

# Your first appointment

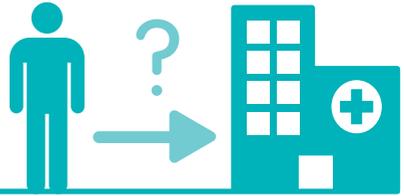
Pulmonary hypertension service  
Information for patients and relatives





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# Introduction

**The purpose of this booklet is to provide you with the information you need for your first appointment at the Royal Free Hospital.**

Coming to hospital can be stressful and this booklet has been designed to help answer some of the questions you may have about your first visit to the hospital and help you prepare for your appointment. It also tells you who we are and provides details of where you can find out more information. In addition to this booklet, you will receive a phone call from one of the nurses before your first appointment. Please speak to the nurse about any concerns you have.

# Why have I been referred to the Royal Free Hospital to be tested for pulmonary arterial hypertension?

**You may have been experiencing symptoms such as breathlessness, for which one cause could be pulmonary arterial hypertension (PAH).**

PAH is a rare condition where the blood pressure in the blood vessels between the heart and lungs (known as the pulmonary arteries) is higher than it should be. In people with PAH, the pulmonary arteries are thicker and less flexible. This makes it harder for the heart to pump blood through the lungs. For this reason, people with PAH get breathless and tired easily.

There are a large number of causes of pulmonary hypertension and in some people we cannot find the cause even after full investigation. We have effective treatments for all forms of PAH, however it is still important that we look for underlying causes as the treatment used is different for the different causes.

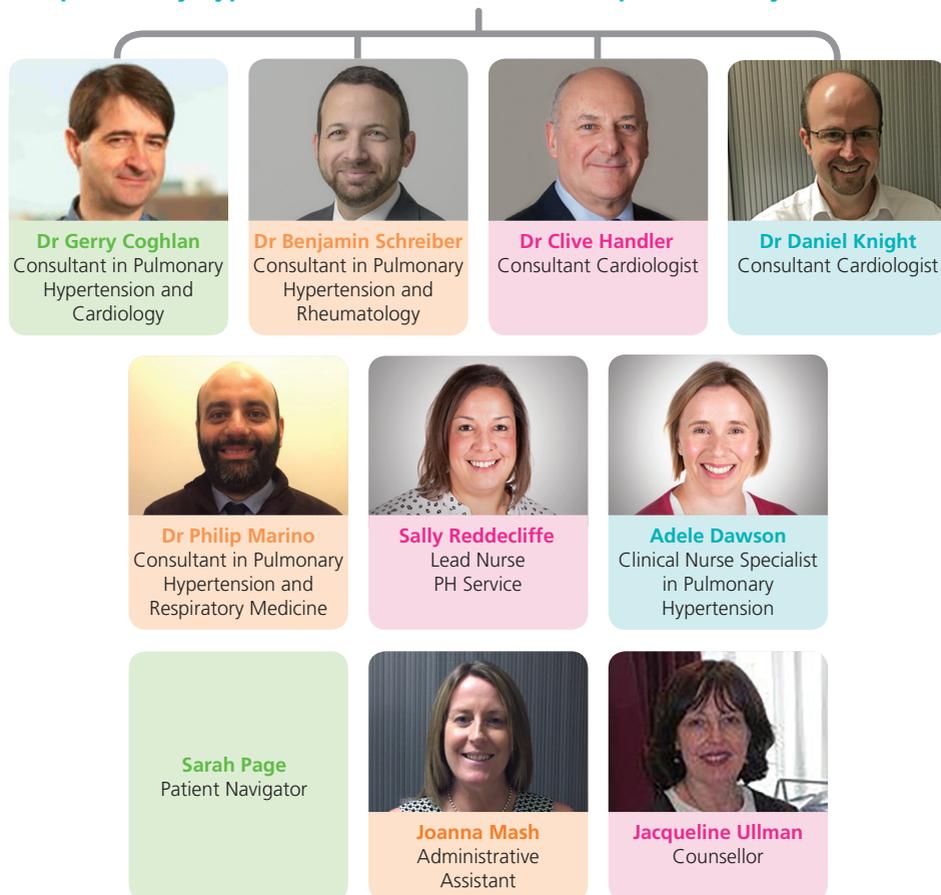
If you would like further information about pulmonary hypertension prior to being seen, we recommend that you contact the patient support group, PHA UK, via telephone on 01709 761450 or access the PHA UK website: **[www.phauk.org](http://www.phauk.org)**.

