

Inherited high cholesterol in the family (familial hypercholesterolaemia)

Information for the public

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Familial hypercholesterolaemia – the care you should expect

One in 500 people are born with a type of high cholesterol that runs in families, called familial hypercholesterolaemia, or FH. Without treatment people with FH have a high chance of developing heart disease earlier than most people. Starting on the right treatment as soon as possible is important, but many people don't know they have the condition.

We want this guideline to make a difference to people with FH by making sure:

- doctors are using the best ways of finding people who might have FH, for example by looking at everyone's medical records
- family members of people diagnosed with FH are traced and offered a gene test if they could also have the condition
- people with FH are offered lifelong treatment with statins as early as possible.

Making decisions together

Decisions about treatment and care are best when they are made together. Your health professionals should give you clear information, talk with you about your options and listen carefully to your views and concerns.

To help you make decisions, think about:

- What are you most worried about – are there aspects of testing or treatment that worry you?
- Will the treatment affect your day to day life?
- What lifestyle changes could you make to help lower your cholesterol?

If you can't understand the information you are given, tell your health professional.

Read more about [making decisions about your care](#).

Where can I find out more?

NHS Choices has more information about [familial hypercholesterolaemia](#).

The organisations below can give you more advice and support.

- [British Heart Foundation](#), 0300 330 3311
- [CLIMB – Children Living with Inherited Metabolic Disorders](#), 0845 241 2173
- [HEART UK – The Cholesterol Charity](#), 0345 450 5988

NICE is not responsible for the content of these websites.

We wrote this guideline with people who have been affected by familial hypercholesterolaemia and staff who treat and support them. All the decisions are based on the best research available.

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