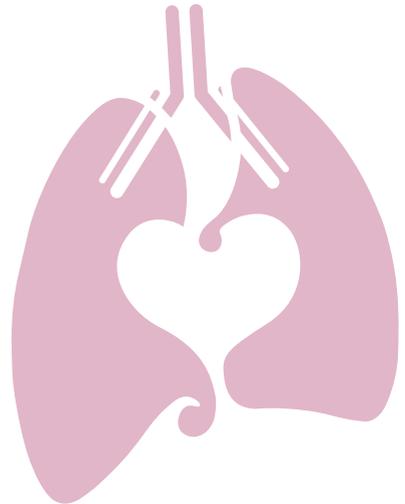


Having a lung transplant

Information for patients



Cardio-Respiratory
Service

Your healthcare team have discussed lung transplantation with you today. This may have been the first time you have discussed it, or it may have been something you had already thought about. This leaflet is by no means comprehensive, it is simply to act as a reminder of some of the issues mentioned.

Lung transplantation involves the removal and replacement of one, or both lungs with those from a deceased donor. In order to prevent your body rejecting the new organs, you would need to be on medications for the rest of your life and be seen regularly by the transplant centre. The lung transplant centre would regularly monitor the way the new lungs were working in a number of ways including x-rays, CT scans, lung function tests as well as more invasive tests such as bronchoscopy. Alongside this they will monitor your overall health and the impact of the medication used for preventing rejection of your transplanted lungs.

Lung transplantation is a substantial operation, and carries with it a certain level of risk of harm, or even death. It is important that we ensure that any person put on the lung transplant waiting list can withstand the operation and the recovery from the operation, but also be unwell enough to justify the risks. Therefore, you will be sent for a number of tests before being referred to a transplant centre. You may have already had some of these tests, or started this process today.

It is not a 'quick fix'

Unfortunately, this is true. The process of lung transplant assessment can be lengthy, and may require you to have a number of investigations with us, and then further tests at the transplant centre prior to any decision as to whether lung transplantation would benefit you. The assessment at the transplant centre can mean up to one week of an inpatient admission at that site. NHS transport/ accommodation for relatives is not routinely provided. If you meet all the assessment criteria you will be placed on the transplant waiting list. This means you will be monitored and as your disease progresses you will be treated as a higher priority.

There are also limited numbers of transplants performed each year - at the end of March 2023 there were 101 lung transplants carried out in the UK, with 301 people in the UK on the active lung transplant waiting list.

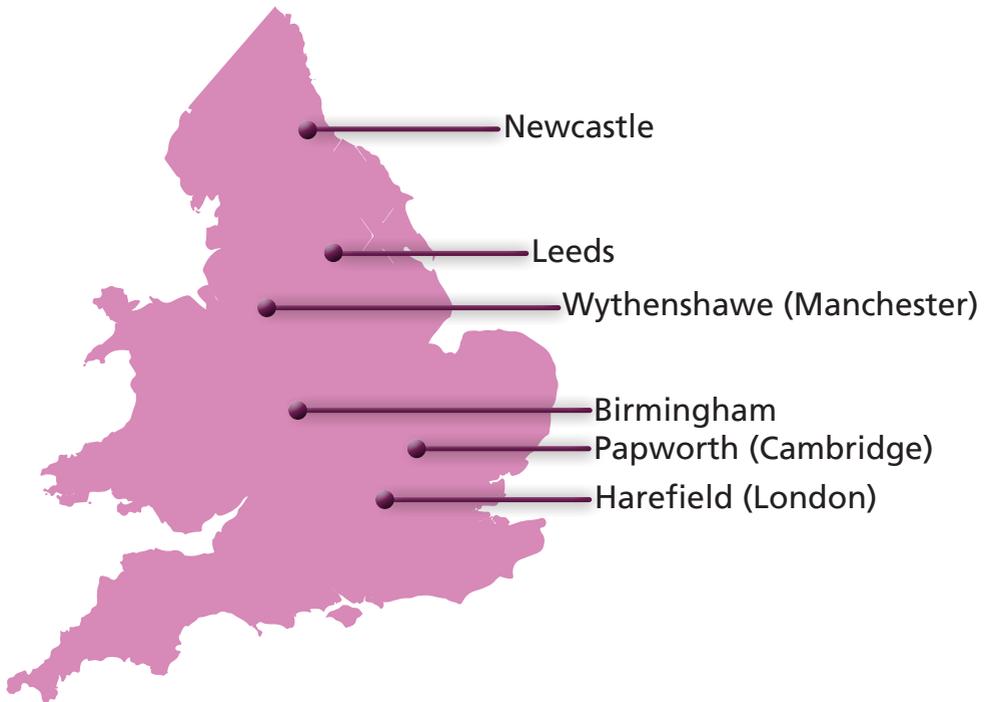
When suitable donor lungs become available you are telephoned and need to be at the hospital within a few hours, you would be required to stay on the UK mainland throughout your time on the list. It is often the case that donor lungs are found to be unsuitable, it is possible that may be called a number of times before a suitable match is found. The operation is complex and carries many risks and usually requires a stay of 4-8 weeks in hospital.

