Living with elevated lipoprotein(a)

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All you need to know if you suspect you have, or have recently been diagnosed with elevated lipoprotein(a)

Begin

The content has been created by FH Europe and people with elevated lipoprotein(a), and reviewed by renowned international medical experts.

This brochure has been brought to you by FH Europe, The European FH Patient Network, in collaboration with Novartis Pharma

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The European FH Patient Network

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Contents

What is lipoprotein(a)?

Lipoproteins are particles made of proteins to which lipids (fat) molecules are attached. Their role is to carry **cholesterol and other lipids** through your bloodstream and around your body.

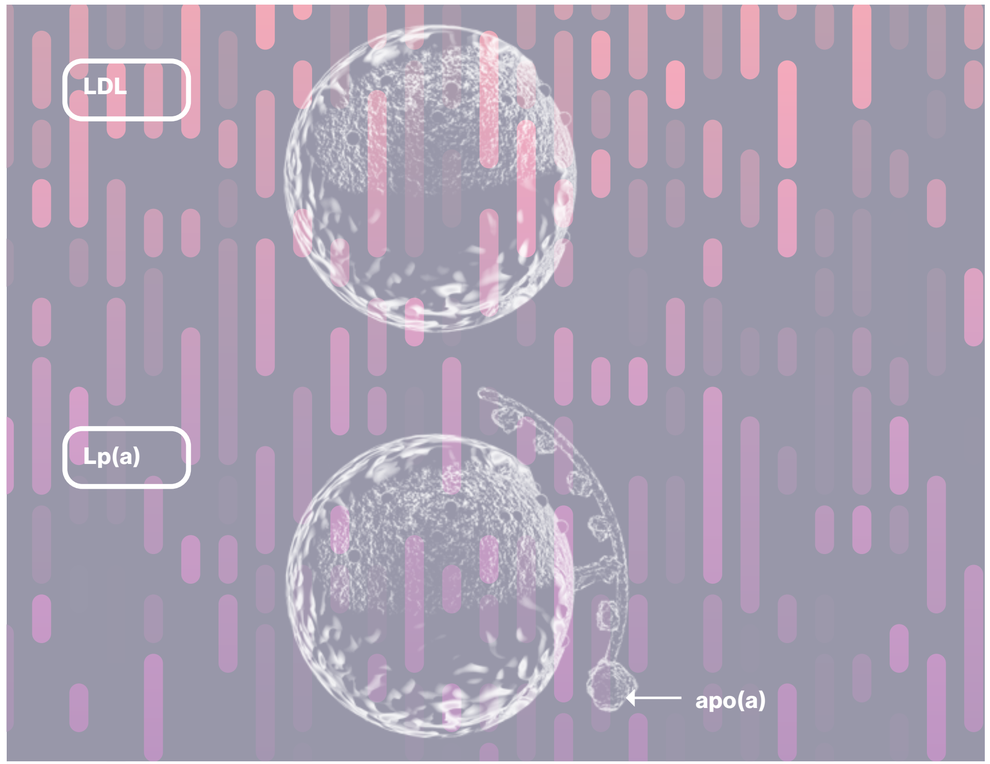
They exist in several forms, including:

- **High-density lipoprotein**, in short HDL, referred to as "good" cholesterol
- **Low-density lipoprotein**, in short LDL, referred to as "bad" cholesterol
- **Remnant lipoprotein**, in short remnants, referred to as "ugly" cholesterol
- **Lipoprotein(a)**, in short **Lp(a)**, referred to as "genetic" lipoprotein

Pronounced "lipoprotein little a" or "L-P-little-a", lipoprotein(a) is often shortened to Lp(a). An excess amount of these particles in your body can cause health problems.

Lp(a) is a low-density lipoprotein (LDL)-like particle with an added second protein, apo(a), which acts similarly to a patch of "velcro" on an LDL particle. It is considered a very "sticky" lipoprotein particle because of the function of the added protein.

Graphical image represents an LDL particle and Lp(a) particle



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Lp(a) – How do the levels increase in the blood?

Your Lp(a) level is generally between 80-90% **genetically determined**. Elevated Lp(a) is an independent cardiovascular disease risk factor. There is a greater chance of inheriting this risk factor if one of your parents also has or had elevated Lp(a). Both male and female populations are equally likely to have the genetic make-up that determine elevated levels of Lp(a).

By the age of 5, you reach your lifetime level of circulating Lp(a). This level remains generally stable through your lifetime, regardless of lifestyle. Lp(a) levels in women can increase slightly after menopause, due to declining oestrogen levels.

