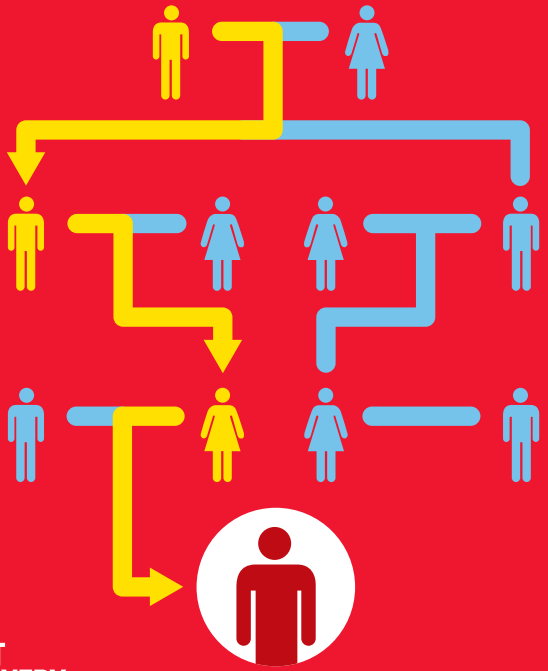
British Heart Foundation

Familial hypercholesterolaemia

Your quick guide



FIGHT FOR EVERY HEARTBEAT

bhf.org.uk

British Heart Foundation

Coronary heart disease is the UK's single biggest killer.

For over 50 years we've pioneered research that's transformed the lives of people living with heart and circulatory conditions. Our work has been central to the discoveries of vital treatments that are changing the fight against heart disease.

But so many people still need our help. From babies born with life-threatening heart problems to the many Mums, Dads and Grandparents who survive a heart attack and endure the daily battles of living with heart failure.

Join our fight for every heartbeat in the UK. Every pound raised, minute of your time and donation to our shops will help make a difference to people's lives.

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What is Familial Hypercholesterolaemia (FH)?

Familial hypercholesterolaemia or FH is a condition that leads to very high cholesterol levels. You usually have these high levels from when you're born and FH stays with you all your life.

FH is an inherited condition. This means that it's passed through your family. It's caused by a problem with one or more of your genes. These are often referred to as 'gene mutations' or 'gene alterations'.

FH is one of the most common inherited conditions. About one in every 200 people in the UK has FH.

FH affects more than

300,000

people in the UK.

Many people have FH and don't know they do.

What causes FH?

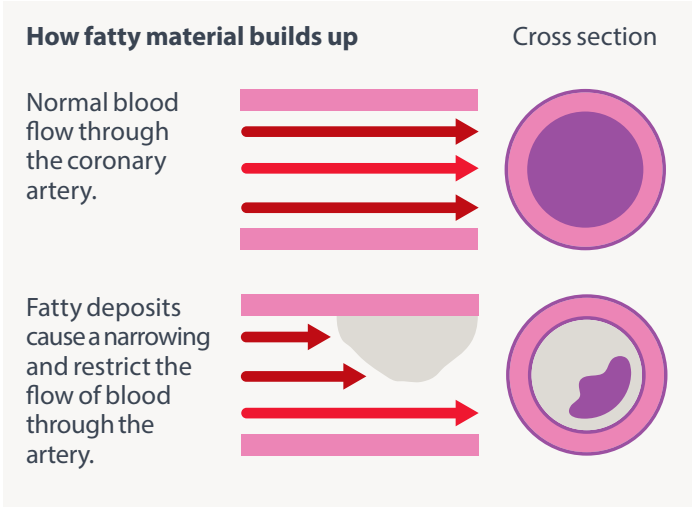
Cholesterol is a fatty substance carried around your body.

People with FH have high levels of the bad type of cholesterol – low density lipoprotein (LDL) cholesterol.

Your liver usually removes LDL cholesterol from your blood, but if you have FH your liver can't remove enough of the bad cholesterol from your body. This means the levels of cholesterol in your blood rise.

Why is FH such a problem?

FH can cause a gradual build-up of fatty material in your coronary arteries.



As you have FH from when you're born, this increases your risk of developing coronary heart disease and having a heart attack at an early age.

If you don't have treatment, 1 in 2 men and nearly 1 in 3 women with FH will develop coronary heart disease by the age of 55.

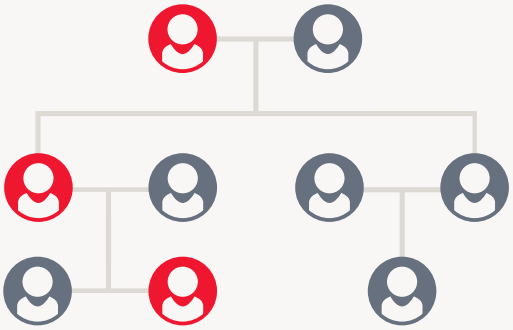
If you have FH, getting it diagnosed and starting treatment as soon as possible can reduce your chance of coronary heart disease or dying early.