It is not performed everywhere

Leeds Teaching Hospitals NHS Trust does not perform the lung transplantation operation (although it does carry out other organ transplants). Therefore you will be referred to one of the other transplant centres in England. Your healthcare team will choose one based on your specific medical history, but please feel free to tell us if you have a particular geographical preference and we will take this into account.

The lung transplant centres in currently are;

- Newcastle
- Manchester
- Birmingham
- Harefield (London), and
- Papworth (Cambridge).



Factors that will stop a lung transplant referral.

The current guidelines state that every patient must have stopped smoking for at least six months before being assessed for lung transplantation. This includes ALL nicotine replacement therapy, including electronic cigarettes.

Another factor that will stop a transplant assessment beginning if you are too overweight (BMI of 30 or above) or underweight (BMI under 17).

The specific issues regarding transplantation will be discussed by the lung transplant team. However, your team at Leeds are happy to discuss any more general questions with you. We recognise this can be a stressful and difficult time, so if there are ways we can help, please feel free to ask.

The outlook for people who have had a lung transplant has improved in recent years and it's expected to continue improving.

In 2022, the NHS Blood and Transplant service reported that on average:

- 83 people out of 100 live for one year after a lung transplant
- 55 people out of 100 live for five years after a lung transplant

Not everyone gets a lung transplant

Again, this is true. After the initial investigations, it may be that the transplant centre decides you would not benefit from a lung transplant. Your healthcare team will discuss this decision with you. If you are declined for lung transplant, you have the right to ask for one of the other transplant centres to review your case as a 'second opinion' (although there may be no change in the decision).

One of the challenges of lung transplantation is the unpredictability of the waiting time. Some patients wait a short time for a suitable donor, whereas others may wait a number of years. The average wait on the lung transplant waiting list is approximately two years, over which time, your health may still deteriorate.

Unfortunately, we also recognise that there are not enough lung donors for people on the transplant list, and some people do not survive long enough to take advantage of the lung transplant operation.

Your regular treatments and investigations will continue alongside a referral. Please tell your healthcare team if there is any change in your health or medications.

For more information visit:

www.nhs.uk/conditions/lung-transplant/

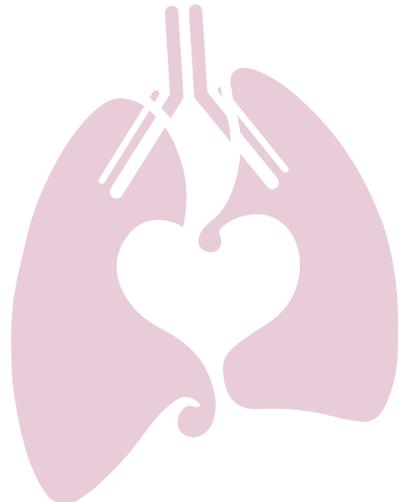
Action for Plumonary Fibrosis:

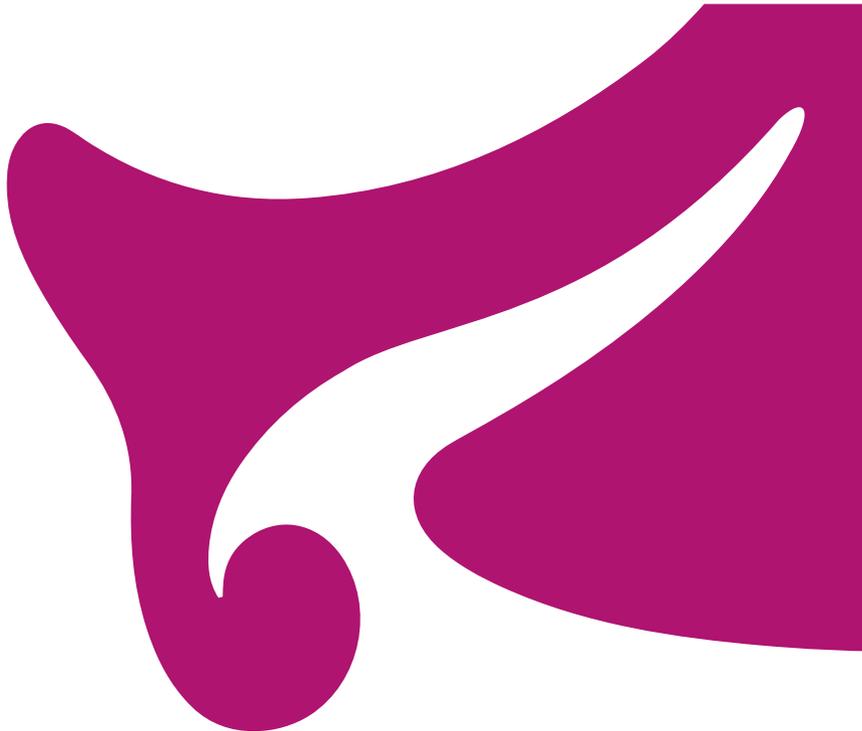
www.actionpf.org/information-support/lung-transplants

For more information contact:

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