

Birth Before 32 Weeks



What to expect when your baby is
born prematurely

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Having a premature baby

Not all pregnancies progress as hoped or planned. Some babies are born too early – this is known as ‘premature’. We do not always know why a baby is born early, although we do know that there are some risk factors such as when a woman is expecting twins or triplets.

Most babies are born ‘at term’ between 37 and 42 weeks. A premature baby is born before 37 weeks. The shorter the pregnancy the more immature the baby’s organs and tissues at birth and the more specialised the care they will need.

The outcome for a premature baby depends mostly on how early they are born, but other factors also influence outcomes. Each year in NSW & ACT, about 1000 babies born before 32 weeks are admitted to a Neonatal Intensive Care Unit (NICU) for highly specialised care until they are mature enough to breathe and feed without intensive care support.

Overall outcomes for premature babies are good. However, there are risks of being born early that you should be aware of. Your doctor will discuss these risks with you and give you as much information as possible to help you decide what is best for your baby, for you and for your family. It is important you understand the potential intensity and duration of intensive treatment that your baby might need, the chance of your baby having a life-long disability and the chance of them dying.

Within these pages is information for you and your family about birth before 32 weeks, the risks and possible outcomes. Please remember that the risks of most of the complications are small and are uncommon in babies born after 32 weeks of pregnancy.

Before birth

Birth before 32 weeks gestation is sometimes due to complications of pregnancy such as early onset of labour or rupture of membranes (water sac around baby), bleeding, high blood pressure, growth problems or a pregnancy with multiple babies. If you have any of these conditions, some treatments can be given which help to protect a premature baby against complications such as respiratory distress syndrome where the baby has difficulty breathing or bleeding in the brain.

Medication to help protect premature babies before birth

- *Corticosteroids* are one of the most important treatments that can help premature babies survive. The drug is given by intramuscular injection to the mother before birth and works best if baby is born at least 48 hours after treatment. Corticosteroids used in this way can also help protect a premature baby’s brain from bleeding and can help immature lungs to function better.

- *Magnesium Sulphate* might also be useful in some circumstances to protect a premature baby's brain. This is given as an intravenous infusion to the mother if birth is expected soon.

Your doctor and midwife will discuss these treatment options with you.

Trying to stop premature labour

Some medications can help to stop contractions and labour for a short time. They may delay labour long enough to allow treatment to help prepare your baby for birth or, if required, to enable you to be transferred before the birth to a hospital with a NICU. Premature birth also increases the chance that your baby will be born by caesarean section.

Where is the best place for my premature baby to be born?

Babies born before 32 weeks (eight or more weeks early) usually require the specialist care provided in a NICU. If there is a risk that your baby will be born before 32 weeks, every effort will be made to transfer you before delivery to a hospital that has the appropriate specialist facilities, if it is safe for you to do so.

Figure 1 shows that survival of babies born before 28 weeks is improved if you are transferred to a hospital with a NICU before birth, emphasising why transfer is important.

