

# Familial Hypercholesterolaemia (FH)

## What is FH?

Familial hypercholesterolaemia (FH) is a cholesterol problem found in certain families. Many people have high cholesterol but people with FH have **very high cholesterol**, starting in childhood or even at birth. People with FH also often have a pattern in their **family history of early severe (or symptomatic) heart disease**. If a family has a pattern of early heart attacks or heart disease (before age 55 for men and age 65 for women), **children in the family should be monitored carefully**. Cholesterol levels can vary, but FH is suspected in adults who have "bad cholesterol" levels (also called LDL Cholesterol) that are above 4.92mmol/L<sup>1</sup>, or in children or teenagers with levels over 4.14mmol/L. Cholesterol can build up in the walls of blood vessels and over time lead to heart attacks, stroke and blood vessel disease. It is important that FH is found early to prevent cholesterol build-up and the blood vessel disease it may lead to.



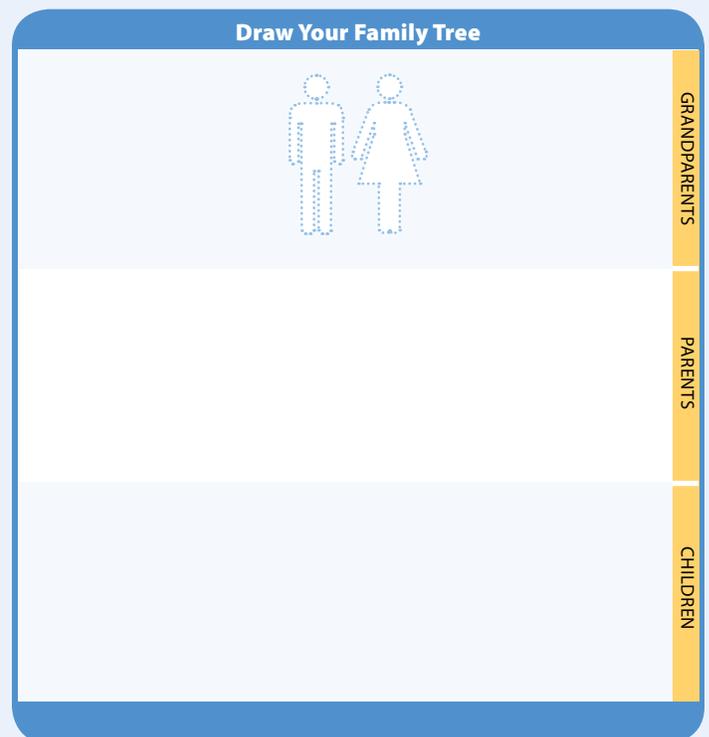
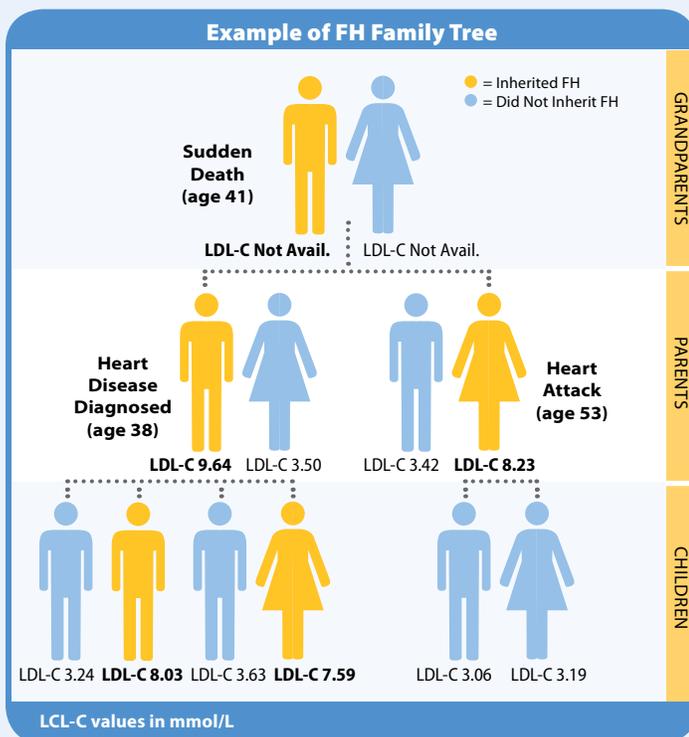
## Is FH common?

