

Anticipating the birth of an extremely premature baby



A grayscale photograph showing a close-up of a hand gently cradling a small, curled object, which is likely a premature baby. The hand is positioned in the center-right of the frame, with fingers slightly curled around the object. The background is a soft, out-of-focus light gray. The text "Anticipating the birth of an extremely premature baby" is overlaid in a dark blue font on the right side of the image.

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Introduction

More than 60,000 babies are born in Victoria each year. Most babies are born at 'term', that is, between 37 and 42 weeks; however, a small proportion are born preterm (before 37 weeks) and admitted to a neonatal unit. The majority of these infants survive and do well. Some infants, particularly those born earlier than seven months or 28 weeks, have problems as a result of immaturity.

It is difficult to predict when preterm birth might occur. It is more common in certain circumstances, such as multiple pregnancy, assisted conception (for example, in vitro fertilisation (IVF)) and when mothers have medical illnesses (for example, high blood pressure, kidney problems, diabetes).

This booklet is designed to provide important information for parents who are likely to deliver a preterm baby less than 28 weeks gestation.



The birth

A team from the Neonatal Intensive Care Unit (NICU) will be present at the birth of your premature infant, regardless of whether you deliver in the birthing suites or operating theatre. This team usually consists of senior medical and nursing staff experienced in 'high-risk' births.

Immediately following birth, your baby will be dried and placed under a radiant warmer for further assessment. It is likely your baby may require some assistance with breathing.

Following a period of stabilisation, your baby will be placed in the specialised transport cot and transferred to the NICU. Parents are encouraged to stay with their infant during this time.



Neonatal intensive care

The NICU, combining dedicated medical and nursing care with advanced life-supporting equipment, is an intensive care unit designed to meet the special needs of premature and sick infants. Most infants in the NICU receive respiratory support from a ventilator to assist with breathing. **Artificial breaths are delivered to the lungs via a tube placed in the baby's nose or mouth.**

Infants born prematurely are yet to develop sufficient fat under the skin to maintain temperature. As a result, they are nursed either in an incubator or under a radiant warmer to keep their temperature stable.

Infants initially receive fluids intravenously (into the vein), although once they are stable, milk feeds are slowly introduced into the stomach via a fine tube placed into the nose or mouth.

Baby's appearance

The baby's appearance depends on gestation at birth. Very premature infants are small, often weighing little more than a tub of butter. They are usually thin and frail-looking, and their skin is seemingly see-through.

Once admitted to the NICU, intravenous (IV) lines will be used to give the baby fluid and medicine. Often these lines are initially placed in the umbilical cord.

The infant will be connected to monitors that measure heart rate, breathing rate, oxygen level and blood pressure.

Emotional support

Having a preterm baby is undoubtedly one of the most stressful experiences a parent can have. Most parents find the NICU to be overwhelming and frightening. For parents of very premature infants, this experience is magnified.

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.

Premature delivery 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 paramount during this difficult time.

The doctors, nurses, and social workers in the unit can be valuable sources of comfort and advice. In addition, a variety of external supports are available. Contact details for a selection of these are provided at the end of this booklet.

Factors affecting survival

Life in the NICU is not always predictable. The most critical period for a premature baby is the first week of life. Despite being fully formed by three months, very premature infants are complex and prone to a number of problems as a result of the immaturity of their fragile bodies.

The chance of survival and the likelihood of long term disability or handicap depend on many factors, including how early the baby is born (gestation), maternal health and the baby's condition at birth.

Gestation

The chance of survival increases with gestational age. Gestation determines if the infant's lungs and other organs are mature enough to allow the infant to live within the limits of today's technology. Infants born before 24 weeks gestation have a small chance of surviving and being normal. Each additional week the baby spends in utero (inside the mother's womb) substantially improves the baby's chances. By 28 weeks, infant survival is well over 90 per cent.

Birthweight

As with gestation, the chance of survival increases with birthweight. It is difficult for infants weighing less than 500 grams or one pound to survive; however, survival is very much greater once the birthweight is 1,000 grams or two pounds.

Infant condition at birth

The baby's chance of survival also depends on their condition at birth. The baby's colour, heart rate, blood pressure and response after delivery are all indicators of the baby's condition at birth. The presence of any additional physical abnormality, such as heart or lung defects, makes it even harder for premature babies to survive.

Multiple pregnancy

Preterm delivery is likely in multiple pregnancies. About half the women carrying twins deliver prematurely (before 37 weeks gestation), and nearly all triplets and quadruplets are born early. The survival rate for these infants is slightly less than that of the single premature baby of similar age, partly because of the complications in both mothers and babies in multiple pregnancies.

Maternal health

Women with conditions such as infection, diabetes, epilepsy, or kidney and heart disease, including high blood pressure, have a greater chance of preterm delivery.

