

Patient information factsheet

Clinical genetics referral: heart condition

We have written this leaflet to explain what will happen if you are offered a clinical genetics appointment.

What is a clinical genetics appointment for?

If your cardiologist has referred you to the Wessex Clinical Genetics Service, it is because they believe you may have an inherited heart condition (a heart condition caused by your genes). The Wessex Clinical Genetics Service supports people who have inherited conditions, and runs genetic tests.

Inherited heart conditions

Inherited heart conditions run in families and are caused by genes passed on from previous generations. There are many different types of inherited heart condition. Some conditions affect the heart muscle and others affect the rhythm of the heart.

Because heart conditions sometimes run in families, your own diagnosis may tell us that your family members are at risk of developing the same condition. If this is the case, we may advise your family members to have their own medical checks or screening.

Who will I see at my appointment?

If you are offered a clinical genetics appointment, your appointment will be with a member of the clinical genetics team. The team consists of clinical geneticists (doctors), genetic counsellors and a specialist nurse. Your appointment may be via video, telephone or face-to-face. We are based in Southampton but many of our clinics are held in hospitals throughout Hampshire, Dorset, South Wiltshire, and the Isle of Wight.

Before your appointment

If you are offered an appointment, we will ask you about your health and the health of your family members. This will help us to find out whether anyone else in the family has a similar heart condition to you, and to work out who else may be likely to develop this condition.

To help you answer these questions, we recommend that you come to your appointment prepared with information about your health and the health of your family members.

Your appointment

Your appointment will last up to 40 minutes. At the appointment, we will talk with you about your health and the health of your family members in detail. We will adapt your appointment to your needs and answer any questions you may have.

We can also give you support and advice about sharing information about your condition with your family members.

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Genetic tests

In some cases, you may be able to have a genetic test to help us find the underlying cause of your heart condition. The results of the genetic test are unlikely to change your diagnosis, but they may help us to work out which of your family members are at risk of developing the same condition.

If we think a genetic test may give us helpful information we will discuss this with you at your appointment. We will talk with you about the implications of having the test and help you decide whether it is the right choice for you.

Genetics tests are usually done via a blood test. This may be at your appointment or at a later date.

Research

This is a clinical appointment for the benefit of you and your relatives.

It is not a research appointment, but we may ask if you would like to take part in research into genetic conditions as well. Research helps us to learn more about genes and how we can help people with genetic conditions in the future. Sometimes, taking part in research can also have benefits for your own care.

Useful links

British Heart Foundation Greater London House, 180 Hampstead Road, London, NW1 7AW

Telephone: **0300 330 3322** Website: www.bhf.org.uk

Cardiomyopathy UK

75A Woodside Road, Amersham, Buckinghamshire, HP6 6AA

Telephone: 0800 018 1024

Website: www.cardiomyopathy.org

Contact us

Wessex Clinical Genetics Service

Princess Anne Hospital, Coxford Road, Southampton, SO16 5YA

Telephone: 023 8120 6170

Website: www.uhs.nhs.uk/genetics

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For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit www.uhs.nhs.uk/additionalsupport