

Parent information for babies born extremely preterm at 23 weeks of pregnancy

You have been given this information booklet because it is possible your baby may be born very early at 23 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?
- What long-term problems/disabilities could my child have?
- 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 23 weeks of pregnancy means being born extremely premature. When babies are born at 23 weeks, their heart, lungs, brain and other organs are very immature (not well grown) and not ready to support life outside the womb. Some 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.

WILL MY BABY LIVE?

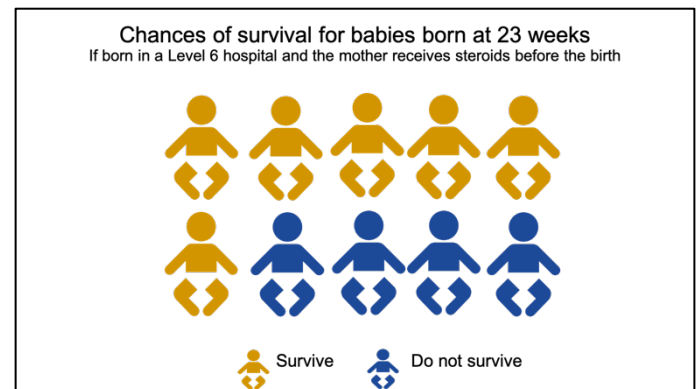
While every baby is different, it is possible to make some prediction about what will happen to your baby if born at 23 weeks.

The best chances for survival after being born at 23 weeks is when the baby is born in a specialist maternity hospital with a NICU (a Level 6 hospital) after their mother has been given steroid medicine.

In best circumstances:

About **6 in every 10 babies** will survive to one year of age

About **4 in every 10 babies** will not survive to one year of age



There is a lower chance of survival if a baby is born at 23 weeks in a hospital without a NICU and if the mother has not received steroid medicine before the baby is born.

In the above circumstances:

About 2-3 in every 10 babies will survive to one year of age

About 7-8 in every 10 babies will not survive to one year of age

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

Some babies born at 23 weeks survive without any obvious lifelong problems.

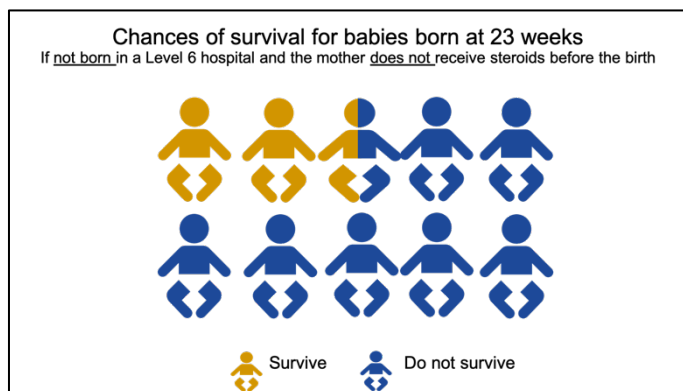
Some babies born at 23 weeks who survive may have lifelong problems with:

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

These disabilities can be mild, moderate or severe.

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.

The following diagram explains the possible outcomes for babies born at 23 weeks' gestation. These are based on outcomes of babies born at 23 weeks in Australia and New Zealand, who were admitted to NICU and survived.



Each pregnancy and baby are different, so these outcomes only provide a general indication of risk. Sometimes babies are born in a Level 6 hospital, but before steroids can be given to the mother. Some babies are not born in a Level 6 hospital, but their mother has received steroids. There are also other risk factors that can change the chance of survival of your baby which your healthcare team may have discussed with you. In all these cases, survival chances are different.

Even when provided with intensive care, not all babies born at 23 weeks survive. Some babies die soon after birth. Some babies survive in the NICU for days or weeks but then die because they develop serious complications during their stay in NICU.

Disabilities in babies born at 23 weeks

In babies born at 23 weeks who survive to go home from NICU, the chances of survival with or without mild, moderate or severe disability are:

About 4 in every 10 babies will not have disability

About 3 in every 10 babies will have mild disability

About 2 in every 10 babies will have moderate disability

Less than 1 in every 10 babies will have severe disability

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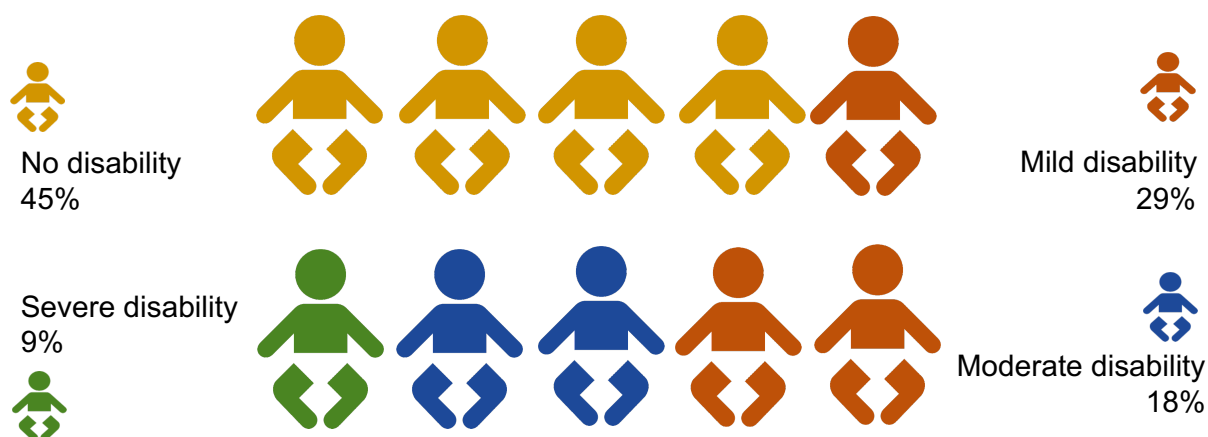
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Chances of disability in babies born at 23 weeks who survive and go home from NICU (intelligence, language, motor, vision, hearing, cerebral palsy)



Data from the Australia and New Zealand Neonatal Network (ANZNN) 2017 for 74 babies born in 2012-2015

Chow et al., (2020). Australian and New Zealand Neonatal Network (ANZNN) data from 74 surviving children born <24 weeks' gestation in 2012-2015 in Australia and New Zealand

What disabilities could my child have?

The table below summarise the risks of major disability in babies born at 23 weeks' gestation in Australia and New Zealand.

	%	Number of children affected
Blind²	5%	1
Deaf (hearing aids or cochlear implants)²	0%	0
Cerebral palsy¹	12%	9
Moderate-severe disability in all survivors¹	27%	18

1: Chow et al., (2020). Australian and New Zealand Neonatal Network (ANZNN) data from 76 surviving children born <24 weeks' gestation in 2012-2015 in Australia and New Zealand.

2: Cheong et al., (2019). Victoria Infant Collaborative Study (VICS) data from 20 surviving children born at 23 weeks' gestation in 1991-92, 97 and 2005 in Victoria, *Lancet the Lancet Child & Adolescent Health*, 2(12), 872-879.

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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, if you are not already in one of these hospitals (Mercy Hospital for Women, Monash Children's Hospital or the Royal Women's Hospital). 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 23 weeks' gestation are born very quickly, before the mother can be moved to a Level 6 specialist maternity hospital. In this situation, the baby will need to be transferred to a newborn intensive care unit (NICU) soon after 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 23 weeks' to have the best 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](#)

[REDNOSE](#)

[SANDS](#)

[Heartfelt \(free professional photography service\)](#)

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