You can also watch a short film which further explains what pulmonary hypertension is on the Royal Free London website: **[www.royalfree.nhs.uk/services/services-a-z/pulmonary-hypertension](http://www.royalfree.nhs.uk/services/services-a-z/pulmonary-hypertension)**.

# Meet the team

At the hospital you will be looked after by the Royal Free PAH team, which consists of doctors, nurses and coordinators who all have specialist training in diagnosing, treating and supporting patients.

The pulmonary hypertension team who will be responsible for your care are:



The Royal Free London is part of the PAH specialist centre network. This means that although your first appointment will be at the Royal Free Hospital, you may be seen at one of the outreach centres later on to reduce the distance you have to travel.

# Your appointment – what happens on the day?

Your appointment will take place in the Institute of Immunity and Transplantation (IIT) on the second floor and is likely to take most of the day. After checking in at reception, you will be welcomed to the service by our patient navigator assistant, who will explain what we have planned for you that day and will arrange your initial tests, before you see the doctors and nurses. She or he will also ensure that you have information about how to contact the department (by phone/email) should you have any concerns between appointments and in the case of an emergency.

You will also have the chance to speak to the other members of the team who are able to provide emotional and social support, if needed. If at any point you do not understand what is happening please do ask questions – all members of our team will either answer your questions or find someone who can.

We are happy for you to bring a friend or family member to the appointment. This may be particularly helpful if English is not your first language and you may require help communicating with the PAH team.

## Investigations

After you have met the team we will take some basic measurements including your weight, blood pressure, oxygen levels and heart rate. You will also need to have a series of tests during your appointment.

Please be assured that you will only be asked to have tests that are necessary to provide a diagnosis. If we know in advance that you have had any of these tests previously, we will try to get the results and avoid repeating them.

Some people also agree for their results to be used for research purposes. You may be asked for your consent for this to happen.

This is a list of tests that you may have during your visit (please note, you may not have all of them):

- six minute walking test
- quality of life assessment (emPHasis-10 Questionnaire)
- blood tests
- chest x-ray
- an electrocardiogram (ECG)
- heart scan: echocardiogram (echo)
- lung function
- a CT chest scan
- a nuclear scan: ventilation perfusion scan (VQ scan)
- an MRI scan
- cardiac catheterisation.

### Six minute walking test

The distance a person can walk in six minutes is a rough measure of your ability to exercise. You will be asked to walk as far as you comfortably can in six minutes. The team will measure your heart rate, oxygen levels and blood pressure before and after this test, and ask you how breathless you feel. It is, of course, possible to stop and rest during the test if you need to.

<b>How long will it take?</b>	<b>When and how will I receive my results?</b>
15 minutes	Immediately and verbally after the test.

## Quality of life assessment (emPHasis-10 Questionnaire)

This is a short series of easy questions that help us understand how your symptoms affect your life. This test is done every time we see you and over time we can see whether our treatments are helping improve the quality of your life overall or not.

How long will it take?	When and how will I receive my results?
5 minutes	During your consultation.

## Blood tests

There are a number of blood tests that may need to be taken during your first appointment. The tests are to assess how well your kidneys, liver and heart are working, and to find other causes of pulmonary hypertension.

How long will it take?	When and how will I receive my results?
15-30 minutes	In a letter sent from the clinic following your appointment.

## Chest x-ray

This routine x-ray is a basic check of your heart and lungs.

