Cystic Fibrosis what, exactly?

Cystic fibrosis (CF) is a life-shortening genetic condition that slowly damages the lungs and digestive system.

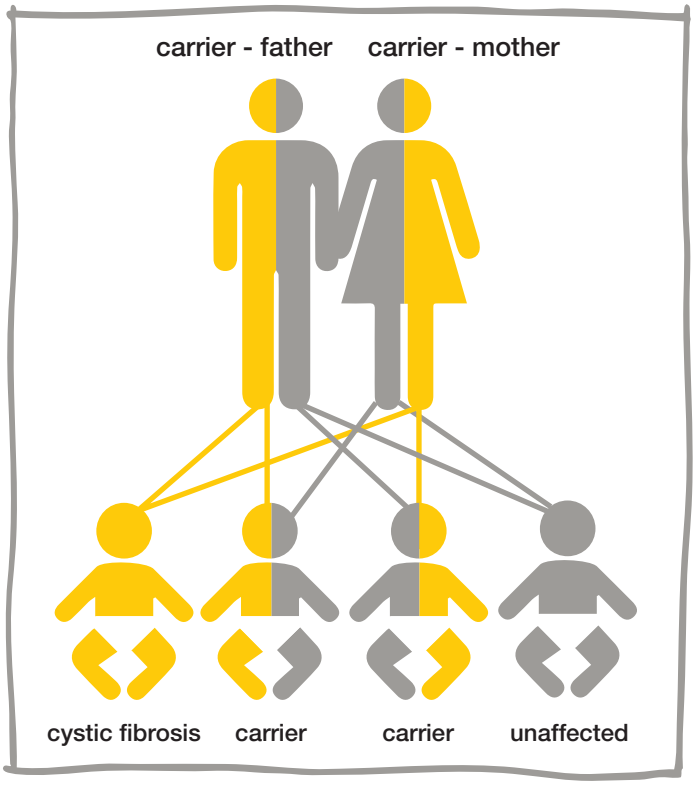
How do you get cystic fibrosis?

Cystic fibrosis is an inherited condition caused by a faulty gene. You can't catch cystic fibrosis, or develop it later in life. For someone to have CF, they must inherit two copies of the faulty gene – one from each of their parents.

The faulty gene is carried by 1 in 25 people.

A carrier does not have cystic fibrosis, they just carry one copy of the faulty gene that causes it. If two people who carry a copy of the gene (carriers) have a baby, there is:

- **a 25% chance the baby will have cystic fibrosis**
- **a 50% chance the baby will be a carrier of the faulty cystic fibrosis gene**
- **a 25% chance the baby will neither be a carrier nor have cystic fibrosis**



How does cystic fibrosis affect the body?

The faulty gene disrupts the movement of salt and water in the body's cells, causing the mucus that naturally occurs in the body to be thicker and stickier than in people without cystic fibrosis. This sticky mucus causes problems, particularly in the lungs and digestive system, but can also affect other parts of the body. The small airways in the lungs can get clogged up with the mucus, causing infection and, over time, damage to the lungs. For many people with CF, blockages in the pancreas mean a lifelong need for enzyme supplements and a special diet.

People with cystic fibrosis often have some or all of these symptoms:

- frequent chest infections
- a severe or prolonged cough
- wheezing or shortness of breath
- abnormal bowel movements
- difficulty gaining weight, and
- for most men, infertility.

How many people have cystic fibrosis?

There are more than 10,800 people living with cystic fibrosis in the UK.

Each week in the UK five babies are born with the condition.

Who gets cystic fibrosis?

The vast majority of people with cystic fibrosis are Caucasian. However the condition is found in many different ethnic groups.

How is cystic fibrosis diagnosed?

Cystic fibrosis is usually diagnosed soon after birth through the routine heel prick test. Older children and adults who were not screened at birth may be diagnosed with cystic fibrosis later in life.

Can I be screened to see if I am a carrier of the faulty gene?

A simple blood test can establish if someone is a carrier of the CF gene. Carrier testing may be available on the NHS if a relative has cystic fibrosis.

How is cystic fibrosis treated?

A range of daily treatments is needed to tackle cystic fibrosis effectively, including:

- antibiotics to fight infection in the lungs
- physiotherapy to help shift the mucus that builds up around the organs
- enzyme capsules with food
- a special diet to ensure the body gets the nutrients it needs
- drugs to thin mucus, and
- if conventional treatments are no longer effective, a lung transplant might be needed.

People with CF can spend a long time each day doing their treatments.

Is there a cure?

There is currently no cure for cystic fibrosis.

Each week in the UK two people die of the condition.

However, understanding and treatment of cystic fibrosis are improving all the time.

What is the life expectancy?

Cystic fibrosis affects everyone differently, so it's hard to say what an individual's life expectancy is. The most recent figures suggest that half of people with CF will live past their 47th birthday, but it's thought that a baby born today with cystic fibrosis, could live longer as life expectancy continues to increase with advances in treatment and care.

Can people with cystic fibrosis live a normal life?

Cystic fibrosis is a serious condition that needs careful management. However, with the right care and treatment, people with cystic fibrosis can lead a full life, albeit with compromises and challenges. Many people with CF are able to work, travel and have families.

I've heard people with cystic fibrosis cannot mix with each other – is that true?

People with cystic fibrosis are prone to lung infections that can be very harmful to others with the condition. Each person may carry different bugs in their lungs, which can be passed on by being around each other. To avoid the risk of cross-infection, people with cystic fibrosis are advised not to mix with each other at all.

How can we help you?

As well as working hard to create a brighter future for people with CF, the Cystic Fibrosis Trust is supporting people affected by CF in the here and now.

Our helpline offers a confidential information and listening service for all worries or questions, big or small. Peer-to-peer support is available through our CF Connect service and on the online forum; both offering support through sharing with others affected by cystic fibrosis.

The Cystic Fibrosis Trust can also provide financial assistance in times of need or even to help with the cost of holidays. Contact our helpline on **0300 373 1000** for more information about these services.

How can you help us?

Supporters of the Cystic Fibrosis Trust generously donate their time, money and voices to help us fight for a life unlimited by cystic fibrosis. There are lots of ways you can help, for example:

- Spare some time to organise a fundraising event
- Make a donation – either personally or get your workplace involved
- Lend your voice to our campaigns or to raise awareness of the condition

Take a look at **cysticfibrosis.org.uk/get-involved** for more information on getting involved with the Trust. To make a donation please visit **cysticfibrosis.org.uk/donate**.

What does the Cystic Fibrosis Trust do?

The Cystic Fibrosis Trust is the only UK-wide charity dedicated to fighting for a life unlimited by cystic fibrosis for everyone affected by the condition. We invest in cutting-edge research to develop improved treatments, drive up standards of clinical care at specialist CF centres and clinics across the UK, provide trusted information, advice and support to those affected, and campaign hard on the issues that matter.

How can I find out more about cystic fibrosis?

Visit our website **cysticfibrosis.org.uk** or call our helpline on **0300 373 1000.**