When should treatment start?

Starting medication as soon as possible can prevent significant heart disease. Children who are affected can be encouraged to have a healthy diet and include exercise. They can be warned that smoking is especially dangerous for them. Adults with FH should follow the same advice. In most cases everyone with FH will benefit greatly from cholesterol lowering medication. They should also be monitored to make sure that their heart stays healthy.

What can you do?

- Have your cholesterol checked
 - o Attend our family screening clinic by calling 02 9515 5062
 - o Your GP can arrange this
- Quit smoking
 - o Quitline: 13 QUIT (1378 48)
- Speak with your family
 - Your children and your sisters and brothers might benefit from having their cholesterol checked too
- Aim for a healthy diet and some regular exercise

Useful Links

www.athero.org.au/fh.htm www.athero.org.au/FH/index.html www.genetics.edu.au

http://www.fhjourneys.com/ http://thefhfoundation.org/

People with FH have 20 times the risk of developing early aggressive heart disease

Who should I go and see?

Relatives can attend our family screening clinic at RPA Hospital by calling **02 9515 5062**. Your GP can order a cholesterol test and explain the results. GPs can prescribe FH medications and monitor how you respond to these.

If you receive a diagnosis of FH you may also be referred to a specialist clinic run by doctors at Royal Prince Alfred Hospital in Sydney. This clinic is called the 'FH Clinical Support Service'.

Can I trust the information in this brochure?

This brochure was compiled by health educators and clinical staff who do not receive money or any support from companies that make and sell FH medications.







Familial Hypercholesterolaemia Clinical Support Service

Inherited high cholesterol

An information guide for those at risk





Familial Hypercholesterolaemia Clinical Support Service

A JOINT PUBLIC HEALTH PROGRAM OF WESTERN & SYDNEY LOCAL HEALTH DISTRICTS

A special cause of Heart Disease: Inherited high cholesterol

What is it?

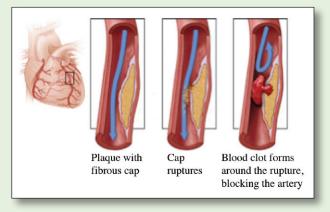
Familial hypercholesterolaemia (also known as FH) is an inherited condition causing high cholesterol levels and early heart disease.

Is it common?

Yes, FH affects at least **1 in every 500** Australians. In families with this condition, around half of the family members will have high cholesterol.

How does it affect our body?

High levels of cholesterol lead to deposits of cholesterol on the walls of blood vessels. This causes the blood vessels to narrow. Sometimes the built up cholesterol, or "plaque", ruptures causing clots that completely block the blood flow (see diagram below). Lower blood flow and clotting leads to heart attacks, strokes and other problems.



Can it be treated?

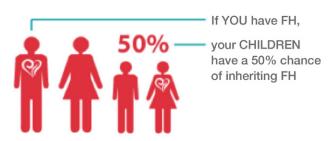
Yes, FH can be treated with medication that lowers the level of cholesterol in the blood. Eating a healthy diet, exercising regularly and not smoking are also important parts of treating high cholesterol and preventing heart disease.

Why does it happen?

FH is caused by alterations in a gene that controls the removal of cholesterol from the blood. We all have two copies of this gene. If one copy of the gene has an alteration that makes the gene faulty, the removal process only works half as well. As a result, the blood cholesterol rises to about double the usual level, even when an individual has a good diet.

What about my family?

If you have FH there is a 50% (or 1 in 2) chance that your brothers and sisters may also have FH. There is also a 1 in 2 chance that your children may inherit the condition. Families may not recognise a pattern of early heart attacks or strokes. People might also not realise that this could be due to FH and that it can be prevented. To prevent FH-health problems, we need to identify people with FH. The best way to do this is to identify family members of people already diagnosed and encourage them to have their cholesterol checked.



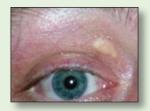
What happens?

Narrowing of arteries and plaques that rupture, mean that heart attacks and strokes can occur twenty or thirty years earlier than in someone without a faulty gene.

How can we tell who might be affected?

People with FH are not usually aware of it because it does not affect the way they look or feel. It does not depend on your sex, weight or fitness level. People with FH often have relatives with high cholesterol or who have had a heart attack in their 50's, 40's or even younger.





The other clue is that adults with FH may get lumps of cholesterol on the back of their hands or on the back of their heels, or near their eyes. Your doctor can assess you to determine if you have FH. This will include a blood test to measure your cholesterol level.

Do I need to see other specialists?

You may be referred to a specialist clinic where more tests could be ordered. These might include a special blood test to look for the faulty gene causing FH. Other tests involve checking your heart. These are to monitor the health of your heart and these tests may be repeated over time.

Is FH the only cause of high cholesterol?

No, there are many causes of high cholesterol levels. Lifestyle issues such as a high fat diet and not much exercise can lead to high cholesterol levels. There are also other inherited influences on cholesterol.