

Family Cardiac Screening Service

A patient's guide

Introduction

This leaflet is for anyone with a relative who has died very suddenly or unexpectedly. It is also for people who are affected by a heart condition that can cause sudden death, or if this is suspected in their family. It tells you what you need to know about screening for yourself and your family for inherited cardiac (heart) conditions. It also tells you where you can get help, support, and more information.

About the Family Cardiac Screening Service

Papworth Hospital aims to save the lives of people who may have an undiagnosed heart condition. Unfortunately, this is often discovered after a sudden cardiac death happens in the family.

Sudden cardiac death is caused by many different conditions. Some of the causes of sudden cardiac death are inherited conditions and this is where we may be able to help.

We understand that this may be an extremely difficult time in your life. However,

it is important that you are aware of the need for you and your family to be screened. If an inherited condition is found in your family, it can be monitored and treated to help prevent further deaths or troublesome symptoms.

For more information on specific illnesses and conditions visit some of the websites listed at the end of this booklet.

What to do now

You are welcome to make an appointment to come and see us. We recommend this but the final decision rests with you. We would be happy to see you and your family at any time, either now or at some later time. Obviously, the earlier you are seen the sooner we can diagnose or rule out a heart problem but some people feel they are not ready to pursue this soon after a bereavement.

Please read through all the information you have been given to help you make a final decision about when and where you would like to be seen.

If you are a first degree relative (parent, sibling or child) of someone who has died suddenly or has been diagnosed with a condition that can cause sudden death and would like to make an appointment, please take this information booklet to your GP and ask them to refer you. The address is on the back page. Once we receive your referral, we will contact you to arrange an appointment time.

What to expect if you are referred

The cardiac genetics nurse will telephone you and confirm the reasons why you have been referred for cardiac screening and explain what will happen next.

During this telephone call, the cardiac genetics nurse will ask you about your family history, we are interested in parents, grandparents, brothers, sisters, cousins, aunts, uncles and children of the person who has died or is affected. For each person we will ask details of their age, any significant illnesses and the cause and date of when they died (if applicable).

We are particularly interested in information about anyone with a heart condition or people who have suffered from fits, blackouts, or other collapses.

The cardiac genetics nurse will draw a family tree, this will help to identify which members of your family may need screening. We will send information to you about your particular situation and explain how other family members can be referred for cardiac screening if this is recommended.

We will arrange an appointment for you to attend our clinic at Papworth, we offer to see family members together if this is what you prefer.

Each person will have an individual consultation and be seen together as a family.

There will be a number of tests performed, most of these will be on the same day if you prefer, but you may need a separate appointment for other tests.

Some of the more common tests are described later in this booklet so that you will know what to expect. You will be able to ask any questions or discuss any concerns that you may have before you have any of the tests.

After you have had your tests, the Cardiac Genetics Nurse and a Cardiologist specialising in inherited cardiac conditions will review the results and discuss the management plan with you. You will be able to ask any questions or talk about any concerns that you may have before you leave or you can call the Cardiac Genetics Nurse at a later time if you prefer.

After the initial appointment, we will write to you and your GP explaining your test results and management plan in detail. You may be offered a further out-patient appointment to see another member of the inherited cardiac conditions team. This will also be explained in the letter.

Screening tests

In order to screen for an inherited heart condition, you will need to have one or more of the following tests.

These are carried out by technicians who specialise in obtaining precise pictures and readings but will not be able to talk to you about the results at the time of the test. This is because each test is like a piece of a puzzle that all need to be seen together and interpreted. This is done by the nurses and doctors involved in your care.

Resting Electrocardiogram (ECG)

This involves placing small sticky pads on to your chest, arms and legs. These are connected by wires to a computer that will enable us to record the rate and rhythm of your heart. The procedure is painless and you will be asked to lie flat while it is carried out.

Signal averaged ECG

This is similar to the resting ECG but the sticky pads are in different positions. This enables us to assess different aspects of the electrical activity within your heart.

Exercise ECG

This is the same as the ECG mentioned previously but instead of lying flat, you will be asked to walk or run on a treadmill. This test is carried out to see how your heart reacts during physical exertion.

24 hour ECG

This is similar to the resting ECG but you only have stickers on your chest which connect to a small box clipped to your waistband. You leave the hospital and go about your normal activities for 24 hours and return the box the next day. If you live a long way from Papworth this can usually be arranged at your local hospital.