Why do people get FH?

FH is an inherited condition and can be passed on through your family. If one of your parents has FH then there's a 50 per cent (or 1 in 2) chance that you could inherit it. If you do, then there's also a 50 per cent chance you could pass it on to each of your own children.

This is how FH could be passed on through your family:

With FH Without FH



How is FH diagnosed?

Your doctor or specialist may suspect FH if:

– you have high cholesterol

– you have a family history of FH

– you've already had a heart attack, especially if it was at a young age

– members of your family have had coronary heart disease at a young age

– you or your doctor have noticed any physical signs of FH.

What tests will I need?

Your blood cholesterol levels can be checked using a simple blood test. It can be done in two ways:

– a blood sample is taken with a needle and syringe and is sent away to be looked at

– a drop of blood is taken from your finger and looked at using a small machine that shows a result after a few minutes.

Another test you may have is a genetic or DNA test. This test looks at your DNA to find out if you have a gene mutation that causes FH. It can also be used to check if you've inherited the same gene mutation as another family member with FH.

Rachel's story

Rachel was told she had FH in 2010.

"My younger sister had a heart attack aged 48. I'd never had a problem with my heart, but my son John had high cholesterol and at times he was passing out. I used to be a dairy farmer and know how genes work so I asked my sister's cardiologist if there could be a condition passing through my family.

The cardiologist referred me to a consultant, who checked my hands and eyes for signs of high cholesterol and sent me to be tested for FH.

It came back positive. The results were sent to John's doctors and as a result he was tested and had emergency bypass surgery that probably saved his life."

“I believe that my son, John, is alive today **because I was tested for FH.**”

Rachel, survivor

What are the physical signs of FH?

Tendon xanthomata
Pronounced zan-tho-mata. These are swellings made from cholesterol on your knuckles, knees or your Achilles tendon at the back of your ankle.

Xanthelasmas
Pronounced zan-thel-as-mas. These are small, usually yellow coloured lumps of cholesterol near the inner corner of your eye.

Corneal arcus
This is a pale white ring around your iris, the coloured part of your eye. If you are under 50 years old and have a corneal arcus, it’s a strong sign that you have FH.

Can I take any medicines for FH?

Medicines called statins are the most common medication for FH. Statins help to remove some of the extra cholesterol from your blood by stopping your liver from making cholesterol.

Are there any other treatments for FH?

A treatment called LDL-apheresis involves regularly cleaning the cholesterol from your blood. A special machine filters out the cholesterol from your blood. The process is similar to having dialysis if you have kidney disease.

Very few people need LDL-apheresis. This treatment is used if your LDL cholesterol levels remain higher than the target set for you by your doctor after treatment with medication, or if you can't take cholesterol-lowering medication.

Is there a cure for FH?

There isn't a cure for FH, but it can be managed very successfully.

Getting treatment can reduce your risk of getting coronary heart disease, having a heart attack or needing other treatments.

How might it affect my day-to-day life?

It's normal to worry about being diagnosed with FH, but if you have treatment you can expect to live a normal healthy life.

Making changes to your lifestyle will help to protect your heart health and help reduce your cholesterol levels whether you have FH or not.

You can reduce your cholesterol levels and protect your heart health by:

- stopping smoking
- eating a healthy diet
- drinking no more than the recommended limits of alcohol
- taking regular physical activity
- being a healthy body weight and shape

Use this space to make notes for discussions with your doctor.

Join us in the fight for every heartbeat.

For 50 years the British Heart Foundation has been funding life-saving heart research. Our work has been central to the discoveries of vital treatments that are changing the fight against heart disease. But we need your support to continue this fight.

Visit bhf.org.uk to make a donation or find out more.

For more information

You can find out more about the topics talked about here in some of our other resources:

Booklets

- Inherited heart conditions: Familial hypercholesterolaemia
- Reducing your blood cholesterol
- I cut the saturated fat
- Keep your heart healthy
- Angina
- Your quick guide to heart attack
- Peripheral arterial disease
- Medicines for your heart

Other resources

- Risking it (DVD)
- Know your heart (online tool)

To order our booklets or DVDs:
call **0300 200 2222**
email **orderline@bhf.org.uk**
or visit **bhf.org.uk/publications**

Contact

For more information visit the British Heart Foundation website **bhf.org.uk**

Heart Helpline 0300 330 3311
(a similar cost to 01 and 02 numbers)
For information and support on anything heart-related.