



A lifetime of specialist care

Royal Brompton & Harefield **NHS**
NHS Foundation Trust

Inherited cardiovascular conditions (ICC) day case clinic





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This leaflet gives you information about the inherited cardiovascular conditions service. It does not replace the need for personal advice from a healthcare professional. Please ask us if you need more information.

Inherited cardiovascular conditions (ICC) day case clinic

You have been referred to the inherited cardiovascular conditions clinic 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 electrical activity in your heart. 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.



What happens before my appointment?

Our team of clinical nurse specialists may contact you before your appointment to find out more about your family history, and to draw a family tree to be used during your appointment. A family tree includes information about the health of your immediate family (children, parents, brothers and sisters) and extended family (nieces, nephews, grandparents, and as many other family members you can give us information about). Finding out about your full family history can be very difficult. If you find anything else out after speaking with the clinical nurse specialist (CNS), please bring the information with you to your appointment.

This information helps us to identify any previous symptoms or deaths that may be linked and that could be the result of an inherited condition.

Please include information about adult sudden deaths, miscarriages and sudden infant or childhood deaths in your family history. We ask for the cause of death, if known, and a copy of the post mortem, where possible.

Please also include any symptoms such as palpitations (rapid or irregular heart beat), seizures (epilepsy) and fainting. The clinical nurse specialist will help explain all of this.

What happens during my appointment?

On the day of your appointment you will have a series of tests, followed by meetings with a number of members of our specialist team. We plan the

appointment so that we can do everything we need in one day. We will try to do this as quickly as we can, but you need to be prepared to be with us until 5.30pm.

Where do I need to go?

Please come through the Chelsea Wing entrance, which is on Dovehouse Street. Follow the signs for the ECHO / non-invasive department, which can be found on level 3. Please report to the ECHO / non-invasive reception when you arrive.

For wheelchair access, please come through the main reception in Sydney Wing. Follow the directions to Chelsea Wing – take the lifts in Sydney Wing to level 3 and use the link bridge. If you need help, please ask at Sydney Street reception.

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 additional 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.
- We have a limited amount of toys, so please bring some fun things to do for any children attending the clinic.



Family history

We understand that it can be very difficult to talk about a sudden death in the family. If this has happened in your family, we will need to ask you about the events surrounding the death of your family member. We will do everything we can to be supportive.

We also recognise that you

may not wish to have certain discussions in the presence of other family members. If this is the case, please let us know, either on your arrival, or you can call the CNS before your appointment. 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 tests during your appointment. We aim to arrange these in the morning, but on some occasions these may take place in the early afternoon. You will be given the results of the tests by your consultant in the afternoon, during your consultation. Below is a brief description of some of the tests you may have.

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.

Exercise stress test

This involves walking, and then running on a treadmill (similar to the ones you find in a gym). Please wear suitable footwear, such as trainers. While you exercise, we record your heart rate, electrical activity in the heart and blood pressure. The test tells us how your heart responds during and after exercise. If you have any concerns about the exercise test, please let us know. You will be supervised during the exercise test by a cardiac technician.

Who will I meet?

Clinical nurse specialist

At some point during your appointment the CNS in inherited cardiovascular conditions 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

24-hour Holter monitoring

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 24-hour 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.


Blood tests

You may need to have blood tests, either for genetic or routine testing.

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 agree your treatment plan. 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 may 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 until we are sure there is no inherited condition affecting you.

Various changes occur in the

electrical system of children's hearts while they grow. We will continue to monitor these until we are sure there is no risk from an inherited condition.

What else do I need to know?

Breaks and free time

You will have several breaks during your day. For your information, the hospital canteen is located in Sydney Street wing, on level 1 (basement) of the hospital. There is also a café on the ground floor, close to the main reception in Sydney Street wing.

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:

ICC scheduler

Tel: **020 7352 8121**, extension **2832**

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

The inherited cardiovascular conditions 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 Türkçe tercemesi için tedavi görüyor olduğunuz bölüme bas vurunuz. Bölüm personeli tercemenin gerçekleşmesini en kısa zamanda ayarlayacaktır.

