

Parent information

Queensland Clinical Guidelines

Babies born very early

This information sheet aims to answer some common questions about babies who are born very early.

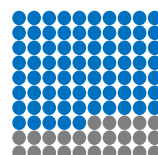
IMPORTANT: This is general information only. Ask your doctor or midwife about what care is right for you.

Outcomes

The pictures in this information sheet are based on what we know about a very small number of babies born in Australia and New Zealand. The babies were between 23 and 26 weeks gestation and were all admitted to an intensive care nursery. The pictures show how many of these babies survived and died at each gestation. They also show (of those who survived) how many did and did not have a moderate to severe disability at around 2–3 years of age.



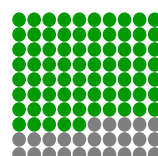
5 in 10 babies survive
5 in 10 babies die



75 in 100 babies
do not have a
moderate to severe
disability
25 in 100 babies do



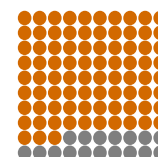
7 in 10 babies survive
3 in 10 babies die



75 in 100 babies
do not have a
moderate to severe
disability
25 in 100 babies do



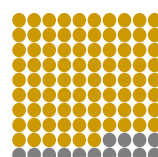
8 in 10 babies survive
2 in 10 babies die



83 in 100 babies
do not have a
moderate to severe
disability
17 in 100 do



9 in 10 babies survive
1 in 10 babies die



86 in 100 babies
do not have a
moderate to severe
disability
14 in 100 do

*Two of 91 babies were 22 weeks | Data source: ANZNN Report 2017



Available from www.health.qld.gov.au/qcg

Effective: Sept 2020 | Review: Sept 2021 | Doc No: C20.32-1-V2-R25

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What does it mean for your baby?

It is not possible to know exactly what the future holds for your baby. It depends on many things. For example, how early your baby is born, how much they weigh and how well or sick you and your baby are around the time of birth. Your doctor and midwife will talk with you about your own circumstances and what they might mean for your baby.

What decisions will you need to make?

Thinking about and deciding what is most important for you and your baby can help you make difficult decisions now and in the future. Some families feel that doing everything possible is the most important thing. Other families believe that it is better not to start treatment if there is little chance of survival. People also have very different views about *disability* and what *quality of life* means. There is no right way to think. Talk with your health care team about what is important for you and your baby. They can answer your questions and help you make decisions that are best for your family.

Will your baby be disabled?

Disability is a very broad term and it means different things to different people. Most babies grow up without a severe disability. The earlier a baby is born, the more likely they are to have problems. Babies who do not have a severe disability may still go on to have milder problems such as learning difficulties, mild cerebral palsy or emotional or behavioural problems.

What is a severe disability?

A severe disability in babies born very early includes problems such as

- not being able to walk or get around independently (like with severe cerebral palsy)
- being unable to talk or see or hear properly
- having trouble swallowing or feeding safely
- having a lot of health problems and needing to visit hospital often
- needing to go to a separate school for children with special needs
- being unable to care for themselves or live independently when they grow up

What can happen to your baby?

Stillbirth: Some babies die before they are born. Your doctor and midwife will support you through this time. You may like to read the information sheet about stillbirth.

Active treatment: You and your health team may decide that active treatment (doing everything possible) is best for your baby. This will include your baby being admitted to a neonatal intensive care unit (in your own hospital or being transferred to another hospital) where they will have:

- assistance with breathing (from a breathing machine)
- antibiotics to help fight infection
- intravenous lines (a drip) to receive medications, fluids and food
- monitoring equipment attached to help detect problems early
- scans and investigations to help decide what treatment is best

Comfort care: You and your health team may decide that comfort care (also known as palliative care) is best for your baby. This may be because, even with the very best treatment, your baby has very little chance of surviving or there is a very high chance of having a severe disability. All care is aimed at making your baby's remaining time as comfortable as possible. Treatment that doesn't add to your baby's comfort is not given. Comfort care may become the right choice for your family later, even if you first decided on active treatment.

What can happen during intensive (active) treatment?

When babies are born very early, their organs and body functions usually haven't had time to develop fully. This can cause problems after birth. Common problems include bleeding on the brain, difficulty with breathing, being unable to digest milk and being less able to fight infection. The earlier a baby is born, the greater the chance they will have these sorts of problems. It is very common for babies to get better and then get sick again. This can happen many times while they are in hospital. It is very stressful for parents and family. Your health care team will talk with you often about how your baby is doing.

Support & Information

13HEALTH (13 432584) is a phone line providing health information www.qld.gov.au/health/contacts/advice/13health

Pregnancy, Birth & Baby Helpline 1800 882 436 (free call) offers free, confidential, professional information and counselling about conception, pregnancy, birthing and postnatal care www.health.gov.au/pregnancyhelpline

Lifeline 13 11 14 offers a telephone crisis support service www.lifeline.org.au

Preterm Infant's Parent Association (PIPA) 1300 773 672 <https://www.pipa.org.au>

Harrison's Little Wings is a high risk pregnancy support service. <https://harrisonslittlewings.org.au>

Sands is a miscarriage, stillbirth and neonatal death support service. <https://www.sands.org.au/>

Bears of Hope Pregnancy and Infant Loss Support provides cuddle cots. <https://www.bearsofhope.org.au>

Angel Gowns Australia supplies angel gown garments for babies that have passed away. <https://www.angelgownsaustralia.org.au>

Precious Wings provides memory boxes. <https://www.preciouswings.org/>

The Pink Elephants Support Network supports women through miscarriage and pregnancy loss <https://miscarriagesupport.org.au>