NHS
Royal Papworth Hospital
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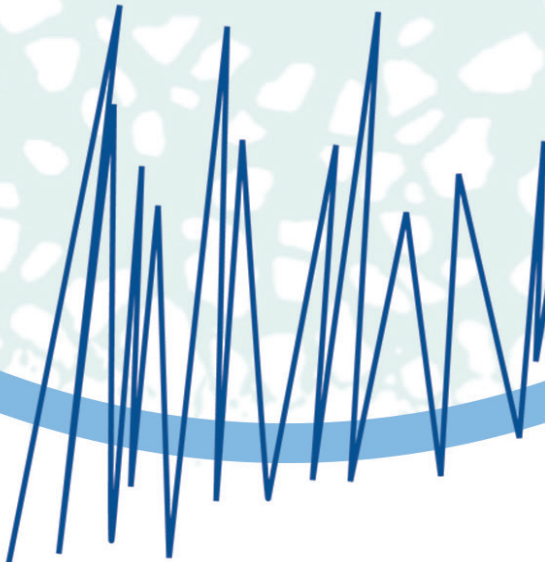
Pulmonary endarterectomy (PEA)

A patient's guide and consent form



Compassion
Excellence
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This information booklet has been prepared to help you and your relatives understand the pulmonary endarterectomy (PEA), also known as pulmonary thromboendarterectomy (PTE) operation.

Prior to your clinic visit you will be given the booklet 'pulmonary endarterectomy (PI 26): a patient's guide', which is a 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 breastbone 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.

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 can 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 can do more than before surgery.

Risks of surgery

Common risks of PEA/PTE

Bleeding

Immediate post-operative bleeding may be experienced because of anticoagulants and use of cardiopulmonary 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 localized infection or a deeper wound infection. If you are a diabetic there is a increased risk of developing a wound infection.

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 and C will be explained during your consultation with the nurse in detail but indicate different care requirements that individuals may experience because of surgery that prolong critical care needs.

Specific risks for PEA

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 more than 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 up to 2% of patients.

ECMO support

Following PEA surgery some patients are initially unwell and in approximately 5% they require further temporary support from a type of heart lung machine called extracorporeal membrane oxygenation (ECMO).

Rare risks

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 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.

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

The general anaesthetic

You will need to have a general anaesthetic for this operation and will have the opportunity to speak to an anaesthetist beforehand. This will typically be in the afternoon/evening before the procedure once you have come into the hospital.

Please let this anaesthetist know if you have had prior problems with anaesthetics, if you have any allergies, or if you have a family history of serious problems with anaesthetic agents, such as a rare condition called malignant hyperpyrexia. You will then typically meet the anaesthetist who will be looking after you during your operation at the time that you come for it.

We do have an anaesthetic pre-assessment clinic which you could be booked into if you wish to discuss the anaesthetic prior to coming into the hospital or if you know of any serious problems with anaesthetics as mentioned above. Please let the pulmonary hypertension team know if this is the case.

There are several members of the anaesthetic team whom you will meet when you come for the procedure. These include an operating department practitioner (ODP) who will assist the anaesthetist and a resident anaesthetic doctor or an anaesthetic associate (AA) who work under the close supervision of the consultant anaesthetist. Skilled anaesthetists who specialise in dealing with heart and lung conditions will look after you.

You will be closely monitored with standard monitoring of your heart, blood pressure and oxygen levels. The general anaesthetic is typically administered through a cannula inserted into a vein, often in your hand or arm. It will also be necessary to insert another monitoring line called an arterial line into an artery usually in your arm before you go off to sleep. Oxygen is given for you to breathe through a clear plastic mask. Once you are asleep you will have a breathing tube inserted into your airway and an echocardiography probe into your oesophagus (food pipe) to monitor your heart. We will need to insert a catheter into your bladder, a couple of lines into the vein in your neck and another line into your groin. The echocardiography probe will be removed at the end of the operation but the rest of the monitoring lines will still need to be kept in for a few days after the operation.

Once the operation has finished we will take you to the critical care area where you will be kept asleep for several hours. When you are woken up you will still have the breathing tube in your mouth for a little while until you are awake enough to be able to have it removed. Many people do not remember this afterwards as they are still quite sleepy but we feel it is important for you to know what to expect.

There are a number of common and a few rare risks associated with a general anaesthetic which are important to know about.

Please affix patient label or complete details below.

Full name:

Hospital number:

NHS number:

DOB:

PIC 131: patient agreement to PI 131 - Pulmonary endarterectomy

Intended procedure/surgery

_____

_____

Statement of healthcare professional

(To be filled in by healthcare 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 breating and the quality of life, and in most patients prolonged life.

Significant, unavoidable or frequently occurring risks:
Common operation risks (see page five for explanations)

- Extended critical care stay
- Would infection.....%
- Irregular heartbeat
- Temporary confusion and delirium
- Bleeding.....%

Specific risks

- Residual pulmonary hypertension
- Subdural haematoma

Severe operation risks

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

Additional risks specific to you or your operation - please specify below:

.....

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

☐ Blood transfusion

☐ Other procedure - please specify below:

.....

I have also discussed what the procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient.

This procedure will involve general anaesthesia.

Healthcare professional

Signed: .....

Date: .....

Name (PRINT): .....

Job title: .....

Contact details

.....

.....