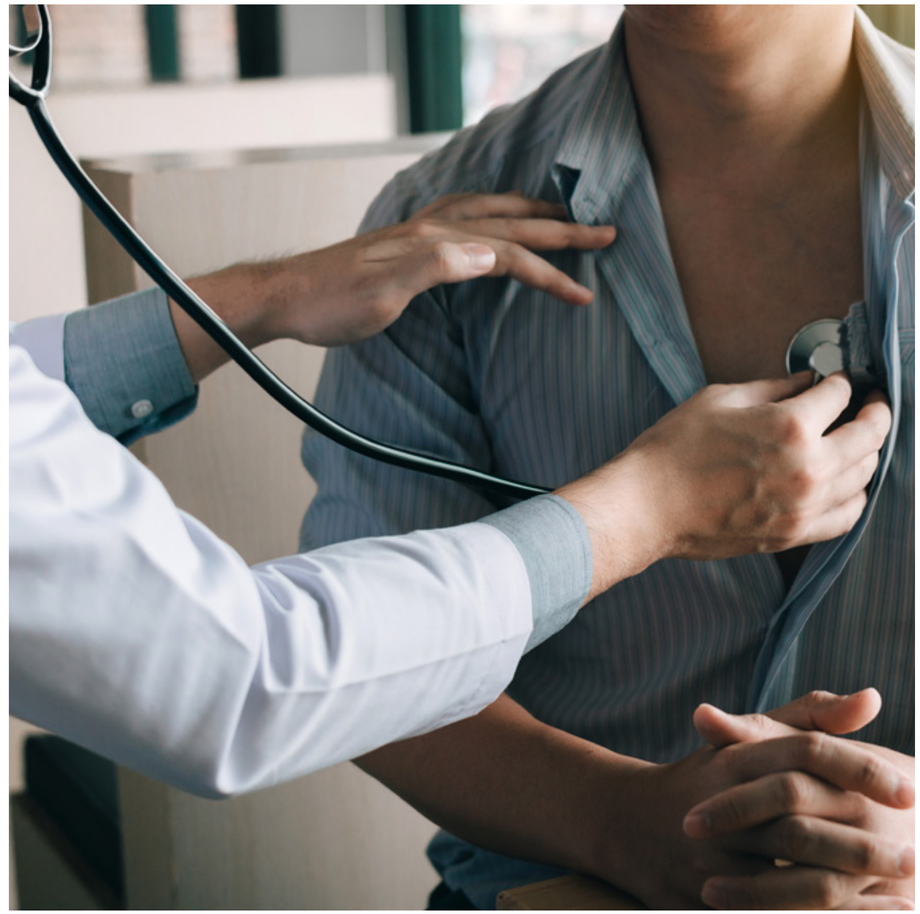
Did you know...
It is estimated that 1 in 5 people worldwide have elevated Lp(a) levels

Lp(a) - A cardiovascular disease risk factor

While most people know that elevated levels of low-density lipoprotein (LDL), or “bad” cholesterol, can cause heart disease, relatively few people know about the risk posed by Lp(a). Elevated levels of Lp(a) have been identified as a risk factor that contributes to **cardiovascular disease**.

Elevated Lp(a) is a risk factor, not a disease. Nevertheless, it should be detected as early as possible to help prevent cardiovascular disease.

Cardiovascular disease
This is a general term for a condition that affects the heart or blood vessels. It is usually associated with a build-up of fatty deposits inside the arteries. This process is called atherosclerosis. Generally there aren’t any symptoms to indicate elevated levels of Lp(a) before cardiovascular disease develops.



