What If I do not want a genetic test?

There is no obligation to have this test performed and you are free to take time to make your decision.

If you wish to discuss any aspect of testing or the implications of potentially having FH please contact The Cardiac Specialist Nursing Team on 01851 608711.

Useful Information

NHSinform	www.nhsinform.scot
NHS 24	Freephone 111 www.nhs24.scot
NHS Choices:	www.nhs.uk
HEART UK	www.heartuk.org.uk
British Heart Foundation	www.bhf.org.uk

Note. The internet is a fantastic way to access information. Unfortunately this information can sometimes be misleading. If you are at all unsure ask your healthcare provider.

Further Information

For more details contact:

The Cardiac Specialist Nursing Team
Ambulatory Care Unit
Western Isles Hospital
Macaulay Road
Stornoway
Isle of Lewis HS1 2AF
Tel. 01851 608711

We are listening - how did we do?

We welcome your feedback, as it helps us evaluate the services we provide. If you would like to tell us about your experience:

- speak to a member of staff
- visit our website www.wihb.scot.nhs.uk/feedback or share your story at: www.careopinion.org.uk or tel. 0800 122 31 35
- tel. 01851 708069 Monday-Friday between 9am-5.30pm.

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Written by: Cardiovascular Prevention & Rehabilitation Service and Dr. David J. Rigby,

Disclaimer
The content of this leaflet is intended to augment, not replace, information provided by your clinician. It is not intended nor implied to be a substitute for professional medical advice. Reading this information does not create or replace a doctor-patient relationship or consultation. If required, please contact your doctor or other health care provider to assist you to interpret any of this information, or in applying the information to your individual needs.

NHS Eileanan Siar Western Isles

Bòrd SSN nan Eilean Siar
NHS Western Isles

Cardiac Specialist Nursing Team

Familial Hypercholesterolaemia (FH)

Identifying FH in you and your family

Useful information for patients and their carers who have/or are at risk of Familial Hypercholesterolaemia

Introduction

You have been referred to the Familial Hypercholesterolaemia (FH) Service as a blood test you had showed raised cholesterol. You may also have a family history of early heart disease.

Together these signs may indicate that you may have an inherited form of high cholesterol which requires further investigation.

What is FH?

FH is an inherited condition that is thought to occur in approximately 1 person in every 200-250 and is one of the most frequently occurring genetic conditions.

People with FH have inherited a faulty or mutated gene from one or, very rarely, both parents, which results in the inability to clear out 'bad' cholesterol sufficiently from the bloodstream. If we have too much bad cholesterol (known as LDL cholesterol) in the bloodstream this can lead to a build up of fatty deposits on the inside walls of arteries and can lead to early heart disease.

Untreated, men with FH have a 50% chance of developing heart disease (stroke, angina and heart attack) before the age of 60 and untreated women have a 30% chance of developing heart disease before the age of 60. The presence of FH carries a 13-fold risk of coronary heart disease compared to those who don't have FH.

If someone has FH each of their children and full siblings has a 50% chance of having it.

Genetic testing for FH

A cholesterol blood test can be a good indicator of the presence of FH but having a genetic test to identify the mutation that is causing high cholesterol can provide a clearer pathway to identifying FH in other family members. Cholesterol tests alone have resulted in under-diagnosis of the condition.

We know that FH can be caused by changes in 3 genes. You will be tested for these 3 genes unless we know which mutation has been identified in your family already, in which case we test you for your family mutation alone.

If FH is confirmed genetically in you, 1st, 2nd and where possible 3rd degree relatives will be offered a genetic test for the mutation we have identified in you. This is known as cascade testing.

Genetic tests are available from as young as age five years and sometimes younger in special circumstances.

Benefits of identifying FH

Fortunately, FH is a treatable condition and the sooner treatment commences the more effective it will be in preventing early heart disease.

Without treatment people with FH may suffer heart problems, such as a heart attack in their 40s or 50s. Treatment is recommended from as young as age 10 to prevent build up of fatty deposits on artery walls.

Potential disadvantages of genetic testing

A positive diagnosis of any condition which involves treatment can lead to increased insurance premiums.

Some insurance companies do not ask if you have ever had a condition genetically diagnosed, but some do which potentially affect premiums.

The cholesterol charity Heart UK is currently working with the British Medical Association (BMA) and Association of British Insurers (ABI) to prevent people with treated FH being discriminated against with a diagnosis of FH.

Having treated FH can lower your risk of heart disease to the same as those without FH and the BMA and ABI work to ensure insurance company underwriters are aware of this.

Heart UK has a list of sympathetic insurers for travel and life insurance online at: www.heartuk.org.uk