



Royal Papworth Hospital
NHS Foundation Trust

Pulmonary Endarterectomy

Patient's guide and
agreement to consent form

This information booklet has been prepared to help you and your relatives understand the pulmonary endarterectomy (PEA/PTE) operation and what the risks and benefits of having the procedure will be for you.

During the clinic visit you will be given the booklet; Pulmonary Endarterectomy, a patient's guide, which is a more detailed booklet for you to refer to. It contains more detailed descriptions of the pathways that you may follow as a patient choosing to undergo this surgery.

Chronic Thromboembolic Pulmonary Hypertension (CTEPH)

Chronic Thromboembolic Pulmonary Hypertension (CTEPH) is a form of pulmonary hypertension that is caused by blockages in the blood vessels to your lungs due to scar tissue. The scars are the result of blood clots that the body has not properly cleared. These scars cause a complete or partial blockage leading to difficulties in blood flowing through the lungs causing increased blood pressure. The right side of the heart which pumps blood through the lung blood vessels is forced to work harder than normal and gets bigger and weaker as it tries to cope. If left untreated, the heart will eventually start to fail.

Treatment with blood thinning agents such as Warfarin stop more clots from forming but has no effect on the scarring left by previous clots. There is no medical treatment to break down the old scars and the treatment of choice is surgery for those suitable to remove these scars.

In most patients this will improve breathlessness and quality of your life.

The surgical procedure

The operation involves opening the chest through the breast bone and manually peeling away the inner lining of the blood vessel wall to remove the scar tissue. To do this the body is put on a bypass machine which takes over the function of your heart and lungs during the operation and your body is then cooled down to 20° centigrade.

The average length of stay of a patient having this operation is between 7 and 10 days. The operation always involves a stay in the critical care area (CCA) and all patients will be moved to the ward from CCA needing oxygen.

The risks and benefits of surgery

Benefits of surgery

If the surgeon confirms that you may be helped by this operation the benefits that you may notice are;

Improved symptoms of breathlessness and quality of life

Some patients are able to return to a normal active life and employment. Patients generally experience gradual improvement immediately following surgery with the maximum benefit being realised up to a year.

Living longer

Over 90% of patients who have surgery are likely to be alive and well at three years post surgery, and over 70% of patients at ten years post surgery.

Some patients whose blockages are more distal do not get as much improvement in their health and may have residual pulmonary hypertension despite surgery. Of these patients many still feel better and are able to do more than before surgery.

Please affix patient label or complete details below.

Full name:

Hospital number:

NHS number:

DOB:

Consent 024 Patient agreement to Pulmonary Endarterectomy

Intended procedure/surgery

Statement of health professional

(To be filled in by a health professional with appropriate knowledge of proposed procedure, as specified in consent policy). I have explained the procedure to the patient. *In particular I have explained:*

The intended benefits

- An improvement in breathing and the quality of life, and in most patients prolonged life.

Common operation risks (see page 5 for explanations)

- Bleeding
- Extended Critical Care stay
- Wound infection
- Irregular heartbeat
- Temporary confusion and delirium

Specific risks

- Residual pulmonary hypertension
- Subdural haematoma

Severe operation risks

- Death%
- Major disability (for example, stroke or brain injury)

Any extra procedures, which may become necessary during the procedure:

- Blood transfusion
- Other procedure - please specify below:

.....
I have discussed what the procedure is likely to involve, including the benefits and risks, and any particular concerns of this patient.

Consultant/Performer

Signed:

Date:

Name (PRINT):

Job title:

Contact details

(If patient wishes to discuss options later)

.....

Statement of patient

Please read the patient information and this form carefully.

If your treatment has been planned in advance, you should already have your own copy which describes the benefits and risks of the proposed treatment. If not, you will be offered a copy now.

