Community Channel

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Cystic Fibrosis Factsheet

What Can Science Do for Me?
This 5 x 30 minutes series of films takes five individuals each with a chronic health condition to meet the scientists working on treatment, prevention and diagnosis of their particular condition. The series was funded by the Wellcome Trust and made by Media Trust Productions.

Cystic Fibrosis – Ian's Journey
Thirty five year old Ian Tucker was born with Cystic Fibrosis, a life-threatening, inherited disease affecting the lungs and digestive system. This film looks at Ian's daily routine of pills, nebulisers, and physiotherapy, and shows how CF prevents him from engaging in his passion for singing. We follow Ian and fiancée Lydia as they meet some of the country's leading scientists to find out how their research might help people living with Cystic Fibrosis.

Key Facts

*Cystic Fibrosis (CF) is the UK's most common life-threatening inherited disease.

*It affects over 7,500 people in the UK.

*More than two million people in the UK carry the faulty gene that causes Cystic Fibrosis - around 1 in 25 of the population.

*If two carriers have a child, the baby has a one in four 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, and three people lose their fight against Cystic Fibrosis.

*Average life expectancy is around 31 years, although improvements in treatments mean a baby born today could expect to live for longer.

What are the symptoms?
When a child is born with cystic fibrosis, symptoms usually appear in the first year of life, although occasionally they can develop later. The symptoms and related

problems of cystic fibrosis may vary from person to person, and may be worse for some than for others.

The **main symptoms** are:

*Troubling cough and wheeze - this is caused by the thick mucus in the lungs, which the body tries to shift by coughing it up.

*Recurring chest and lung infections - these can be quite severe, such as bronchitis or pneumonia. To prevent the risk of cross infection, it is recommended that people with cystic fibrosis do not come into close contact with one another.

*Malnutrition - this is due to the mucus clogging the digestive system. The mucus blocks the ducts in the pancreas that produce a food-digesting enzyme, so not enough of this enzyme reaches the intestines. As a result, the body cannot digest much of the essential nutrients in food.

*'Clubbed' fingers and toes - people with cystic fibrosis often have swollen or very rounded fingers and toes. The reason for this is not fully understood but is thought to be to do with mucus collecting at the ends of the digits.

*Polyps inside the nostrils - these are small, soft growths in the nasal passages. They are caused by inflammation due to a build up of mucus.

*Large, odorous stools - this is a result of poor digestion caused by mucus build up in the digestive system.

*Salty tasting skin - this is caused by high levels of salt in the sweat.

What is the treatment?
The aim of treatment for cystic fibrosis is to ease the symptoms and make the condition easier to live with. It can also prevent or reduce the long term damage caused by infections and other complications. The different types of treatment and physiotherapy for cystic fibrosis are:

- Medication
Medical treatments for cystic fibrosis can help to clear and control infections in the lungs and digestive system. They can also be used to treat some of the health problems related to cystic fibrosis. The main medications include:

* Antibiotics - these can be taken to fight infections in the lungs. They can be inhaled through a nebuliser (a device which turns drugs into a mist that can be breathed in), or they may be injected if the infection is more severe.
* Bronchodilator drugs - these are inhaled to help with breathing more easily. They work by relaxing the muscles that surround the airways in the lungs, helping them to open up.
* Steroids - these can be taken to reduce swelling of the airways in the lungs, which can help with breathing. Steroid nasal drops and sprays can be used to treat nasal polyps (small growths inside the nostrils).
* DNase - this treatment, which is usually inhaled, helps to thin and break down the sticky mucus in the lungs so that it is easier to cough up.
* Pancreatic enzymes - these should be taken before every meal to help the digestive system break down food, so that the body can get the nutrients it needs. The pancreas cannot produce enough food-digesting enzymes due to the

mucus clogging the digestive system, so these pills supply the enzymes instead.

* Bisphosphonates - these can be taken to treat osteoporosis (weak and brittle bones), that can occur as a result of cystic fibrosis. They help to maintain bone density and can reduce the number of fractures that can occur.
* Insulin – sufferers will need to take this, and other appropriate treatments, if they develop diabetes as a result of cystic fibrosis.
* Immunisations and flu jabs - it is particularly important that people with cystic fibrosis are up to date with all required immunisations.

- Lung transplants

In advanced and severe cases of cystic fibrosis, a lung transplant may be recommended if there is respiratory failure, and all medical treatments have failed to aid breathing. Both lungs must be transplanted as they are both affected by the condition. A lung transplant is a serious operation which carries certain risks, but it can greatly improve the length and quality of life for people with severe cystic fibrosis. The longest surviving patients who had lung transplants as a result of cystic fibrosis had their operations over fifteen years ago.

- Physiotherapy

Physiotherapy for cystic fibrosis helps to clear mucus build up in the lungs so that it can be coughed up. It is an important part of the treatment for cystic fibrosis as it helps to prevent infections and lung damage caused by the mucus.

Physiotherapy is carried out by 'clapping' on the patient's back and chest while they are lying down, which helps to shift the mucus in their lungs. It should be done everyday, and the length of physiotherapy sessions may vary according to how clogged the lungs are.

- Diet and Exercise

As well as treating cystic fibrosis with medications and physiotherapy, there are things that you can do at home to improve the symptoms of the condition. Both diet and exercise are very important in treating cystic fibrosis.

Organisations

Cystic Fibrosis Trust

The CF Trust was founded in 1964, and works to improve the lives of people with CF, to raise the profile of CF and fund research into a cure.

Address: 11 London Road, Bromley, Kent BR1 1BY.
Support Helpline: 0845 859 1000
Tel: 020 8464 7211
Fax 020 8313 0472
Email: (general enquiries) enquiries@cftrust.org.uk
(medical enquiries) AskTheExpert@cftrust.org.uk
Website: http://www.cftrust.org.uk/

Haemair Ltd

Haemair Limited are the developers of a patented prosthetic lung and respiratory aid shown in What Can Science Do for Me? Their mission is to reduce acute deaths,

improve the lives of chronic sufferers and to provide an alternative to lung transplantation.

Address: Unit 212, Technium Digital, University of Wales at Swansea, Singleton Park, Swansea SA2 8PP
Tel: 01792 602 466
Email: info@haemair.com
Website: http://www.haemair.com

The Wellcome Trust

The Wellcome Trust was established in 1936 and is an independent charity funding research to improve human and animal health. It is the UK's largest non-governmental source of funds for biomedical research.

Address: Gibbs Building, 215 Euston Road, London NW1 2BE.
Tel: 020 7611 8888
Fax 020 7611 8545
Email: contact@wellcome.ac.uk
Website: http://www.wellcome.ac.uk/

Community Channel

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Web: http://www.communitychannel.org/
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