

# THE FACTS

## An introduction to Cystic Fibrosis



### Where can I find out more?

You can visit our website at [www.cftrust.org.uk](http://www.cftrust.org.uk)  
Call the CF Trust on 020 8464 7211  
Email [enquiries@cftrust.org.uk](mailto:enquiries@cftrust.org.uk)

or write to

Cystic Fibrosis Trust  
11 London Road  
Bromley  
Kent BR1 1BY

TFL-0110

Registered as a charity in England and Wales (1079049)  
and in Scotland (SC40196)  
Registered Company No. 3880213

### Cystic Fibrosis – The Facts

Cystic Fibrosis (CF) is one of the UK's most common life-threatening inherited diseases.

Cystic Fibrosis affects over 8,500 people in the UK.

Over 95% of the UK CF population is Caucasian, but CF affects many ethnic groups.

Over two million people carry the faulty gene that causes CF – 1 in 25 of the population.

If two carriers have a child, the baby has a 1 in 4 chance of having Cystic Fibrosis.

Cystic Fibrosis affects the internal organs, especially the lungs and digestive system, by clogging them with thick sticky mucus. This makes it hard to breathe and digest food.

Each week five babies are born with Cystic Fibrosis.

Half of those with Cystic Fibrosis can expect to reach 38.8 years, although improvements in treatments mean a baby born today could expect to live for longer.

Each week three young lives are lost to Cystic Fibrosis.

The Cystic Fibrosis Trust is the UK's only national charity dedicated to all aspects of Cystic Fibrosis. We fund research to treat and cure CF, aim to ensure that those with CF receive appropriate care, and provide information, advice and support to people with CF and their families.

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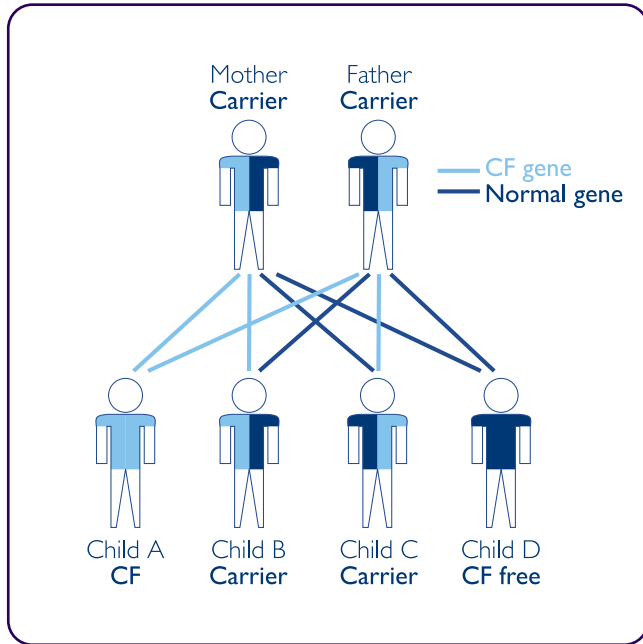
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## What is Cystic Fibrosis?

Cystic Fibrosis (CF) is one of the UK's most common life-threatening inherited diseases. It is caused by a single faulty gene that controls the movement of salts through the body. In Cystic Fibrosis, the internal organs, especially the lungs and digestive system, become clogged with thick, sticky mucus, resulting in infections and inflammation making it hard to breathe and digest food. Other complications in people with CF can include diabetes, liver disease, brittle bones and gallstones.

## Why is a baby born with Cystic Fibrosis?

For a baby to be born with Cystic Fibrosis, both parents must be carriers of the faulty CF gene. A baby born to two carriers has a one in four chance of having Cystic Fibrosis.



The diagram shows that if both parents are carriers, a child has a one in four chance of having CF, a two in four chance of being a carrier of the CF gene and a one in four chance of not having any CF genes.

## Could I be a carrier?

Yes, possibly. 1 person in 25 carries the faulty gene, often without knowing it. This means there are well over two million carriers in the UK.

## What tests are available?

There are three types of screening for Cystic Fibrosis: carrier testing, antenatal testing and newborn (neonatal) testing.

### Carrier testing

A simple mouthwash test can be taken to tell if you are a carrier. This is important if a relative has CF or is a known carrier. It is very important to have the test if your partner is a known carrier.

### Antenatal testing

This test is used early in pregnancy to tell whether a baby has Cystic Fibrosis. It is usually offered to mothers who are recognised as being at high risk of having a child with Cystic Fibrosis.

### Newborn screening

Following a campaign by the Cystic Fibrosis Trust, newborn screening has now been implemented across the whole of the UK. The test takes the form of a heel prick to sample blood as part of the normal Guthrie test carried out on all children. The sooner CF is diagnosed, the sooner appropriate treatment can begin.

## Is there a cure?

Not yet, but leading scientists believe they could be close to an effective treatment for Cystic Fibrosis through gene therapy. 90% of deaths of people with CF are as a result of lung damage. Effective gene therapy would stop lung damage from developing.

The CF Trust set up the UK CF Gene Therapy Consortium to develop a gene therapy product. A single-dose pilot study involving 27 young people with CF began in 2009. Once the results of this are analysed, a further round of safety tests will be conducted before a major multi-dose clinical trial involving around 100 young people with Cystic Fibrosis. It costs around £4.5 million each year to fund this work and the clinical trial will cost at least £6.5 million.

## What treatments are available?

People with Cystic Fibrosis can have serious symptoms and complications including digestive problems and recurrent lung infections. Enzyme tablets taken with food help to control the digestive problems. Physiotherapy helps to clear the lungs of the mucus that attracts infection. Inhaled and injected drugs help clear the airways and fight lung infections.

## What does the Cystic Fibrosis Trust do?

The Cystic Fibrosis Trust is the UK's only national charity dedicated to improving the length and quality of life for those with Cystic Fibrosis. It funds medical research to treat the symptoms of, and find a cure for, Cystic Fibrosis. The CF Trust also aims to ensure that people with Cystic Fibrosis receive appropriate care and provides information, advice and support to those with CF and their families.

## What can I do to help?

The Cystic Fibrosis Trust relies on donations to continue its work. Through the support of the CF community, we have funded advances that have helped people with Cystic Fibrosis live longer. In 1964 when the CF Trust was founded, a baby was lucky to reach five years. Today, around half of those with Cystic Fibrosis will live to 38 years or older – not good enough, but getting better.

You can help by making a donation, getting involved in our events or fundraising for us. Please visit our website [www.cftrust.org.uk](http://www.cftrust.org.uk) or give us a call on 020 8464 7211 to find out more.



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