SCARSTORIES · A LITTLE COMPANY ON THE WAY

Familial hypercholesterolaemia — when high cholesterol runs in the family

FH is a genetic condition that raises cholesterol from birth — it explains “why me,” and it changes the conversation for your whole family.

Understanding the diagnosis

> Educational content.

Familial hypercholesterolaemia (FH) is an inherited condition that makes the body clear LDL cholesterol — the “bad” cholesterol — out of the blood much more slowly than usual, so levels run very high from birth.

If you have just been told you have it, you may be feeling a strange mix: relief that there is finally an explanation, and worry about what it means. FH is not a lifestyle failure. You did not eat your way here, and neither did your parents. It is a genetic instruction your body has been following since day one — which is also why it matters so much to name it: it changes the conversation for your children, your siblings and your parents.

What FH actually means

Most published estimates put FH at around 1 in 250 people (European Society of Cardiology guidelines, 2019) — far more common than people assume. Untreated, the high LDL slowly builds plaque in artery walls across decades, which is why heart attacks in people with untreated FH can come early — sometimes in the 40s or 50s. Treated — and treatment is usually long-term medicines, plus lifestyle — the risk comes down substantially. The gap between untreated and treated is the whole story of FH: it is one of the most manageable genetic conditions there is.

Some people notice physical clues — yellowish cholesterol deposits near the eyes or on knuckles, elbows or tendons, or a pale ring around the iris. Many people have no clues at all; the blood test is the real detector.

Why your family matters here

FH is passed down in families — a child of a person with FH has a one-in-two chance of inheriting it, by the basic rules of inheritance. This is why teams usually suggest testing close family members, including children — because for them, an early diagnosis means decades of prevention instead of a first heart attack. That conversation can be delicate; people are not always ready to hear it. But naming FH is one of the few times a diagnosis is a gift to the people you love.

What to ask your team

- What is my LDL level, and what target should we be working toward?
- Should my children, siblings or parents be tested — and how does that work?
- What would genetic testing add for me, and is it worth doing?
- How often will my levels and my heart be re-checked?

> **Take it to your team**
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> Bring your family history with you — early heart attacks, high cholesterol, or heart procedures in parents, grandparents or siblings. That history is part of the diagnosis, and it is the key that unlocks screening for the next generation.

> **Call for help if**
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> You get chest pain or pressure — especially with effort — that lasts more than a few minutes, or comes with breathlessness, sweating or faintness. People with FH can carry risk silently for decades; symptoms are never “probably nothing.”

FH is a long conversation, not a one-off verdict. Let your team set your targets, explain your options, and walk your family through screening — the decisions, as always, belong to you and your team.

Questions to take to my team

- [ ] What is my LDL level, and what target should we be working toward?

- [ ] Should my children, siblings or parents be tested — and how does that work?

- [ ] What would genetic testing add for me, and is it worth doing?

- [ ] How often will my levels and my heart be re-checked?

For discussion and personal reference. Your care team's individual instructions take priority. For an emergency, contact your local emergency service; do not wait for a community reply.