How long will it take?	When and how will I receive my results?
15-30 minutes	In a letter sent from the clinic following your appointment.

## Electrocardiogram (ECG) heart tracing

The ECG is a simple and painless check on the electricals of your heart. Small, metal patches, set in sticky plaster, are put on your arms, legs and chest. These patches (electrodes) are connected to wires which lead to the ECG recorder.

The ECG checks if your heart rate and rhythm is regular and normal, or whether there are signs of heart strain which can point towards the diagnosis.

How long will it take?	When and how will I receive my results?
15-20 minutes	Verbally in clinic and in a letter following your appointment.

## Heart scan: echocardiography (echo)

Echocardiography (echo) is an ultrasound scan of your heart. It is very similar to the sort of test that pregnant women have to give a picture of their baby. Gel is spread over your chest and a probe is used to take pictures to look at the size of the heart, and how well it works.

How long will it take?	When and how will I receive my results?
30-90 minutes	In a letter sent from the clinic following your appointment.

## Lung function

These involve a number of breathing tests. They will assess how well your lungs are able to work.

How long will it take?	When and how will I receive my results?
20 minutes	We often have results from your referring hospital. For tests done at the Royal Free Hospital, the results will be included in a letter sent following your appointment.

## Computerised tomography (CT) chest scan

CT scans give a very clear picture of your lungs and their blood vessels. You are passed through a 'doughnut' shaped scanner, which takes lots of x-ray pictures all the way through your chest. This is painless, although you need to stay very still and hold your breath for a short while.

For more information about having a CT scan, visit our website:  
**[www.royalfree.nhs.uk/services/services-a-z/radiology/](http://www.royalfree.nhs.uk/services/services-a-z/radiology/)**

How long will it take?	When and how will I receive my results?
15 minutes	We usually have your results from this test when we first see you, and will discuss during your appointment. Alternatively the results will be included in a letter sent following your appointment.

## Nuclear scan: ventilation perfusion (VQ) scan

The VQ scan is used to examine blood and air supplies to your lungs. You will be given a very small amount of radioactive dye and a few minutes later you will be scanned with a special camera. We then ask you to breathe in a gas containing a small amount of radiative tracer through a facemask while the camera takes more pictures. This test is essential to find if there have been any blood clots in your lungs.

How long will it take?	When and how will I receive my results?
30-60 minutes	Depending on the results, we will discuss with you immediately after the test or the results will be included in a letter sent following your appointment.



## Magnetic resonance imaging (MRI) scan

Cardiac magnetic resonance imaging (MRI) is a way to take pictures of the heart without using x-rays. The scanner is a large magnet which is shaped like a short tube and open at both ends. When you lie in the scanner, it uses a strong magnetic field, radio waves and a computer to take detailed pictures of your heart. We can check the size of the heart, take moving pictures to see how well it works, and look at the heart muscle itself.

This is particularly useful in patients with pulmonary hypertension and/or connective tissue disease. The only thing you might notice is that the scanner makes some loud noises when the pictures are being taken. You will be given headphones to help reduce the noise and to hear the radiographer talk to you. You will also have an alarm buzzer to squeeze if you need any assistance. People who do not like enclosed spaces may find this test difficult. The team are very aware of this and can usually make changes to the way the test is done to ensure you are comfortable. If you think you might find this test difficult, please let us know when we first talk to you and we shall do our best to help.

For more information about having an MRI scan, visit our website: [www.royalfree.nhs.uk/services/services-a-z/radiology/](http://www.royalfree.nhs.uk/services/services-a-z/radiology/)

How long will it take?	When and how will I receive my results?
30-60 minutes	Interpreting the results can take some time. We will normally include the results in a letter sent a few weeks after your appointment.

## Cardiac catheterisation

This test is carried out by a different department known as the interventional radiology and cardiology unit (IRCU) on the ground floor near the main lifts of the Royal Free Hospital. This test measures the pressure in the blood vessels of the heart and lungs and is absolutely necessary to diagnose pulmonary hypertension. Unlike the other tests, this is an invasive investigation and can occasionally cause harm. We will discuss the risks and benefits with you before the test is conducted and will only perform the test with your written consent.

