

Chronic Thromboembolic Pulmonary Hypertension (CTEPH)

Frequently asked
questions

Introduction

Welcome to the National Pulmonary Endarterectomy 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). We hope that your doctor has explained the reason for your referral to Royal Papworth Hospital but more detailed information will be given to you during your outpatient visit by the surgeon and specialist nurse.

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.

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. 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 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 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 operation called a Pulmonary Endarterectomy (PEA).

Not all patients with CTEPH are suitable for PEA; it depends where the scars are located in the lungs. Unfortunately in some patients, the scars are too deep within the lungs so 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 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 PEA specialist nurse;
2. Discussion of surgical patient pathway i.e. from clinic to discharge after surgery;
3. Patient information booklet given;
4. Individual consultation with specialist nurse;
5. Identification of personal situation and care requirements;
6. Whenever possible an ex-patient attends to give an account of their journey during and after surgery;
7. 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 join the sessions with our specialist nurses and be able to attend the surgeon's clinic

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

This is an outpatient appointment so no accommodation is provided. You will be sent a list of local bed and breakfast places in the nearby villages.

If you have no transport there is some accommodation in the village which can be booked through the car parking office. There is also a flat on-site which is for research patients' use and occasionally a room is available for other patients for a small donation. This can be booked through the PALS office.

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 latest accommodation list and you or your family can book this directly prior to your travel. As this is an outpatient appointment, your accommodation costs are not met by the hospital.

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 need to phone your oxygen provider and arrange for oxygen to be delivered to the B&B ready for your arrival.

If you use oxygen during the day, please arrange to bring oxygen with you or have enough oxygen delivered for the day in clinic. No oxygen is available in clinic.

How long does the appointment take?

It is a day visit to Royal Papworth Hospital; some clinics start at 9.00am and some at 10.30am. The group session takes one and a half hours and the individual session takes at least half an hour with each patient.

Mostly we 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 within the hospital campus where you will be able to buy food. Alternatively there are pubs and restaurants available within 10 to 15 minutes drive.

Why can't I have surgery nearer home?

Royal Papworth Hospital is the only provider of this surgery in the UK.

Do I have any other tests on the day of the 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

Royal Papworth Hospital website

www.royalpapworth.nhs.uk

Please select; 'Patients and Visitors' from the top menu and within this link you will find information about getting to Royal Papworth Hospital, accommodation, and information leaflets about the surgery.

How to contact the specialist nurse team at Royal Papworth Hospital

If you have any queries about your appointment please call 01480 364952. There is an answerphone on this direct line.

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www.royalpapworth.nhs.uk

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