FH is one of the most common of all genetic problems. It affects one out of every 500 people and is found in all populations and ethnic groups.<sup>2,3</sup> However, in some groups, FH can be 2 to 5 times more common than in the general population. Some of these groups include people of Lebanese, French Canadian, South African Afrikaner, and Ashkenazi Jewish descent.<sup>2</sup>

## How is FH inherited?

The closest relatives of people with FH (parents, brothers and sisters, children) all have a 50% chance of also having FH. Because of this, FH families often have a pattern of people with very high cholesterol who may have had a heart attack or heart disease early, in their 20's, 30's, 40's or 50's.

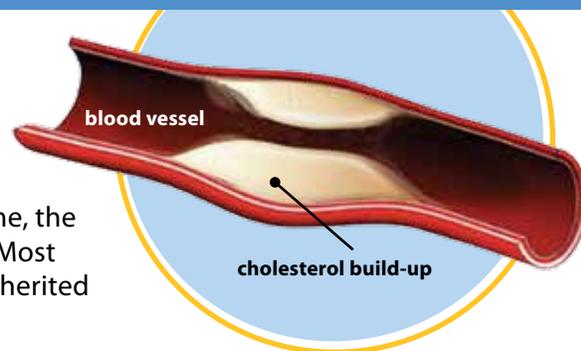
On the left is a picture of an FH family. Below each family member are the numbers from their cholesterol test. The people in yellow have higher cholesterol levels, and some also have heart disease at an early age: these family members have inherited FH. Can you draw your family on the right? Your nurse or doctor will know your Total or LDL Cholesterol levels. Start with what you know, and add information after sharing this sheet with family members.



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## What causes FH?

Cholesterol is a wax-like, fatty substance that can build up in the walls of blood vessels. In most people, the liver helps remove cholesterol from the blood. In FH, the liver does not remove cholesterol as well, and cholesterol levels can build up earlier than for other people. Over time, the cholesterol build-up can cause events such as heart attacks and strokes. Most people with FH inherit it from one parent. It is uncommon for FH to be inherited from both parents.



## Why look for FH?

If FH is found early, serious problems of the heart and blood vessels may be prevented or delayed by making changes such as not smoking, eating a healthy diet and taking your medications.<sup>1</sup> The National Institute for Health and Clinical Excellence (NICE) recommends that cholesterol levels should be checked in children at risk of FH (one affected parent) by the age of 10 years or at the earliest opportunity thereafter.<sup>4</sup> It is important to identify FH and take action at any age, because when treated, the risk of heart disease can be reduced to levels similar to those of the general population.<sup>1</sup>

## How do you know if you have FH?

People with FH may look perfectly healthy. FH may not even be found during a routine health check-up. Nurses and doctors may find FH by a cholesterol test and a review of your family history. They may also order a special blood test to see the specific type of FH you have.

### What can you do if you have FH?

#### TAKE ACTION NOW

- Tell your family that you have FH and encourage them to have their cholesterol checked too
- Take your medicines as directed – it can become a routine, like brushing your teeth
- Have your children's cholesterol checked – this is recommended by the National Institute for Health and Clinical Excellence (NICE)

### How can you and your family learn more?

#### ■ Ask to be referred to a Consultant Lipidologist.

- A Consultant Lipidologist is a doctor that specialises in disorders like FH

A list of lipid clinics in the UK can be found at:  
<http://www.heartuk.org.uk/lipidclinics/index.php>

#### ■ Learn about FH online or via the following helplines:

- **HEART UK, The Cholesterol Charity**  
[www.heartuk.org.uk](http://www.heartuk.org.uk)  
Tel: 0845 450 5988
- **British Heart Foundation**  
[www.bhf.org.uk](http://www.bhf.org.uk)  
Tel: 0300 330 3311

#### References:

- <sup>1</sup> Goldberg A, et al. *J of Clinical Lipidology*. 2011.04.003.
- <sup>2</sup> Austin M, et al. *Am J Epidemiol*. 2004;160:407-420.
- <sup>3</sup> Genetic Alliance UK. Available at <http://www.geneticalliance.org.uk/education3.htm>.
- <sup>4</sup> NICE Guideline 71. Identification and management of familial hypercholesterolaemia. August 2008. Available at: [www.nice.org.uk/CG071](http://www.nice.org.uk/CG071)

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