

## PARENT INFORMATION

### For Babies Born at 23<sup>+0</sup> – 25<sup>+6</sup> Weeks

If you are reading this pamphlet it is likely that you or someone you love has an increased chance of giving birth (or may have already given birth) to a baby born very early, before 26 weeks. This is known as an extremely premature birth since the normal length of pregnancy is around 40 weeks. Giving birth early is a difficult time for parents and families, and we hope that this pamphlet will provide you with information and will assist you to make decisions if they need to be made.

Babies born **before 23 weeks** have body systems that are too under-developed to survive.

As a result, hospitals do not offer active treatment before 23 weeks even if parents ask for it. Instead, comfort care is given while the baby passes away, which usually happens within a few hours of birth.

Babies born **from 26 weeks** mostly survive and do quite well and hospitals generally offer full care (intensive treatment) unless the baby has other problems.

For babies born in the window between **23 weeks + 0 days and 25 weeks + 6 days**, survival and long-term health outcomes are much less predictable. In this window of time, the wishes of the parents are very important in the decision to provide intensive treatment or not.

This is because, even with the very best of high-technology care, some babies born extremely early will develop moderate to severe life-long disabilities.

On the other hand, some babies will do quite well.

Because of the range of possible outcomes - which generally cannot be predicted - **it is the family's right to have a say in the care that is provided** (see page 3).

If you are in the difficult situation of having to make decisions around the care of your baby, you will not be doing it on your own. Our expert baby doctors (called neonatal paediatricians or neonatologists) are available to explain your individual situation and help you make decisions about your baby's care.

This pamphlet should be used together with the discussions you have with our neonatologists.

### How will my baby be born – Vaginal Birth or Caesarean Birth?

Most extremely preterm babies have a vaginal birth which is a healthy way to be born and good for the baby's lungs. Occasionally a caesarean birth is needed.

However, even if full resuscitation and intensive treatment have been agreed to at 23 weeks or 24 weeks, caesarean birth is not generally recommended before 25 weeks. This is because babies who are sick enough to need caesarean birth are less likely to do well. In addition, early caesarean is a more difficult operation than caesarean at the end of pregnancy and may affect future pregnancies.

Your obstetrician will discuss the type of birth carefully with you.

## Will my baby survive?

Babies born between **23 weeks + 0 days and 25 weeks + 6 days** have internal organ systems that are not fully developed. Instead, they are fragile and not ready for life outside the uterus.

Some of these babies will die during birth or the first few minutes of life. Others will survive to reach the neonatal intensive care unit (NICU) but may die in the next few days or weeks.

On the other hand, some extremely premature babies will survive and do well.

You can see from the **diagrams** on the next few pages that the chance of a good outcome increases with the number of weeks of pregnancy.

The commonest reasons for extremely premature babies to die are because their immature lungs don't breathe very well or they develop bleeding inside their brain or they get a severe infection or have serious problems with their gut (bowels).

While medical treatment is often very helpful for babies born between 23+0 and 25+6 weeks, sometimes it can cause suffering and harm to a baby who is unlikely to survive.

The neonatology doctors will give you advice about the best care for your baby.

## Will my baby have problems in the long-term?

Of the babies who go home from NICU, some grow up completely healthy without any problems. However, some develop problems that may cause difficulty with seeing, hearing, walking and understanding / thinking. We call these longer-term problems 'disabilities' because they affect a person's 'ability' to do everyday things. It may take a few years before we know completely what disabilities a child may have. The level of disability can be mild, moderate or severe:

### Mild Disability

Children with mild disability have mild learning problems in school and are **slower** to reach certain milestones, for example learning to walk or talk. However, once these abilities are reached, there is **little impact** on the child's everyday life, although it may sometimes affect their success in high school.

### Moderate Disability

Children with moderate disability are **slower** to reach certain milestones, **and** even if they develop these skills, they **still need support** for daily activities. Examples include children with:

- cerebral palsy who need sticks or other equipment to help them walk
- lower than normal intelligence (lower IQ)
- deafness which requires wearing a hearing aid or having a cochlear implant

### Severe Disability

Children with severe disability **never reach** certain milestones. Examples include children with:

- cerebral palsy who need a wheelchair to move around
- severe intellectual disability (very low IQ); very limited communication; cannot speak
- blindness
- unable to feed themselves, wash themselves; need 24-hour care for their whole life.

