

# What is FH?

# ...AND WHAT DO I DO ABOUT IT?



**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

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

FH is different. It's genetic.  
It's not your fault.  
Treatment can lower risk.

## **H** Help Your Patient Explore and Compare Treatment Options

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

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.

## **A** Assess Your Patient's Values and Preferences

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

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.

## **R** Reach a Decision With Your Patient

What would treatment look like 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.

## **E** Evaluate Your Patient's Decision

What if I have challenges in sticking to my goals?

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

## **D** Decide Which Local Resources Will Effectively Support the Patient and How To Connect

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

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

\* Note. Adapted from "The SHARE Approach," by the Agency for Healthcare Research and Quality, Content last reviewed August 2018. Retrieved from <http://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html>

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# Shared Decision Making for Familial Hypercholesterolemia

## S

### Seek Your Patient's Participation

#### Why Does FH Diagnosis and Management Matter?

- 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.
- Protect your family. If you have FH, each of your children has a 50% chance of also having it. Get them screened to find out.

## H

### Help Your Patient Explore and Compare Treatment Options

#### What can you do to lower your LDL-C? FH Management

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.

Treatment:	Approximate LDL-C Lowering Effect:
Heart Healthy Diet and Regular Exercise .....	↓10-15%
Statins: First line treatment. Safe and effective. ....	↓35-55%
Non-statins:	
• Ezetimibe .....	↓18-25%
• PCSK9 inhibitors .....	↓40-65% (above that achieved by statin therapy alone)
• Bile acid sequestrants .....	↓18-25%
Other options:	
• LDL apheresis .....	↓20-40%
• Lomitapide for HoFH only .....	↓35-50%

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

\*Hegele RA, Gidding SS, Ginsberg HN, McPherson R, Rader DJ, Robinson JG, Welty FK. Nonstatin Low-Density Lipoprotein-Lowering and Cardiovascular Risk Reduction—Statement from ATVB Council. Arterioscler Thromb Vasc Biol. 2015; 35:2269-2280. DOI: 10.1161/ATVBAHA.115.306442.

Let's take a look at the treatment options that are best for you



## A

### Assess Your Patient's Values and Preferences

#### 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.

*Are there side effects to the medications?*

- Some people who take statins will experience muscle aches but most muscle symptoms are not related to statin therapy. Stopping and retrying statins can help determine if symptoms are related to treatment. If you experience rhabdomyolysis symptoms (muscle pain or weakness, or dark/decreased urination), a very rare side effect, stop your statin and call me right away.
- There are seven statins available. Usually you can find one that works for you without side effects.
- There is a small increased risk for diabetes with statins in people who have other risk factors for diabetes. The benefit of statins for reducing heart attack and stroke risk outweighs the small increase in risk of diabetes. Regular physical activity and weight control also reduce the risk of diabetes.

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# Shared Decision Making for Familial Hypercholesterolemia

## R 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

## E 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.*

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

### Connect 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



Connect with the FH Foundation for Support and Education  
[www.theFHFoundation.org](http://www.theFHFoundation.org)

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