

Familial hypercholesterolemia

Talking with children about family heart disease

Answers to commonly asked questions | Info sheet

If you have **familial hypercholesterolemia (FH)**, there will come a time when you'll need to talk with your children about it - if you haven't already.

But when is the right time, and how can you help them understand what having FH might mean for their health and future? When should you think about having children tested to know whether or not they carry the same gene variant? What will you do with the information once you have it?



If you're like most parents, you probably have a lot of questions. Use this handout to find answers to some common questions and learn more. The good news is that FH can be treated.

Familial-what? Familial hypercholesterolemia (FH) is a mouthful. So how can you best explain it to your child or children?

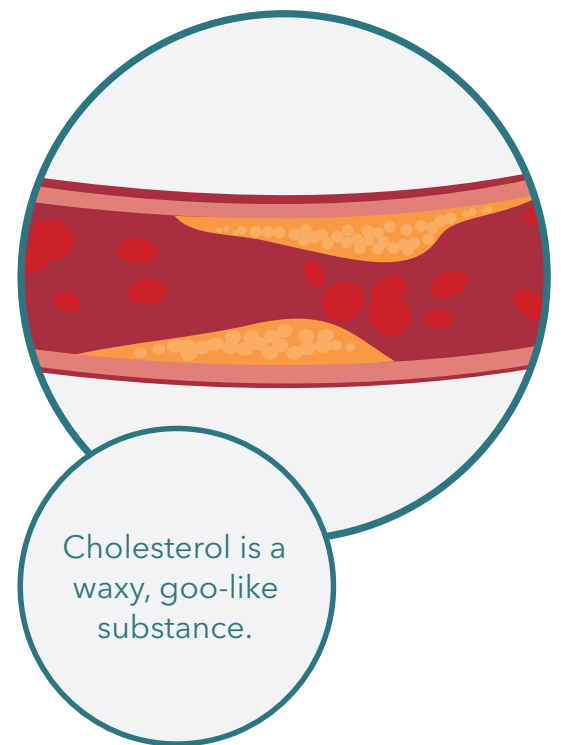
Very simply, FH is a condition you're born with. It is passed down in families through our genes. With FH, you have high levels of "bad" cholesterol or low-density lipoprotein (LDL) cholesterol. As a result, FH makes heart disease more likely, and at much younger ages.

Of course, the words you choose to use and how much detail you go into will depend on your child's:

- Age
- Readiness to know about the condition

It can be helpful to let your child lead the conversation. Start by introducing the idea of FH broadly. Doing so will help you decide what level of information your child or children are ready for.

Let them ask the questions and start with simple answers. For younger kids, cholesterol can be described as a waxy, goo-like substance. You'll find some sample language to use as a guide on Page 6.



How is FH treated in children?

Treatment depends on the type of FH a child has, HeFH or HoFH. In general, children with FH should be started on a statin between the ages of 8 and 10. Other medication to lower cholesterol may be added if levels aren't within a target range.

Although exercise and diet alone aren't enough to lower LDL cholesterol and reduce the health risks that come with FH, staying active and making healthy choices are important. Being healthy overall can also help prevent other types of heart disease, diabetes and some cancers.

If my child ends up having FH, do they really need medicine or can we wait?

FH is often a "silent" disease in children. They usually won't have any symptoms.

Still, they may have dangerously high levels of LDL cholesterol in the bloodstream. This can set the stage for heart disease - even heart attacks or strokes - at a very early age. The sooner children with FH can start taking medication to help lower LDL cholesterol, the better.



Some people may opt to try to reduce their LDL cholesterol by changing their diet and lifestyle. While this is important to stay healthy and manage other health conditions, for people with FH, this is not enough to get their LDL cholesterol to a healthy range.

Before getting your child tested



It's important to think through what steps you are willing to take if your child is found to have the FH

gene. Most parents are happy to have their children tested for FH. But many are hesitant for their child to start on a drug to lower cholesterol at such a young age. This is most often due to concerns over side effects.