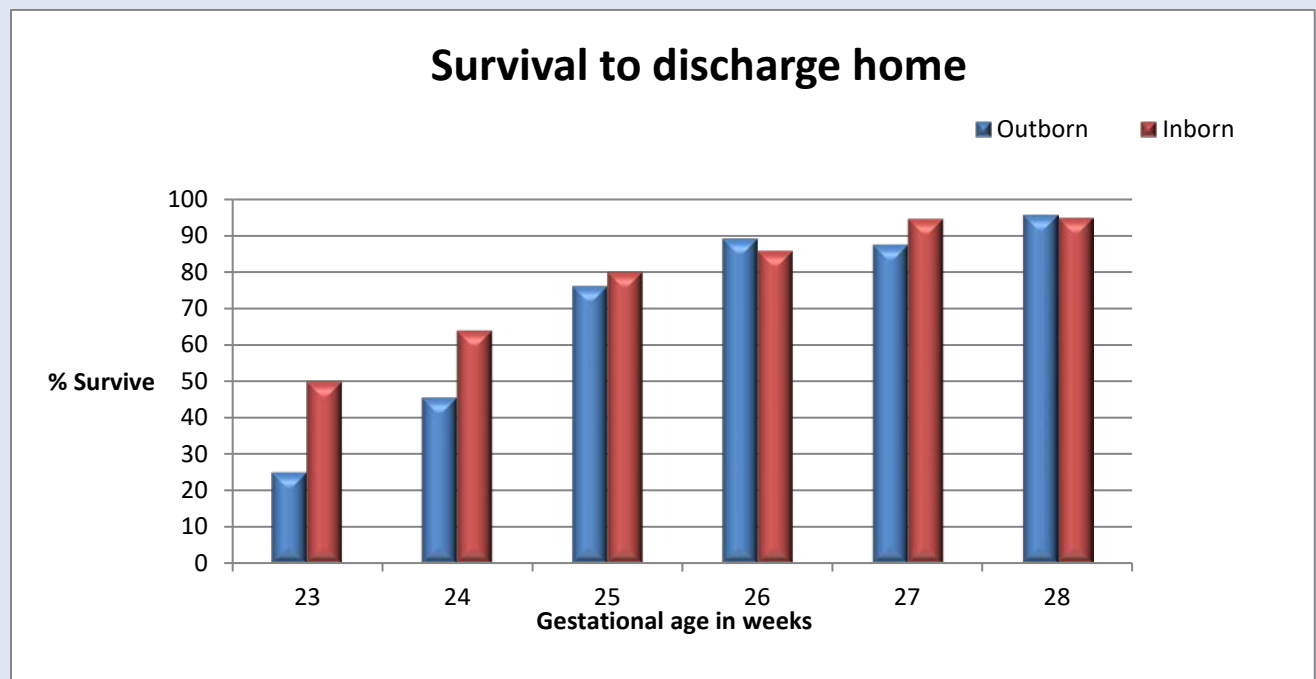


Figure 1. All babies ≤ 28 weeks gestation born 1/1/2012 – 31/12/2016 and admitted to a NICU
 Inborn means born in a hospital that has a NICU.
 Outborn means born in a hospital that does not have a NICU.

It is important to note that while these figures are useful guides, they do not predict the outcomes for individual pregnancies.

What if my baby is born in a hospital without a NICU?

Sometimes there isn't time to move you safely to another hospital before birth. Your baby may then need to be transferred after birth to a hospital that does have a NICU. This may not be to the NICU that is closest to your home but may be to where an intensive care bed and the appropriate equipment and staff are available to provide care for your baby at that time. The Newborn and paediatric Emergency Transport Service (NETS) will transfer your baby to the most appropriate hospital. The doctors and nurses of the NETS team will come to the hospital where your baby was born and transfer him or her by road, helicopter or air ambulance to a hospital that has a NICU. Every effort will be made to keep you and your baby together. Your midwife or doctor can provide advice about transferring you and your baby to a specialised centre. If you are separated from your baby, ask your midwife to help you express milk for your baby.

Moving from one NICU to another

Even if you are in a hospital with a NICU, occasionally that Unit may not have an intensive care bed available at the time of the birth of your baby. The safest way to manage this situation is to transfer you to another hospital before birth. If this is not possible, your doctor may discuss with you the need to transfer your baby to another NICU for intensive care after birth. Transfer to another NICU after birth might also be needed if your baby requires specialised treatment, for example, bowel or heart surgery.

Accommodation for parents

If you live a long distance from the NICU, finding accommodation at or near the Unit can be difficult. Some NICUs have short stay accommodation for parents of babies who are critically ill; others have longer stay accommodation available. You can discuss accommodation options with the nurses or the social worker in the NICU.

How will my baby be born?

Some premature births progress very rapidly and vaginal birth is the usual way that these babies are born. Sometimes labour can be slowed with medications, and there is time to discuss the options available for the birth of your baby. In general, for healthy women, vaginal birth is safer than Caesarean birth. Caesarean birth carries similar risks to all surgical procedures, such as infection and haemorrhage.

For women having a premature baby, a Caesarean birth may be recommended, for example if the baby is distressed and also for some breech babies, but there is controversy about whether caesarean or vaginal birth is best. If a Caesarean birth is planned, the doctor performing the surgery will need to consider your general health, your need for either a general or epidural anaesthetic or what type of Caesarean surgery is most appropriate for the gestation of your pregnancy. There are two types of Caesareans, known as 'classical' and 'lower segment' Caesarean - each with their own risks and benefits. A Caesarean birth may affect a woman's fertility and future pregnancies, and the risks of Caesarean birth to the mother should be carefully considered, particularly when there is high risk of a poor outcome for a baby.

Your doctors and midwives will explain the risks and benefits of vaginal and caesarean birth for premature babies, and recommend the safest birth plan for you and your baby, keeping in mind any plans you may have for future pregnancies.

Will my baby survive?

Each increasing week of pregnancy increases a baby's chance of survival significantly. By 27 weeks, over 90% of babies will survive (see Figure 2). The degree of intensive care required and risk of death or survival with a disability is increased greatly with each week less than 27 weeks gestation.

There are several reasons why babies die. The internal systems of premature babies are not always quite ready for life outside the uterus. Immature lungs, bleeding in the brain and infection are the main problems that threaten survival. Knowing exactly how many weeks pregnant you are when your baby is born is important.

