

JOURNALIST FACTSHEET

TRANSPLANTATION

Lung transplantation is a form of treatment for some patients with Cystic Fibrosis, and is being performed in the UK and the other parts of the world in both children and adults. Lung transplantation is major surgery and therefore carries considerable risks but it can offer an improved quality of life and better survival for those with advanced Cystic Fibrosis (CF), with 50% of CF recipients now living over 10 years in experienced centres. It is appropriate only for a patient who is severely ill and for whom all other forms of conventional treatment are no longer helpful. Not all patients at this stage of the disease are suitable for a transplant.

The first successful heart-lung transplant for Cystic Fibrosis (CF) was performed in 1985. Since then, hundreds of transplants have been performed on patients with Cystic Fibrosis.

Transplantation is not a cure for Cystic Fibrosis. Although patients have new lungs, which won't develop Cystic Fibrosis, patients still have to continue with all their medication for other parts of their body as they still have CF. Their new lungs also need very specific care because transplanted lungs are liable to episodes of infection and rejection. However many people with CF are leading full lives years after transplantation.

About the procedure

Some patients still receive heart and lung transplants but most patients with CF now keep their own heart and only the lungs are transplanted. This is decided by the surgeon and the transplant centre.

After an operation patients are normally in the Intensive Care Unit for a few days and then in a single room for another four to six weeks. After a lung transplant operation most patients take 6-9 months to get the maximum benefit.

Problems that can occur

Life with transplanted lungs is not always trouble-free. For example:

- Most patients with transplanted lungs occasionally get episodes of infection or rejection. That is why it is vital that daily diaries are completed and that patients contact the transplant centre at once if they have any unexplained temperature or deterioration in lung function. Second transplants have been carried out but they carry a higher risk than the first operation
- Some patients get chronic rejection, which leads to a condition called obliterative bronchiolitis. When this happens the transplanted lungs do not work as well and patients become more breathless, although there are improved treatments available to help with this.

Bilateral living donor lobe donation

There is a shortage of donor organs and approximately 30-40% of patients will die whilst on the waiting list. Doctors in the USA have pioneered a technique in which two people, usually close relatives, each donate a lung lobe to the patient with Cystic Fibrosis. The potential donors need intense pre-operative assessment, must be very fit and must understand the risks involved for themselves and the patient with Cystic Fibrosis. Although a small number of such operations have been performed in the UK since 1995, techniques are still being developed and this option is not available at all transplant centres, nor is it appropriate for all patients.

Ex-Vivo Lung Resuscitation

75% of available donor lungs in the UK are considered unusable due to poor function. The CF Trust is funding research by Dr Andrew Fisher at Newcastle University who is assessing ways to transform unusable donor lungs into lungs suitable for use in clinical lung transplantation. Unusable donor lungs are placed on a modified bypass machine called an ex-vivo lung perfusion circuit, which repairs and resuscitates damaged lungs. This research is showing great promise.

Transplant Centres

There are five main centres where lung transplantation operations are performed: Royal Brompton & Harefield NHS Trust, London; Great Ormond Street Hospital for Children, London; Freeman Hospital, Newcastle upon Tyne; Wythenshawe Hospital, Manchester; and Papworth Hospital, Cambridge.

ENDS

For all media enquiries, please contact:

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Notes to Editors

- The Cystic Fibrosis Trust is the UK's only national charity dealing with all aspects of Cystic Fibrosis (CF). It funds research to treat and cure CF and aims to ensure appropriate clinical care and support for people with Cystic Fibrosis.
- Cystic Fibrosis (CF) is one of the UK's most common life-threatening inherited diseases. Cystic Fibrosis is caused by a single defective gene. As a result, the internal organs, especially the lungs and digestive system, become clogged with thick sticky mucus resulting in chronic infections and inflammation in the lungs and difficulty digesting food.
- Each week five babies are born with Cystic Fibrosis and three young people die – 90% from lung damage. Around half of the CF population can expect to live over 38 years, although improvements in treatments mean a baby born today is expected to live even longer.

- Further information can be found on our website www.cftrust.org.uk. Help and advice for those affected by Cystic Fibrosis is available through our Helpline on 0300 373 1000. For further information, media should contact Gemma Foy on 0208 290 7912 or email gfoy@cftrust.org.uk

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