makeup all influence the baby's weight at birth. Table 1 provides the average birth weight of premature infants admitted to NICUs across Australia and New Zealand between the years 2000 and 2002.

Table 1

Gestation	Average birth weight	Interquartile* range
23 weeks	588 grams	532–642 grams
24 weeks	657 grams	605–721 grams
25 weeks	767 grams	685–841 grams
26 weeks	884 grams	786–971 grams
27 weeks	1,002 grams	876–1,096 grams
28 weeks	1,134 grams	994–1,256 grams

*Interquartile refers to the range between the 25th and 75th percentiles.

Common equipment

Incubator	A specialist enclosed bed used to provide a warm, protected environment for the baby
Monitor	A device for measuring heart rate, breathing rate, blood pressure, and oxygen level. There are many different types of monitors, including oximeters and trans cutaneous monitors (TCMs)
Phototherapy light	A blue light used to reduce bilirubin levels (yellow skin pigment) in a jaundiced baby
Syringe pump	A pump that delivers milk via feeding tubes in the mouth, and fluid and medications via intravenous (IV) and arterial (IA) lines
Radiant warmer	An open cot with a radiant heater overhead
Ventilator	A machine that provides assistance with breathing via a tube placed in the mouth or nose and passing into the trachea (wind pipe)
Continuous positive airway pressure (CPAP)	A machine that gives the baby oxygen/air into the nose at a low pressure to help hold open the throat and lungs and help the baby breathe

Caring for your baby in the NICU

The NICU welcomes parents, their questions and their telephone calls at any time day or night. Families are not considered visitors and are encouraged to spend unlimited time with their baby; however, you may at times be asked to limit the number of people visiting your baby. During very busy periods or when surgical procedures are being performed in the unit, parents may be asked to step out of the nursery.

To reduce the chance of infection, we ask everyone to thoroughly wash their hands as they enter the NICU and before touching their baby. People with infections should not visit until they are better. Please consult the staff if you are unwell, have a cold sore or have had a recent exposure to chickenpox, etc.

Having a preterm baby is one of the most stressful experiences a parent can have. Most parents find the NICU overwhelming and frightening.

It is common for parents to feel a range of emotions, including grief, hurt, fear, worry, anxiety, confusion and vulnerability. Feelings of sadness and depression are also common. Many grieve the loss of a normal pregnancy and lost experiences and dreams.

Delivering a very premature baby is a period of crisis for many families. The emotional 'rollercoaster' can place undue pressure on relationships between parents and other family members. Often parents struggle to deal with a sense of losing control. Support is important during this difficult time.

The doctors, nurses and social workers in the unit are very experienced and can help with comfort, information and advice. A variety of external sources of support are also available. Contact details for some of these are at the end of this booklet.

Your involvement is essential in the care of your baby. The best way to help your baby in the NICU is to be there. Learning when your baby is stressed and needs to rest and when your baby

is ready to bond with you is one of the most important things you can do for your baby, especially in the early days.

You can also determine what interaction your baby likes. By hand holding, head stroking, talking or singing, you establish a bond with your baby. The nurses will help you learn about how much and what type of contact is best.

Most babies find comfort in the gentle yet firm cupping of hands on the head and feet. You should avoid light finger touching because it can be arousing, not soothing. For some very premature babies, being touched can be stressful and staff may suggest you limit physical contact. If this is the case, it is important you still spend as much time as possible with your baby. Your baby will slowly learn to enjoy being touched.

Depending on your baby's health, a hold or kangaroo cuddle may be possible even while your baby is still being helped by a ventilator.

Although you want to make time for interacting with your baby, you should allow periods of undisturbed sleep. Let your baby set the pace for your time together.

As your baby grows and recovers, it is important you become comfortable with providing all of your baby's daily care needs.

Developmental care

A premature baby is born during an important period of their development and cared for in an environment very different from the mother's womb. Excessive noise and light, poor positioning and over-handling may have harmful effects on the infant's long term development.

Developmental care refers to a range of strategies aimed at reducing the effect of the NICU environment on the premature baby. These include minimising noise and light exposure, careful positioning, minimal handling, clustering care, positive touch and kangaroo care.

Noise

Excessive noise in the NICU is a major source of stress, which not only interrupts a baby's sleep, but can cause hearing damage. Parents can help by avoiding loud talking in the NICU, limiting visitors and closing their baby's incubator doors quietly.

Light

Bright light also interferes with a baby's sleep patterns. In the NICU, overhead lighting is kept to a minimum by using individual spotlights and natural lighting as much as possible. Cot covers made with dark material are used on incubators to shield the baby's eyes from direct light. Many units provide these covers for each baby, but parents are encouraged to make their own if they wish.

Positioning

Very premature babies benefit from being positioned in a way that promotes normal development, provides comfort, promotes sleep and reduces the chance of later neuromuscular complications.