Before the procedure is carried out, local anaesthetic is injected into the skin of the groin or arm. The initial injection can be uncomfortable, but after that, the procedure will be entirely pain free. A tube is inserted into the blood vessel and fed up to the heart allowing us to measure pressures and blood flow in the heart and lung arteries, and to take pictures if needed.

While this procedure will take 15-30 minutes to complete, you will need to spend a further two to three hours on the IRCU afterwards. Please be aware that the Royal Free Hospital is a heart attack treatment centre and this sometimes causes delays and cancellations.

How long will it take?	When and how will I receive my results?
15-30 minutes, with a further 2-3 hours on the IRCU	Immediately after the procedure and in a discharge letter.

The link below provides access to a short film to further explain what you can expect when you are referred to the Royal Free Hospital for pulmonary hypertension testing:

**[www.royalfree.nhs.uk/services/services-a-z/pulmonary-hypertension/testing-for-pulmonary-hypertension/](http://www.royalfree.nhs.uk/services/services-a-z/pulmonary-hypertension/testing-for-pulmonary-hypertension/)**

## How to prepare and what to bring

- Think about the questions you would like answered and write them down in the notes section at the end of this booklet. It is easy to forget important questions at the time of your appointment.
- You may find it beneficial to bring someone with you to the appointment to take notes, provide support, or help you remember what has been said.
- Your next of kin's name, contact telephone numbers and full address, including postcode.
- Your appointment letter.
- Any medication you are currently taking (or a list of) in the original packaging.
- Something to read or listen to.

At the back of this booklet please find a symptom tracker that you can use to record any symptoms you would like to discuss during your appointment. You can find this on page 24.

## How long will I be there?

You will be at the Royal Free Hospital for most of the day. During your phone call with one of the nurses before your first appointment, they will indicate the exact time you should arrive.



# What happens after my appointment?

## Will there be any follow up?

We aim to see most people more than once and often, we continue to care for people for many years either at the Royal Free Hospital or via our outreach services. We will try to arrange any further appointments before you leave and if further tests are required, we will aim to do these on the same day as your other appointments. This could mean we contact you again after you leave to co-ordinate any subsequent tests and appointments on the same day, to save additional journeys.

## Will I receive a letter?

Yes. After every appointment we will always send you a copy of the letter we send to your GP and other doctors (this can take a couple of weeks to work through our system). There will often be medical terms in the letter, which can make it difficult to understand. We will only use these terms where necessary. If you feel that the letter is wrong in any way or misses out important things, please let us know. If you do not understand what is written please contact us or your GP.

## What happens after my tests?

Your test results will help to determine your next steps and if relevant, treatment, to improve your symptoms.

## What if I don't have PAH?

If there is no evidence of PAH from your tests we will try to establish the cause of your symptoms and aim to provide advice for your local team to manage your symptoms.

## What if I do have PAH?

If you have PAH, it is important to find out which type of PAH you have, so you may need to have more tests on another day. Some types of PAH are more difficult to treat than others and require different treatment.

If you do require treatment, you may start receiving it straight away which should help improve your symptoms.

Do not hesitate to ask the PAH team doctors and nurses if you have any questions or concerns about your diagnosis or treatment.

There is a lot of support available for people with PAH and their family and friends, so you do not have to cope on your own. Your specialist PAH team will discuss with you the impact PAH can have on your life and where you can access more support. PHA UK is a patient support group that provides support and advice for anyone affected by PAH.

For further information you can contact PHA UK via telephone on 01709 761450 and access the PHA UK website: **[www.phauk.org](http://www.phauk.org)**.

Should you feel it would be helpful, we have a counselling service available.

# Useful information

## The Royal Free Hospital address is:

Royal Free Hospital  
Pond Street, London  
NW3 2QG

The Royal Free Hospital phone number is: 020 7794 0500.