# PARENTS' ROLE IN DECISION-MAKING

between 23 weeks 0 days and 25 weeks 6 days

## Current Hospital Guidelines

In keeping with the New South Wales (NSW) and Australian Capital Territory (ACT) Perinatal Care at Borderline Viability Consensus Workshop Committee recommendations (1), Westmead Hospital's current (2018) practice is:

- Babies born **before 23 weeks 0 days** will not be provided intensive treatment even if parents request it.
- Babies born **at or after 26 weeks 0 days** will be resuscitated if the baby is in good condition and has a good chance of a reasonably healthy life and if providing intensive treatment appears to be in the best interests of the baby.  
This applies even in the unlikely situation that parents ask us not to provide intensive treatment.
- Babies born **between 23 weeks 0 days and 25 weeks 6 days** will be managed according to parents' wishes together with assessment by our neonatologists and obstetricians.

## What are parents' options between 23 weeks 0 days and 25 weeks 6 days?

Our doctors will **talk** to you about the possible outcomes for your baby. We will then **listen** to you about your personal situation to understand what is important for you and your family so we can work with you to make the best decisions for you, your family and your baby.

After these discussions, we may offer 'intensive treatment' from birth or we may suggest providing 'comfort care'.

**INTENSIVE TREATMENT** involves giving specialised treatment to support your baby's under-developed organ systems, trying for the best chance of survival. If you decide that intensive treatment is the right choice for your baby, our NICU staff will attend your baby's birth. We will provide the early care your baby needs and then take your baby to NICU for further care. Remember however, as discussed earlier, even with the best care some babies will die during or soon after birth and not reach NICU.

**COMFORT CARE** is special care provided for babies whose time is precious but short. If you have decided that **comfort care** is the right choice for your baby, our obstetric and midwifery staff (but generally not our NICU staff), will attend your baby's birth and look after you and your baby during this time. Your baby will be carefully wrapped to keep him/her warm and comfortable. You will be able to hold your baby if you wish.

**Please note** that the decision for **comfort care cannot be changed** to intensive treatment after the baby is born - such delay almost always results in a very poor outcome for the baby. Intensive treatment for extremely premature babies must be planned before birth and commenced from the first minutes of life to have the best chance of a good outcome.

## Sometimes pregnant women or babies have to move to another hospital

It is important to know that babies born in a hospital where there is a **NICU cot immediately available** for the baby do better than babies who have to move to another hospital after birth.

Therefore, if a NICU cot is not immediately available at Westmead, we occasionally need to **move women** at high risk of premature birth **to another hospital** that does have a NICU cot available. We greatly regret having to do this but must make the best decision for the baby.

## Stopping Intensive Treatment

Before birth, soon after birth, or in the days / weeks while your baby is in NICU, our team may decide that your baby no longer has any chance of survival or that the chance of survival without major health problems is extremely low.

In such situations, we may decide that medical treatment is causing your baby pain and suffering without any benefit. If we believe continuing with intensive treatment is not in the best interests of your baby, we will discuss this carefully with you.

## Giving you support and information

Our doctors, nurses, midwives, social workers and chaplains are here to support you and your family while you are in hospital and when you go home. If you have any concerns or questions, please talk to our staff about them.

## SURVIVAL AND OUTCOME CHARTS

The information on the pie charts over the page is based on outcomes of babies born in New South Wales (NSW) and Australian Capital Territory (ACT) from 2007 – 2012.

These babies received intensive treatment at birth and survived long enough to reach the NICU. They were then followed to 2 years of age if they survived (Bolisetty 2018)(2). The information does not include babies who died during or very soon after birth, before they reached the NICU. Therefore, these results are the best for each age group.

This information is the most recent we have which has **follow-up into childhood**.

**It is important to note that these charts are general guides and do not predict what will happen to your baby. The chances for your baby may be better or worse than these diagrams show. Your doctor may be able to give you more guidance.**

**However, it is important to know that, even for expert neonatologists and obstetricians, it is often not possible to predict what the outcome will be for an individual baby.**

