

FAMILIAL HYPERCHOLESTEROLEMIA (FH):

Shared Decision-Making Resource for Providers & Patients

In shared decision-making, healthcare providers and patients work together to make the best possible healthcare decisions. These decisions consider evidence about available options, the clinician's experience, and the patient's values and preferences. There is evidence that shared decision-making contributes to improvements in health. This resource is a guide for healthcare providers and patients to engage in shared decision-making about FH treatment using the SHARED approach.

STEPS OF SHARED DECISION MAKING

SAMPLE TALKING POINTS

S

Seek Your Patient's Participation

Why do I have high cholesterol? Aren't I too young?

You have FH (familial hypercholesterolemia). People with FH are born with very high levels of cholesterol. It is a genetic condition, which means one or both parents passed it to you.

H

Help Your Patient Explore and Compare Treatment Options



If you treat FH to lower your cholesterol to a healthy level, you can lower your risk for early heart attack. What have you heard about treatment for high cholesterol?

I've heard that statins are taken for high cholesterol.

A

Assess Your Patient's Values and Preferences

Ok, that sounds good. But what happens if I forget to take my pills or if I'm too tired to exercise?

Yes, taking a daily statin is a safe and effective way to lower high cholesterol. Also, regular exercise and a heart-healthy diet are very important in lowering your cholesterol. Let's create a realistic plan for these treatment goals.

R

Reach A Decision with Your Patient



Let's discuss these challenges and ways to address them. I will also check in with you after today to see how you are doing and whether we need to adjust the plan to better work for you.

E

Evaluate Your Patient's Decision

What resources are available to help me?

Your care team includes me, a cholesterol specialist, a dietitian, and a pharmacist. We can all help you. There is also an organization called the Family Heart Foundation that provides information to people with FH.

D

Decide Which Resources Can Support the Patient



Find this resource online at <http://bit.do/shareddecisions>.



FH Treatment Shared Decision-Making Guide



Step 1: Seek Your Patient's Participation

Many patients are unaware that they can and should participate in their health care decision-making. Communicate that a choice exists and invite your patient to participate in the process.

Summarize the health problem:

- “FH is an inherited condition, meaning one or more parents passed down FH to you. People with FH are born with dangerously high levels of LDL cholesterol.”
- “Your LDL cholesterol will remain very high without treatment. A person with FH can have a heart attack as early as in their 40s or younger.”

Invite your patient to be involved in decisions. Invite your patient to ask questions and discuss options with you.

- “What questions do you have about FH?”
- “High LDL cholesterol can be lowered with a combination of medicine, lifestyle changes, and other therapy. I'd like to discuss these treatment options with you. Then, we can decide together what may be best for you.”



Step 2: Help Your Patient Explore and Compare Treatment Options

Discussing options with your patient can help you build a trusting relationship.

Assess what your patient already knows about his or her options.

- “What have you heard about treating FH or high cholesterol?”

Explain each option clearly, using plain language. Avoid using technical or medical jargon. Point out when there are clear differences between specific options.

- “A healthy diet, regular exercise, a healthy weight and not smoking are important steps to control high cholesterol.”
- “Many people with FH also need to take one or several medicines to lower their cholesterol levels.”
- “Statins are the most common medications used to lower LDL cholesterol. Your doctor may also recommend other medications.”

Some resources include:

- Family Heart Foundation “FH Treatments”: <https://familyheart.org/fh-treatments>
- Foundation of the National Lipid Association: <https://www.learnyourlipids.com/lipid-disorders/familial-hypercholesterolemia>
- National Lipid Association Clinician's Lifestyle Modification Toolbox: <https://www.lipid.org/clmt>

Talking points are provided in the accompanying patient handout, **“Living with FH” (page 5 of this document)**.

FH Treatment Shared Decision-Making Guide

A

Step 3: Assess Your Patient's Values and Preferences

Encourage your patient to talk about what is important to him or her regarding the options. Use open-ended questions and listen actively to your patient.

- "What are the benefits of treating FH for you?" "What are the disadvantages?" "Do the benefits outweigh the disadvantages?"
- "Which lifestyle and treatment goals are achievable for you?"
- "What worries you the most about FH treatment?"

Acknowledge the values and preferences that matter to your patient. Paraphrase what you have heard from your patient. This signals to your patient you are listening to his or her perspective.

R

Step 4: Reach a Decision With Your Patient

Ask if he or she is ready to make a decision or if they have any additional questions. Follow up with your patient if they request more time to consider the options.

- "Now that we discussed your treatment options, which treatment do you think is right for you?"
- "What additional questions do you have about your treatment options?"

The decisions can be documented in the accompanying **"FH Treatment Planning Worksheet" (page 4 of this document).**

E

Step 5: Evaluate Your Patient's Decision

Make plans to review the decision in the future. Remind your patient that decisions may be reviewed and some can be changed if they are not working well for your patient.

- "We will check your cholesterol levels to see how well the treatment is working."
- "Side effects are uncommon, but if you do have any, we can try a different medicine or change the dose (amount) you are taking."