Lp(a) - A cardiovascular disease risk factor

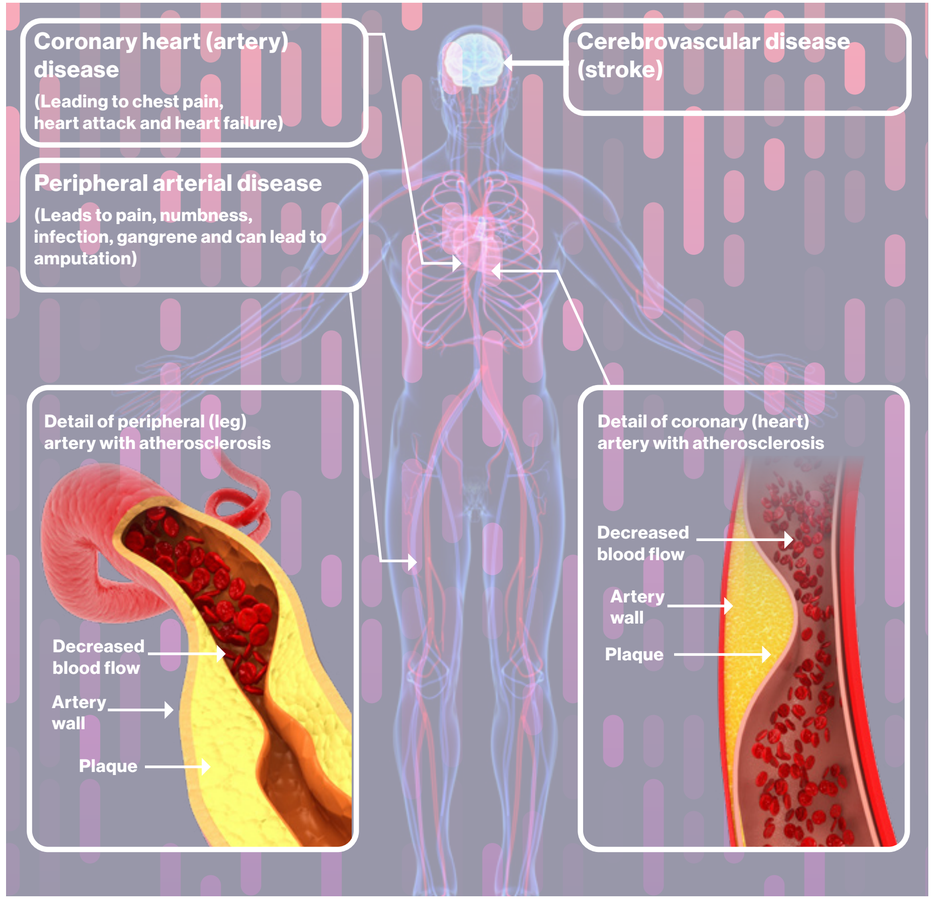
Atherosclerotic plaques cause arterial blood vessels to harden and narrow, restricting the blood flow and oxygen supply to vital organs, and increase the risk of arterial blood clots forming. These blood clots can block the flow of blood causing cardiovascular disease, such as heart attacks, heart failure, peripheral artery disease or stroke.

Many people may be unaware that they have atherosclerosis, as there may not be symptoms, but it can eventually cause life-threatening problems.
It's very important to be aware of cardiovascular disease risk factors and how to manage them, to reduce the risk of cardiovascular disease development.

People with elevated Lp(a) and atherosclerosis may have an increased risk of heart attack, heart failure, peripheral artery disease and stroke, compared to people with low Lp(a) levels. Elevated Lp(a) levels may also be associated with an increased risk of aortic valve stenosis (narrowing of the valve allowing blood to come from the heart into the aorta).

Did you know...
An estimated 17.9 million people worldwide died from cardiovascular diseases in 2019, representing 32% of all global deaths. Of these deaths, 85% were due to heart attacks and strokes

Graphical image represents atherosclerotic plaques and the consequence they may have in the heart, brain and periphery



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Why you should arrange a test

Most people with elevated levels of Lp(a) experience no symptoms and have no idea that they are affected. You will not be aware you have elevated Lp(a) unless it is specifically tested. Lp(a) levels are currently not routinely screened in general practice and standard cholesterol tests do not look for Lp(a). Therefore, it may go undetected for many years, if ever.

One or more of the following occurrences should trigger Lp(a) testing, as recommended by different international scientific guidelines:

- You experienced a **heart attack** or **stroke**
- **Your family member(s)/blood relative(s) suffered from a premature heart attack or stroke** (for men it would be younger than 55 years of age, for women less than 65 years of age)
- You have a family history of elevated Lp(a) – **a direct blood relative being diagnosed**
- You have **familial hypercholesterolemia (FH)** – meaning inherited high cholesterol
- You have **aortic valve stenosis**
- You have suffered **recurrent heart attacks despite lipid lowering treatment** (statins)

It is important that you act ...
If any of the scenarios listed resemble your case, you should consult your doctor and request a test for Lp(a). Be sure to enquire if such tests are offered by your health system or covered by your health insurance. In some cases, tests might be an out-of-pocket expense. Nevertheless, we strongly believe having a correct diagnosis can help you prevent serious health issues

In addition, several international guidelines advise that everybody at risk of cardiovascular disease should have their Lp(a) levels measured once in a life-time due to the genetic nature of elevated Lp(a).

Testing for Lp(a)

Getting a test for Lp(a) is a simple process. A health care professional will take a blood sample from a vein in your arm. You don't need any preparation for the test or need to fast before an Lp(a) test.

Certain situations and factors can affect the accuracy of your test results. You should not get an Lp(a) test if any of the below are relevant:

- Fever
- Infection
- Recent and considerable weight loss
- Pregnancy
- Large wound/injury

The test results:
Elevated Lp(a) is generally defined as levels higher than 50 mg/dL (500 mg/L) or 120 nmol/L. Depending on the laboratory, they can use one system or the other to analyse Lp(a) and express the result in either mg/dL or nmol/L.