A premature baby has low muscle tone and, without support, lies in a flattened and extended position. In this position, the head falls to one side, the pelvis lies flat and the hips and shoulders rotate. This may affect their early mobility.

In the NICU, the premature baby is usually placed on their side or tummy, with support, boundaries and positioning aids, such as sheepskins, 'nests' and water pillows. Rolled towels or nappies are placed between the legs, under the hips and along the back to improve the baby's position. A sheepskin provides a soft surface for the baby to lie on. A 'nest' (rolled towel placed around the baby) provides a physical boundary the baby can nestle into and lean against, and offers a sense of security and comfort. Water pillows are used under premature babies' heads to reduce head flattening. Infants are moved regularly so they do not hold any position for too long.

Touch and kangaroo care

Touch, handling and cuddling are essential for both your baby and you as parents. We encourage this as much as possible. Touch can include holding your baby's hand, gently stroking the head and cuddling.

'Kangaroo care' is the term given to skin-to-skin holding in which a baby is placed on their parent's bare chest. Many babies enjoy this special time. Kangaroo care promotes closeness and bonding. Other proven benefits for infants include improved weight gain, decreased oxygen need and earlier breastfeeding.

Minimal handling and clustering care

Minimal handling is aimed at making sure babies have periods of uninterrupted sleep so they use less energy and grow more. NICU staff try not to wake a sleeping baby unless they really have to. Parents can do the same by waiting for their baby to wake before touching them. Sometimes it is really nice to just watch your baby sleep.

Clustered care is where tasks are performed together rather than individually at different times. This depends on each baby's sleep-wake cycles, state of alertness and medical needs. For example, if your baby has to have a blood test or an X-ray, then this may be an appropriate time to change their nappy. This will allow for longer periods of rest and 'quiet times' afterwards. Clustered care should be individualised and each baby must be watched for signs of stress.



Baby's cues

Babies respond in different ways to touch and handling. Sometimes, premature babies become stressed when handled and give signals to let us know how they are coping (see Table 2). Most babies display a range of these signs at one time or another without necessarily being stressed; however, a baby who consistently displays 'not coping' signs while being handled may need the activity modified and frequent breaks introduced.

Table 2

Baby coping	Baby not coping
alert	yawning, crying hiccups, sneezing
steady gaze	turning away, back arching
sucking	grimacing, frowning
hand to mouth movements	finger splaying
stable heart and breathing rate	change in heart or breathing rate
tolerating feeds	vomiting
smooth body movements	jitteriness
stable colour	change in skin colour

Immunisation

Immunisation against certain infectious diseases is an important part of your baby's medical care. Immunisation for the extremely premature baby usually commences at two months of age.

More information can be found in the *Understanding childhood immunisation* booklet in your baby's Child Health Record.

Common problems and treatments

The major complications very premature babies experience are the result of the baby being very immature.

Breathing

The lungs of very premature babies are small and not fully developed. Many lack an oily substance on the lung surface, called surfactant, which helps keep the lungs open. The steroid injection given to mothers before delivery helps mature the baby's lungs and stimulates surfactant production.

Some babies only need continuous positive airway pressure (CPAP) to help keep their lungs and throat open. While on CPAP, oxygen/air is delivered under a low pressure through the baby's nose, allowing the baby to do all the breathing. However, many premature babies can't breathe adequately by themselves and need support from a ventilator.

Using a ventilator requires a small tube to be passed through the baby's mouth into the trachea. The ventilator then blows small, frequent puffs of oxygen/air into the lungs. Most babies still do a lot of breathing themselves, even while ventilated. When the baby's lungs are better, the ventilator pressures and rate are weaned. The baby is then taken off the ventilator and treated with CPAP before needing no help at all.

You will notice the doctors and nurses will often adjust the ventilator and oxygen level to make sure the baby's oxygen and carbon dioxide levels are normal and to keep the baby's lungs in the best condition. X-rays are used to examine the lungs and make sure the breathing tube is in the correct position. This is all part of the normal day-to-day care of the premature baby.

Pneumothorax

About 10 per cent of babies who need help from a ventilator develop a small hole in their lung. The hole, also referred to as an air leak or pneumothorax, allows air to escape under the chest wall, thus compressing the lung. Treatment involves draining the air leak by placing a small tube through the chest wall for a few days. Infants with a chest tube are given pain relief and sedation for comfort during this time.

Chronic lung disease of prematurity

Ventilators can be life-saving in very small babies, but unfortunately, they can also damage the lungs. There is often a balance between keeping babies on the ventilator to help them with breathing and getting them off the ventilator completely. Sometimes this is not easy.

Many of the smallest babies develop a condition called chronic lung disease of prematurity (CLD). This is caused by a combination of factors, including infection of the placenta before birth, ventilators, oxygen and infection after birth. These infants usually need prolonged treatment with oxygen while their lungs slowly heal. Some will be discharged home while still being treated with oxygen.