Antenatal steroids

Before preterm delivery, mothers are usually given a steroid injection, similar to Cortisone. This helps the baby's lungs to mature, reducing the severity of premature lung disease. In addition, the steroid injection also protects the infant's fragile brain.

Delivering in a perinatal centre

Perinatal centres are hospitals that offer specialist obstetric and neonatal care, including a Level III NICU. Some babies are delivered in Level I or II hospitals (that is, those without NICU facilities) and are transferred to a perinatal centre by the Newborn Emergency Transport Service (NETS).

Long term outcomes

Disability can be difficult to predict and takes many forms. Mild disability is relatively common in preterm infants and can include short attention span, difficulty with learning or speech, poor coordination, and vision loss requiring glasses. Many preterm infants are delayed in reaching specific developmental milestones, such as smiling, sitting and walking unaided.

Unfortunately, some premature infants survive with major disability, including blindness, deafness, mental retardation, and/or cerebral palsy. Cerebral palsy is a motor disorder affecting movement, muscle tone and posture. Children with severe cerebral palsy may require a wheelchair or walking frame to aid their mobility. Problems with speech and feeding are also common for these special children.

Regardless of outcome, most children who are born extremely prematurely are likely to enjoy life and are a source of great pleasure to their parents and family.

Chronic lung disease

Many infants born before 28 weeks develop a condition called chronic lung disease of prematurity. These infants usually need prolonged treatment with oxygen while their lungs slowly heal. Despite this, they are likely to be able to run around the playground with other children by the time they are ready for school.

The following pages provide gestation-specific outcomes for Australian and New Zealand infants who were offered intensive care following birth *and* survived to be admitted to a NICU during 2002. Survival data is collected at two years of age.

Before 24 weeks

Average birthweight at 23 weeks: **588 grams**

Some infants born before 24 weeks are not resuscitated at birth because survival without severe disability is unusual. Others are resuscitated but do not live long enough to be admitted to the NICU. Less than one-third of infants born before 24 weeks and admitted to a NICU will survive.

Hospital stay

Most surviving babies will spend about four to five months in hospital. Generally these babies need assistance with breathing for at least two months and almost all will develop chronic lung disease of prematurity and be discharged home on oxygen. Some will develop severe damage to their eyes (retinopathy of prematurity) necessitating laser therapy.

Long term outcomes

Overall, two-thirds of those infants discharged home are without disability or will be mildly disabled. The remaining third will have severe disability, affecting hearing, vision and overall development.

24 weeks

Average birthweight: **657 grams**

Almost 200 infants of 24 weeks gestation are admitted to NICUs across Australia and New Zealand each year. About half will survive.

Hospital stay

Most infants are in hospital for three to four months. Generally these babies need respiratory support of some kind for the first few months. Again, almost all these babies will develop chronic lung disease of prematurity and require home oxygen. Some infants will need laser therapy for retinopathy of prematurity.

Long term outcomes

At this gestation, long term outcomes are similar to those for the 23-week infant. Approximately two-thirds of infants discharged home will be without disability or mildly disabled, although still independent. One-third will be severely disabled and require help with daily tasks.



25 weeks

Average birthweight: **767 grams**

More than 200 infants born at 25 weeks gestation are admitted to Australian and New Zealand NICUs each year. By this gestation, survival rates have climbed to around 70 per cent.

Hospital stay

Generally infants at this gestation spend approximately three to four months in hospital and about six to seven weeks on respiratory support.

Long term outcomes

Many infants discharged home at this age will be without disability or be mildly disabled. Some will be severely disabled.

26 weeks

Average birthweight: **884 grams**

Each year, nearly 250 infants of this gestation are admitted to Australian and New Zealand NICUs, 80 per cent of whom survive.

Hospital stay

These infants spend approximately three months in hospital. In most cases respiratory support is required for about five weeks.

Long term outcomes

Most infants discharged home at this age will be without disability or be mildly disabled. Some will be severely disabled.

27 weeks

Average birthweight: **1,002 grams**

More than 300 infants of 27 weeks gestation are admitted to Australian and New Zealand NICUs each year. The survival rate at this gestation is around 90 per cent.

Hospital stay

Babies born at 27 weeks spend an average of three months in hospital. These infants often need less time on respiratory support.

Long term outcomes

Almost all infants discharged home will be without disability; however a few will have some disability. Some infants will be discharged home on oxygen.



28 weeks and beyond

Average birthweight at 28 weeks: **1,134 grams**

Approximately 450 infants born at 28 weeks are admitted to Australian and New Zealand NICUs each year. The survival rate at this gestation is greater than 90 per cent.

Hospital stay

Babies born at this age usually spend nine or ten weeks in hospital. They usually require breathing support for only a few weeks.

Long term outcomes

Long term outcomes are brighter for infants born at or beyond 28 weeks. The majority of these infants survive without disability.



Breastfeeding

Breast milk provides the premature infant with important growth factors and protection against infection. Since the extremely premature infant is too small and weak to suck at the breast, mothers are encouraged to express breast milk during the baby's hospital stay.

