

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 to fight lung infections.

Cystic Fibrosis – the facts

Cystic Fibrosis (CF) is the UK's most common inherited disease in children of European heritage. It does occur in children of all ethnicities.

- C.F affects over 8,000 people in the UK.
- Over 2 million people carry a change in the gene that causes C.F. This is around 1 in 25 of the population.
- Two carriers have a 1 in 4 chance of having a child with C.F in each pregnancy.
- Each week five babies are born with C.F.
- C.F 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.
- For those couples who know they both carry a change in the C.F gene, it is possible to avoid conceiving a child with C.F by having P.G.D. For details of this and testing in early pregnancy see the **C.F trust booklet called 'genetics'** available on line from the CF trust website.
- The average life expectancy of someone with C.F is around the fourth decade. This is likely to improve with early detection and better treatment of the condition.

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 C.F. It funds medical research to treat symptoms of, and find a cure for C.F. The C.F trust also aims to ensure that people with C.F, and their families, receive appropriate care and support.

Where can I get more information: or support?

The C.F trust provides information, advice and support to those with C.F and their families.

Cystic Fibrosis Trust
11 London Road
Bromley
Kent, BR1 1BY

Tel: 02084647211
Fax: 02083130472

Email: enquiries@cftrust.org.uk
www.cftrust.org.uk

Birmingham Women's NHS Foundation Trust is not responsible for the third-party information and does not endorse any product, view or process or opinion from such sources.

Acknowledgements: thank you to the C.F Trust.

**Birmingham Women's
NHS Foundation Trust**
Edgbaston, Birmingham, B15 2TG
Telephone: 0121 472 1377
Fax: 0121 627 2602

Reference Number: GG 4

Author: Chris Morgan, Genetic Counsellor
Reviewed: June 2011 Next Review: June 2014

Birmingham Women's 
NHS Foundation Trust

Cystic Fibrosis

An information leaflet for
patients and families

If you need more advice about any aspect
of Cystic Fibrosis please contact:

Clinical Genetics Unit
Birmingham Women's
NHS Foundation Trust
Mindelsohn Way
Edgbaston
Birmingham
B15 2TG

Telephone: 0121 627 2630

Fax: 0121 627 2618

Email: Clinicalgenetics.info@bwhct.nhs.uk

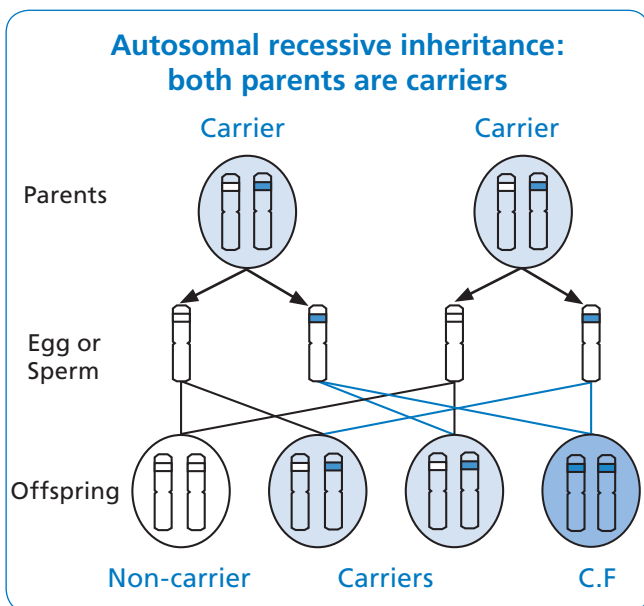
What is Cystic Fibrosis?

Cystic Fibrosis (C.F) is one of the UK's most common inherited diseases. It is caused by a **change in a gene** that controls the movement of salt 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 harder to breathe and digest food. Other complications in people with C.F include diabetes, liver disease, brittle bones and gallstones.

Why is a baby born with C.F?

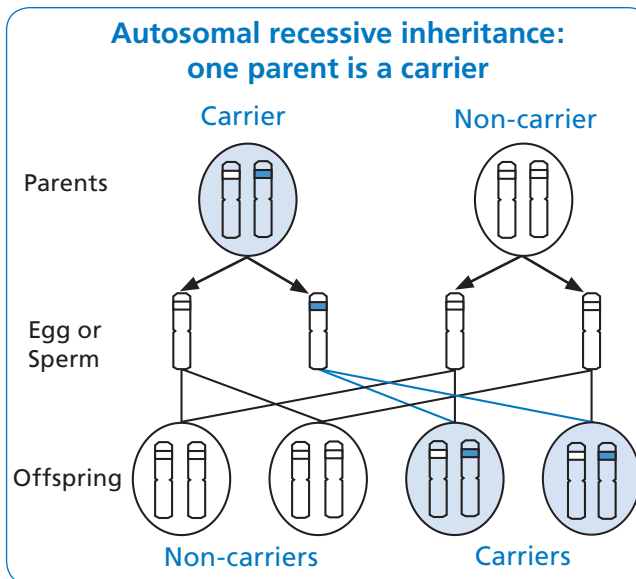
For a baby to be born with Cystic Fibrosis, both parents must be carriers of the change on the gene.

Each baby born to two carriers has a 1 in 4 chance of having Cystic Fibrosis. Each child has a 2 in 4 chance of being a carrier.



Could I be a carrier?

Yes, possibly. One person in 25 is a **carrier of the gene change** often without knowing it. This means there are over two million carriers in the UK. If your partner is not a carrier your children will not develop cystic fibrosis but have a 1 in 2 chance of also being a healthy carrier.



Are any tests available?

There are three types of C.F screening. Carrier testing, newborn (neonatal) testing, and antenatal testing.

A) Carrier testing: a simple blood test can be taken to tell if you are a carrier. This is important if a relative has C.F or is a known carrier. It is very important to consider testing if your partner is a known carrier. We can only screen for the common 29 changes on the C.F gene so if a person carries a very rare C.F gene change it can not be detected.

B) Newborn testing: following a campaign by the Cystic Fibrosis Trust, the National

Screening Committee recommended that all babies should be screened for Cystic Fibrosis. The Screening program in the West Midlands has been in place since 2007. The heel prick test taken by the midwife is used to screen babies likely to be a C.F carrier or affected with C.F. **An early diagnosis of C.F allows the appropriate treatment to begin sooner.**

C) Antenatal testing: a test called chorionic villus sampling (C.V.S) at 11 weeks of pregnancy or an Amniocentesis at 16 weeks can be performed to check if a baby has Cystic Fibrosis. It is usually offered to mothers who are recognized as being at high risk of having a child with Cystic Fibrosis. Both tests have a risk of miscarriage. It is also possible to have I.V.F (test tube baby) and screen the C.F gene in the embryos (a baby in the very early stage of development at 6 days after egg is fertilized).

This is known as pre-implantation genetic diagnosis (P.G.D.) You can discuss the pros and cons of all these difficult decisions with you Genetic Counsellor.

Is there a cure?

Not yet, but leading scientists believe they could eventually develop an effective treatment for Cystic Fibrosis through gene therapy. Around 90% of deaths of people with C.F are as a result of lung damage. Effective gene therapy would stop lung damage. The UK C.F gene Therapy consortium has developed a gene therapy product, which is currently being tested on people with C.F.

What treatments are available?

People with C.F can have serious symptoms and complications including digestive problems and recurrent lung infections.