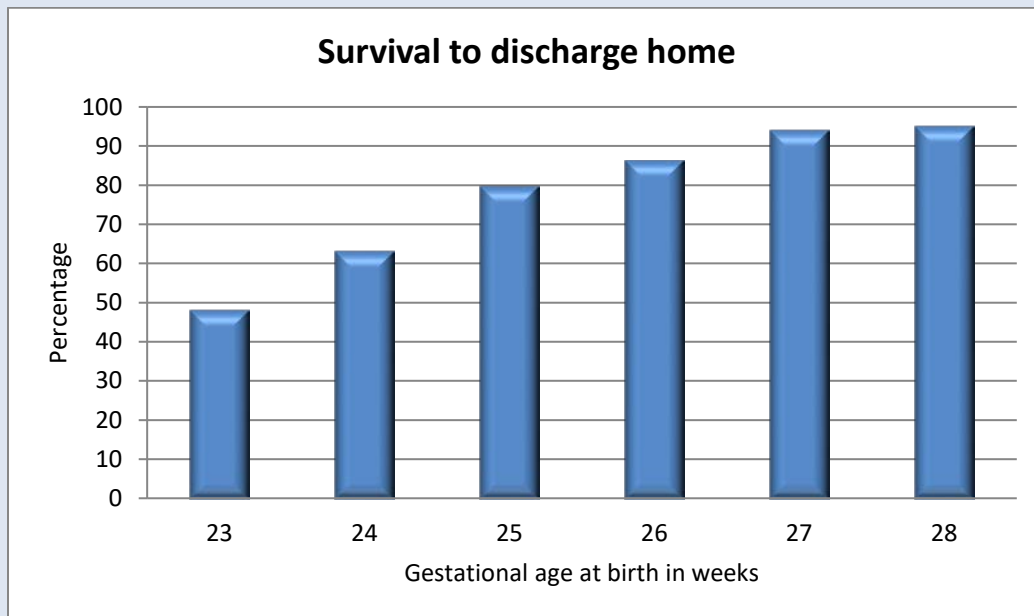


Figure 2. Neonatal Intensive Care Units' (NICUS) Data Collection - Babies 1/1/2012 – 31/12/2016 and admitted to a NICU

Difficult Decisions

Before, during and after the birth of your baby, you will be making complicated decisions. During this stressful time, Australian law supports a woman's decision to choose what is best for herself and her unborn baby. Once you give birth, your baby acquires individual rights and in discussion with you, doctors will ethically act in the best interest of your baby. The following information is a summary of some of the issues families face when having a baby at 22-26 completed weeks of gestation.

Many babies born between 22 completed weeks and 22 weeks and 6 days gestation are stillborn. If born alive, the internal organs of these babies cannot support life outside the uterus.

Babies born between 23 completed weeks and 23 weeks and 6 days are very immature at birth. Although survival rates are improving for babies at this gestation, they often require prolonged intensive care support (for many weeks or months) and may have an increased risk of disability compared with more mature babies. Decisions about options for care for your baby will be discussed with you by your doctor and health care team, so that the best decision can be made for your baby. Intensive care may not always be commenced for babies at this gestation, especially if the baby has an associated health condition or there are other complications.

From 24 weeks, although the chances of survival and a good quality of life are improved, the risk of death and disability still remains. At 24 weeks, babies will usually be offered intensive care unless a decision has been made by parents and the health care team that this is not in the best interests of the baby. Treatment is usually offered when there has been an opportunity for discussions between the family and health care team from the Newborn Intensive Care Unit. After birth, the decision for Intensive Care may be reconsidered; especially if the baby has a serious associated health condition or develops a serious new complication with a high risk of poor outcome.

From 25 weeks onwards, most babies will be provided with intensive care support, except in exceptional circumstances such if the baby has an associated health condition or there are other complications.

There are no rules that cover all circumstances. We recommend your particular circumstances are discussed with senior doctors experienced in providing Intensive Care to sick newborn babies. The opportunity to discuss your pregnancy should be offered as soon as possible - even if you are only at 22 weeks gestation. Your gestation alone is not the only factor taken into consideration when clinicians are offering intensive care.

The factors listed below also influence outcomes for babies born early:

- Twin or triplet pregnancy
- Ruptured membranes before 20 weeks
- Mother did not receive corticosteroids before birth
- Being born in a hospital that does not have a NICU
- Male baby
- Being born with an infection
- A birth weight that is much lower than expected for gestational age

It is important that you discuss with your doctor which risk factors are relevant to you and understand what this means for your baby

Intensive treatment

If intensive treatment is right for your baby, doctors and nurses from the neonatal unit will be there for the birth. Immediately after the birth, the team will take your baby to an area in the delivery room or operating suite where they have the appropriate equipment and space to provide the care your baby needs.

The team keep your baby warm and place an oxygen mask over their face to help breathing and inflate the lungs. A breathing tube may be placed in their nose or mouth and medicine called *surfactant* given (at that time or some time later) to help their lungs work better. For most babies, helping them breathe is enough to make them stable. Occasionally if a baby's heartbeat remains very slow, doctors may massage their chest through cardio-pulmonary resuscitation (CPR) and give a medicine called *adrenaline*. Where possible, you will have a chance to see and touch your baby before he or she is transferred to the NICU.

Ongoing assessment of your baby's response to resuscitation and intensive care is crucial.

What happens if intensive care is not started or is stopped?

Comfort care is special care for babies with a very poor outlook and whose life is precious but expected to be short. If the doctors feel that providing intensive medical treatments would not keep a baby alive or parents do not want to put their baby through treatments that might not work or cause suffering, comfort care is provided. This means providing care that will make the baby's time as comfortable as possible. Often simple things like making the baby dry and warm and holding them close are enough. However, doctors may recommend pain relief if the baby appears uncomfortable. Although it is extremely difficult to accept that a baby is not going to survive, for some families a decision to let their baby go peacefully is the right decision for them.