Has a ReSPECT form been considered and, if relevant, appended to this form?

☐ Yes ☐ No

Statement of patient

Please read the patient information and this form carefully. If the treatment has been planned in advance, you should already have your own copy of 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.

Yes	No	
☐	☐	**I agree** to the procedure or course of treatment described on this form and have read this information leaflet on pulmonary enderterctomy (PI 131 and 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** what the procedure is and I know why it is being done, including the risks and benefits.

Please affix patient label or complete details below.

Full name:

Hospital number:

NHS number:

DOB:

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- **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:

.....

.....

.....

.....

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 Jacob disease).

☐ Yes ☐ No

(Where patient indicates 'yes' health professional to refer to Trust CJD procedure DN092)

Statement of interpreter (where appropriate)

If an interpreter was present to support this consent, please state the name and number of the interpreter present:

Date: ……

Interpreter's number:……

Name (PRINT): ……

If a telephone / video service has been used, please document the name of the interpreter and company below

.....

.....

.....

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: ……

Important notes (tick if applicable).

☐ Patient has advance decision to refuse treatment

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

Patient signature: ……

Date: ……

Name (PRINT): ……

Please use and attach Consent form C for a young person who is not Gillick competent.

Recommended summary plan for emergency care and treatment (ReSPECT)

What is ReSPECT?

ReSPECT stands for 'Recommended summary plan for emergency care and treatment'. It is a process that helps people to think about what treatment is suitable in an emergency, should they be unable to make decisions at the time.

Why is it important?

We know that, when people are very unwell, they are often unable to think clearly about what treatment they may or may not want because their brain and body are overwhelmed by the illness. It is also normal for people to feel anxious about what is happening when they are sick and in hospital, and this can also make it difficult to think clearly. This is why we think it is a good idea, where possible, for decisions about medical treatment to be made in advance – before there is an emergency situation or crisis.

How does it work?

The ReSPECT process is designed to help conversations between you and your healthcare professionals: they need to make sure you understand your health problems and which treatments may or may not benefit you. You need to make sure the healthcare professionals understand what matters most to you and whether there is anything you are particularly worried about or would want to avoid.

This conversation is used to complete a ReSPECT form that records a person's health problems, their preferences and which medical treatments may or may not be suggested. The original form should stay with the patient, though it is extremely helpful to have a record of the content of the form on their electronic patient record.

A ReSPECT form is NOT a legally binding document and can be changed or withdrawn at any point.

The ReSPECT form is often used to indicate treatments that someone may not want and/or treatments that their healthcare professionals consider would no longer be of benefit to them.

If people are getting worse from progressive conditions, it may be helpful to consider in advance about things such as whether they would wish to go back into hospital and, if in hospital, what sort of treatments might or might not be helpful for them.

This often includes a decision on whether or not they should have attempted cardiopulmonary resuscitation (CPR) if their heart was to stop.

Who is it for / is this relevant for me?

This process has increasing relevance for people who have complex health needs, people who may be nearing the end of their lives and those who are at risk of sudden deterioration or cardiac arrest.

However, many people come to Royal Papworth to have major procedures or surgery with the intention of curing a progressive disease or with the intention of substantially prolonging their life and, if that is you, you may wonder how a ReSPECT discussion applies to you and others like you. One of the key things to understand about the ReSPECT process is that it can be used simply to document a person's wishes and priorities, without setting any limitations on what treatment they should have.

This is important because all the procedures and operations we do here come with the risk of complications. In the unlikely event that things do not go as planned, it is really helpful to have some idea about a person's preferences and about their fears, worries and hopes.

Once again, the document is not legally binding, but it can help those looking after you to know what you might want if you weren't able to say for yourself.

Common risks (1 in 10) include:

- Bruising or bleeding around the site of any lines inserted
- A dry mouth or lips
- A sore throat
- Shivering
- Itching
- Nausea and vomiting

All of these common risks are temporary and should settle down soon afterwards.

Less common risks (1 in 100 – 1 in 3,000) include

- Infection of an arterial or venous line.
- Dental damage - please let us know if you have any loose teeth or fragile dental work that might increase this risk.
- Corneal abrasion (1 in 2,800). We will protect your eyes whilst you are asleep, however 1 in 2,800 patients may suffer an accidental scratch to the eye called a corneal abrasion. This can cause pain and blurred vision for a few days, but usually heals without long term consequences. More serious damage to the eyes resulting in permanent loss of vision is very rare.
- Hoarse voice.
- Vocal cord damage is also possible after an anaesthetic for this procedure. This is because we will need to use a tube that passes between the vocal cords.

Uncommon risks (roughly 1 in 10,000 – 1 in 20,000):

- Aspiration of gastric contents into the lungs.
- Allergy to an anaesthetic drug.
- Awareness during a procedure under general anaesthetic (1 in 20,000).

The risk of death resulting purely from a general anaesthetic rather than the operation is extremely rare, around 1 in 100,000. The reason we tell you about these potential complications is so that you can tell us if you think you may be at higher risk for getting one of these complications than another person and so that you can make an informed decision about whether or not to go ahead with the procedure. Overall, for most people it is probably riskier to travel in a car than it is to have a general anaesthetic.

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Author ID:	Nurse specialist for pulmoary endarterectomy
Department:	PVDU
Printed:	March 2025
Review date:	March 2027
Version:	3
Leaflet number:	PI 131