

Patient education: Hemochromatosis (The Basics)

[Written by the doctors and editors at UpToDate](#)

What is hemochromatosis? — Hemochromatosis is a condition that can cause too much iron to build up in the body. This can lead to problems, such as liver damage, joint pain, and weakness.

Hemochromatosis is caused by abnormal genes and can run in families. If your parent, brother, sister, or child has hemochromatosis, ask your doctor or nurse about getting tested for it.

Most people find out they have hemochromatosis after a routine blood test or after being tested because a family member has it.

What are the symptoms of hemochromatosis? — Many people find out they have hemochromatosis before they have any symptoms.

If people do have symptoms before they are diagnosed, the symptoms can include:

- An increase in the size of the liver ([figure 1](#))
- Feeling weak or tired
- Changes in the color of the skin that make it look darker
- Joint pain

If hemochromatosis is not treated, it can lead to long-term problems that include:

- High sugar levels in the blood (diabetes mellitus)
- Trouble getting or keeping an erection (in men)
- Absent or irregular monthly periods (in women)
- Heart, thyroid, or liver problems

Is there a test for hemochromatosis? — Yes. Your doctor or nurse can do different blood tests to check the iron level in your blood. Based on the results, your doctor or nurse might order other tests.

How is hemochromatosis treated? — Sometimes, doctors do not treat hemochromatosis right away. People who do not have any symptoms are not usually treated at first. But their doctor will follow them closely by doing tests until treatment is needed.

When treatment is needed, most people are treated by having some of their blood removed on a regular basis. Having blood taken from your body is also called “phlebotomy.” This treatment works because taking blood from a person’s body can lower his or her iron level.

If you are being treated for hemochromatosis, you will probably have blood taken once a week until your iron level is normal. This usually takes about 9 to 12 months. To track how well the treatment is working, your doctor or nurse will probably do a blood test to check your iron levels every 1 to 2 months.

Once your iron level is normal, you will have treatment to keep your iron level from getting too high again. This involves having blood taken every 2 to 4 months. Most people need this treatment for the rest of their life.

What other treatments might I need? — You might need other treatments if your hemochromatosis leads to long-term problems. For example, if you get diabetes, you might need to take diabetes medicines.

If you have certain liver problems, you will need follow-up tests to check your liver for the rest of your life. That's because people with certain liver problems caused by hemochromatosis have a higher chance of getting liver cancer.

Is there anything I can do on my own to help keep my iron levels low? — Yes. You should avoid iron and [vitamin C](#) supplements. Supplements are pills, capsules, liquids, or tablets that have nutrients in them. Vitamin C supplements can cause the body to take in too much iron.

Can I drink alcohol? — It depends. Ask your doctor or nurse if it is OK for you to drink alcohol. People who have hemochromatosis and certain liver problems should not drink alcohol.

What if I want to get pregnant? — If you have hemochromatosis and want to get pregnant, talk with your doctor or nurse. He or she might suggest that your partner be tested for hemochromatosis. That way, you will know if your child has a higher chance of getting it.

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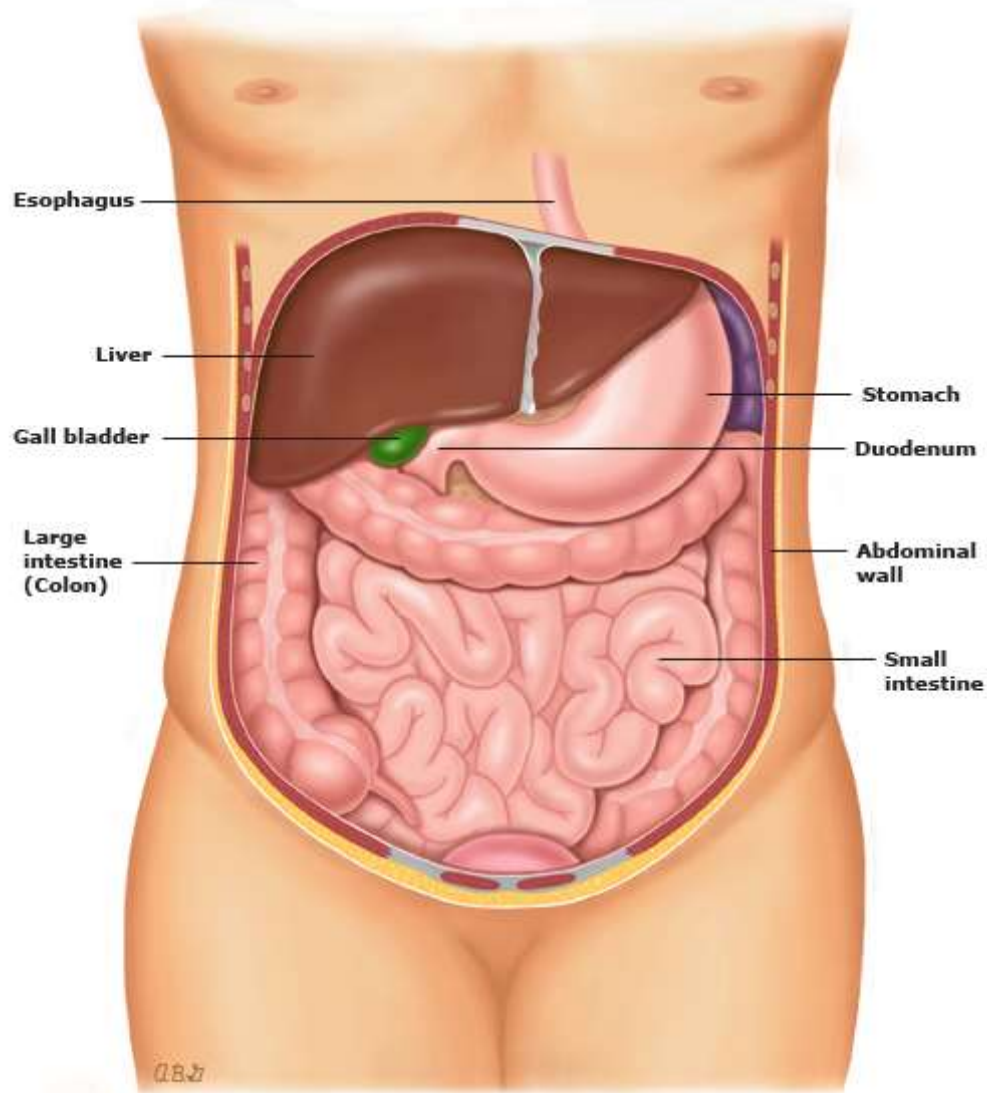
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GRAPHICS

Organs inside the abdomen (belly)



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