

Cystic Fibrosis and Transplantation

Lung or heart - lung transplantation.

Lung transplantation was first performed in 1963 but was only really successful in the 1980's. Recently survival rates have improved to 80% at 1 year and 70% at 2 years. There are still many patients who are alive and well over ten years after their operation. Transplantation can help some people live longer and bring them a better quality of life.

When to have a lung or heart-lung transplantation.

Transplantation should be considered for everyone with CF well before it is actually needed.

What does the transplant centre do?

Your surgeon and transplant team will want to get to know you. They will discuss options to help you decide whether to be considered for a transplant. If the team agrees that transplantation may help you and you agree, you will be placed on the waiting list. A number of medical tests will be performed at this stage.

You will be offered transplant when a suitable donor becomes available. Remember you can say no at any stage in this process. There are not enough donor lungs for everyone who needs a transplant and many people never have the opportunity. This is why we aim to place you on the waiting list approximately two years before you need a transplant but this does vary considerably.

What does the operation involve?

In a double lung transplantation the surgeon will remove your two damaged lungs and put two new lungs into your chest. They will stitch them to your windpipe and attach them to your heart.

In heart-lung transplantation the surgeon removes your damaged lungs and heart and places new lungs and heart into your chest. If your old heart is healthy it will be offered to someone else who needs a heart transplant. This is called a "domino operation". To prevent rejection of the new organs you will need to have to take medication which partially suppress your immune system. You must always take these exactly as prescribed.

Information for Patients

What are the benefits?

The new lungs do not develop cystic fibrosis. Hundreds of people with CF have had successful transplants. Transplantation is not for everyone but it can completely transform a life. Many people from the Heartlands centre have benefited and their quality of life has been improved by transplantation.

What are the risks and complications?

Transplantation is a major operation and some people develop complications. These can be as a result of any operation. Very occasionally people may die from this type of surgery, despite a high standard of care. It is important that you understand that there are risks involved with these types of operations.

Sometime the anti rejection drugs are not fully effective and the new organs can be rejected either straight away or more slowly over a period of years. With modern medicines this has become less common.

Any procedure will only be carried out with your consent and you will be asked to sign a consent form.

Contact us:

If you are concerned about any of the points raised in this leaflet or have any further queries please speak to your consultant or the CF team.

Additional Information Sources

For more information on all aspects of living with Cystic Fibrosis you can visit the Cystic Fibrosis Trust web site at : www.cftrust.org.uk. For local news and events the West Midlands Regional Cystic Fibrosis Unit based at Heartland Hospital has its own website at: www.heartlandscf.org.uk .

Our commitment to confidentiality

We keep personal and clinical information about you to ensure you receive appropriate care and treatment. Everyone working in the NHS has a legal duty to keep information about you confidential. We will always ask you for your consent if we need to use information that identifies you. We will share information with other parts of the NHS to support your healthcare needs, and we will inform your GP of your progress unless you ask us not to. You can help us by pointing out any information in your records which is wrong or needs updating.

Please use the space below to write down any questions you may want to ask: