What is FH?

Family History of early heart disease + High LDL cholesterol = Familial Hypercholesterolemia

Shared Decision Making for Familial Hypercholesterolemia

Shared Decision Making (SDM) is a collaborative process enabling both patients and providers to make healthcare decisions together. It takes into account both medical information and patient preferences.

The SHARED approach was created to help facilitate the SDM process, which can help improve patient outcomes, rates of self-management, satisfaction with care, and lower healthcare costs.*

S Seek Your Patient’s Participation

H Help Your Patient Explore and Compare Treatment Options

A Assess Your Patient’s Values and Preferences

R Reach a Decision With Your Patient

E Evaluate Your Patient’s Decision

D Decide Which Local Resources Will Effectively Support your Patient and How To Connect

Seek Your Patient’s Participation

What do I need to do? How does this impact my family?

Can you tell me about my treatment options, do I have to take medication?

Are there side effects? Will these treatments work for me?

Let’s take a look at your goals for the next month. We want to focus on healthy eating, exercise, and sticking to your medication.

What would treatment look like for me?

What if I have challenges in sticking to my goals?

Are there any other resources available to help me? Is there an advocacy group for FH?

What do I need to do? FH is different. It’s genetic. It’s not your fault. Treatment can lower risk.

The goal of treatment is to lower LDL cholesterol and therefore, lower your risk for heart disease. Often, a combination of treatments are needed, including medication.

There are several statins available. Usually, you can find one that works for you without side effects. Some people experience muscle aches from statins, but most muscle symptoms are not related to statin therapy.

By sticking to these goals, we hope to see a decrease in your LDL cholesterol. Don’t be discouraged as challenges arise.

Your FH Care Team includes myself, a nurse practitioner, registered dietician, and a pharmacist. We can help.


* National Forum’s Value & Access Initiative is made possible through support from Amgen (Founding Sponsor), Sanofi & Regeneron, Mended Hearts, National Lipid Association, Partnership to Improve Patient Care, and Preventive Cardiovascular Nurses Association.
FH is different. It’s genetic and it’s not your fault. Having FH means a lifelong exposure to high LDL cholesterol (LDL-C).

FH is high risk, meaning that it increases your risk for the following: early heart attack, the need for stents or bypass, peripheral artery disease, and even sudden cardiac death.

The good news is that FH treatment can lower risk. Large reductions in LDL-C result in large reductions in CV risk. The benefit of statins for reducing heart attack and stroke risk outweighs the small increase of risk of diabetes. Regular physical activity and weight control also reduce the risk of diabetes.

Because people with FH start with such high LDL cholesterol, a combination of more than one treatment might be needed to lower LDL-C enough.

Stop your statin and call me right away.

There are some people who take statins will experience muscle aches but most people over 30 years and have been shown to be safe and effective in preventing cardiovascular disease.

• There are other risk factors (manage blood pressure & diabetes, maintain a healthy weight, don't smoke).

Connect with the FH Foundation for Support and Education at www.theFHFoundation.org

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Approximate LDL-C Lowering Effect*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart Healthy Diet and Regular Exercise</td>
<td>10-15%</td>
</tr>
<tr>
<td>Statins: First line treatment. Safe and effective.</td>
<td>35-55%</td>
</tr>
<tr>
<td>Non-statin:</td>
<td></td>
</tr>
<tr>
<td>1. Ezetimibe</td>
<td>18-25%</td>
</tr>
<tr>
<td>2. PCSK9 inhibitors</td>
<td>40-65% (above that achieved by statin therapy alone.)</td>
</tr>
<tr>
<td>3. Bile acid sequestrants</td>
<td>18-25%</td>
</tr>
<tr>
<td>Other options:</td>
<td></td>
</tr>
<tr>
<td>1. LDL apheresis</td>
<td>20-40%</td>
</tr>
<tr>
<td>2. Lomitapide for HoFH only</td>
<td>35-50%</td>
</tr>
</tbody>
</table>

Are there side effects to the medications?

• Some people who take statins will experience muscle aches but most people have other risk factors for diabetes. The benefit of statins for reducing heart attack and stroke risk outweighs the small increase of risk of diabetes. Regular physical activity and weight control also reduce the risk of diabetes.

Questions to Ask about Treatment:

Will these treatments work for me?

• Statins have been studied in clinical trials in 200,000+ people over 30 years and have been shown to be safe and effective in preventing cardiovascular disease.

• Large reductions in LDL-C result in large reductions in CV risk.

• All of these treatments have shown a benefit for both men and women.

• Women who are pregnant or breastfeeding should not take statins.

Reach a Decision With Your Patient

My Treatment Plan

Date: ____________________________ For the next _____ months

Diet goals: ____________________________ Exercise goals: ______________

Other risk factor goals: ____________________________

Medication: ________________ Medication: ________________ Medication: ________________

Dose Frequency Dose Frequency Dose Frequency

Lab test: ____ months Next appointment: ____ months

Evaluate Your Patient’s Decision

What do we hope to see?

• ____________________________

What might get in the way of achieving your goals and what can we do about that?

• ____________________________

Start small – each change you make adds up.

Decide Which Local Resources Will Effectively Support Your Patient and How To Connect

Connect with the FH Care Team

• Primary Care Physician: ____________________________

• Nurse Practitioner: ____________________________

• Registered Dietician: ____________________________

• Genetic Counselor: ____________________________

• Pharmacist: ____________________________

• Other Specialist Referrals: Pediatric Specialist, Cardiologist ____________________________

• Health Insurance Plan: ____________________________

This is how I connect with my FH Care Team.