Remember, these medications are being used to lower LDL cholesterol and, most important, a child's chance of developing heart disease, heart attack and stroke early in life. Side effects are rare. If side effects do happen, several medications can be tried. Keep an open conversation going with your child's doctor.

When is the right time to talk with kids about it?

How and when to talk with children about FH being in your family is a very personal choice. Many genetic counselors suggest talking to children about FH by the time they are 8 to 10 years old. Use general and simple terms. This is also the age when treatment should ideally start.

Other opportunities to talk about FH are when it might affect decisions about their health or their activities. For example, if they need blood tests to check their cholesterol more often or echocardiograms, a test that takes moving pictures of the heart, before playing sports or because it was recommended by their doctor.



If your child has homozygous FH (that means both parents have FH), the earlier you can talk with them the better. That's because related heart problems can happen at a very early age. Finding out if they have the condition and beginning treatment as soon as possible is important.

How likely is it that my child will get FH?

If you have FH, there is a 50% chance that each child you have will have FH, and a 50% chance he or she will not (like a flip of a coin). If both parents have FH, then the chance of passing it along is a little more complicated. In this case, for each child there is a:

- 50% chance of having heterozygous FH, or HeFH, getting 1 FH gene from a parent
- 25% risk of homozygous FH, or HoFH, getting 2 FH genes - one from each parent
- 25% chance the child will inherit a normal gene from each parent

A genetic counselor can be a helpful resource. Genetic counselors will review your family's history of heart disease and explain the risks and benefits of genetic testing. Genetic testing is the only way to confirm if someone has inherited FH. To find a counselor near you, visit FindaGeneticCounselor.nsgc.org.

Why is FH a concern for kids?

While children with FH may seem healthy, their LDL cholesterol can spike early on. It's also important to remember that the high LDL cholesterol caused by FH is very different from high cholesterol that is common in older age or because of lifestyle choices.

With FH:

- High cholesterol levels can start from birth because the body isn't able to get rid of extra LDL cholesterol.
- The chance of developing heart disease or having a heart attack or stroke occurs at much younger ages.

Why would I want to do genetic testing for my child? What's the difference between genetic testing and cholesterol testing?

Genetic testing is done with a simple blood or saliva test to see if your child carries the same gene variant as you. It's helpful to know if a child has FH because you can step up efforts to lower cholesterol and help prevent heart disease.

Cholesterol testing (sometimes called **cholesterol screening** or **lipid test**) involves taking a sample of blood to check cholesterol levels. Cholesterol levels are rechecked over time.

Experts recommend that all children have their cholesterol checked between ages 9 and 11. Lipid testing should be done at a younger age if a child has a parent, sister or brother with FH, or if there is a family history of early heart disease.

So **genetic testing and blood cholesterol tests give you different, but important information:**

- A genetic test can tell you whether or not a child has the gene variant that runs in your family, which can cause FH.
- A cholesterol or lipid test can show levels of LDL and other types of cholesterol. These tests are helpful over time to see patterns and find out if treatments are working or if more needs to be done to manage their cholesterol.

Clinicians will usually recommend checking a child's cholesterol first. If LDL cholesterol is high, genetic testing is often the next step.



FH is a lifelong condition. While it won't go away, you can take steps to lower LDL cholesterol and reduce the risk of heart disease - or even prevent it. With treatment, many individuals with FH never develop heart disease.

When should a child's cholesterol be checked?



- As early as age 2 if there is a strong family history of FH or heart disease, heart attack or strokes at younger ages (before age 55 for males and 65 for females)
- All kids should have a lipid test:
 - » Between ages 9 and 11
 - » Again between ages 17 and 21

Source: 2018 Cholesterol Guidelines

What's the best way to get genetic testing?

Talk with your child's doctor (pediatrician), heart doctor (cardiologist) or lipid (cholesterol) specialist and ask to speak with a genetic counselor.

Genetic counselors will review your family's health history and can provide more background information on the risks, benefits, and limitations of testing. You might also talk about concerns of potential discrimination, especially in getting life insurance, long-term care or disability insurance.

