

# 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) 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 (PI 26) 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 10 and 14 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 five 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 the quality of life and life expectancy

#### Common risks (see page 5 for explanations)

- Bleeding
- Reperfusion pulmonary oedema
- Extended CCA stay
- Wound infection
- Irregular heartbeat

#### Less common risks

- Subdural haematoma
- Heart failure
- Renal failure
- Residual pulmonary hypertension

#### Rare risks

- Death .....%
- Perforated pulmonary artery
- Stroke/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:

.....

.....

Please affix patient label or complete details below.

Full name:

Hospital number:

NHS number:

DOB:

- 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. Approximately 5% of patients may require return to the operating room for the wound to be re-explored.

#### **Pulmonary oedema**

As a result of the stripping away of the inner lining of the pulmonary arteries fluid can leak through the vessel walls into the lung air sacs and will require interventions depending on its severity. Some interventions are used routinely, others less frequently but all care decisions will be discussed with your family should the need for them arise. Occasionally if this complication is severe, treatment with an artificial lung (ECMO) and a period of prolonged ventilation may be required.

#### **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 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 CCA by the third day after surgery. Some patients require a longer stay. 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.

## Less common risks

### ***Subdural haematoma (bleed between your brain and skull bone)***

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

### ***Heart function and failure***

As a result of the disease process and the operation on your heart, it may not pump as well as usual immediately following surgery and this may need treatment with drugs or help from an artificial pump machine (called ECMO).

### ***Renal failure***

The blood supply to your kidneys is reduced as a result of surgery and some patients who are vulnerable may experience failure of their kidneys. This is usually temporary and is treated with an artificial kidney machine on the CCA.

### ***Residual pulmonary hypertension***

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

## Rare risks

### ***Perforation of the pulmonary artery***

This is a very rare complication and happens in less than 1% of patients.

### ***Stroke***

Stroke or severe brain injury is seen only in 2-3% of patients.

Therefore, 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.

### ***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.

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