



**Royal Papworth Hospital**  
NHS Foundation Trust

# Chronic Thromboembolic Pulmonary Hypertension (CTEPH)

Frequently asked  
questions



## **Introduction**

Welcome to the National Pulmonary Endarterectomy (PEA) Service at Royal Papworth Hospital.

Royal Papworth Hospital is the only centre in the UK offering surgery to patients with a certain type of pulmonary hypertension (PH) called chronic thromboembolic pulmonary hypertension (CTEPH). We hope that your doctor has explained the reason for your referral to Royal Papworth Hospital.

Information in this leaflet should give you an understanding of what to expect during your visit so that you can get as much out of the day as possible. More detailed information will be given to you during your outpatient visit by the surgeon and the PEA specialist nurse.

## **Chronic thromboembolic pulmonary hypertension**

Chronic thromboembolic pulmonary hypertension (CTEPH) is a form of PH that is caused by blockages in the blood vessels to the 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 the blood flow through the lungs. This causes high blood pressure in the lung blood circulation. 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. Initially people get short of breath on exertion and with time this could progress to shortness of breath even at rest. Patients may struggle to do any type of physical activity. Swelling of the legs and tummy may be noticed by some patients.

Treatment with blood thinning agents such as warfarin, rivaroxaban, apixaban, edoxaban, dabigatran and any other form of anticoagulants stops the form of clots, 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 pulmonary endarterectomy (PEA) surgery to remove these scars. In most patients this will improve breathlessness and quality of life.

You have been referred to Royal Papworth Hospital, where a team of specialists have discussed your case at a meeting and feel that you may potentially benefit from an PEA operation.

Consideration for this type of operation is based on where the scars are located in the blood vessels of your lungs. Unfortunately, a few patients are not suitable for PEA; in some patients, the scars are so deep within the lungs that they are impossible to reach and surgery is therefore not possible. Occasionally patients may be considered for this operation with other types of blockages not necessarily due to clots.

The appointment at Royal Papworth Hospital is an opportunity for you and your family to find out about the proposed surgery and all that is involved in the management of your condition.

The aim of your visit to the National Pulmonary Endarterectomy Service is to provide you with all the

information you need to help you make the right decision.

During your visit you will meet one of the pulmonary endarterectomy surgeons and the specialist nurses.

*The programme for the visit is:*

1. Group session with a PEA specialist nurse;
  - Discussion of surgical patient pathway i.e. from clinic to discharge after surgery;
  - Patient information booklet given;
2. Individual consultation with specialist nurse;
  - Identification of personal situation and care requirements;
3. Whenever possible an ex-patient attends to give an account of their journey during and after surgery;
4. Individual consultation with a surgeon to discuss the risks and benefits of surgery.

## **Frequently asked questions on attending the clinic at Royal Papworth**

### **Will Royal Papworth Hospital provide transport?**

Patients are expected to make their own way to Royal Papworth Hospital. However if you are on benefits, you may be eligible for refunded costs or hospital transport. Please see the enclosed information on travelling to Royal Papworth Hospital.

### **Can my family members accompany me to Royal Papworth Hospital?**

We strongly recommend you to bring a member of your family with you to both the nurse's and the surgeon's clinic.

Unfortunately we may not be able to accommodate more than one relative for the group session as there will be other patients with their relatives.

However your family will be able to attend the individual session where you will meet with the surgeon to discuss the benefits and risks of PEA surgery.

**Will Royal Papworth Hospital provide accommodation for me and my family?**

Unfortunately, we do not provide accommodation but you have a list of local accommodation enclosed in this pack and you or your family member can book this directly prior to your travel.

**How do I arrange my accommodation if I travel from long distance and would like to stay in a B&B the night before the appointment?**

The clinic invitation pack contains the list with information on local bed and breakfast (B&B) places where you or your family can book directly prior to your travel. More information is available at <https://royalpapworth.nhs.uk/patients-and-visitors/accommodation-relatives>.

**Will Royal Papworth Hospital arrange my oxygen in the B&B if I decide to travel the night before?**

If you are using oxygen, please speak to the B&B you plan to stay in and ask if they are happy for you to use oxygen. You will make arrangements

with your oxygen provider by phoning them to arrange for oxygen to be delivered to the accommodation where you are planning to stay so that it is ready for your arrival. Please make sure they remove it when you vacate the room.

Oxygen is available in the clinic rooms for use during the day time when you are with us in clinic. Please remember to bring enough oxygen for your travel as the hospital will not give any cylinders out for you to take home.

**How long does the appointment take?**

PEA clinics are held on all Mondays and Thursdays, starting at 10:00. Monday clinics are shorter, finishing between 15:00-16:00. Thursday clinics are longer, finishing between 17:00-18:00, to allow for surgeons to review any additional images if available prior to seeing you in clinic. This group session takes an hour and a half and the individual session takes at least half an hour with each patient.

It takes the whole day for you

on the day of your visit to Royal Papworth Hospital, especially on Thursdays, and you will break for lunch prior to the surgeon's appointment. Please ensure that you bring enough medication for the entire day visit.

### **Is lunch provided by the hospital?**

We appreciate most of you travel from long distances, but unfortunately the hospital will not be able to provide lunch so you will need to bring some money for refreshments.

There is a restaurant on the hospital campus where you will be able to buy food.

### **Why can't I have surgery nearer home?**

Royal Papworth Hospital is the only provider of this surgery in the UK, although you will have all the investigations completed at your local PH centres.

### **Do I have any other tests on the day of the clinic?**

Few patients would be required to have additional scans at Royal Papworth Hospital on the day of clinic. If you require

further tests on the same day as your clinic visit you will be made aware of this in advance.

### **Where can I find further information on PH and CTEPH?**

**The PHA Association UK**  
[www.phauk.org](http://www.phauk.org)

### **Royal Papworth Hospital website**

[www.royalpapworth.nhs.uk](http://www.royalpapworth.nhs.uk)  
Please select 'Patients and visitors' from the top menu and from here you will find information about getting to Royal Papworth Hospital, accommodation and information leaflets on the surgery.

### **How can I contact the specialist nurse team at Royal Papworth Hospital?**

The phone number to contact the specialist nurses is 01223 638866. However, if you have any queries about your appointment please call 01223 638765. If this phone is not answered, please leave a message and we will get back to you as soon as we can.

**Royal Papworth Hospital NHS Foundation Trust**  
Papworth Road  
Cambridge Biomedical Campus  
Cambridge  
CB2 0AY

Tel: 01223 638000

[www.royalpapworth.nhs.uk](http://www.royalpapworth.nhs.uk)

A member of Cambridge University Health Partners

Author ID: Lead PEA Nurse  
Department: Thoracic  
Printed: February 2020  
Review due: February 2022  
Version: 3.1  
Leaflet number: PI 87

© Royal Papworth Hospital NHS Foundation Trust

Large print copies and  
alternative language  
versions of this leaflet  
can be made available  
on request.