Elevated Lp(a) and how to reduce the cardiovascular risk

It's important to be aware of an elevated Lp(a) level.

Did you know...
European clinical practice guidelines also recommend Lp(a) testing in people who are already between a moderate and high cardiovascular risk. Knowledge of Lp(a) levels can improve patient risk reclassification by clinicians and help determine appropriate treatment strategies

You should discuss the situation with your doctor and agree on the next steps. This could result in being referred to a specialist, such as a cardiologist or a lipidologist.

The earlier elevated Lp(a) levels are diagnosed (e.g. in childhood, for children of diagnosed adults), the earlier you can make positive lifestyle choices to reduce the risk.

In some countries, for severe cases, lipoprotein apheresis is available (which can reduce Lp(a) levels by up to 75% temporarily, by removing Lp(a) particles from your blood). Lipoprotein apheresis is a weekly/fortnightly treatment similar to renal dialysis.

There are several Lp(a) medications that are now being tested in clinical trials.

Elevated Lp(a) and your well-being

Remember you are not alone once you are diagnosed with elevated Lp(a). New management and treatments are being researched and developed. Your health care professional will evaluate this on your behalf.
Talk with them if you are worried at all.

In the meantime, you can ask your doctor for advice from a specialist experienced in Lp(a). You can also connect with a patient group that offers additional information and peer support.

For more information visit:

www.fheurope.org

Elevated Lp(a) and your well-being

After diagnosis it is possible to experience feelings of anxiety as you come to terms with the reality of living with a higher risk of cardiovascular disease. This is natural, and it is important to develop coping strategies or seek help to support positive mental health.

Based on our experience we wanted to share some tips to get you through it:

1. **Become an expert on elevated Lp(a)**
   - Learn as much as possible about elevated Lp(a) and what you can do to reduce the risk of cardiovascular disease
   - Keep note of test results, such as cholesterol tests and blood pressure readings
   - Apps are available to keep track of cardiovascular risk factors
   - Talk to someone with elevated Lp(a) – shared experiences can be helpful
   - Patient groups provide up-to-date information and valuable support

Elevated Lp(a) and your well-being

2. Make positive lifestyle choices

- Make the necessary changes to reduce and control other cardiovascular risk factors
- Follow recommendations and specific expert advice on modifying lifestyle factors that can impact your cardiovascular health
- You might be given medication to manage other risk factors for cardiovascular disease such as high cholesterol and blood pressure, and raised blood glucose. It is important to take these as directed

How to reduce other cardiovascular disease risks by making positive lifestyle changes:

- Choose a healthy diet, high in 'good' fats, such as nuts, fish, avocado and olive oil (a Mediterranean type of diet can be a good option). Eat plenty of vegetables and wholegrains and limit other types of fat and sugar
- Aim for 30 minutes of moderate to vigorous physical activity every day
- Avoid smoking and drinking excessive amounts of alcohol. Your doctor can discuss options with you if you need help
- Reduce the risk of obesity. Your doctor can provide support and information on achieving and maintaining a healthy weight

Elevated Lp(a) and your well-being

3. Take care of your mental health

The diagnosis may change your perception of yourself and leave you feeling anxious about the future. The fact that there is currently no approved treatment for elevated Lp(a) can leave you feeling exposed and vulnerable. It is important to develop coping strategies for positive mental health and to focus on the fact that many of the other risk factors associated with cardiovascular disease can be managed, to a greater or lesser extent.

Taking an active role in positive lifestyle changes can allow you to feel more positive and in control. If negative feelings are becoming difficult to cope with, it is important to ask for help, including seeking advice from a medical professional.

There is a large range of coping techniques, such as:

- Relaxation techniques
- Breathing exercises
- Meditation and mindfulness
- Cognitive behavioural therapy
- Counselling
- Being open and honest with your family and friends about how you are feeling

“Knowledge, lifestyle and positivity will help you manage the Lp(a) challenge.”

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The content has been created by FH Europe and people with elevated lipoprotein(a), and reviewed by renowned international medical experts.

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For transparency they have collaborated with some private companies:

- Prof. André Miserez M.D., Director, Diagene Research Institute, Reinach, Switzerland. For the last two years, he got contributions for research projects from Amgen and Sanofi
- Prof. Elisabeth Steinhagen-Thiessen M.D., Senior Professor in Charité - Universitätsmedizin Berlin, Berlin, Germany. She has received speaker fees, funds for research projects and consulting work from the following companies in the past five years: Fresenius Medical Care, Daiichi-Sankyo, Novartis, Sanofi and Amgen
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