

Parent information for babies born extremely preterm at 22 weeks of pregnancy

You have been given this information booklet because it is possible your baby may be born very early at 22 weeks of pregnancy. It provides you with written information about topics your healthcare team have discussed with you.

It is often difficult to recall everything that has been discussed, given this is an extremely stressful situation. Your healthcare team will provide information specific to you and your baby's (or babies') circumstances. This information sheet covers the following areas:

- Will my baby live?
- If my baby lives, will they have any long-term problems?
- Do I need to be transferred to another hospital to give birth?
- What choices do I have?
- What is comfort (palliative) care?
- Can I/we change my/our minds after choosing comfort (palliative) care?
- Where can I go for more information?

WHAT IS EXTREME PREMATUREITY?

Being born at 22 weeks of pregnancy means being born extremely premature. When babies are born at 22 weeks, their heart, lungs, brain and other organs are very immature (not well grown) and not ready to support life outside the womb. Many babies born this early do not survive labour and birth. Babies born alive will need a lot of medical care in a newborn (neonatal) intensive care unit (NICU) and will spend many months in hospital if they survive the first days and weeks in NICU.

WILL MY BABY LIVE?

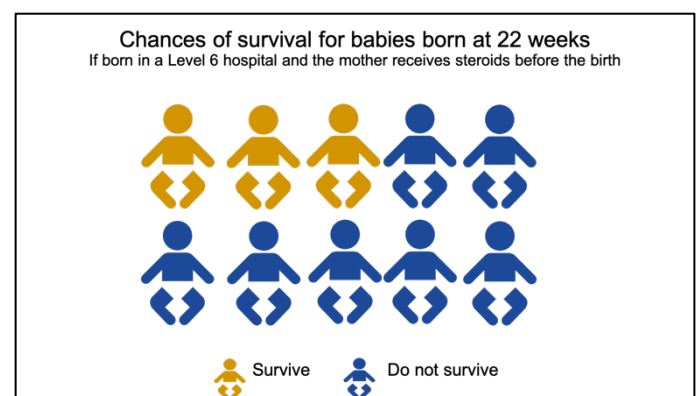
In the best of circumstances, about 3 in 10 babies born at 22 weeks survive.

In Victoria best circumstances includes babies born in a specialist maternity hospital with a NICU (a Level 6 hospital) after their mother has been given steroids before the birth. Even in these circumstances, most babies born at 22 weeks will not survive.

In best circumstances

About **2-4 in every 10 babies** born at 22 weeks will survive to one year

About **6-8 in every 10 babies** born at 22 weeks will not survive to one year



IF MY BABY LIVES, WILL THEY HAVE ANY LONG-TERM PROBLEMS?

Babies born at 22 weeks who do survive may have lifelong problems with:

- walking and coordination (cerebral palsy)
- talking, thinking, learning, understanding and behaviour
- hearing or seeing.

These disabilities can be mild, moderate or severe.

About 36% (between 3 and 4 in every 10 babies born at 22 weeks) will survive with a severe disability, affecting walking, talking, thinking, seeing and/or hearing.

The following diagram explains the possible outcomes for babies born at 22 weeks' gestation. These are based on outcomes of babies born at 22 weeks in high-income countries who were admitted to NICU and survived. As the numbers of survivors in each country are small, the outcomes are reported for a group of 53 babies born in eight countries from 2000-2015.

Disabilities in babies born at 22 weeks

In babies born at 22 weeks who survive to go home from NICU, the chances of survival with or without mild, moderate or severe disability are:

