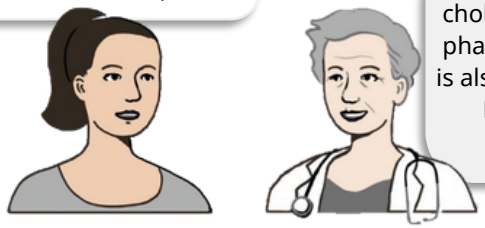
FAMILIAL HYPERCHOLESTEROLEMIA (FH):

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	1 Why do I have high cholesterol? Aren't I too young?
	2 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	3 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?
	4 I've heard that statins are taken for high cholesterol.
A Assess Your Patient's Values and Preferences	5 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.
	6 Ok, that sounds good. But what happens if I forget to take my pills or if I'm too tired to exercise?
R Reach a Decision With Your Patient	7 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	8 What resources are available to help me?
D Decide Which Resources Can Support Your Patient	9 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.



Find this resource and other guides at natforum.org/FH_Guide and natforum.org/Shared_Decision.

© 2026 National Forum for Heart Disease & Stroke Prevention

FOR PROVIDERS

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 healthcare 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 both 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 their 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.

- "Eating a healthy diet, exercising regularly, maintaining a healthy weight, and not smoking are important steps to control high cholesterol."
- "Most 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, such as PCSK9 targeted therapies."

Some resources include:

- Family Heart Foundation "FH Treatments," familyheart.org/fh-treatments
- Foundation of the National Lipid Association, learnyourlipids.com/lipid-disorders/familial-hypercholesterolemia

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

The Value & Access Collaborative facilitated by the National Forum for Heart Disease & Stroke Prevention developed this resource.

It was made possible by support from AstraZeneca, BMS-Pfizer Alliance, Novartis, and Regeneron.

© 2026 National Forum for Heart Disease & Stroke Prevention

FOR PROVIDERS

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 them 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 that you are listening to their perspective.

R

Step 4: Reach a Decision With Your Patient

Ask if they are 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 have 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 them.

- "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 Your Patient

Share resources to support your patient, including their cardiovascular care team, such as an FH specialist, lipid (cholesterol) specialist, pharmacist, and registered dietitian). Give contact information for each resource. The Family Heart Foundation maintains a directory of FH specialists: familyheart.org/find-specialist.

References

- The SHARE Approach. Content last reviewed February 2026. Agency for Healthcare Research and Quality, Rockville, MD. ahrq.gov/health-literacy/professional-training/shared-decision/index.html
- 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.

© 2026 National Forum for Heart Disease & Stroke Prevention

FOR PROVIDERS & PATIENTS

FH Treatment Planning Worksheet

Visit date: _____

Reason for treatment/Treatment goals		
Reduce LDL cholesterol to: ☐ Below 100 mg/dL (for people who do not have heart disease) ☐ 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:**	

Date	**Lab Results**						**Medication Changes**
	LDL-C	HDL-C	Non-HDL-C	Total cholesterol	TG	Lp(a)	
	Desirable values						

LDL-C = low-density lipoprotein cholesterol; HDL-C = high-density lipoprotein cholesterol; Non-HDL-C = non-high-density lipoprotein cholesterol; TG = triglyceride; Lp(a) = lipoprotein(a) cholesterol

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

© 2026 National Forum for Heart Disease & Stroke Prevention

FOR PATIENTS

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 levels (mg/dL)

Adults with FH	190 or above
Children with FH	160 or above

An LDL cholesterol level of 100 mg/dL or below is considered a healthy level for a person without cardiovascular risk. For people with a high risk of heart attack or stroke, the goal level may be 70 mg/dL or even 55 mg/dL.

High levels of LDL cholesterol can increase the risk of heart attack and stroke.

People with FH are more likely to have an 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	Eat a heart-healthy diet
	Maintain a healthy weight
	Get 2.5 hours of physical activity per week
	Do not smoke, vape, or use tobacco
Medicine	Statins, ezetimibe 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).

© 2026 National Forum for Heart Disease & Stroke Prevention

FOR PATIENTS

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

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%.

Treatment	Type	Can lower LDL cholesterol
Ezetimibe	Pill taken daily	18 to 25%
Evolocumab	Self-administered injection 1-2 times a month	55 to 71%
Alirocumab	Self-administered injection 1-2 times a month	48 to 58%
Bempedoic acid	Pill taken daily	15 to 25%
Inclisiran	Injection by a healthcare provider every 6 months (after starter shots)	48 to 52%
Enclicitide	Pill taken daily	56 to 59%

Citations: 1. Repatha® (evoloucmab) Prescribing Information, Amgen. 2. Praluent (alirocumab) Prescribing Information, Regeneron.3. Leqvio® (inclisiran) Prescribing Information, Novartis. 4. Lipfendra®(enlicitide), Prescribing Information, Merck.

Lp(a) Levels	
Classification	**Level (nmol/L)**
Low	<75
Moderate	75-124
High	125-250
Very High	≥250

Reference: American Heart Association. (2026). What is lipoprotein(a)? American Heart Association

Target LDL-C Levels	
Risk of Cardiovascular Events	**Target LDL-C Level**
Very High	<55 mg/dL
High	≤70 mg/dL
Low	100 mg/dL

Reference: Family Heart Foundation. (2026). Know your LDL Safe Zone. Family Heart Foundation

© 2026 National Forum for Heart Disease & Stroke Prevention

How does FH affect the family?

FH is a genetic disorder. Each child of a person with FH has a 50% chance of having it. Family members, including siblings, children, and parents, should have their cholesterol checked. Genetic testing can also help find FH in families. Children should have their cholesterol checked between ages 9 and 11 to see if they have high cholesterol early. Children as young as 2 may need testing if high cholesterol or early heart disease runs in the family. Healthy lifestyle habits should start early, and even children may also need medicine.

Who can help me manage my condition?

Your care team can help you. Learn more online:

- Family Heart Foundation, familyheart.org
- Foundation of the National Lipid Association, learnyourlipids.com/lipid-disorders/familial-hypercholesterolemia
- Preventive Cardiovascular Nurses Association, pcna.net/resource/what-is-homozygous-familial-hypercholesterolemia-fact-sheet

Find this resource and other guides at natforum.org/FH_Guide and natforum.org/Shared_Decision

© 2026 National Forum for Heart Disease & Stroke Prevention