For more information about the pulmonary hypertension service at the Royal Free London, visit our website:

**[www.royalfree.nhs.uk/services/services-a-z/pulmonary-hypertension/](http://www.royalfree.nhs.uk/services/services-a-z/pulmonary-hypertension/)**

## Contacting the pulmonary hypertension team directly:

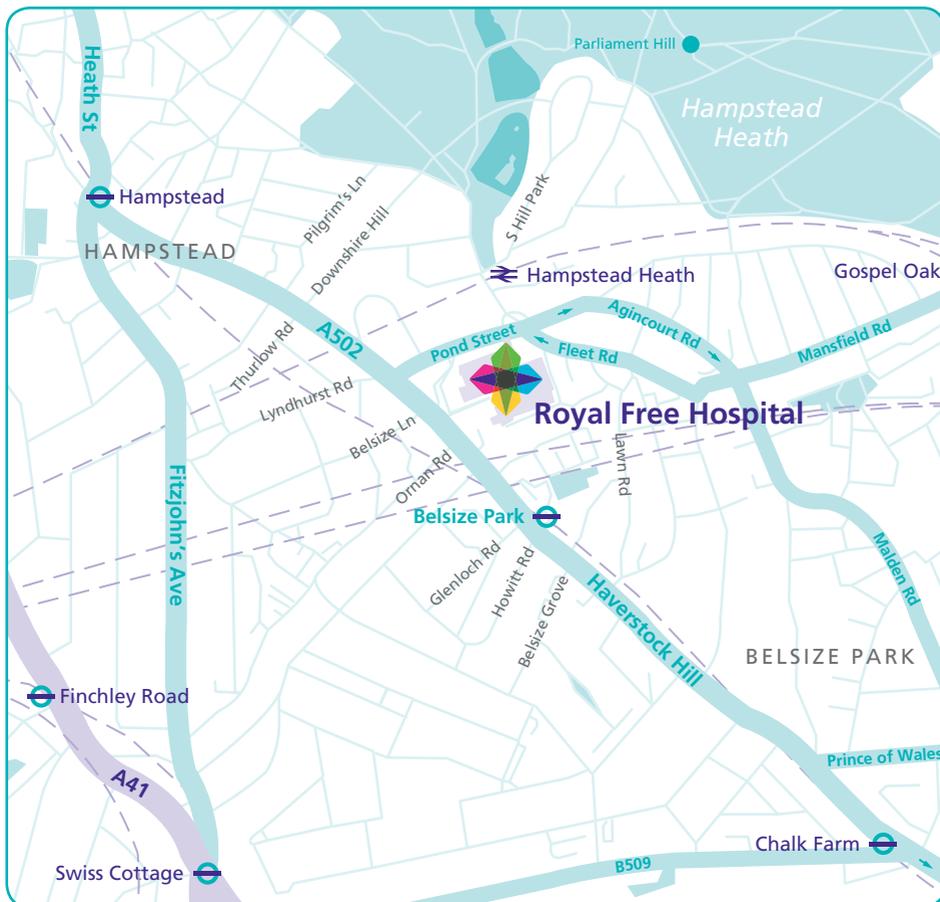
The pulmonary hypertension team can be reached on: 020 7472 6354 and also via email to: **[rf.royalfreepah@nhs.net](mailto:rf.royalfreepah@nhs.net)**.

## Out of hours/emergency contact:

The out of hours team can be reached via the hospital switchboard on: 020 7794 0500. Please ask for the on call cardiology registrar – bleep 2027.

# Getting to the hospital

The Royal Free Hospital is located on Pond Street in Hampstead, north London. See the map below for the best route to get to us.



## Planning your journey to Royal Free Hospital

**By tube:** The nearest tube station to the Royal Free Hospital is Belsize Park station, on the Northern Line. The walk from Belsize Park station to the Royal Free Hospital takes seven minutes. It is partly uphill.

