Outcomes for Premature Babies

An information booklet for parents
A NSW Health Department Initiative.

The information on outcomes for premature babies in NSW and ACT comes from the ongoing Neonatal Intensive Care Units’ Data Collection of the NSW Pregnancy and Newborn Services Network. The findings are published annually by the NSW Health Department in the NSW Mothers & Babies Report. The cooperation of parents has been essential for the success of this long term audit.

Advice on decision making about extremely preterm birth comes from a series of consensus conferences involving clinicians and consumers. The most recent was held in February 2005. The Ethics Advisory Committee (NSW Health) and the Maternal and Perinatal Health Priority Taskforce have endorsed this publication.

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A copy of this booklet is also available from the following web site: www.psn.org.au
Having a Premature Baby

Not all pregnancies go as planned. Some babies are born too early - prematurely or preterm. We do not always know why a baby is born early, although we do know that the chance of an early birth is higher when a woman is expecting twins or triplets.

A full term baby is born between 37 and 42 weeks of pregnancy. These babies are usually fully developed. A preterm baby is born before 37 weeks of pregnancy. The shorter the pregnancy, the more immature the baby’s organs and tissues at birth and the more specialised the medical and nursing care he or she will need.

The outcome for a premature baby depends largely on how early he or she is born. Each year in NSW, about 1000 babies are born more than eight weeks early (before 32 weeks of pregnancy). Almost all of these babies need highly specialised care in a Neonatal (Newborn) Intensive Care Unit until they have developed enough to breathe and feed without clinical help.

The overall outcomes for premature babies are good. However, there are risks to being born early. This booklet explains those risks and answers the common questions asked by parents. Please remember that the risks of most of the complications mentioned here are small and are uncommon in babies born after 30 weeks of pregnancy.

We encourage you to discuss any concerns with your doctor or midwife.
Before Your Baby Is Born

Where is the best place for my premature baby to be born?
Babies born before 33 weeks of pregnancy (seven or more weeks early) have a better chance of survival if they are born in a hospital which has a highly specialised Neonatal Intensive Care Unit. If there is a risk that your baby will be born as early as this, it is likely that your doctor will arrange for you to be transferred before delivery to a hospital which has these specialist facilities for your baby.

Even if you are in a hospital with a Neonatal Intensive Care Unit occasionally that unit may not have an intensive care bed available at the time of the birth of your baby and the need for transfer to another unit may be discussed.

What if my baby is born in a hospital without a Neonatal Intensive Care Unit?
If this happens, your baby may need to be transferred to another hospital which does have a Neonatal Intensive Care Unit. The transfer is done by the NSW newborn and paediatric Emergency Transport Service (NETS).

The highly trained doctors and specialist nurses on the NETS team will come to the hospital where your baby was born and transfer him or her, by road or air ambulance, to a hospital which has a Neonatal Intensive Care Unit. Every effort will be made to keep you and your baby together. Your midwife or doctor can provide advice about transferring you with your baby to the specialised centre.

If your baby requires transfer and you would like more information about how NETS works, ask your doctor, nurse or the NETS team to give you a copy of the NETS booklet, NETS medical retrieval: information for parents and families.

The Newborn and paediatric Emergency Transport Service (N.E.T.S.)
PO Box 205, Westmead NSW Australia 2145
Phone: 1800 10 NETS
Email: info@nets.org.au Website: www.nets.org.au
What can be done before birth to help my baby?
Very premature birth is usually due to complications of pregnancy such as premature labour or rupture of the membranes, bleeding, high maternal blood pressure or fetal growth problems. Should you have any of these conditions some treatments can be given which help to protect a premature baby against complications of immaturity such as respiratory distress syndrome, where the baby has difficulty breathing, and the serious complication of bleeding in the brain.

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 Neonatal Intensive Care Unit.

Medication to help your baby’s lungs develop
Drugs called corticosteroids can help a premature baby’s immature lungs to function better. They also work to protect the baby’s immature brain from bleeding. These drugs are one of the most important treatments that can help premature babies survive. They are given by injection to the mother before the birth to help her baby’s lungs develop.
Will my baby survive?

Babies born before 33 weeks of pregnancy are more likely to survive and do well if they receive the highly specialised medical and nursing care available in a Neonatal Intensive Care Unit. Each extra week of time spent growing in the mother's womb increases a baby's chances of survival significantly and by 27 weeks of pregnancy, over 90% babies will survive (see graph below.) The degree of intensive care required and risk of death or survival with a disability is greatly increased with each week less than this (see graph page 10).

Predicting the outcome for your baby depends on knowing exactly how many weeks pregnant you are when the baby is born. At 23 weeks, the risks are very high so starting neonatal intensive care is usually actively discouraged. At 24 weeks, the risks are still very high and it may not be advisable to commence intensive care. At 25 weeks, active treatment is usually offered but may not be given if, after discussion the parents decide against that option, or the baby has a serious condition. At 26 weeks, in an otherwise normal infant, intensive care will generally be given except in exceptional circumstances.