Your baby in the NICU

What you will see

The NICU can appear to be a frightening and, at times, a noisy place and seeing your premature baby in the NICU for the first time can be distressing for parents. The nurses and doctors are there to support you. Sometimes parents are offered a 'tour' of the NICU prior to premature birth.

Your baby's appearance

How your baby looks very much depends on gestation, weight and condition at birth. The size and appearance of your baby is very different to that of a full term baby. Very premature babies look very small and fragile. They have thin, transparent (see-through) skin that has no fat under it so you can see tiny blood vessels and it feels sticky to touch. Your baby will be attached to monitors and other pieces of life-saving equipment including those that provide fluids, nutrition and medicines through lines via veins and arteries.



The NICU environment may be new to you and you will see many things that you have never seen before. Different types of equipment provide the necessary care for your premature baby.

The types of equipment you will see include:

An *Incubator* is designed to keep babies warm and comfortable but still allow access for doctors and nurses to provide treatments and parents to see and touch their baby.



Oxygen is essential for life. Premature babies often need more oxygen than is found in the air. If a baby is breathing well on his or her own but still needs some extra oxygen, this can be given via small prongs in the nose. This is called **Low or High Flow Oxygen**. This extra oxygen can also be given by other methods.

A *Ventilator* is a breathing machine for babies who are unable to breathe well enough on their own. A small plastic tube is placed in the baby's windpipe, either via the mouth or nose. This tube connects to the ventilator, which inflates the lungs and provides extra oxygen as needed. **The tube is called an endotracheal or ET tube.**

CPAP (Continuous Positive Airway Pressure) provides support for babies who can breathe on their own but just require a little extra help. The baby is attached to a CPAP circuit by either small plastic 'prongs' in or a mask over his/her nose.



Cardio Respiratory Monitors display heart rate, breathing rate and blood pressure and have built in alarms if levels are too low or too high. **Oximeters** and **Transcutaneous Monitors** measure levels of oxygen in the small blood vessels under the skin. All these monitors attach to the baby's skin.

Umbilical Lines or Catheters are used to give premature babies fluids, nutrition and medication and can also be used to obtain blood for testing and to monitor blood pressure. These are often used in the first days after a baby is born and are long thin tubes inserted into the blood vessels in the umbilical cord.

Central Venous Lines are very thin, plastic tubes that are inserted into veins in the arms or legs and are used to give nutrition, fluids and medication. These tubes are called **long lines** or **PICC** lines (Peripherally Inserted Central Catheters).

The staff you will meet

You will meet many different health professionals while your baby is in intensive care. Some of these are included below.

Neonatologists are paediatricians who specialise in the medical care of premature and sick babies and are responsible for the medical care of your baby.

Fellows, Registrars and Residents are doctors that are undergoing specialised training in neonatology and carry out the day-to-day review of your baby needs. (The fellows are the most senior, the residents the most junior and the registrars are in between the two). All are supervised by the attending neonatologist.

Nurses - you will meet nurses who have very different roles within the NICU. Nurses at the bedside provide continuous care for babies. There may be one nurse to one or two babies depending on their needs. Others include nurse practitioners, clinical nurse consultants, nurse managers, and clinical educators.

Lactation Consultants or Infant Feeding Nurses assist with the expression of breast milk and breastfeeding.

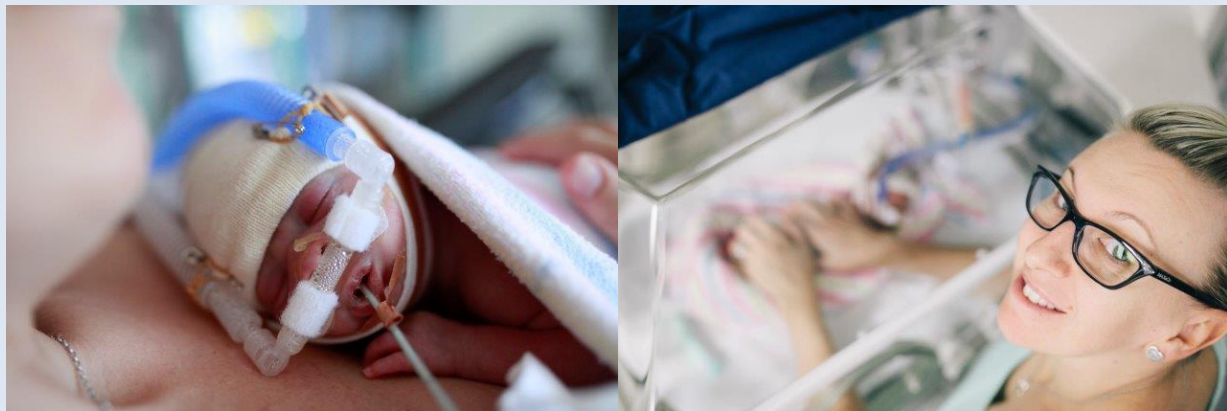
Physiotherapists, Occupational Therapists and Speech Pathologists also provide care for babies in the NICU.

