A lifetime of specialist care

Royal Brompton & Harefield NHS
NHS Foundation Trust

Cardiomyopathy day case clinic

Contents

This leaflet gives you general information about your appointment in the cardiomyopathy day case clinic. It does not replace the need for personal advice from a healthcare professional. Please ask us if you have any questions, using the contact details on page 10.

Cardiomyopathy day case clinic

You have been referred for a cardiomyopathy clinic appointment at Royal Brompton Hospital. The most likely causes for your referral are that:

- a family member has been diagnosed with an inherited heart condition
- a family member has died suddenly from a suspected or confirmed heart condition that may be inherited
- you have experienced symptoms that need further investigation.

However, you may have been referred for another reason and this will be discussed with you.

What does the clinic team do?

We check for inherited conditions that can affect the size, structure and function of your heart muscle. If we find a heart condition, we hope to be able to reduce the risk that this may cause and help alleviate any symptoms that you may be experiencing.

Often we can also reassure members of your family who are not at immediate risk. We hope to be able to answer all your questions, offer advice and possibly treatment, but this is not always the case.

Getting a positive or unclear test result can be very worrying.

A positive test result may confirm that you have inherited a heart condition, in which case, treatment options will be discussed with you. An unclear test may show that further tests are needed. If this is the case, these will be discussed and arranged with you.

If you would like to discuss what your results might mean ahead of your appointment, please call the clinical nurse specialist team. The contact details are on page 10.

Where do I need to go?

On the day of your appointment, please come to the main hospital reception on Sydney Street. The receptionist can give you directions, or follow the blue signposts, to the NIHR Cardiovascular Biomedical Research Unit (cBRU) on level 1 (basement) in Sydney Wing. Accessible via stairs or lift.

What should I bring?

- An up-to-date list of all your medication, including doses.
- Any medication that you may need during the day.
- A pair of trainers if you are having an exercise test.
- Any information you have learned about your family history.
- Some things to do, such as reading and puzzle books as there will be time between tests and meetings.

Family history

We need more information about your family, so we can completely understand any inherited heart conditions. This includes details on the age and illnesses (past or present) of your parents, grandparents, brothers, sisters, cousins, aunts, uncles and children. For anyone who has died, please be aware that we will need to know the cause of death.

We understand that talking about your family can be difficult. If you do not wish to discuss this at the appointment because other family members will be present, please let us know on the day or call the clinical nurse specialist before your appointment. Their details are on page 10. Your medical details will remain confidential at all times unless you tell us that you are happy to share medical information for the benefit of your relatives.

What tests will I have?

You will have several cardiac (heart) tests during your appointment. The tests marked with a tick have been specifically booked for you:

- **Blood tests**

You will have routine blood tests to check your general health, specific blood tests that relate to the heart and possibly genetic blood tests.

- **Electrocardiogram (ECG)**

This is a recording of your heart's electrical activity. It tells us if there are any problems with your heart's rhythm. You lie down on a bed and electrodes (small sticky pads) are placed on your chest. Leads from the electrodes connect to the ECG machine. The test does not hurt and only takes five minutes.

- **Echocardiogram (echo)**

This is an ultrasound scan that shows the structure of your heart, and how well it is pumping blood around your body. We will ask you to lie down on a bed. A lubricating gel will be put on your chest and we will move the ultrasound probe across your chest to create an image of your heart. The scan does not hurt and only takes about 30 minutes.

- **Cardiac magnetic resonance scan (CMR)**

A CMR scan uses a strong magnetic field and radio waves to create detailed images of your heart. It gives us information about the structure of your heart and blood vessels, and how well they are working. It does not use radiation.

Please do not bring any watches, jewellery (gold rings excepted), metal items or credit cards with you to the scan.

You will be asked to change into a hospital gown. Sticky pads (electrodes) and leads from the machine are attached to your chest underneath the gown before you lie down on the bed that sits in front of the machine. During the scan, the bed will slide into a hole in the middle of the scanner. You will stay lying on the bed throughout the scan. The radiologist will be in the room next door reviewing the computer screen. The scan takes approximately 45 to 50 minutes.

Some patients may need a special injection of dye (contrast), called gadolinium, to help us assess heart muscle fibrosis (scar).

- **Cardiopulmonary exercise test (MVO2)**

This checks how the heart muscle is working by measuring the amount of oxygen used during exercise. It helps when studying problems such as breathlessness and fatigue / tiredness.

You will have small sticky pads (electrodes) and leads from the ECG monitor attached to your chest. You will also be asked to wear some breathing equipment, a bit like a mask and snorkel. You will breathe in and out of it while you are exercising on a treadmill or exercise bike. Your heart rate and rhythm, blood pressure and lung function are monitored closely by the team throughout. The test lasts up to 30 minutes.

Please wear comfortable shoes such as trainers, and loose fitting clothes for this test.