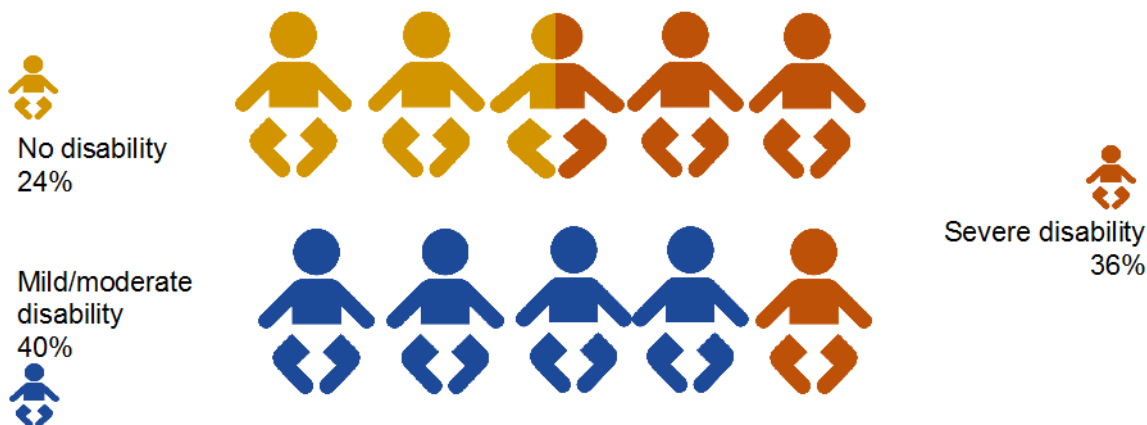
About **2 in every 10 surviving babies** will not have disability

About **4 in every 10 surviving babies** will have mild or moderate disability

About **3-4 in every 10 surviving babies** will have severe disability

Predicting the chance that an individual baby will or will not have a disability is difficult. For each day that your baby survives in the NICU after birth, free of serious complications, survival chances increase and the risk of disability decreases.

Chances of disability in babies born at 22 weeks who survive and go home from NICU (intelligence, language, motor, vision, hearing, cerebral palsy)



Data from 53 surviving babies born at 22 weeks in high-income countries
Myrhaug, et al., Pediatrics 2019; 143(2):e20180933

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DO I NEED TO BE TRANSFERRED TO ANOTHER HOSPITAL BEFORE I GIVE BIRTH?

One of the decisions that may need to be made quickly is whether to move you to a specialist Level 6 maternity hospital in Melbourne that can provide intensive care for babies born extremely premature. Your healthcare team may advise that it is best to transfer you to one of these hospitals before your baby is born, if it is safe to do so.

If after counselling with your local healthcare team, you prefer your baby to have comfort care from birth, then you do not need to be transferred to Melbourne to a Level 6 hospital. You may decide being closer to home and closer to your family will be best for you.

No matter which maternity hospital your baby is born in, comfort care can be provided to your baby.

Sometimes babies born at 22 weeks' gestation are born very quickly, before the mother can be moved to a Level 6 specialist maternity hospital. In this situation, the only option will be to provide the baby (babies) comfort care from birth.

WHAT IS COMFORT (PALLIATIVE) CARE?

Based on the risks of dying or surviving with a major disability, you and your doctor may decide that providing intensive care would not be in the best interests of your baby. If you decide this, then your baby would be offered comfort (palliative) care.

Comfort (palliative) care

Comfort (palliative) care is a special type of care for babies, allowing parents to provide love and comfort for the duration of their baby's short life without interruption from medical tests and procedures. It prioritises keeping your baby pain-free and allowing time to spend with your baby before your baby dies.

Your healthcare team will discuss with you what you would like to do after your baby is born, including whether you wish to hold your baby, bath and dress your baby, have any extended family visit to meet your baby, and any other specific wishes you have.

Many families will spend this time to create memories of your baby, which your healthcare team can help you with.

Your baby can stay with you as long as you wish.

CAN I/WE CHANGE MY/OUR MINDS AFTER CHOOSING COMFORT (PALLIATIVE) CARE?

For babies born at 22 weeks' to have the only chance of survival and the lowest risk of disability, important interventions must be provided before birth as well as immediately after birth in the delivery room. If you are considering changing your mind about the management plan for your baby (especially just before or immediately after the birth of your baby), it is important you discuss this with your healthcare providers, to understand why this may or may not be encouraged.

If the decision is made to offer your baby intensive care, this will be provided from birth. However, this does not commit you to continuing intensive care if serious complications arise in the NICU in the first hours and days after your baby is born. Comfort (palliative) care may be discussed should this situation arise.

If the decision before birth is to provide comfort care from birth, then continuing this management will be strongly advised. This is because important life-saving interventions may not have been provided if you opted for comfort care prior to your baby's birth.

Where can I go for more information?

Parent support groups:

Life's Little Treasures

Miracle Babies

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