Inherited Cardiac Conditions (ICC) service

Cardiology and Clinical Genetics

Information for Patients

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Introduction

Welcome to the ICC service at Glenfield Hospital. This leaflet will explain

- about inherited cardiac conditions,
- why you have been referred and
- what will happen during appointment with one of our health / medical care professionals.

If you have any questions or concerns, our contact details are in this leaflet. There are also helpful links / QR codes for more information.

What is the ICC Service?

We diagnose and support those with heart conditions that can be passed on in a family (inherited). Inherited cardiac conditions (ICC) mainly affect the heart or the main blood vessels.

We work as a team across

- adult cardiology,
- clinical genetics, and
- children's (paediatrics)

to deliver a service that is here to support you and your family.

We are continuing to develop this service.

The aim is to see families together, with multiple tests / investigations done on the same day. Although we aim to do your tests and clinic appointment on the same day, sometimes your tests and scans will be done at another time.

Why have I been referred?

You may have been referred to the ICC service for 1 of 4 reasons:

1. You have been diagnosed with an ICC. You need ongoing care and treatment, including the possibility of genetic testing.
2. You have a first degree relative (parent, sibling or child) with a diagnosis of an ICC and need screening, risk assessment, and the possibility of genetic testing.
3. You have a relative who has sadly passed away suddenly with a high suspicion of or confirmed heart problem. It might be advised for you to have ongoing screening, one-off risk assessment, and the possibility of genetic testing.
4. You have a relative who has had an unexplained cardiac arrest. It might be advised for you to have ongoing screening, one-off risk assessment, and the possibility of genetic testing.

What will happen during my appointment?

At your appointment (or before) you might have the following tests:

- Heart tracing (ECG),
- Heart scan (Echocardiogram)
- Treadmill test (exercise tolerance test)
- Heart rate monitor (holter monitor). This might be asked for after your appointment
- Sometimes we might talk about you having more tests during your appointment. This could be an MRI scan, drug provocation test or genetic testing.

The health care professional that you see will

- assess any symptoms you might be having,
- talk through your family history,
- discuss the results of your investigations and
- any further investigations or treatment you might need.

Please ask about any concerns or worries you might be feeling.

During your appointment there will be a lot to talk about, and you will have been given a lot of information. This will all be included in a letter.

You will also be given some

- helpful resources about the relevant heart condition,
- contact details of the Inherited Cardiac Conditions Specialist Nurse, and
- possibly some information letters to give to your relatives.

If a heart problem is found, it is our aim to work with you to lessen any symptoms you might be having. Our team will work towards reducing any further risk to you, give emotional support and reassure other family members who may or may not be at risk.

How can I prepare?

Knowing about your family history including any medical conditions, or unexpected young deaths will be useful as ICCs might affect more than 1 member of the family. You might be contacted before your appointment to get this information. Do not worry if this does not happen.

Useful information:

- Please bring with you any information about you or your family members heart diagnosis. This includes the name of their diagnosis or any clinic/test letters they are happy to share. As these conditions can run in families, it is often helpful and important to share medical information with other family members. This will only be done after checking with each individual and it is your choice if you wish to do so.
- Death certificates, or post-mortem reports will also be valuable if you have them.
- If you take any medications yourself, bring an up-to-date list including the doses.
- You might have an appointment to see more than 1 of our team on the same day, or there might be some time between tests and consultations. Please bring a book or something to help pass the time. You can bring toys if you have children with you.
- You may wish to bring something to eat/drink with you especially if you are diabetic

More information about the tests you might have

- ### Heart tracing – ECG:

An electrocardiogram (ECG) records the rate, rhythm, and electrical activity of your heart. Small sticky pads called electrodes are put on your chest. Leads are then connected to these from an ECG machine.

- ### Heart scan – Echocardiogram:

Often called an ‘Echo’, this is an ultrasound scan of the heart. It looks at the structure of the heart and how well it is pumping blood out to the body.. In ICC, it is used to investigate, help diagnose and monitor conditions that affect the heart muscle (cardiomyopathy).

- ### Treadmill test – Exercise tolerance test:

This test measures how your hearts responds when you exercise. You will have an ECG. Then while you are on a treadmill, we will do a continuous tracing of your heart.

You will need to bring a pair of trainers if you are having this test (you will get a letter or a phone call to tell you about it).

- ### Heart rate monitor – Holter monitor:

A small monitor is used. It has 3 electrodes attached to your chest. These monitor your heart rate and rhythm all the time. The reading will be for 24, 48 or 72 hours.

This device can be attached to your clothing.

- **Heart scan – cardiac MRI:**

It uses an MRI scanner to take detailed images of the inside of your heart. This might be requested if we cannot see enough from previous tests or for certain heart muscle conditions.

- **Drug provocation tests:**

This test is used to further investigate when there is a suspicion of an electrical disorder—a problem with the electrical signalling through the heart.

This test involves the controlled administration of a drug whilst attached to an ECG machine. The point of the test is to see if a pattern in your ECG is revealed when the drug is given, that would show you have Brugada Syndrome.

- **Genetic testing**

Genetic testing can be more difficult to understand. It might be offered to a person who has an ICC. It can also be offered to family members of someone with an ICC and an identified specific genetic cause. Genetic testing cannot be offered to everyone, and not everyone would want it. We can discuss this option with you and support you through the decision.

Meet the team

The ICC Service is based at Glenfield Hospital in the cardiology department.

Your appointment might be with our consultant cardiologist or clinical nurse specialist (CNS). If you are seeing the Clinical Genetics Team, this will most likely be at the Leicester Royal Infirmary.

Consultant cardiologist: Harshil Dhutia
Clinical nurse specialist: Chloe Ferguson
Genetic counsellor: Laura Vilajuana

More information, sign posting and ongoing support

There are some helpful charities that you may find useful before or after your appointment with the ICC service.

Sometimes your referral to the service has come at the cost of losing a loved one, or after a traumatic family experience. We aim to support you and your family through this difficult time. If you feel during your appointment that you wish to stop or pause – please let us know and we will support this.

There is some support available for you to access if you have not already:

Self-referral for talking therapies.
https://www.vitahealthgroup.co.uk/nhs-services/nhs-mental-health/leicester-leicestershire-rutland/

Leicester’s Hospitals Bereavement services:
https://www.leicestershospitals.nhs.uk/patients/patient-and-visitor-services/bereavement-services/

Other bereavement services: www.cruse.org.uk www.thelauracentre.org.uk

We have been given generous support from a local charity of The Joe Humphries Memorial Trust. Their funding means we have this chance to build and develop our service.

Below are some links and QR codes to some helpful charities including the Joe Humphries Memorial Trust.

Joe Humphries Memorial Trust

Cardiomyopathy UK

Arrythmia Alliance

British Heart Foundation

Cardiac Risk in the Young

Joe Humphries Trust www.jhmt.org.uk

Cardiomyopathy UK www.cardiomyopathy.org

Arrythmia Alliance www.heartrhythmalliance.org

British Heart Foundation www.bhf.org.uk

Cardiac Risk in the Young www.c-r-y.org.uk

Contact details:

Chloe Ferguson CNS: 07508 110539/0116 250 2904

Email: InheritedCardiacConditions@uhl-tr.nhs.uk

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغةٍ أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।
Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

Previous reference:

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk

LEICESTER'S RESEARCH

Leicester's Hospitals is a research active trust so you may find research happening on your ward or in your clinic. To find out about the benefits of research and become involved yourself, speak to your clinician or nurse, call 0116 258 8351 or visit www.leicestersresearch.nhs.uk/patient-and-public-involvement