

What You Need to Know Familial Hypercholesterolemia (FH)

What is Familial Hypercholesterolemia?

- FH is an inherited high blood cholesterol condition. If a parent has the FH gene, there is a 1 in 2 chance that their child will have FH. About 1 in 500 people has FH.
- When a person has FH, the liver cannot clear cholesterol out of the body in the usual way. People with FH have extremely high LDL (bad) blood cholesterol levels even when they are children.
- High blood cholesterol levels can lead to blocked arteries which can cause a heart attack, a stroke, or other circulation problems. This can happen at a young age in people who have FH.
- It is important that FH is found early to prevent the build-up of cholesterol in the arteries and damage to blood vessels.



Reasons why you may need to be tested for FH

- If your “bad” cholesterol, or LDL level, is higher than 5.0mmol/L, FH should be suspected. In children or teenagers, an LDL level over 4.0 mmol/L is a reason for further testing.
- If you or other people in your family have had a heart attack or a stroke at a young age, like in their 20’s, 30’s, 40’s or 50’s.
- If your nurse or doctor can detect signs of cholesterol deposits around your eyes, heels, or elbows when they examine you.

If You Have FH: What You Can Do

- Remember that FH, even though not curable, is easily treatable. You can lead a full and normal life.
- Ask questions if there is something you don’t understand.
- Take your medicine as prescribed. Cholesterol-lowering medicines can prevent heart attacks, strokes, and other circulation problems.
- If you smoke cigarettes, ask for help in quitting.
- Ask your nurse or doctor to help you make a plan for exercise.
- Talk to your nurse or doctor about whether you need an appointment with a specialist in FH.
- Tell your immediate family members that you have FH and ask that they have their cholesterol levels checked. You should also have your children tested for FH.



PCNA
Preventive Cardiovascular
Nurses Association
www.pcna.net

Details About FH

How is FH treated?

- **Cholesterol-lowering medicine** is a very important part of treating FH and lowering the risk of early heart disease. **A healthy diet and physical activity alone cannot lower blood cholesterol levels enough in people with FH.**
- If you have FH, controlling your other risk factors for heart disease is important. Do not smoke cigarettes. Have your blood pressure checked. Take your prescribed blood pressure medicine regularly. Strive for a healthy weight, and take regular exercise.
- If you have FH, your nurse and doctor will talk to you about eating **foods that are low in saturated fat and dietary cholesterol**. A dietitian can give you expert advice and good tips about what kinds of foods to eat and ways to make healthy changes.

If I have FH, what does this mean for the people in my family?

- If you have FH, your children, parents, brothers and sisters each have a 1 in 2 chance of having FH. These close family members are known as your “first degree relatives.”
- If you have FH, have your children checked for FH. We recommend that your children have their blood cholesterol checked between the ages of 7 to 11 and, if not elevated, have it re-tested in their early twenties. Certain children, including those who have a first degree relative with FH, may have their cholesterol levels measured earlier—as young as age 2 yrs. You should also ask your other first degree relatives to be checked for FH. The sooner FH is found, the sooner treatment to prevent heart disease can be started.

Important Things to Remember about FH

- If you have FH, you will need regular medical follow-up and prescription medicines to lower your blood cholesterol for your lifetime.
- If you have FH, a healthy diet and physical activity, while important, are **not enough** to lower your cholesterol level.
- **Treating your blood cholesterol level and other heart disease risk factors will lower your risk of heart attack, stroke, and other circulation problems.**

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Learn More About FH Online

- **FH Australasian Network:** www.athero.org.au
- **Australian Heart Foundation:** www.heartfoundation.org.au
- **Heart UK – the Cholesterol Charity:** www.heartuk.org.uk
- **Preventive Cardiovascular Nurses Association:** www.pcna.net/patients/familial-hypercholesterolemia
- **The Foundation of the National Lipid Association:** www.learnyourlipids.com

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