Are there any downsides to genetic testing?

In most cases, knowing whether or not your child carries the FH gene is a good thing so that they can take steps to prevent heart disease.

In some cases, testing positive for the FH gene - or any other genetic condition for that matter - may make it harder for them to get life insurance or long-term care or disability insurance later in life.

There are laws to protect people, but they don't cover everything. Talk with a genetic counselor so that you can make the best decision. Depending on your children's ages, a genetic counselor may say it's OK to hold off on getting a genetic test as long as they have regular blood tests to check their cholesterol.

What does it feel like to have FH?



In most cases, there are no symptoms. In fact, for many people who don't know they have FH, a heart attack may be the first sign.

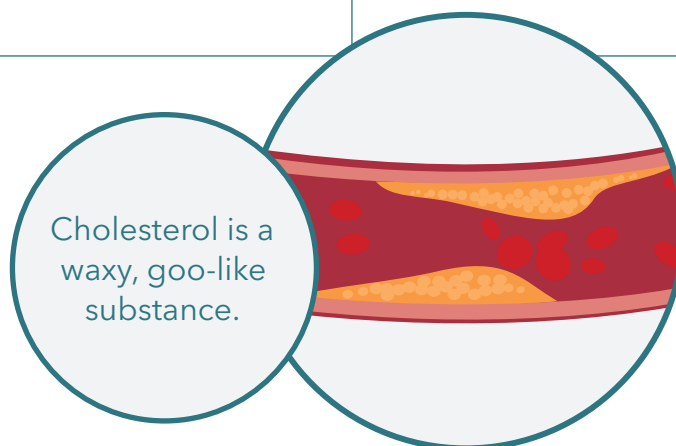
How will having FH affect my child's ability to take part in sports or activities?

Having FH shouldn't affect your child taking part in sports or other activities. If anything, it's even more important for your child to be active to prevent other health conditions and stay strong.

Helpful language to explain FH

You know your child best, but here are some suggestions to help you describe FH and explain genetic testing to your children, depending on their ages.

 Elementary, middle school age	 High school, young adult
<p>You share many of the same traits as us [mom/dad/birth parent].</p> <p>For example, the color of your hair and eyes. Inside our bodies, we have cells that do certain things. For example, these cells tell our bodies how to grow and heal. Sometimes these cells don't do work as well as they should.</p> <p>I [mom/dad/birth parent] have something called high cholesterol. Cholesterol is a waxy, goo-like substance. Our bodies make cholesterol (like our bodies make saliva or tears), but we also get some of it from food.</p> <p>I [mom/dad/birth parent] have high cholesterol because my body can't get rid of it. That means I have to be careful about the foods I eat, exercise more and take medicines.</p> <p>We need to see if you got high cholesterol from [mom/dad/birth parent] too so that you can take a medicine to help keep you healthy.</p>	<p>Even though you are healthy now, we need to talk with you about how to stay healthy and prevent heart disease based on our family history.</p> <p>[Mom/dad/birth parent] was born with a change in a gene that can cause high amounts of LDL cholesterol in the bloodstream. Think of the change as a typo because the gene no longer works as it should. LDL cholesterol – or the “bad” cholesterol – can build up in the walls of your blood vessels.</p> <p>We need to know if you have the same FH gene, so you can start treatment.</p> <p>Without treatment, LDL cholesterol can narrow or block the blood vessels, which can lead to heart disease, a heart attack or stroke at very early ages.</p> <p>The good news is that there are medicines and ways to help us – and you if you have the gene – stay healthy and protect our hearts.</p>



More information

Find these tools and more at CardioSmart.org/FH.



[Familial Hypercholesterolemia: Making Sense of Family Heart Disease](#)



[Homozygous Familial Hypercholesterolemia](#)

Other resources:

National Society of Genetic Counselors - Find a Genetic Counselor

<https://findageneticcounselor.nsgc.org/>

NIH's National Human Genome Research Institute - Genetic Discrimination

<https://www.genome.gov/about-genomics/policy-issues/Genetic-Discrimination>