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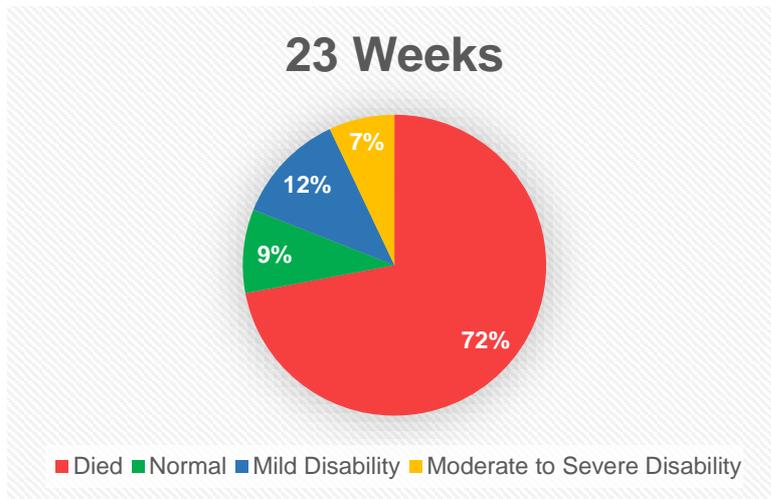
<sup>1</sup> Lui K, Bajuk B, Foster K, Gaston A, Kent A, Sinn J, et al. Perinatal care at the borderlines of viability: a consensus statement based on a NSW and ACT consensus workshop. Medical Journal of Australia.185(9):495-500. 2006 Nov 06

<sup>2</sup> Bolisetty S, Tiwari M, Sutton L et I for the NSW/ACT NICU Data Register. J Paediatrics & Child Health 2018 Nov 30. doi10.1111/jpc.14323 (Epub ahead of print)

## Outcomes of babies born 23 - 25 weeks gestation

**23 WEEKS** = 23 weeks 0 days to 23 weeks 6 days.

Outcomes for babies who received **intensive treatment** and reached NICU; followed to 2 years of age

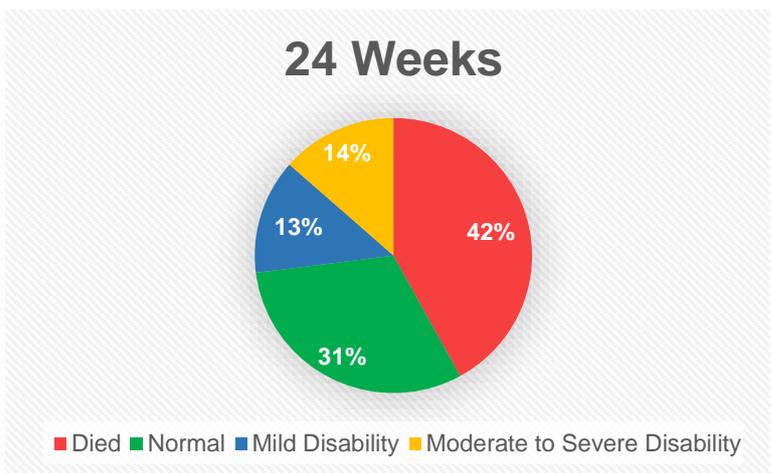


At **23 weeks**, even with full resuscitation and intensive medical care, the chance of your baby surviving is small. And if your baby survives the chance of serious health problems is very high.

Because of this, we generally **do not recommend starting active treatment for babies born at 23 weeks**

**24 WEEKS** = 24 weeks 0 days to 24 weeks 6 days.

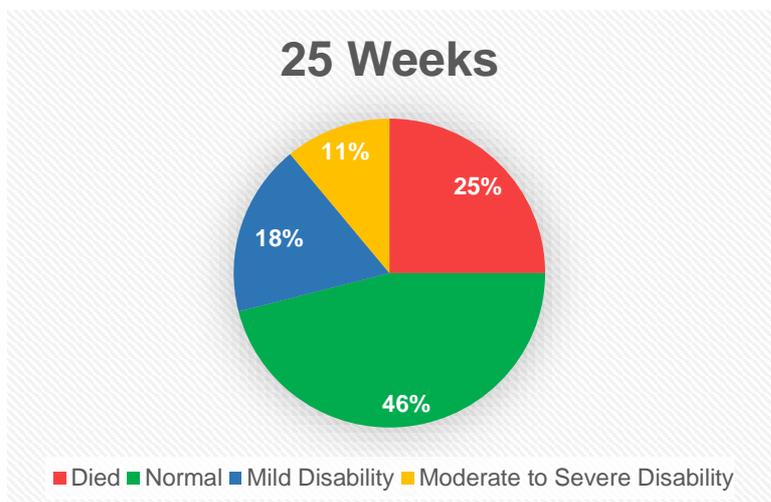
Outcomes for babies who received **intensive treatment** and reached NICU; followed to 2 years of age



At **24 weeks**, even though your baby's chances of survival are better, the risks of problems are still high. Active treatment and intensive care are usually offered unless you and your family decide this is not in the best interest of your baby after discussion with the medical team. In some situations, starting active treatment may not be advisable.

