

Where can I find more information or support?

If your baby does indeed have CF, you can find out more from the doctor and other members of the CF team who will answer any questions you may have. You can also find more information or support from the following organisations:

Cystic Fibrosis Trust

11 London Road
Bromley
Kent
BR1 1BY
Telephone: 020 8464 7211
Website: www.cftrust.org.uk

Contact a Family

209-211 City Road
London EC1V 1JN
Telephone: 020 7608 8700
Helpline: 0808 808 3555
Freephone for parents and families (10am-4pm, Mon-Fri)
E-mail: info@cafamilly.org.uk

BDF Newlife

BDF Centre
Hemlock Business Park
Hemlock Way
Cannock
Staffordshire WS11 7GF
Telephone: 01543 468888
BDF Nurse Service
Telephone: 08700 70 70 20
Website: www.bdfcharity.co.uk

Results of Newborn Blood Spot Screening

Cystic fibrosis is suspected



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All records kept relating to newborn blood spot screening meet the requirements of the 1998 Data Protection Act.

This leaflet is based on high-quality research evidence and the views of parents and health professionals. It has been produced for the Cystic Fibrosis Screening Programme based at the UK Newborn Screening Programme Centre, which is funded by the Department of Health for the whole of the UK.



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What does my baby's screening result mean?

When your baby was about a week old, your midwife took some blood from your baby's heel. The blood was used to test for some rare conditions, including cystic fibrosis (CF).

The screening test results suggest that your baby has cystic fibrosis, though further tests will be needed to confirm this. This leaflet gives you some information about your baby's screening result, and what you can expect to happen next.

What happens next?

Your baby does not need any urgent treatment or special care from you now. The most important next step will be for you to go to the hospital to see the doctor about further tests for your baby. You have an appointment to visit a doctor who is a specialist in children who have CF. The doctor will examine your baby and, if necessary, arrange further tests. The doctor will tell you more about the tests and explain the results to you.

Sweat tests

Some babies have a 'sweat test' because people with CF have a large amount of salt in their sweat, and measuring the amount of salt in the sweat can help determine whether or not your baby has CF. For this test, a small amount of sweat is collected from the skin on the baby's arm or leg. You will be given the test results usually later the same day.

If the sweat test result supports a diagnosis of CF, the doctor will discuss with you the 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. This 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.



What is cystic fibrosis?

Cystic fibrosis (CF) is an inherited condition, affecting mainly the lungs and digestion. A child with CF has inherited two altered genes, one from each parent, which together cause CF. Children with CF can suffer from chest infections, and difficulties digesting their food. This means that they may not put on weight as well as they should.

What treatment is available for cystic fibrosis?

Screening means that babies with CF can be treated early with an appropriate diet, medicines and chest physiotherapy. Treatments for CF are improving all the time, helping people with CF to live longer and healthier lives.

How do you feel?

You may feel a sense of shock, disbelief or anger. These reactions are quite normal and experienced by many parents in a similar situation. Remember that it is not yet known for certain that your baby has CF. You will be able to discuss your concerns with the doctor when you go to the hospital for the appointment to find out whether or not your baby has CF.