

Networked

Services

Inherited cardiac conditions service



Information for patients

This leaflet helps explain what will happen when you come to the Inherited cardiac conditions (ICC) clinic and how we can help.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your **name** and **date of birth** and check your **ID band**. If you don't have an ID band we will also ask you to confirm your address.

If we don't ask these questions, then please ask us to check.

Ensuring your safety is our primary concern.

Introduction

You have been referred to our service because you are suspected of having or are at risk of developing an inherited heart condition.

These conditions include cardiomyopathies (affecting the heart muscle), for example:

- Hypertrophic cardiomyopathy
- Dilated cardiomyopathy
- Arrhythmogenic cardiomyopathy
- Non-compaction cardiomyopathy.

Or inherited arrhythmias (affecting the electrical function of the heart), for example:

- Long QT syndrome (LQTS)
- Brugada syndrome
- Catecholaminergic polymorphic ventricular tachycardia (CPVT)
- Sudden arrhythmic death syndrome (SADS).

About the ICC service

You will be attending a multi-disciplinary clinic and you may be seen by a number of people during your visit:

- **Consultant Cardiologists**
 - o Specialist senior doctors with significant knowledge and experience in managing heart conditions
- **Cardiology Specialty Registrars**
 - o Doctors receiving advanced training in the specialist field of cardiology in order eventually to become a consultant
- **Cardiac Genetic Nurses/Genetic Counsellors**
 - o Nurses and counsellors who care for patients with inherited heart conditions and provide genetic counselling, genetic testing and facilitate family screening
- **Consultant Geneticists**
 - o Specialist senior doctors who are focused on the diagnosis and management of inherited conditions



- **Physiologists**

- o Health care professionals who carry out and interpret specialist cardiac investigations.

We will see you in the outpatient clinic at King's College Hospital, Guy's Hospital and St Thomas' Hospital.

What to expect

Your first and follow up appointment includes tests and consultations with our team. It can take up to two-three hours.

At your first appointment or over the telephone we will draw your family tree. We are interested in the significant illnesses and heart problems of your parents, brothers, sisters, children, cousins, aunts, uncles and grandparents (age and the cause of death if applicable). It helps if you bring any relevant information with you on the day. These include medical letters, death certificates, post-mortem results and other results.

Investigations

You will be offered one or more of the following tests:

Electrocardiogram (ECG)

Small sticky patches called electrodes are put on your arms, legs and chest. These are connected by wires to a machine, which picks up the electrical signals that make your heart beat. This electrical activity is recorded and printed out. The whole test takes about five minutes and is completely painless. You will need to lie still though because moving can affect the results.

Echocardiogram (echo)

An echocardiogram is where a small probe with jelly lubricant is placed on your chest. Ultrasound waves are used to build up a



detailed picture of your heart. It is similar to the ultrasound scan used in pregnancy. The echo looks at the structure of your heart and the heart valves, and also gives information on the function and pumping action of your heart. This test takes about 20-30 minutes.

Exercise test

This involves exercising on a treadmill or bicycle while we monitor your ECG, blood pressure and symptoms with exercise. The aim of this test is to see how your heart works when you are more active. This test takes around 20 minutes and you might feel hot and sweaty afterwards. Please make sure you bring comfortable shoes and clothes.

24-hour ECG recording (Holter monitor)

Also called Holter monitoring or ambulatory ECG monitoring this involves continuously recording your heart's electrical activity for 24 to 48 hours. Sticky patches will be applied to your chest connected by thin cables to a small monitor for you to wear home. This can help find heart rhythm problems.

Cardiac Magnetic Resonance Imaging (MRI)

A cardiac MRI scan is a non-invasive test that uses a machine to create magnetic and radio waves to create clear pictures of your heart. Unlike an X-ray, an MRI scan does not use radiation. It is used to view your heart's structure (the muscle, chambers and valves of the heart) and to assess how well it's pumping.

Genetic testing

This test is to help find a genetic explanation for your condition or determine your risk for an inherited condition. The result might change the management of your condition and ongoing follow up. It also might lead to other family members being able to benefit from testing.



You will be offered this test if appropriate. Genetic counselling will be provided to enable you to make a decision about going ahead. The test is not always available depending on the condition and in a family should start with the person most affected by the condition.

Other tests

If any other tests are recommended we will discuss them with you.

Following your investigations

You will have a consultation including a medical history and physical assessment. If you take any medications then please bring a list to clinic. You will be given feedback on your test results. We will provide management, treatment advice and information on support groups if relevant. If you are identified as having an inherited condition you will receive information on how your family can access screening.

How to contact us

If you have any queries or concerns please contact

King's College Hospital

Tel: 020 3299 4475

Fax: 020 3299 3489

Clinic location:

Cardiology Outpatients, King's College Hospital

Suite 6, Golden Jubilee Wing

Denmark Hill, London SE5 9RS

Guy's Hospital

Tel: 020 7188 9491

Fax: 020 7928 3091

Clinic location:

Outpatients, First floor, Southwark Wing

Great Maze Pond, London SE1 9RT



St Thomas' Hospital

Tel: 020 7188 9491

Fax: 020 7928 3091

Clinic location:

Cardiology Outpatients, Saint Thomas Hospital

Ground Floor, North Wing

Westminster Bridge Road

London SE1 7EH

Patients under the age of 16 are seen at:

Evelina London Children's Hospital

St Thomas' Hospital

Westminster Bridge Road

London SE1 7EH

The Cardiac Genetic Nurses provide information and support, and can be contacted initially via the above numbers.

Further information

Arrhythmia Alliance

Tel: 01789 867501

Email: info@heartrhythmcharity.org.uk

Website: www.heartrhythmcharity.org.uk

A coalition of charities, patient groups, patients, carers, medical groups and allied professionals working together to improve the diagnosis, treatment and quality of life for all those affected by arrhythmias.

British Heart Foundation (BHF)

Tel: 0300 4568383 (Genetic Information Service)

Website: www.bhf.org.uk

Provides general and condition specific information, bereavement support and links with other charities and organisations.



Cardiomyopathy UK

Tel: 0800 0181024

Email: info@cardiomyopathy.org

Website: www.cardiomyopathy.org

Gives information and support to families affected by the heart muscle disease cardiomyopathy.

Cardiac Risk in the Young (CRY)

Tel: 01737 363222

Email: cry@c-r-y.org.uk

Website: www.c-r-y.org.uk

Supports young people diagnosed with potentially life-threatening cardiac conditions and offers bereavement support to families.

Sudden Arrhythmic Death Syndrome (SADS UK)

Tel: 01277 811215

Email: info@sadsuk.org

Website: www.sadsuk.org

Providing information and supporting individuals and families affected by cardiac conditions especially following a sudden cardiac death.

Sharing your information

We have teamed up with Guy's and St Thomas' Hospitals in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas'. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.



Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS:

Tel: **020 3299 3601**

Email: **kch-tr.pals@nhs.net**

You can also contact us by using our online form at

www.kch.nhs.uk/contact/pals

If you would like the information in this leaflet in a different language or format, please contact PALS on 020 3299 1844.

www.kch.nhs.uk

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