**By train:** Hampstead Heath station is approximately a six minute walk to the hospital and is on the London Overground network. The station accepts Oyster cards.

**By bus:** There are lots of buses that pass by the Royal Free Hospital. Bus routes 24, 46, 168, 268 and C11 all serve the hospital. You can plan your journey on London transport and check for live tube travel updates here: [www.tfl.gov.uk/tube-dlr-overground/status/](http://www.tfl.gov.uk/tube-dlr-overground/status/).

**By car:** The entrance to the Royal Free Hospital is on Pond Street. Royal Free Hospital parking is available and is charged at £3 per hour, 24 hours a day, 7 days a week. Visitors can pay for their parking by cash, card, and phone or by downloading the app. The payment line number is 033 0400 7275 and the site code is 79499. For your convenience, payment points at the Royal Free Hospital are located at both the Pond Street entrance and within Lawn Road car park.

**By hospital transport:** If this is your first visit to the Royal Free Hospital, you will need to contact your GP to arrange transport for you for the first clinic appointment. Thereafter, if you meet the hospital criteria for transport you will be able to arrange this yourself by contacting the transport department via the switchboard number 020 7794 0500. If you usually have hospital transport for your appointments at the Royal Free Hospital, then you will be able to request this in the usual way.

**Overnight accommodation:** If you live a long way from the Royal Free, it may be possible to arrange overnight accommodation before or after your appointment. Please contact the pulmonary hypertension team on 020 7472 6354 so that we can help to arrange this for you.

## Useful contact details

### **Royal Free London**

#### **switchboard**

020 7794 0500

#### **Pulmonary hypertension**

##### **advice line**

020 7472 6354

#### **Pulmonary hypertension**

##### **fax number**

020 7317 7747

#### **Out-patient appointment**

##### **centre**

020 7443 9757

#### **Cardiology admissions**

##### **coordinator**

0207 7940500 on ext 35182

#### **Cardiology (echo)**

020 7794 0500 on ext 33583

#### **Lung function**

020 7472 6848 or

020 7794 0500 on ext 22466

#### **Nuclear medicine**

##### **(VQ scanning dept.)**

020 7830 2196

#### **Cardiac MRI (CMR)**

020 7433 2780

#### **X-ray**

020 7830 2035 or

via switchboard ext 34174

#### **CT**

0207 8302106 or

02077940500 on ext 35643

#### **Ultrasound**

0207 8302106

#### **The Institute main reception**

020 7794 0500 ext 22500

#### **10 West ward**

020 7794 0500

on ext 35604/35605/35606

#### **IRCU ward**

020 7794 0500

on ext 37901/74002

#### **PITU ward**

020 7317 7507

#### **Patient transport booking line**

033 3240 4909

#### **Patient advice and liaison**

##### **service (PALS)**

020 7472 6446/6447

#### **Pulmonary hypertension**

##### **team email:**

rf.royalfreepah@nhs.net

#### **Medicines information**

##### **helpline**

020 7830 2983 or

020 7794 0500 on ext 33114

# Questions you may like to ask during your visit

You may have lots of questions for the doctors and nurses. Use the space below to write these down before your visit, as you may not remember them all.

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**Here is a list of some questions you may like to ask during your visit:**

- Why am I having all these tests?
- What happens if I have PAH?
- What happens if I don't have PAH?
- Will I have to come back for further appointments?
- Should I stop taking any of my medication?





# Symptoms tracker

Day/ Date	What symptoms* did you experience? <small>*breathlessness, dizziness, chest pain etc.</small>	How long did your symptoms last? Did anything make your symptoms stop?	Can you identify any potential triggers for your symptoms? <small>Eg walking, vigorous exercise, house work etc.</small>
Mon			
Tue			
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## Royal Free Hospital

Pond Street

London

NW3 2QG

**Tel: 020 7794 0500**

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

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This leaflet is also available in large print. If you need this leaflet in another format – for example Braille, a language other than English or audio – please ask a member of staff.

