

Cystic fibrosis (CF) suspected: description in brief

Public Health England (PHE) created this information on behalf of the NHS. In this information, the word 'we' refers to the NHS service that provides screening.

Your baby's screening result

Congratulations on the birth of your baby.

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

Of all the babies screened in the UK each year, about 300 need extra CF tests.

Your baby's screening result means they need these extra tests.

Your baby's screening result does not mean your baby definitely has CF. Of the 300 babies each year that need extra CF tests, around 225 will have the condition, 60 will not have CF, and 15 results will be inconclusive. Please see illustration below.

For 300 babies that need extra tests for cystic fibrosis each year:



**225 will have
cystic fibrosis
(15 in 20)**

**15 will be
inconclusive
(1 in 20)**

**60 will not have
cystic fibrosis
(4 in 20)**

By identifying CF early, babies and their families can be offered treatment and support as soon as possible.

Your baby's appointment

Your baby has a hospital appointment to have the extra tests and see a team that cares for children with CF.

A doctor will examine your baby and you will have time to ask any questions.

One of the tests is a sweat test that measures the amount of salt in sweat, which is increased in people with CF. A small amount of sweat is collected from the skin on your baby's arm or leg. This is not painful.

You will usually be given the sweat test results later the same day. Sometimes the test needs to be repeated if not enough sweat is collected.

Cystic fibrosis

CF is an inherited condition, affecting mainly the lungs and digestion.

A baby with CF has inherited 2 altered genes, one from each parent, which together cause the condition.

Babies with CF can have chest infections and difficulties digesting their food and putting on weight.

CF is a lifelong condition and all families receive regular support from a team experienced in caring for babies and children with CF.

Treatment

During the hospital appointment you will meet some members of the CF team. The team includes a doctor, nurse specialist, physiotherapist and dietitian who can explain what help your baby might need and what you can do to keep them well. Treatment is improving all the time, helping people with CF live healthier lives.

Your baby does not need any immediate treatment today or overnight.

Support for your family

We understand this screening result is unexpected and unsettling for you and your family. You may feel a sense of shock, disbelief or anger. These are quite normal reactions experienced by many families in this situation.

You can discuss any concerns with the CF team at your hospital appointment. Everything will be done to support your family and make sure you know the test results quickly.

If your baby has CF, please remember that the condition has been identified very early because of newborn screening and that this will help to give your baby the best possible start in life.

Information, advice and support

The NHS website has information about newborn blood spot screening at <https://www.nhs.uk/conditions/pregnancy-and-baby/newborn-blood-spot-test/>

Information and support is also available from the Cystic Fibrosis Trust charity that aims to improve the lives of people with CF and their families. This is available at <https://www.cysticfibrosis.org.uk/>. You may find the information on how cystic fibrosis is diagnosed and the sweat test helpful.

More information

The NHS Screening Programmes use personal information from your NHS records to invite you for screening at the right time. Public Health England also uses your information to ensure you receive high quality care and to improve the screening programmes. Find out more about how your information is used and protected, and your options at www.gov.uk/phe/screening-data.

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