Social Workers help families who have a baby in the NICU with the many problems that they might face, including the emotional and social stress that is caused by having a premature or sick baby.

Specialists/Surgeons are doctors that can provide care when surgery or other specialised treatments are required.

What you can do

You will be encouraged to visit and be as involved in the care of your baby as much as possible as this promotes bonding and might improve longer term outcomes. This may include skin-to-skin contact when holding your baby, helping with bathing, changing nappies and clothes, and feeding your baby. Your baby's nurse can assist you with these activities.





Feeding

Breast milk is the best food for premature babies as it contains important nutrients essential for growth and protection against infection. After birth, very premature babies are too small or too sick to suck at the breast and so mothers are encouraged to express breast milk as soon as possible after birth. Sometimes milk can be expressed before birth. The nurse or midwife will show you how to do this, at first by hand and later with a breast pump as milk volumes increase. Frequent expression is recommended to establish a good milk supply (we recommend at least 3 hourly including overnight). Expressed breast milk (EBM) can be frozen until your baby is ready for milk feeding.

Soon after birth, very premature babies receive intravenous nutrition called TPN (total parenteral nutrition). This is a mixture of carbohydrate, protein and fat, which is infused into a vein. As soon as clinically safe, tiny amounts of milk can be fed into your baby's mouth then through a tube that goes from the baby's mouth into the stomach (called trophic feeding). The amount of milk is gradually increased, this may take several weeks. Your baby's weight will be monitored closely and EBM may be fortified, meaning having extra calories and nutrients added to aid growth.



Babies start to suck and swallow between 32 and 34 weeks and sucking feeds are introduced slowly and increased over time. Help with breastfeeding is available to you in hospital, with some units having dedicated infant feeding nurses. Many mothers are breastfeeding by the time their baby goes home. However, it is not always easy to continue expressing breast milk in the NICU and there are times when breast milk feeding is not possible. There are options available to assist in these situations.

How you may feel

Giving birth early can be a shock, even if you knew it was coming. Parents often experience a range of emotions after the premature birth of their baby. Joy, exhaustion, sadness, anxiety, fear, guilt and numbness are just some of the feelings that can overwhelm new mothers and fathers whose baby is very sick or receiving intensive care.

The nurses, doctors and social worker looking after you and your baby are there to support you and your family and will do their best to answer your questions and discuss the situation with you when you are ready. As parents, you may have many questions, it is useful to write these down and discuss them with your nurse or doctor at your next visit. See your own doctor if you feel depressed, anxious or stressed at any time.

Understanding research in the NICU

You may be asked by your doctor, midwife or nurse to participate in research before or after your baby is born. It is important that you understand what that means.

Research in partnership with parents

Outcomes for premature babies have vastly improved in the last 50 years, as new research evidence – particularly from clinical trials - has been put into practice. Before each clinical trial begins, an Ethics Committee composed of professionals and members of the public approves it.

In a clinical trial, patients are placed into groups that receive different treatments. The groups are selected at random - usually by computer. That means that no one knows or can choose which treatment any patient will receive.

A study of hundreds of clinical trials in the journal, *Nature*, showed that, in just over half, outcomes were better with newer treatments. That means that, as more clinical trials are done, we can expect that outcomes for babies will continue to improve as they have in the past.

It's important to know that you can decline to take part in a clinical trial and you don't have to give a reason why. Choosing not to take part will not affect your relationship with the staff or the care that you or your baby will receive.

Taking part in clinical trials and other studies can improve outcomes for babies. The National Health and Medical Research Council recommend that parents, consumers and professionals work together as partners in clinical research. More information for parents on clinical trials is available at the end of this booklet.

Problems in the early days

Lung problems

We can help most premature babies to breathe more easily by giving their mother steroids before the birth. After birth, we can replace the substance (surfactant) which is missing from the premature baby's lungs. Most babies born before 32 weeks need some help with breathing because their lungs are not fully developed. Even after 32 weeks, some babies need help to breathe. To ensure best outcomes for a premature baby we need to maintain enough oxygen in the baby's bloodstream.

The most premature babies cannot get enough oxygen because the lung sacs that are important for breathing are only just starting to develop and we cannot keep them alive because their lungs are so immature.

For other babies we can support them until their lungs improve by giving mechanical ventilation. A machine (ventilator) does the work of breathing for the baby or the baby breathes for him or herself but some extra pressure is supplied to keep the airways open using CPAP. Some babies may develop scarring or damage to their lungs caused by this essential treatment.

Most premature babies are breathing normal air without extra oxygen by the time they go home. However, some babies continue to need help with breathing and extra oxygen even though they have recovered from their lung problems immediately after birth. If they need oxygen at 36 weeks corrected age, this is known as *chronic lung disease*.

Some babies born before 30 weeks will need extra oxygen treatment after they go home. Despite this, the lungs continue to recover and most babies only require extra oxygen for a few months. By one year of age, very few babies will still need oxygen. In the longer term, there may be subtle changes in the ways their lungs function but the majority of babies born prematurely are able to take part in the normal activities of everyday life at home and school.