If you have any further questions, do ask - we are here to help you. *You have the right to change your mind at any time, including after you have signed this form.*

- **I understand** what the procedure is and I know why it is being done, including the risks and benefits.
- **I agree** to the procedure or course of treatment described on this form and have read the information leaflet on Pulmonary Endarterectomy (PI 26) and had the opportunity to ask questions.
- **I agree** to the use of photography for the purpose of diagnosis and treatment and I agree to photographs being used for medical teaching and education.
- **I understand** that any tissue removed as part of the procedure or treatment may be used for diagnosis, stored or disposed of as appropriate and in a manner regulated by appropriate, ethical, legal and professional standards.
- **I understand** that any procedure in addition to those described on this form will be carried out only if necessary to save my life or to prevent serious harm to my health.
- I have listed below any procedures **which I do not wish to be carried out** without further discussion:

.....

.....

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- I have been told in the past by Public Health that I am at increased risk of CJD (Creutzfeldt-Jakob disease) or vCJD (variant Creutzfeldt-Jakob disease).

Yes (Health professional to refer to Trust CJD procedure DN92.)

No

Patient

Patient signature:

Date:

Name (PRINT):

Confirmation of consent

(To be completed by a health professional when the patient is admitted for the procedure, if the patient has signed the form in advance).

On behalf of the team treating the patient, I have confirmed with the patient that they have no further questions and wish the procedure to go ahead.

Signed:

Date:

Name (PRINT):

Job title:

Statement of interpreter (where appropriate).

I have interpreted the information above to the patient to the best of my ability and in a way which I believe he/she can understand.

Signed:

Date:

Name (PRINT):

A witness should sign below if the patient is unable to sign but has indicated his or her consent. Young people/children may also like a parent to sign here (see notes).

Signed:

Date:

Name (PRINT):

Important notes (tick if applicable).

Patient has advance decision to refuse treatment (e.g. Jehovah's Witness form)

Patient has withdrawn consent (ask patient to sign/date here)

Patient signature:

Date:

Name (PRINT):

Risks of surgery

Common risks of pulmonary endarterectomy

Bleeding

Immediate post-operative bleeding may be experienced as a result of anticoagulants and use of cardio pulmonary bypass intra operatively. Up to 5% of patients may require return to the operating room for the wound to be re-explored.

Wound infection

Following any operation you have a risk of developing an infection in the wound. This may be a little localised infection or a deeper wound infection. If you are a diabetic there is a slightly increased risk of developing a wound infection. Overall the wound infection rate is less than 5%.

Irregular heartbeat (cardiac arrhythmia)

Following PEA surgery some patients experience an irregular heartbeat. This is usually temporary and treatable with drugs and a regular rhythm return.

Prolonged stay in critical care area

Most patients will be well enough to leave the Critical Care by the second day after surgery. Some patients require a longer stay - reasons for this include ongoing need to support your heart, lung or kidneys. Pathways A, B & C will be explained during your consultation with the nurse in detail but indicate different care requirements that individuals may experience as a result of surgery that prolong critical care needs.

Specific risks for PEA/PTE

Subdural haematoma (bleed between your brain and skull bone)

Undergoing a pulmonary endarterectomy and requiring anticoagulation increases your risk of this happening.

Residual pulmonary hypertension

Some patients will continue to have pulmonary hypertension after surgery and may need medical therapy at some point in their follow-up.

Serious operation risks

Death

On average over 97% of patients survive surgery. The risk of PEA in some patients may be higher than average and your surgeon will discuss your individual risk.

Disability

Stroke or severe brain injury is seen in less than 2% of patients.

Risks of surgery (continued)

During heart (and some lung) operations the body is cooled and warmed by the heart lung machine (cardiopulmonary bypass machine). To do this the bypass machine is connected to a heater/cooler unit, which is kept in the operating theatre.

Tests on these heater/cooler units in Europe and the UK have revealed a growth of a Mycobacterium species (which is a type of bacteria that is common in the environment but does not frequently cause human infections), with the potential for growth of other organisms. There have been reports of a particular organism called Mycobacterium Chimera causing serious infections in a very small number of patients having operations on their heart valves, in some cases several years after the operation. In the United Kingdom a small number of such infections have been reported since 2007. Given that around 35,000 heart operations on bypass are performed each year of which approximately 15,000 have been heart valve operations, this represents a very small risk. This level of risk is so small that surgery should not be delayed, as the risks of delaying surgery are greater than proceeding. No recent infections have been reported.

Further reading: www.gov.uk/government/collections/mycobacterial-infections-associated-with-heater-cooler-units

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