You must not eat or drink anything containing caffeine for two hours before this test. Caffeine is found in tea, coffee, some soft drinks, chocolate and nuts and can affect your heart rate.

- **24 or 48 hour ECG monitor (Holter)**

This is a 24-hour recording of your heart's electrical activity. It is painless. We place electrodes on your chest. Leads from the electrodes connect to a small, portable monitor, which you wear at home overnight. You should continue with your normal daily activities. The monitor is returned the following day. We are not able to give you the results of the Holter monitor on the day of your appointment. However, you can call our team of clinical nurse specialists for the results approximately two weeks after the test.

Who will I meet?

Clinical nurse specialist (CNS)

At some point during your appointment the CNS in inherited cardiovascular conditions (ICC) will meet you, and may also be with you when you have your consultation. The CNS's role is to give any advice and support that may be needed. You can contact the CNS before and after your appointment, with any questions or concerns you may have.

Consultant cardiologist

After your tests are completed, you will see a consultant cardiologist to discuss the results that are available, and plan your future care.

Clinical geneticist or genetics counsellor

Geneticists specialise in gene abnormalities that can cause inherited conditions by analysing DNA. We may ask our geneticist to test for inherited conditions in you or a member of your family. Testing family members is important as some individuals may not have the symptoms of a heart condition, or it may not have been picked up by their own tests. However, they may carry the abnormal gene for a heart condition. The geneticist will counsel you through your options.

What happens if an inherited heart condition is found?

If we diagnose an inherited heart condition, we will plan your treatment with you. Treatment is based on the results of your tests, your medical history and the effect the inherited condition is having on your daily life. Treatment may include medication or lifestyle changes, such as doing gentle rather than competitive exercise.

If we find out that you have an inherited condition, we can screen other relatives, such as children, brothers and sisters.

We appreciate that finding out you may be affected by an inherited cardiovascular condition can be difficult emotionally for you and your family. We can discuss any anxieties you may have and, if you feel it would be helpful, we can refer you to our clinical psychologist for further support.

What happens if no inherited heart condition is found?

We may continue to see you in our outpatient clinic and run further tests until such time that we are sure you do not have an inherited cardiac condition. We will discharge you after this, back to your local hospital consultant or GP.

What else do I need to know?

Breaks and free time

You may have several breaks between tests during your appointment. If you choose to leave the unit, or the hospital grounds, we will provide you with a "patient pager". This will allow us to contact you regarding the time of your next test.

The hospital canteen is located next to the BRU (where you are having your tests) on level 1 (basement). There is also a café on the ground floor, close to the main hospital reception in Sydney wing. Please remember not to have any caffeine.

Please return your pager at the end of your appointment

Personal possessions

Please do not bring anything of value with you on the day. Space is limited, so only a small locker is provided.

Research studies

Research into cardiovascular (heart) and respiratory (lung) medicine is central to the Trust's mission, and as a result, we have an international research reputation. Should you wish to take part in our research trials, we would be extremely grateful for your help.

During your visit you may be approached by a member of the research team for a particular study. He / she will explain the research study to you and, if you are interested, provide information to help you decide if you want to take part.

If you decide not to take part, your clinical care will not be affected in any way.

Who can I contact for further information?

- If you have any queries regarding **your appointment date,** please contact:

  Cardiomyopathy scheduler

  Tel: **020 7352 8121,** extension **2919**

- If you have **any other questions or concerns**, please contact:

  The ICC clinical nurse specialists

  Tel: **020 7352 8121,** extension **2205** or **8823**

  If we cannot take your call, please leave a message and a nurse specialist will call you back.

If you have concerns about any aspect of the service you have received in hospital and feel unable to talk to those people responsible for your care, call PALS on:

- Royal Brompton Hospital – 020 7349 7715
- Harefield Hospital – 01895 826 572

You can also email pals@rbht.nhs.uk. This is a confidential service.

Royal Brompton Hospital
Sydney Street
London
SW3 6NP
tel: 020 7352 8121
textphone: (18001) 020 7352 8121

Harefield Hospital
Hill End Road
Harefield
Middlesex
UB9 6JH
tel: 01895 823 737
textphone: (18001) 01895 823 737

Website: www.rbht.nhs.uk

إذا كنت ترغب في الحصول على ترجمة فورية لمضمون هذه الوثيقة إلى اللغة العربية، يرجى منك الاتصال بأحد مستخدمينا بجناح المصلحة التي يتم فيها استشفائك. أحد موظفينا سيسعى لترتيب إجراءات الترجمة وإتمامها في الوقت المناسب لك.

Brosurteki bilginin Turkçe tercumesi için tedavi goruyor oldugunuz bolume bas vurunuz. Bolum personeli tercumenin gerçeklesmesini en kisa zamanda ayarlacaktir.

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