Many of these babies have trouble with viral lung infections in the first year following discharge and need to be admitted to hospital. Despite this, they are likely to be able to run around the playground with other children by the time they are ready for school.

Intravenous fluids and medicines

Umbilical lines

In many small babies, special lines are placed into the umbilical cord blood vessels. (These vessels connected the baby to the placenta while in the womb.) This does not hurt the baby.

Often two umbilical lines are used. A venous line is used to give the baby nutrition, such as sugar, protein, fat, salt and water. An arterial line is used to continuously measure the baby's blood pressure and take blood samples.

Intravenous lines ('drips')

An intravenous (IV) line is used soon after birth if the umbilical vein cannot be used. Later, IV lines are also used to give the baby fluids, antibiotics or a blood transfusion. IV lines are often replaced every day or two because they have become blocked or are leaking, or to reduce the chance of infection.

Long lines

After about a week, the umbilical lines are removed and the belly button heals over to be normal. Subsequently, many of these babies have 'long lines' inserted. These are long, narrow IV lines that can stay in the veins for a couple of weeks. They are used for intravenous nutrition until the baby is tolerating milk feeds.

Blood transfusions

Blood travels around the body taking oxygen and food to the cells and carrying away waste. Blood contains several components, including red blood cells, platelets and plasma (the liquid).

Red blood cells contain haemoglobin, which carries oxygen. Very premature infants become anaemic (a lack of red blood cells) as a result of blood sampling and immature production of red blood cells, and need a transfusion. Transfusions of red blood cells are referred to as 'blood transfusions' or 'top-ups', and more than 90 per cent of infants born weighing less than 1,000 grams require them. On average, these infants require four or five transfusions during their hospital stay.

Platelets are blood cells that help the blood clot. Some infants have a low level of platelets at birth.

Severe infections and poor production by the bone marrow also lead to a low platelet count. These infants may require platelet transfusion to prevent or control bleeding.

Very premature babies commonly have low levels of other blood clotting factors. If these factors are too low, the baby may be given substances called fresh frozen plasma (FFP) or 'Cryo' through a drip.

Before the transfusion, the baby's blood is checked for blood type and cross-checked against the mother's blood. The transfusion is given through a drip into the baby's vein. Depending on the blood product and reason for its use, a transfusion can take anywhere from minutes to several hours.

All blood components are produced from donated blood. The Australian Red Cross Blood Service carefully screens the donors, cross-matches the blood for each individual, and manages the supply and distribution.

As with all medical procedures, blood transfusions involve some risks. These are limited as much as possible by the care taken when the blood is collected and by ensuring that blood is only given when appropriate.

The risk of viral infection is extremely low; for example, the risk of contracting HIV is less than one in 7,000,000.

ROP is very common and in most babies it is mild, settling completely without treatment and therefore not affecting the baby's vision. For those few babies who require treatment, it is usually successful.

Sometimes an eye examination is necessary after you take your baby home. This will be arranged prior to discharge. It is very important you keep this appointment.

Hearing

Hearing problems are more common in sick and very premature babies. As such, all infants in this hospital have a hearing screening test just before discharge. This is a simple, pain-free procedure performed by specialist staff in the nursery.

Some of the smallest babies do not 'pass' their first hearing screen because they may have fluid in their middle ear as a result of having had feeding and/or breathing tubes through their nose.

This will often disappear. These infants will receive a more detailed hearing test following discharge.

Inguinal hernias

Inguinal hernias present as a lump or bulge in the groin or scrotum and develop because of a weakness in the muscles of the abdomen. The swelling often gets bigger when the baby cries and may get smaller or go away when the baby relaxes.

The incidence of inguinal hernia in premature infants weighing less than 1,000 grams at birth is around 30 per cent. Hernias are more common in male infants and those who have a history of prolonged breathing support. They are usually painless, but may cause discomfort, fussiness, or even bowel obstruction. Surgical repair is often recommended before the baby goes home.

Long term outcomes

The long term effects of early birth can be difficult to predict in premature babies. Some very premature babies are slow to reach early milestones, such as rolling, sitting and crawling, although this does not necessarily indicate a long term problem.

Mostly, paediatricians follow up premature babies to make sure they are growing and developing normally. Some of these babies will be referred to other health professionals, such as physiotherapists and speech therapists. It is likely premature babies will have many appointments with paediatric specialists in the first few years.

Mild disability is relatively common in infants who are born very prematurely. Infants with mild disability are likely to be independent, although they may need some extra support through their preschool years. They may have minor difficulties with coordination, learning, speech and sometimes problems with vision, such as a squint in one eye.

Few very premature infants have major disabilities. Those who do can have several problems, such as difficulty with feeding, walking, hearing, language development and vision. Overall, the majority of premature babies do well.