Maternal breast milk production is an automatic response to birth, regardless of whether the baby is born premature or at term, vaginally or by caesarean section. To establish a good supply, frequent expression is encouraged soon after delivery. The nurse caring for you will show you how to express your breast milk by hand. As your milk supply increases, you may prefer to use a breast pump.

In the early days of life, premature infants are usually fed a sugary solution directly into the vein. During this time, and until oral feeds are started, the mother's breast milk can be frozen.

Feeds are initially given via a fine tube passing from the mouth or nose directly into the stomach. The baby starts on tiny amounts of milk, slowly increasing over the next few weeks. By around 34 weeks, infants are learning to suck and may graduate to breast, bottle or cup feeds.

Going home

Generally speaking, premature infants are discharged home from hospital at or slightly before the date they were due to be born. Critically ill infants and those requiring long term breathing support may require a longer hospital stay.

Not all infants go home directly from the NICU. Many infants are transferred to a special care nursery closer to home to be nurtured until ready for discharge. This reduces the travel burden and eases the pressure on families.

Infants with chronic lung disease of prematurity may be discharged home on oxygen therapy. Parents of these infants will be provided with extensive education and support prior to and following discharge.

Death

Many parents facing the prospect of losing their baby experience feelings of sadness, shock, anger and sometimes confusion. The need to make decisions about ongoing care often compounds these feelings.

If it is believed that further treatment cannot help the baby, parents may be asked to consider removing life-supporting equipment. In most cases, this decision need not be rushed. It is important for parents and doctors to make the decision that is right for the baby and the family. It can be valuable for parents to discuss the withdrawal of life support with their family, close friends and other health professionals.

Some parents may wish to have their baby blessed or baptised, especially when faced with the decision to withdraw treatment. The parents, a friend or close family member, nursing staff, hospital chaplain or a celebrant of the family's faith can perform this.

Usually when a loved one dies, there are many memories of time spent together, which serve as a comfort to those who grieve them; however, in the case of a preterm baby, these memories will be limited to the NICU. While treatment is being withdrawn, and after the baby has died, parents and family are given the opportunity to spend time with their baby. For many parents, this is the only time they have cuddled their baby.

During this time, many parents choose to hold and comfort the infant. Some also choose to bathe and dress them. Everlasting memories can be made by taking photos and video and making ink or clay prints of the baby's tiny hands and feet.



Web sites and support services

Austprem

Providing friendship, information and support to parents and carers of prematurely born babies and children

www.austprem.org.au

Australian Multiple Birth Association

www.amba.org.au

Bonnie Babes Foundation

Grief counselling for the loss of a baby through miscarriage or stillbirth, or following death in the neonatal period

Telephone: (03) 9758 2800

www.bbf.org.au

Featherweight Club

Providing support and information for premature babies and their parents c/o Mercy Hospital for Women

www.featherweightclub.com

Maternal and Child Health Line

Telephone: 13 2229 (24 hours)

Post and Ante Natal Depression Association (PaNDa)

Telephone: (03) 9428 4600

Preterm Infants' Parents' Association (PIPA)

www.pipa.org.au

SANDS (Victoria)

24-hour support for bereaved parents, families and friends following the death of a baby through miscarriage, stillbirth, or shortly after birth

Telephone: (03) 9899 0218

www.sandsvic.org.au

SIDS and KIDS Victoria

24-hour crisis and ongoing bereavement support

Telephone: (03) 9822 9611

Freecall: 1800 240 400
(from most landlines)

www.sidsaustralia.org.au

Translating and Interpreting Service

24 hours

Telephone service:
13 1450

On-site service bookings:
1300 655 082

Victorian Infant Collaborative Study (VICS)

Dedicated to providing support and information to the parents and families of premature babies

www.vics-infantstudy.org.au

Victorian hospitals with NICU facilities

Mercy Hospital for Women

163 Studley Road, Heidelberg 3084

Telephone: (03) 8458 4444

Monash Medical Centre

246 Clayton Road, Clayton 3168

Telephone: (03) 9594 6666

Royal Children's Hospital

Flemington Road, Parkville 3052

Telephone: (03) 9345 5522

Royal Women's Hospital

132 Grattan Street, Carlton 3053

Telephone: (03) 9344 2000

Further reading

The book, *Care around preterm birth: a guide for parents*, by the National Health and Medical Research Council (1997) can be downloaded at

www.nhmrc.gov.au/publications/synopses/cp52syn.htm

Further reading material is available on request from the hospital's Social Work Department.

The Bonnie Babes Foundation has a free publication, *You are part of our lives and will always live in our hearts*. This book contains information that can help families cope in their time of grief. Many hospitals have copies of this book. If yours does not, please contact the Foundation on (03) 9758 2800 and a copy will be mailed to you.

Notes

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