Echocardiogram

An echocardiogram is similar to the ultrasound that is used on pregnant women to look at their baby, but in this case it is used to look at your heart. A hand-held metal tube, a little larger than a marker pen, coated with a small amount of gel will be placed on your chest, and using harmless ultrasound waves a picture of the heart can be seen and recorded.

Genetic testing

We can rarely offer genetic testing straight away, even if we think that a sudden death could be due to a genetic condition. This is because we need to have some clues as to what condition to test for and these clues usually come from the cardiac tests in other family members. Also, genetic testing for inherited cardiovascular conditions is relatively new and not all the genes that can cause sudden death have been identified.

If we are in a position to test you for a specific gene fault, you will have the opportunity to talk about the benefits and risks of this with a genetic counsellor before deciding to be tested.

If there is not a test currently available, we can offer to take a small blood sample for storage in case testing is available in the future. New discoveries are being made all the time so it is likely that new tests will be available in years to come. We would always contact you to talk about this option before testing a stored sample.

Other tests

Other tests may be required. We will discuss this with you before you have them. These include:

- Cardiac MRI scan
- Drug provocation challenge

Bereavement support for families

At this difficult time you may find it helpful to talk to someone who has experienced a similar loss. The organisations below offer a variety of support and information.

British Heart Foundation (BHF) Genetic Information Service

Tel: 0300 4568383

www.bhf.org.uk

Information and support: provides details of the nearest inherited cardiac conditions clinic, bereavement support and details of other relevant charities.

Cardiac Risk in the Young (CRY)

Tel: 01737 363222

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

www.c-r-y.org.uk

Information and telephone counselling by people who have suffered bereavement, trained in British Association for Counselling skills and theory.

Sudden Arrhythmic Death Syndrome (SADS UK)

Tel: 01277 811215

Email: Info@sadsuk.org

www.sadsuk.org

Cardiac charity providing information and support to those bereaved through sudden cardiac death (SADS, sudden death syndrome, adult cot death). Qualified counsellors and a network of bereavement supporters assist families after sudden death.

The Compassionate Friends

Tel: 0845 1232304

Email: info@tcf.org.uk

www.tcf.org.uk

Helpline staffed by bereaved parents (not professionals). Callers are signposted to other bereaved parents in the local area.

Cruse Care

Tel: 0844 4779400

Email: helpline@cruse.org.uk

www.cruse.org.uk

Promotes well-being of bereaved people through information, support and advice via a network of local areas and branches.

Cruse Care RD4U

Tel: 0808 8081677 (Monday to Friday 9.30am to 5.00pm)

Email: info@rd4u.org.uk

www.rd4u.org.uk

Information and advice specifically for bereaved children/young people. Provides telephone helpline and email to share and exchange views.

Support Line

Tel: 020 854 9004

Email: info@supportline.org.uk

www.supportline.org.uk

Free telephone counselling and support. Signposts callers to local support services.

Winston's Wish

Tel: 08452 030405 (helpline) or 01242 515157 (general enquiries)

Email: info@winstonswish.org.uk

www.winstonswish.org.uk

Offers practical support, information and guidance to families, professionals and anyone concerned about a grieving child.

The Cardiomyopathy Association (CMA)

Tel: 0800 0181024 (Monday to Friday 8.30 am to 4.30 pm)

Email: info@cardiomyopathy.org

www.cardiomyopathy.org

Provides support and easy-to-understand information on the difficult types of cardiomyopathy.

Contact Us

If you have any questions, please do not hesitate to contact:

Cardiac Genetics Nurse
Lakeside Crescent
Papworth Hospital
Papworth Everard
Cambridge
CB23 3RE

Tel: 01480 364361

Feedback

We appreciate and encourage feedback. If you need advice or are concerned about any aspect of care or treatment please speak to a member of staff or contact the Patient Advice and Liaison Service (PALS): 01480 364896

Referrals should be made to:

Family Cardiac Screening Services

Dr Simon Fynn
Lakeside Crescent
Papworth Hospital
Papworth Everard
Cambridge
CB23 3RE

Papworth Hospital NHS Foundation Trust
Papworth Everard, Cambridge, CB23 3RE

Tel: 01480 830541

Fax: 01480 831315

www.papworthhospital.nhs.uk

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