If it looks as though your baby might be born very early, your doctor will discuss the risks with you. It is important that you are involved in all decisions about your baby and your doctor will give you as much information as possible to help you decide what is best for your baby, for you and for your family. Important things include an understanding of the intensity and duration of intensive care that your baby might need to go through and the likely outcome.

Why do some premature babies die?

The body systems of a premature baby are not quite ready for life outside the womb. There are three main problems that can threaten a baby's survival:

1. **Lung Immaturity**
To keep a premature baby alive, we need to maintain enough oxygen in the baby's bloodstream. Most babies born before 30 weeks of pregnancy need some help with their breathing because their lungs are not fully developed. Even at 32 weeks, four out of ten babies need help to breathe.

We can help most premature babies to breathe more easily by giving the mother medication before the birth. After the birth, we can replace the substance (surfactant) which is missing from the premature baby's lungs. We can also support the baby until the lungs improve by giving ventilation, where a machine (ventilator) does the work of breathing for the baby or with CPAP (Continuous Positive Airway Pressure) where the baby breathes for him or herself but some extra air pressure is supplied to keep the airways open.

However, in a few babies, despite all the treatments we have, we cannot maintain enough oxygen in the blood stream to keep them alive.
2. Bleeding in the brain
Bleeding in or around the brain, known as intraventricular haemorrhage, is very rare in babies born after 30 weeks of pregnancy but it does occur in about one in five babies born before 30 weeks. In the immature brain of a premature baby there is an area which has very delicate blood vessels. These blood vessels can burst and bleed (haemorrhage) into the brain causing a bruise. Usually, the bruise is small and causes no brain damage. In a few babies (about one in twenty) the bruising can be larger and can cause brain damage or death.

3. Infection
Premature babies are more likely to get infections because the body's defence mechanisms are not fully developed. Most of these infections can be treated with the powerful antibiotics available today. However, occasionally, even these will not control an infection well enough to keep a baby alive.
Will my baby’s lungs develop normally?

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. This is called chronic lung disease.

About one out of every ten babies born before 30 weeks will need extra oxygen treatment after they go home. The rate is even higher in those born before 25 weeks (one in three). 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.
Can I breastfeed my baby?
In the early period after birth, almost all very premature babies are fed with glucose, salt and water infused into their veins. Breast milk is the best food for premature babies and mothers can start expressing milk once the baby is born. This can be frozen until your baby is ready for milk feeds. After a few days, tiny amounts of milk can be fed to your baby through a tube which goes from the baby's mouth into the stomach. The amount of milk is gradually increased over one to three weeks. Babies start to suck well between 34 and 36 weeks and most mothers are breastfeeding when their baby goes home. Help with breastfeeding is available for you in hospital.

How long will my baby stay in hospital?
Most premature babies go home at, or slightly before, the date they were originally due to be born (40 weeks). Babies born very prematurely spend the initial period in intensive care. The time in intensive care will depend on how early the baby is born and how sick he or she is. For example this could be 10 weeks for a baby born at 24 weeks and 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. This means that if your baby is born ten weeks early, it could be eight weeks until he or she goes home. Weight gain and the ability to suck feeds properly are usually the factors which determine exactly when your baby can go home.

Premature babies who are transferred before or after birth to a Neonatal Intensive Care Unit are usually transferred back to the hospital closest to home as soon as they no longer need to be cared for in a specialist intensive care unit.
How you may feel

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

How will my premature baby develop in the long term? This is an important question for all parents. Problems with development are unusual in babies who were only slightly premature, so regular developmental check-ups are mainly done on those babies who are born about ten or more weeks early. As this varies from hospital to hospital, the specialist looking after your baby will discuss this with you.

The majority of babies born before 30 weeks gestation develop normally, but these very premature children are more likely to have problems with eyesight, hearing, movement and understanding than full-term children. For example, about 3 out of every 10 babies born at 24-25 weeks gestation will have one or more of these problems, as will about 2 out of every 10 babies born at 26-27 weeks.

Eyesight and hearing problems can range from minor problems such as short-sightedness or mild hearing impairment to more serious problems, such as blindness or profound deafness. Premature babies are also more likely to have mild or severe problems with movement, language and learning.

Of the babies who do have 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.

Percentage of survivors with moderate or severe disability at 2 – 3 years of age

Key Developmental Areas

These include overall movement, fine movement, vision, hearing, speech and language, social development and learning and understanding.

Follow up assessment

1. Overall Movement

This is 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 which controls the muscles is not giving smooth signals to the muscles. As a result, movements either become stiff and jerky or sometimes the muscles can be very floppy.

