Hemochromatosis

What is hemochromatosis?
Hemochromatosis [hee-muh-kroh-muh-TOH-sis] is a condition in which your body absorbs too much iron from the food you eat. Over time, the extra iron builds up in your organs, especially your liver. As the buildup increases, it can lead to serious problems, including liver disease, pain, and fatigue. However, proper treatment usually prevents complications.

What are the symptoms?
In men, symptoms usually show up between 30 and 50 years of age. In women, symptoms usually develop later, after age 50. (The reason younger women tend to have fewer symptoms is that they regularly lose extra iron through menstruation, childbirth, and breastfeeding.)

Symptoms can include:
- Abdominal (belly) pain
- Fatigue, low energy, or weakness
- Darkening of the skin (sometimes called “bronzing”)
- Joint pain
- Loss of body hair
- Weight loss

What causes it?
Doctors don’t know exactly what causes hemochromatosis. They do know, however, that it is inherited (passed down through families), and it is fairly common. It affects about 5 in every 1,000 people in the U.S. It’s most common in white people of western European descent. Family members of people with hemochromatosis should be tested for it.

How is it diagnosed?
Hemochromatosis is often diagnosed before symptoms develop, because it can show up on routine blood tests. Many people also undergo testing after a family member has been diagnosed. Tests to show if you have the disease can include:
- Blood tests to show iron and certain proteins in the blood
- Physical exams to look for swelling of the liver or spleen, and changes in skin color
- Tests for blood glucose (sugar), heart function, and liver function
- Imaging tests such as CT scans, MRI, or ultrasound to check for changes in the liver or heart
- Liver biopsy (removal of a small piece of the liver for testing)
- Genetic (DNA) tests

What do I need to do next?
1. Stay away from iron in your diet. Don’t take vitamins, supplements, or cereals fortified with iron.
2. Keep your alcohol consumption low (less than 2 drinks each day) to protect your liver. Do not drink at all if you already have liver disease.
3. Don’t eat raw seafood. It may contain bacteria that grow well in an iron-rich environment.
How is hemochromatosis treated?

The goal of treatment is to lower the amount of iron in your body. Hemochromatosis can be treated easily and effectively with blood donation (also called phlebotomy). A certain amount of blood is removed from the body each week until the iron level becomes normal. Once your iron levels are more normal, blood will be removed less often.

If you’ve developed complications from hemochromatosis, they will also be treated. For example, testosterone hormone therapy can help improve loss of sexual desire and changes in testicles. Other treatments may address diabetes, arthritis, liver failure, or heart failure.

What happens if it goes untreated?

If hemochromatosis is not treated, iron can build up in your body organs and lead to severe organ damage. This increases your risk for:

• Liver disease (fibrosis or cirrhosis)
• Liver cancer
• Bacterial infections
• Severe fatigue

It may also increase your risk for:

• Diabetes
• Arthritis
• Heart disease
• Thyroid disease
• Changes in skin color
• Loss of sex drive

Should my family members be tested?

Yes. If you have been diagnosed with hemochromatosis, members of your biological family should be tested. If they know they have the disease they can get simple treatments that prevent disease.

What can I do?

The most important thing you can do is to stay in touch with your doctor and follow your recommended treatments.

When should I call my doctor?

Call your doctor if you have any of the following symptoms:

• Abdominal pain
• Fatigue, low energy, or weakness
• Darkening of the skin
• Joint pain
• Loss of body hair
• Weight loss