

Babies born extremely preterm at 22 weeks of pregnancy

You have been given this information sheet because your baby may be born very early at 22 weeks of pregnancy. This 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.

What is extreme prematurity?

Babies born at 22 weeks of pregnancy are extremely preterm. When babies are born this early, their heart, lungs, brain and other organs are very immature (not fully developed) and not ready to support life outside the uterus.

Sadly, some babies born at 22 weeks do not survive labour and birth. Babies born alive will need to be on life support in a neonatal (newborn) intensive care unit (NICU) and spend many months in hospital.

Will my baby live?

While every baby is different, the best chance for survival is when the baby is born at a specialist maternity hospital with a NICU (a Level 6 hospital) after their mother has been given steroid medicine. Even in these circumstances, most babies born at 22 weeks will not survive.

In ideal circumstances

(Born in Level 6 hospital and mother has received antenatal steroids)

About 2-4 in every 10 babies will survive to one year of age

About 6-8 in every 10 babies will not survive to one year of age



 2-4 in 10 babies survive to 1 year

 6-8 in 10 babies do not survive to 1 year


In less than ideal circumstances


(Not born in Level 6 hospital and no antenatal steroids)

About 1 in every 10 babies will survive to one year of age (rare)

About 9 in every 10 babies will not survive to one year of age



 1 in 10 babies survive to 1 year

 9 in 10 babies do not survive to 1 year

Each pregnancy and baby is different, so these outcomes only provide a general indication of risk. There are other risk factors that can change your baby's chances of survival, which your healthcare team may have discussed with you.

Even when provided with intensive care, some babies survive for days or weeks but then die because they develop serious complications during their stay in NICU.

If my baby lives, will they have any long-term problems?

Some babies born at 22 weeks survive without any obvious lifelong problems. Some babies born at 22 weeks who survive may have lifelong problems with:

- physical movement including walking, balance and coordination (cerebral palsy)
- talking, thinking, learning, understanding and behaviour
- hearing and/or seeing.

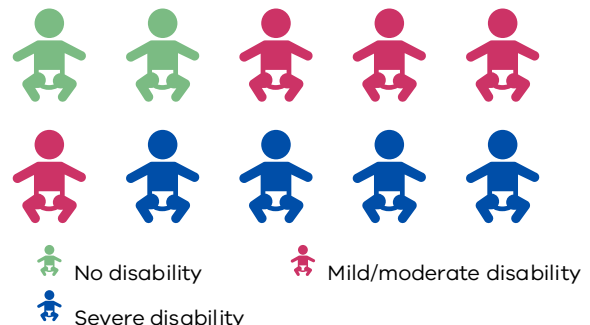
Predicting these disabilities can be difficult. The disabilities can be mild, moderate or severe. Each day your baby survives in the NICU after birth, free of serious complications, survival chances increase and the risk of disability decreases.

Disability in babies born at 22 weeks who survive and go home from NICU (Intelligence, language, motor, vision, hearing, cerebral palsy)

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

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

About **4 in every 10 babies** will have severe disability



Note: As the number of survivors is small, these data are from 53 surviving babies born at 22 weeks in eight high-income countries like Australia, from 2000 to 2015 (Myrhaug, et al, *Pediatrics* 2019;143(2):e20180933)

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 (Mercy Hospital for Women, Monash Children's Hospital or the Royal Women's Hospital) 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.

You and your healthcare team may decide to provide comfort care for your baby. This may be provided in a hospital closer to home and family if you prefer. You therefore would not need to be transferred to a Level 6 hospital.

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

What is comfort (palliative) care?

Based on the risks of your baby dying or surviving with a major disability, you and your healthcare team 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 extended family visit, or 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 change my mind after choosing comfort (palliative) care?

For babies born at 22 weeks' gestation to have the only chance of survival and the lowest risk of disability, interventions must be provided before and immediately after birth, in the delivery room.

If you are considering changing your mind about the plan for your baby, your healthcare providers need to know as early as possible (before or immediately after the birth of your baby) so they can discuss this with you. If you had decided 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.

What is neonatal intensive care?

If you decide on intensive care, your baby will need to be cared for in a specialist neonatal nursery from birth until near their due date at term or later. For babies born at 22 weeks, this means they will be in hospital for at least five months. As all their body systems are immature, babies born this early need additional support. This includes:

Breathing – Immediately after birth, a breathing tube will be inserted into your baby's windpipe. This will be attached to a machine called a ventilator, which helps your baby breathe. Once your baby is able to breathe without the help of a ventilator, the tube will be removed and replaced with small prongs, which sit just inside the nose to continue helping your baby breathe, often with added oxygen. Some babies will need to go home on oxygen.

Body temperature – Your baby will be placed into a special warmed cot called an incubator until they are big enough to maintain their own temperature.

Monitors – Your baby will need close observation while in NICU. They will have monitors attached to their body and hands or feet to measure their heart rate, breathing, blood pressure, temperature and oxygen levels.

Heart – Your baby may need medicines to help their heart beat strongly.

Nutrition and feeding – Initially, your baby will receive specially formulated fluids through a thin tube placed in their belly button or into a vein in their arm or leg. Your baby will progress to milk feeds through a tube in the nose or mouth and – when your baby is old enough – breast or bottle feeds.

Antibiotics to fight infection – Your baby may develop an infection. This can make babies very unwell. An infection will require treatment with antibiotics.

Blood transfusions – Your baby is very likely to require one or more blood transfusions while in NICU.

Phototherapy for jaundice – Jaundice, a yellow discoloration of the skin, is very common in premature babies. Jaundice is treated with a special light, called phototherapy.

Tests – Your baby will have regular blood tests as well as x-rays to check their lungs and abdomen. Your baby will also have ultrasounds (of their head and their heart) and possibly a special scan called an MRI scan to check for bleeding in the brain, or brain injury. Your baby's eyes will be examined by a specialist to monitor for eye conditions resulting from being born so early.

Can I change my mind after choosing intensive care?

Sometimes babies in intensive care who are born at 22 weeks develop serious complications, which increases their risk of dying or surviving with major disability. If this happens, you and your healthcare team may discuss the option of changing to comfort care for your baby. You will be supported in making this difficult decision by your healthcare team.

Parent support groups for families with premature and sick babies

Life's Little Treasures: lifelittletreasures.org.au

Miracle Babies: www.miraclebabies.org.au

Parent support groups for babies who die

Red Nose: rednose.org.au

Heartfelt (A free professional photography service for families whose baby is seriously ill or dies): www.heartfelt.org.au

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