

What is cystic fibrosis?



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Cystic fibrosis is a life-limiting, genetic condition. It impacts physical and mental health and has no cure.

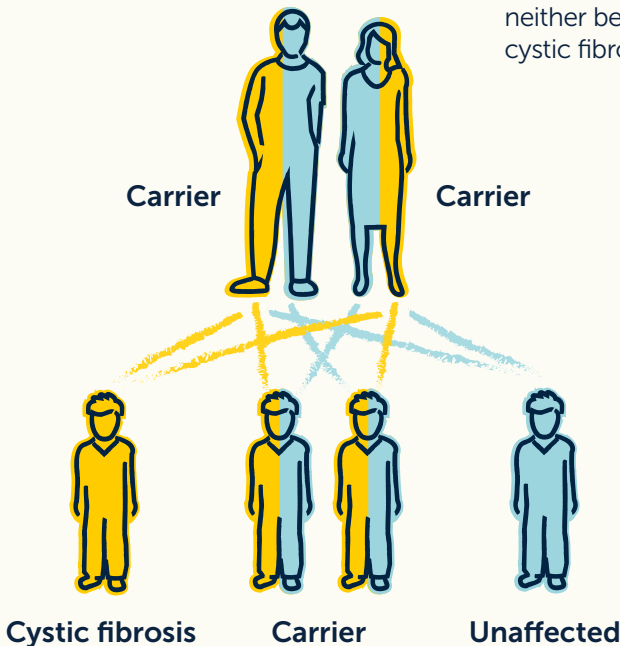
How do you get cystic fibrosis?

You are born with CF. You cannot catch CF, or develop it later in life. For someone to have CF, they must inherit two copies of a faulty gene – one from each of their parents.

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

The faulty gene is carried by 1 in 25 people

- **1 in 4** chance the baby will have cystic fibrosis
- **1 in 2** chance the baby will be a carrier of the faulty CF gene
- **1 in 4** 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 over 11,300 people living with cystic fibrosis in the UK, and each week four people are diagnosed with the condition.

Who gets cystic fibrosis?

CF can affect anyone from any ethnicity. The majority of people diagnosed with CF in the UK are White (94.6%).



How is cystic fibrosis diagnosed?

Since 2007, in the UK, CF 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.

How is cystic fibrosis treated?

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

- antibiotics to fight infection in the lungs
- physiotherapy to help shift the mucus that builds up, in and around the organs
- enzyme supplements 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 no cure for CF, but there have been huge advances in care and medicines in recent years. Researchers continue to work hard to improve treatments.

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.



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 those born in the UK with CF today will live past their 64th birthday, but life expectancy continues to increase with advances in treatment and care.



Can people with CF live a normal life?

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

I've heard people with CF cannot meet with each other in person – is that true?

People with CF 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 CF are advised not to meet in person.

“CF doesn't need to define you, but it is a massive part of who I am. And whenever I tell people I have CF ... they are inspired or in awe of how I can stay fit and healthy despite my condition.”

Kieron (left) who has CF



How can we help you?

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

Our confidential Helpline is available to anyone looking for information or support with any aspect of cystic fibrosis, a listening ear, or just to talk things through. We can also offer financial support through our welfare grants and provide advice on benefits. Peer-to-peer support is available through our CF Connect service. Our online forum provides a safe space to connect and share with others in the CF community.

Our Helpline is open Monday to Friday by phone on **0300 373 1000**. Message us on WhatsApp on **07361 582053** or email **helpline@cysticfibrosis.org.uk**

What does Cystic Fibrosis Trust do?

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out and support each other as we race towards effective treatments for all. We invest in cutting-edge research, 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.

Find out more about cystic fibrosis on our website
cysticfibrosis.org.uk

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How can you help us?

Cystic Fibrosis Trust is here to make sure that everyone with cystic fibrosis can live without limits but we cannot do what we do without your support. Here's how you can get involved:

- Donate, either personally or get your workplace involved. Organise a fundraising activity or sign up for one of the many events across the UK.
- Lend your voice to our campaigns or to raise awareness of CF through social media or share your story with us.

Look at **cysticfibrosis.org.uk/get-involved** for more information.

To donate please visit **cysticfibrosis.org.uk/donate**

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