If you or your partner smoke, it is important that you make every effort to stop before your baby is discharged home.

Heart problems

Babies may have problems with low blood pressure after birth and poor supply of blood to their body. They may need medicines to help their blood pressure. They may have problems with a blood vessel next to the heart (the '*duct*'). The duct normally closes after birth but in premature babies it may stay open. Babies may receive medicines to help the duct to close, and a few need surgery.

Brain problems

Bleeding in or around the brain, known as *intraventricular haemorrhage* (IVH), is very rare in babies born after 30 weeks. However, there is a risk of bleeding in babies born before 30 weeks. This is because there is an area in the middle of the immature brain of a premature baby where the blood vessels are very delicate. These blood vessels can burst and bleed (haemorrhage) into fluid filled cavities in the brain called ventricles. This is picked up via ultrasound of the baby's brain.

Usually the bleed is small and is not a big problem. In a few babies, the bleed can be large and increases the chance that the baby will have serious learning and movement problems when they are older. Some babies require transfer to a specialist NICU in a children's hospital if they need surgery for this problem. In some babies, the bleeding is so severe and the risk of brain damage is so great, that the baby might die.

Babies can also develop damage to the brain from lack of oxygen that is hard to see on ultrasound. It may show up later as cysts or 'holes'.

Eye problems

The back of the eye (retina) is still growing and developing for babies born very early. Because of being born so soon and needing extra oxygen, some babies develop a problem where the blood vessels at the back of their eyes grow too fast (known as '*retinopathy of prematurity*' or ROP). This can affect their vision later. Very premature babies who have serious problems with retinopathy may need laser treatment to one or both of their eyes.

Infections

Premature babies are more likely to get infections because the body's defence mechanisms are not fully developed. Sometimes babies are born with an infection, but they can also develop an infection during their time in the NICU. Most of these infections are treated with antibiotics. Serious infections can be life threatening and occasionally antibiotics will not control an infection well enough to keep a baby alive.

For this reason, the nurses and doctors in NICUs are very careful to minimise the chance of exposing a baby to an infection and this is something the staff will talk to you about when you are visiting. You can help by washing your hands before and after touching your baby and using alcohol gel at the bedside. If anyone visiting your baby is unwell, discuss this with the doctors and nurses before they visit.

It is also important that you and your family be vaccinated against whooping cough and influenza as soon as possible.

Necrotising enterocolitis

Necrotising enterocolitis (NEC) is a condition that causes inflammation of the bowel in premature babies. The bowel can be seriously damaged by this inflammation. Some babies may respond well to treatments such as antibiotics, pain relief and resting the bowel. Others will require surgery to remove the damaged part of the bowel. If

surgery is required, your baby will be transferred to a specialist NICU in a children's hospital. Some babies with NEC have developmental problems or can die from this complication of prematurity. Breast milk and probiotics can reduce a baby's chance of developing NEC.

Preparing to take your baby home

Returning closer to home

Premature babies who are transferred before or after birth to a NICU are usually transferred back to the hospital closest to home once intensive care is no longer required. This occurs as soon as it is safe and your baby is ready for the care available in your local hospital. Being closer to home makes visiting easier, especially at a time when breastfeeding is being established and may assist with the transition to home. For more information, please speak with the nursing in the NICU.

Length of stay in hospital

Most premature babies go home at, or before, the date they were originally due to be born. Babies born very prematurely spend the initial period in intensive care. The length of time spent in intensive care will depend on how early your baby is born and how sick he or she is. For example, this could be 10 weeks for a baby born at 24 weeks or only about one week for those born at 31 weeks. Babies then spend time in a special care nursery, growing and maturing before discharge to home. Temperature control, weight gain and the ability to suck feeds properly are usually the factors that determine exactly when your baby can go home.



Growing

When your baby is first born, there will be an initial weight loss as is the case with all newborn babies. Premature babies require more calories and nutrients than babies born at full term. By the time you take your baby home, he or she will be close to the size of a newborn at term (2 to 3 kg). After discharge home your baby will need to continue with nutritional supplements such as iron and vitamins and might need additional calories added to feeds to ensure adequate growth. After discharge home, some babies continue to have longer term feeding and growth problems.



Problems later in life

How will my baby develop in the long term?

This is an important question for all parents. The majority of babies born before 30 weeks gestation develop normally, but extremely premature babies are, in addition to some of the problems identified above, more likely to have mild or severe problems with overall movement, fine movement, vision, hearing, speech and language, social development, behaviour, learning and understanding. Regular developmental check-ups at a clinic or with your doctor are mainly done on those babies who are born about ten or more weeks early. As this varies between hospitals, the specialist looking after your baby will discuss this with you.



It is important however that even babies who are born slightly premature are reviewed regularly by your own doctor who will monitor progress and detect early any problems that might become apparent.

Of the babies who survive with a disability, about two thirds will have a mild disability and will be able to lead independent and productive lives. For the other children, their disabilities may be severe enough for them never to be totally independent.

