Cystic fibrosis and your baby

Newborn Screening
Free health checks for your baby

You have just learned that your baby may have cystic fibrosis or be a carrier of the disorder. The information in this leaflet will help you understand more about this condition and answer some of your questions.

Cystic fibrosis screening test

When your baby was a few days old, some blood was collected from your baby's heel. The blood was used to test for some rare disorders, including cystic fibrosis (CF).

The screening test result suggests that your baby may have CF or be a carrier of this disorder, though further tests are needed to confirm this. It is important to note that most babies with a positive screening result for CF are found to be carriers and will not have CF.

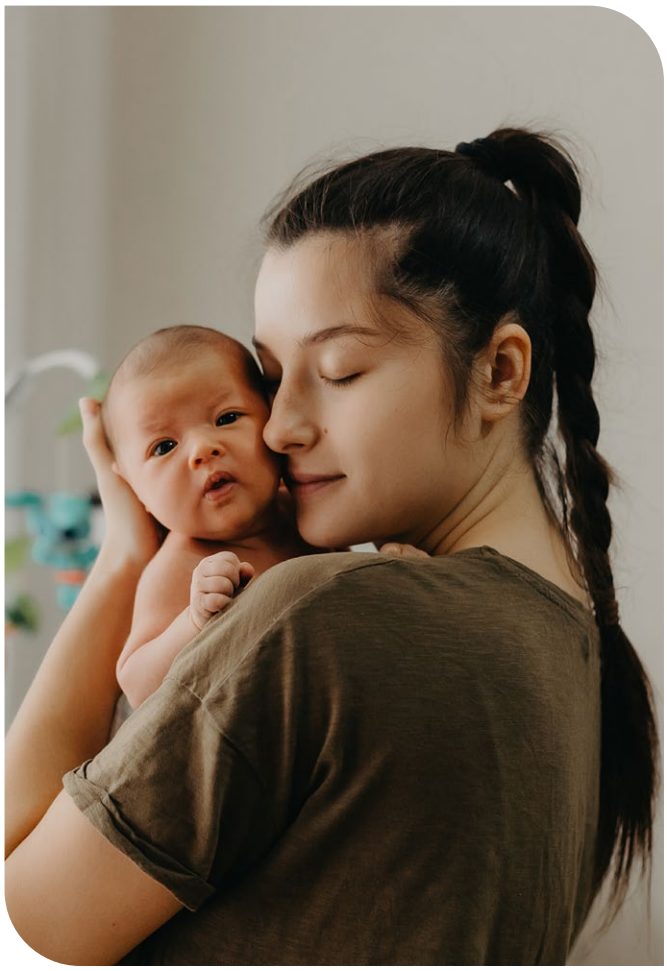
Children who are carriers of CF will not be affected by the disorder and will not need any special treatment. Further testing is needed to find out whether your child is a carrier of CF. Each year in NZ about 30 – 50 babies are diagnosed as carriers of the CF gene and about 10 babies are diagnosed with CF.

Difference between having a carrier and having cystic fibrosis

We all have two copies of each gene in our body; one we inherit from our mother and one from our father.

If a baby inherits only a copy of the altered CF causing gene, they will be a carrier of the gene and will not have CF. They may pass this altered gene to the next generation, just like the parent they inherited the altered gene from.

If a baby inherits two copies of the altered gene ile one from each parent) they will have CF.



Cystic fibrosis

CF is a genetic disorder inherited from both parents. CF is a lifelong illness that can affect all of the organs of the body It often causes problems with digestion and breathing. It does not affect a person's look or intellectual development.

The condition is caused by an altered gene that controls the movement of chloride in and out of the cells in the body.

Normally, the mucus secretions in our body, such as in our lungs, are thin and lubricating. In CF, the mucus turns thick which clogs up the body's tubes, ducts and passageways in many organs particularly the lungs and digestive system.

Testing

Your midwife will talk with you about referring you and your baby to the regional CF paediatrician. You will be seen at the hospital for further testing to find out if your baby is a carrier of the altered gene or has CF. This will occur within a few days of the newborn hearing screening results.

The doctor will

- talk to you about your baby and family
- examine your baby
- organise further tests:
  - a blood test
  - a sweat test
  - sometimes a sample of baby's faeces.

Blood test
A small sample of blood is taken by a heel prick from your baby. This is sent to the laboratory to find out whether your baby carries one or two copies of the altered gene. This result may take a couple of weeks.

Sweat test
A sweat test is a safe procedure but can cause slight irritation to the baby's skin. The sweat test measures the amount of salt in their sweat. In CF these levels are high. For more information on a sweat test see www.kidshealth.org.nz

Faeces test
Sometimes a small sample of your baby's faeces is sent to a laboratory to look for a pancreatic enzyme. Babies with CF have a low level of this enzyme.

If the sweat test and other results support a diagnosis of CF, the doctor will discuss treatments available for your baby. You and your baby will be referred to a team of health professionals who take care of children with CF in your area.

The team often includes a specialist doctor, a specialist nurse, a dietitian and a physiotherapist. The CF team will be able to give you support and detailed information about your baby's diagnosis. They will carefully discuss what treatments your baby will need and what you can do to help keep your child well.

Treatment

Babies with CF are treated as soon as they are diagnosed. The care of CF aims to:

- prevent lung problems with daily chest physiotherapy, daily exercise and frequent antibiotic therapy.
- promote normal growth and good health with high calorie foods.

The CF team will explain treatments to you more specifically, as they are prescribed.

Further Information

- Talk to the nurse specialist and the CF paediatrician
- View https://www.newbornscreening.info/cf-cystic-fibrosis/
- For more information about newborn screening, go to: www.tewhatuora.govt.nz/health-services-and-programmes/newborn-metabolic-screening-programme/

This resource is available at **healthed.govt.nz** or the Authorised Provider from your local health district.

Te Kāwanatanga o Aotearoa
New Zealand Government

Health New Zealand
Te Whatu Ora

Revised April 2026. **Code HE1090**