About 1 out of every 10 babies born at 27, 28 or 29 weeks will have some degree of cerebral palsy. About 1 out of every 5 babies born at less than 27 weeks will have cerebral palsy. However, over half of these children will be able to walk by themselves. There is a range of abilities among children with cerebral palsy from very mild balance problems alone to the need to use a wheelchair for mobility and special ways to communicate.
2. Fine 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.

3. Vision
Most eye problems are minor and can be easily treated, such as squints or long or short sightedness. However, about 1 or 2 out of every 100 babies born before 30 weeks gestation will become blind. This is the result of a disorder called retinopathy of prematurity which is due to immaturity of the baby’s eyes.

It is important that any eye problems are recognized 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 Neonatal Intensive Care Unit and will continue to check them after they have left hospital.

4. Hearing, speech and language
All newborn babies, whether full term or premature, have their hearing checked before they go home from hospital. About 2 or 3 out of every 100 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. Talking and reading to your premature baby is an important way to assist in the development of language.

5. Social Development and Behaviour
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 of development. Many very premature babies are very wriggly and tend to become distracted easily. 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 distraction.
6. Learning and Understanding
Premature babies are more likely than full term babies to have learning problems once they are older. If it is a major problem, then this can sometimes be predicted early in the preschool period. However, most children with learning problems are normally intelligent children, who just find it very difficult to learn to read, spell or do mathematics once they are at school.

If a child has an overall intellectual disability, then he or she may need to attend a special class or school, or to have extra assistance in a regular classroom. Children who have difficulty with reading, spelling or mathematics will usually benefit from extra help within their regular school class.

Conclusion

As parents of a very premature baby you may face challenging times ahead. However, you are not alone and your doctor, hospital staff and early childhood centre staff can assist you if have any additional questions. We have also included at the back of this booklet a list of organisations which provide support to families with a premature baby.
Other Items of Interest

Accommodation for parents whose baby is in neonatal intensive care.
Each hospital has different arrangements to support parents. Medical, nursing and social work staff of the unit will inform you of what is available.

Research
The improving outcomes for premature babies are the result of recent and ongoing research. The statistics and other information in this booklet are only known because of the generous co-operation of many families whose premature babies have required the specialist services of a Neonatal Intensive Care Unit.

Whilst your baby is receiving intensive care, you may be asked to give consent for him or her to be included in a research project which has been approved by an Ethics Committee. It is not compulsory to participate in research and the care your baby receives will not be affected in any way should you exercise your right to refuse consent. However, your participation and the contribution it will make towards the advancement of care for babies would be greatly appreciated.
Where can we find more information about preterm birth?

This booklet will have been given to you after a discussion with your doctor, midwife or nurse. If you would like to discuss issues raised in this booklet, please contact the referral hospitals that are part of the NSW Pregnancy and Newborn Services Network.

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<th>Referral Maternity Hospitals with Neonatal Intensive Care Units</th>
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<tbody>
<tr>
<td>John Hunter Hospital, Newcastle, NSW 2305</td>
<td>02 4921 3000</td>
</tr>
<tr>
<td>Liverpool Hospital, Liverpool NSW 2170</td>
<td>02 9828 3000</td>
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<td>Nepean Hospital, Penrith NSW 2750</td>
<td>02 4734 2000</td>
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<td>Royal Hospital for Women, Randwick NSW 2031</td>
<td>02 9382 6111</td>
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<td>Royal North Shore Hospital, St Leonards NSW 2065</td>
<td>02 9926 7111</td>
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<td>Royal Prince Alfred Hospital, Camperdown, NSW 2050</td>
<td>02 9515 6111</td>
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<tr>
<td>The Canberra Hospital, Woden ACT 2606</td>
<td>02 6244 2222</td>
</tr>
<tr>
<td>Westmead Hospital, Westmead NSW 2145</td>
<td>02 9845 5555</td>
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<tr>
<th>Referral Children’s Hospitals with Neonatal Intensive Care Units</th>
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<td>Children’s Hospital Westmead, Westmead, NSW 2145</td>
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<tr>
<td>Sydney Children’s Hospital, Randwick NSW 2031</td>
<td>02 9382 1111</td>
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Other related publications:

Care around preterm birth: A guide for parents (NHMRC 1997). This booklet is available free on the Internet at www.health.gov.au/nhmrc. It can also be purchased from your nearest Government Bookshop.

Other support services

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

Contact
• Australian Multiple Birth Association 1300 886 499
• Austprem www.austprem.org.au
• Preemie www.preemie-l.org
• Interpreter services 13 14 50
• Australian Breastfeeding Association helplines 1800 686 268
• SIDS and Kids NSW* 1800 651 186
  *support families who experience pregnancy loss, or neonatal or infant death

See government services in your local telephone directory or your hospital social worker for the following services:
• Aboriginal health workers and liaison officers
• Domestic violence / sexual assault centres
• Hospital chaplains / ministers / priests
• Lactation consultants
• Preterm support groups
• Social workers.
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Nguyen Family
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