**25 WEEKS** = 25 weeks 0 days to 25 weeks 6 days.

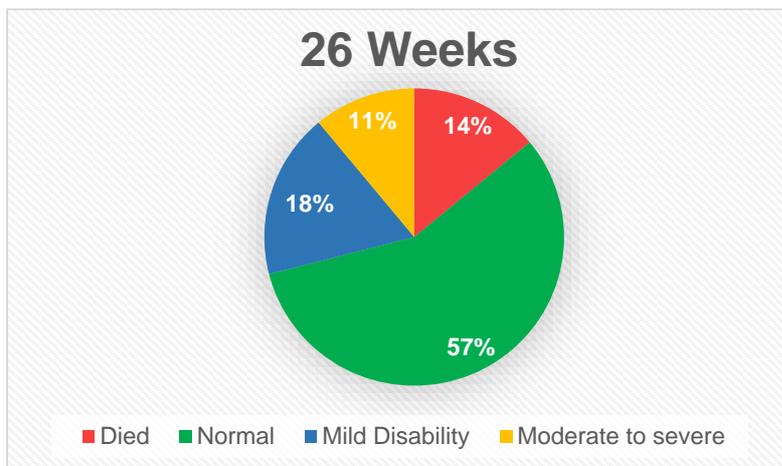
Outcomes for babies who received **intensive treatment** and reached NICU; followed to 2 years of age



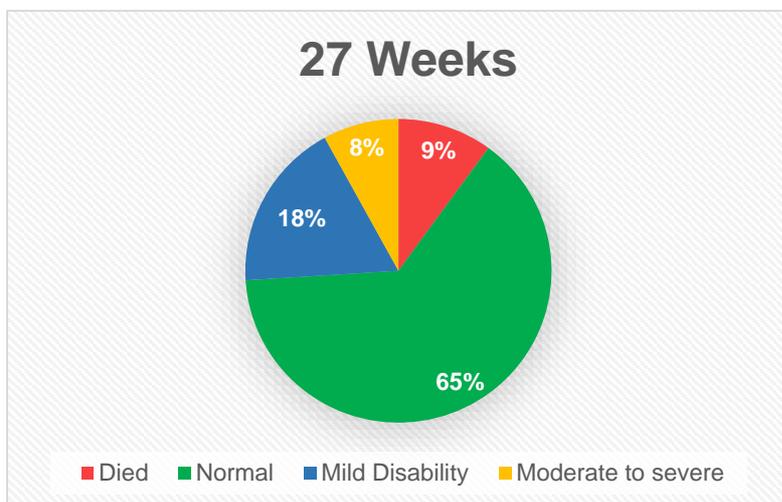
At **25 weeks**, **active treatment is usually recommended** as most babies at this gestation survive and most of those who survive do not have moderate to severe problems. However, intensive treatment may not be started if your baby has a serious health condition.

## Outcomes of babies born 26 - 28 weeks gestation

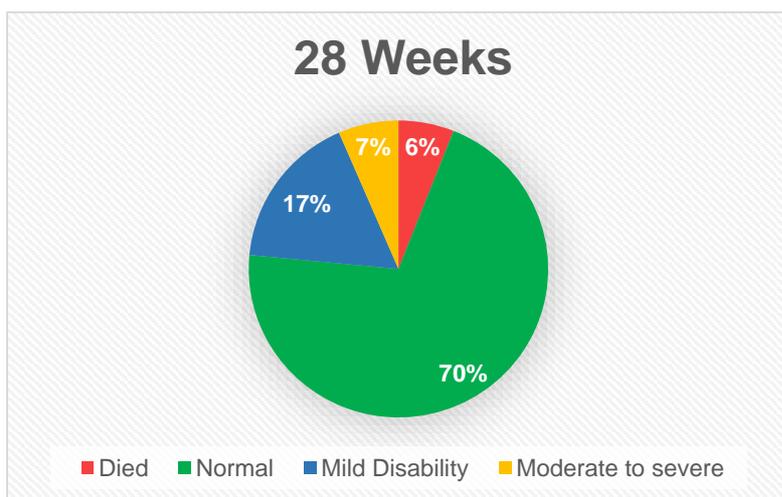
The **focus** of this pamphlet is birth **before 26 weeks**. However, to provide families with more information, we have included survival and outcome data for babies born 26 - 28 weeks.



The majority of babies born after 26 weeks gestation develop normally, but some will still have mild to severe problems.



For all babies born at 28 weeks or below, Westmead offers **regular check-ups in the years after birth**.



Some health problems are not detectable until the child is older and we like to keep in touch with you and your child so that we can identify any problems early. This often allows us to improve outcomes by early intervention. And it allows us to provide you with the support you need.