Disability

'Disability' usually means a problem that affects someone's ability to do everyday things. There is a wide range of disabilities and they may affect one or many parts of a person's life. They may be mild or very severe. Sometimes parents find the possibility that their child might have a disability scary or very upsetting.

A child with a mild disability might be one who attends a normal school but is a year behind his or her peer group; or they might be receiving additional assistance with reading or writing in the classroom and might be attending therapy outside of school (such as speech therapy). They might be wearing glasses that help with vision without making their vision as good as those of classmates. They might need extra support from teachers to maintain attention or be clumsier in movement than most of the other children in the class.

Some children will need additional assistance. Some children might be slower than peers to the extent that they will be in a special needs class at school or even a special school and might require medication to help control hyperactivity.

When we talk about serious lifelong disabilities or severe disability, we are referring mostly to movement problems that mean that a child is not likely to be able to walk and may require a wheelchair for mobility.

We are also referring to severe learning problems or cognitive disability that means that the child has major limitations with caring for themselves, communicating and getting around. Children with severe learning disability may be able to have some basic conversations or they may have very limited or no ability to communicate. They may be able to learn some everyday tasks (getting dressed, toileting, feeding), or may be fully dependent on others. They may be able to live in supported accommodation when they are adults or may need full-time care. Some children are blind and/or require a hearing aid.

Problems with movement

Gross motor movement

Damage to the baby's brain from being born early can lead to problems with movement in later life. This affects how a child moves - from sitting, crawling, standing, walking, running, climbing and balancing. Premature babies can have problems with floppiness (decreased muscle tone) or stiffness (increased muscle tone). Both of these problems can hinder development of normal movement. These problems often disappear completely as the baby gets older (towards one year of age).

Sometimes there is a permanent muscle tone problem called *cerebral palsy*. This term means that the area of the brain that controls the muscles is not giving smooth signals to the muscles. As a result, either movements can become stiff and jerky or sometimes the muscles can be very floppy.

Cerebral palsy varies. It can sometimes be quite mild, for example, the child might have trouble moving one hand or one leg but have no trouble moving other parts of their body. Children with mild cerebral palsy are usually able to do most things like other children, are able to walk by themselves and go to a regular school.

Alternatively, cerebral palsy can be much more severe. Some children have problems affecting all of the muscles in their body. They may not be able to walk and need to use a wheelchair for mobility and special ways to communicate. They may need others to help them with most or all of their everyday needs.

According to recent data, just over 40% of children with cerebral palsy were born prematurely (less than 37 weeks gestation) compared with 8% of the total population. Cerebral palsy occurs in approximately:

- 1 in 25 babies born before 27 weeks
- 1 in 30 babies born between 28 - 31 weeks
- 1 in 220 babies born between 32 - 36 weeks

Fine motor movement

Fine movement means small movements of the arms and hands that are necessary for such things as manipulating small objects, drawing and building with blocks etc. These skills give a young child important early practice for when they learn to draw and write later at school. This is an area of development where many premature babies have difficulty, despite having normal overall movement. Problems with fine movement may not be identified until the child is older.

Eye problems

Most eye problems are minor and can be easily treated, such as squint, long, or short sightedness. However, a small number of babies who are born before 30 weeks gestation will become blind. This is the result of a disorder called retinopathy of prematurity (ROP). Abnormal blood vessels can spread across the retina—the part of the eye that sees. These blood vessels are fragile, can leak and cause scarring of the retina causing blindness.

It is important that any eye problems are recognised early for treatment to be given so that visual development is not affected. An ophthalmologist (eye doctor) will carefully check the eyes of all babies who are very premature while they are still in the NICU and will continue to check them after they have left hospital.

Hearing, speech and language problems

All newborn babies, whether full term or premature, have their hearing checked before they go home from hospital. Some babies born before 30 weeks will need to wear hearing aids because they will have some degree of hearing loss. This can range from mild to severe loss.

The understanding of words and language is very important for communication, social interaction, reading and learning. Many very premature babies will have some degree of difficulty with speech, language or reading. Children with severe disability may be able to have basic conversations or they may have very limited or no ability to communicate. Talking and reading to your premature baby is an important way to assist in the development of language.

Social development

Early social skills such as smiling, laughing, socialising, feeding and dressing usually develop at normal ages, adjusted for their prematurity, unless there is an overall problem with development.

Attention and behaviour problems

Attention and behaviour problems can affect children who were born very prematurely. They are more likely to be very active, even hyperactive children and to have a shorter attention span than babies born at full term. This may improve with early encouragement to sit and play for brief periods in an environment where there is not too much noise or other distractions. It can also be a complicating factor in fitting in and learning new skills at preschool and school.

Learning and understanding problems

A baby's brain is still growing and developing in the last months of pregnancy. For the premature baby, this has to occur outside the uterus when they may be very sick.

Children who have been born very early may be slower with their learning and development than children who were born at term. Some children will need some extra help with their schoolwork. Learning problems can be mild where the child needs extra assistance in a normal classroom or they can be much more severe and affect the child's ability to communicate, care for themselves and later on, live independently. Often an assessment of readiness for school can be helpful.