D

Step 6: Decide Which Local Resources Will Effectively Support the Patient

Share resources to support patients, including their cardiovascular care team (such as FH specialist, lipid (cholesterol) specialist, pharmacist, registered dietitian). Give contact information for each resource. The Family Heart Foundation maintains a directory of FH specialists:

<https://familyheart.org/find-specialist>.

References

- [The SHARE Approach](#). Content last reviewed October 2020. Agency for Healthcare Research and Quality, Rockville, MD.
- Hegele RA, Gidding SS, Ginsberg HN, et al. [Nonstatin low-density lipoprotein-lowering therapy and cardiovascular risk reduction-Statement from ATVB Council](#). *Arterioscler Thromb Vasc Biol*. 2015 Nov;35(11):2269-80.
- Wang A, Richhariya A, Gandra SR, et al. [Systematic review of low-density lipoprotein cholesterol apheresis for the treatment of familial hypercholesterolemia](#). *J Am Heart Assoc*. 2016;5(7):e003294.

FH Treatment Planning Worksheet



Visit date: _____

What treatment goals are achievable for you?

Reason for treatment/Treatment goals		
Reduce LDL cholesterol to: <input type="checkbox"/> Below 100 mg/dL (for people who do not have heart disease) <input type="checkbox"/> Below 70 mg/dL (for people who already have heart disease)		
Heart-healthy diet goals		Exercise goals
Medication regimen		
Name:	Dose (amount):	Frequency:
Name:	Dose (amount):	Frequency:
Name:	Dose (amount):	Frequency:
Treatment adherence concerns:		Treatment adherence strategies:

Lab Results

Date	Lab Results					Medication Changes
	Total cholesterol	HDL-C	Non-HDL-C	LDL-C	TG	
	<i>Desirable values</i>					

HDL-C= high-density lipoprotein cholesterol; Non-HDL-C = non-high-density lipoprotein cholesterol;
LDL-C= low-density lipoprotein cholesterol; TG = triglyceride

My Cardiovascular Care Team

Provider	Contact Info	Provider	Contact Info
Primary care provider		Registered dietitian	
Cholesterol specialist		Pharmacist	
Other specialist		Health insurance plan	

Living with FH (Familial Hypercholesterolemia)



What is FH?

FH is an inherited condition passed down from one or both parents. A person with FH is born with dangerously high levels of LDL cholesterol.

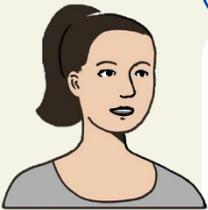


LDL cholesterol level (mg/dL)

Person with FH	190 or above
Healthy level	100 or below

High levels of LDL cholesterol can increase risk for heart attack and stroke. People with FH are more likely to have early heart attack.

How can I lower my risk for early heart attack?



Risk of heart attack and heart disease can be lowered by treating FH early. A combination of medicine, lifestyle changes and other therapy can lower LDL cholesterol to a healthy level.



Strategies to lower LDL cholesterol

 Lifestyle changes	Heart-healthy diet
	Maintaining a healthy weight
	Physical activity (2.5 hours of physical activity per week)
	No smoking
 Medicine	Statins, ezetimibe, bile acid sequestrants, PCSK9-inhibitors, bempedoic acid, inclisiran, lomitapide (HoFH only) and evinacumab (HoFH only)

If LDL cholesterol is not controlled with lifestyle changes and medicine, see a doctor who is a lipid (cholesterol) specialist. The lipid specialist may recommend other therapy, including a procedure to remove LDL cholesterol from the blood (lipoprotein apheresis).

Living with FH (Familial Hypercholesterolemia)



What is the treatment for FH?

There are several treatments for FH. Because people with FH have such high LDL cholesterol, more than one treatment is often needed.



Effect of different FH treatment types on LDL cholesterol:

Treatment type	Diet and exercise	Statins	Ezetimibe
Effect on LDL cholesterol	10 to 15% lower	35 to 55% lower	18 to 25% lower

Treatment type	PCSK9 inhibitors	Bile acid sequestrants	LDL apheresis
Effect on LDL cholesterol	40 to 65% lower	18 to 25% lower	22 to 48% lower*

*variable, discuss with provider

A person who has inherited FH from both parents – the rare and most severe form of FH, known as homozygous FH (HoFH) – can also be treated with lomitapide or evinacumab, which can reduce LDL cholesterol levels by 40 to 50%.



How does FH affect the family?

FH is a genetic disorder. There is a 50% chance that each child of a person with FH will inherit the condition. All children, siblings and parents of people with FH should have their cholesterol checked to see if they have FH. Genetic testing can also be very helpful for diagnosis and family screening.



Who can help me to manage my condition?

Your care team can help you. You can also learn more online:

- Family Heart Foundation (familyheart.org)
- Foundation of the National Lipid Association (learnyourlipids.com/lipid-disorders/familial-hypercholesterolemia)