



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.



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## 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 CNS 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?

When you arrive at the Royal Brompton, go to the main reception in Sydney Wing and follow the signposts to echo/non-invasive department (located on Level 3 Chelsea Wing). Once tests are complete please make your way to the Mezzanine Floor in Fulham Wing for your consultation.

For wheelchair access to Chelsea Wing, 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.

For wheelchair access to Fulham Wing please enter via Dovehouse Street and take the lifts to the Mezzanine level.

## 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.
- Additional documentation or information about affected family members including post mortem reports, coroner's reports, clinic letters and copies of your own clinic letters from other hospitals, if relevant.
- 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.



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## 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. You can find details of these tests in your appointment letter. 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 tolerance test

An exercise tolerance test is also known as a stress test. It involves walking, and then running on a treadmill (similar to the ones you find in a gym). 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 physiologist. The test can take up to an hour.

You need to:

- Wear suitable footwear, such as trainers.
- Eat no food for two hours before the test.
- Arrive 10 minutes before the test.

More information about the test is available on the Trust's website.

## 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 required to be returned the following day either in person or using a pre-paid postage envelope. We are not able to give you the results of 24-hour holter monitoring 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.

More information about holter monitoring is available on the Trust's website.

## Blood tests

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



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## **Additional investigations not performed on the day**

You may need some additional investigations which will be discussed with you during the consultation. If this is the case they will be arranged on another day after the initial consultation. These investigations may include an ajmaline challenge or adrenaline challenge which are performed as day case procedures on our inpatient wards. We will give you separate information leaflets about these procedures if you need to have them.

## **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 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. The hospital canteen is located in Sydney Wing, on level 1 (basement) of the hospital. There is also a café on the ground floor, close to the main reception in Sydney Wing.



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## 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 the ICC (inherited cardiovascular conditions) scheduler:

Tel: **0330 12 88121**, extension **82919**

- If you have **any other questions or concerns**, please contact the inherited cardiovascular conditions clinical nurse specialists:

Tel: **0330 12 88121**, extension **82205** or **88823**

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

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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](mailto:pals@rbht.nhs.uk). This is a confidential service.

Royal Brompton Hospital  
Sydney Street  
London  
SW3 6NP  
Tel: 0330 12 88121

Harefield Hospital  
Hill End Road  
Harefield  
Middlesex  
UB9 6JH  
Tel: 0330 12 88121

Website: [www.rbht.nhs.uk](http://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 tercumesi için tedavi görüyor olduğunuz bölüme bas vurunuz. Bölüm personeli tercümenin gerçekleşmesini en kısa zamanda ayarlayacaktır.