In summary

Mild disability includes children with mild learning problems or other impairments, which do not interfere significantly with everyday life.

Moderate disability includes children who have:

- reached a reasonable level of independence e.g. a child with cerebral palsy who can walk
- a lower than average IQ
- hearing loss correctable by a hearing aid
- impaired vision without blindness

Severe disability includes children who have:

- disorders requiring high dependency on carers e.g. a child with cerebral palsy that prevents the child from walking
- profound hearing problems (requiring two hearing aids)
- blindness

As parents of a premature baby, you may face challenging times ahead. You are not alone and your doctor, nurse, hospital staff and early childhood centre staff can assist you if you have any questions. It is however not always possible to predict what problems your baby will have later in childhood. Living with the 'not knowing' aspect can be very difficult. A list of organisations that provide support to families with a premature baby that you might find useful is included.

If your baby dies

Sometimes babies are born too soon or are so sick that they do not survive.

Post mortem examination

If your baby dies, your doctor may discuss the possibility of post mortem with you. Deciding about a post mortem can be very difficult. A post mortem can only be conducted with your consent.

A post mortem examination of your baby's body and of the placenta (afterbirth) may help to find out why your baby has died. A post mortem can also reveal a problem that might affect future pregnancies. However, in some cases, a post mortem does not provide any new information about why your baby died. You can discuss the potential benefits of a post mortem for you with your doctor, family and friends. It is important that you make the right decision for you and your family.

Social worker

The social worker within the hospital offers support before and after your baby's death and can advise you on what assistance is available locally. The social worker will assist you with the decisions about funeral directors and funeral arrangements and provide practical help and assistance with legal requirements.

Follow-up Care

After the loss of your baby, your obstetrician, paediatrician, neonatologist and social worker will organise appointments for you to discuss what happened during your pregnancy and to your baby. Such discussions may include a plan for extra monitoring and interventions in a subsequent pregnancy.

More information about premature birth

If you would like to discuss any of the issues raised, please contact the referral hospitals that are part of the NSW Pregnancy and newborn Services Network (PSN).

Referral Maternity Hospitals with a NICU

John Hunter Children's Hospital, Newcastle, NSW 2305	Switchboard 02 4921 3000
Liverpool Hospital, Liverpool, NSW 2170	02 9828 3000
Nepean Hospital, Penrith, NSW 2750	02 4734 2000
Royal Hospital for Women, Randwick, NSW 2031	02 9382 6111
Royal North Shore Hospital, St Leonards, NSW 2065	02 9926 7111
Royal Prince Alfred Hospital, Camperdown, NSW 2050	02 9515 6111
The Centenary Hospital, Woden, ACT 2606	02 6244 2222
Westmead Hospital, Westmead, NSW 2145	02 9845 5555

Referral Children's Hospitals with a NICU

The Children's Hospital at Westmead, Westmead, NSW 2145	02 9845 0000
Sydney Children's Hospital, Randwick, NSW 2031	02 9382 1111
John Hunter Children's Hospital, Newcastle, NSW 2305	02 4921 3000

Newborn and paediatric Emergency Transport Service (NETS)

Hotline	1300 36 2500
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Support services

The hospital caring for your baby will know of a parent support group and will be happy to put you in touch with someone who can give you more information. Other contacts you may find helpful are presented below.

Organisation	Phone	Website
Australian Breastfeeding Association	1800 686 268	www.breastfeeding.asn.au
Australian Multiple Birth Association	1300 886 499	www.amba.org.au
MotherSafe	1800 647 848	
Miracle Babies Foundation	1300 622 243	www.miraclebabies.org.au
PregnancyBirthBaby		www.pregnancybirthbaby.org.au
SANDS (Stillbirth & Newborn Death Support)	1300 0 SANDS	www.sands.org.au
Rednose (SIDS & Kids NSW)	1800 651 186	www.rednose.com.au
Translating & Interpreting Services	13 14 50	-

See government services in your local telephone directory or contact your hospital social worker for the following services:

- *Aboriginal health workers and liaison officers*
- *Domestic violence / sexual assault centres*
- *Hospital chaplains*
- *Lactation consultants*
- *Premature birth/baby support groups*
- *Social workers*

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http://www.flourishpaediatrics.com.au/docs/anticipating_birth.pdf

Further reading about clinical trials

www.TestingTreatments.org This multimedia site clearly explains why treatments need to be tested.

<http://healthtalkonline.org/> - and search for “clinical trials” This site features video clips of people sharing their experience of clinical trials and is a rich source of information, in words and videos.

www.bt4k.com.au

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With thanks to

The PSN Executive Committee

The Sydney Children's Hospitals Network

The NICUS Data Collection Group

The information on outcomes for premature babies in NSW and the ACT comes from the ongoing Neonatal Intensive Care Units' (NICUS) data collection of the NSW PSN. The findings are published annually by the NSW Ministry of Health in the Mothers and Babies Report. The cooperation of parents has been essential for the success of this long term audit.

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Miracle Babies Foundation

The Cerebral Palsy Alliance

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