

Hemochromatosis

AN IRON OVERLOAD DISEASE

You can live a healthy life, if you get treatment early



Department of Health and Human Services
Centers for Disease Control and Prevention



Iron overload

What is iron overload?

Iron overload is a serious chronic condition that develops when the body absorbs too much iron over many years and excess iron builds up in organ tissues (for example, heart tissue and liver tissue).

What causes iron overload?

Iron overload usually occurs as a result of a gene mutation that causes the body to absorb more than a healthy amount of iron. Iron overload less often occurs as a complication of other blood disorders, chronic transfusion therapy, chronic hepatitis, or excessive iron ingestion.

Is iron overload dangerous?

Yes. Iron overload is dangerous because it can lead to hemochromatosis, a disease characterized by fatigue, weakness, joint pain, abdominal pain, or organ damage. It can eventually become a serious health problem. The key to preventing hemochromatosis is early diagnosis and treatment.

How can I get tested for iron overload?

Simple blood tests can measure the iron levels within your body. The tests are inexpensive and can be done at your doctor's office.



“I have hemochromatosis, and so do my daughter, Ashleigh, and my son, Adam. We take this disease very seriously and follow our treatment regimen rigorously. Early treatment is so important to saving lives, improving the quality of life, and reducing health care costs.”

Eric G.

Hemochromatosis (he-mo-kro-ma-toe-sis)

What is hemochromatosis?

Hemochromatosis is the disease that occurs as a result of significant iron overload. It can have genetic or nongenetic causes. In the United States about one million people have the disease, usually because of a gene mutation. When the disease is genetic, it is called hereditary hemochromatosis.

When do people with hemochromatosis begin to get sick?

The age varies from person to person. Usually symptoms begin during middle age. Some people get sick sooner, others later.

What are the early symptoms of hemochromatosis?

Hemochromatosis affects everyone differently. Early symptoms may include fatigue, weakness, weight loss, joint pain, or abdominal pain. There is no definite set of symptoms to indicate that a person has too much iron. Diagnosing hemochromatosis is difficult because the symptoms are like the symptoms of many other diseases.

What happens if I don't get treatment?

If hemochromatosis is not treated, it can lead to these conditions:

- Liver cancer
- Heart disease
- Impotence for men
- Infertility and premature menopause for women
- Diabetes
- Arthritis
- Cirrhosis of the liver
- Bronze skin

Treatment for hemochromatosis

Hemochromatosis can be treated by a phlebotomy (fle-bot-o-me).

What is a phlebotomy?

It's the same procedure that is used when you donate blood. A nurse takes about a pint of blood from a vein in your arm. The procedure takes about an hour.

Is a phlebotomy safe?

Yes. A phlebotomy is safe, simple, and effective. Because you will have frequent phlebotomies, your doctor will monitor your health more closely than if you were just donating blood.

How often must I have a phlebotomy?

How often you have phlebotomies—and how many you have—depends on how much iron has built up in your body. Most people have them once or twice a week for a year or more.

Must I have phlebotomies for the rest of my life?

Yes. The good news is that after your iron is lowered to a safe level, you will have phlebotomies less often, usually a few times a year.

Does a phlebotomy have side effects?

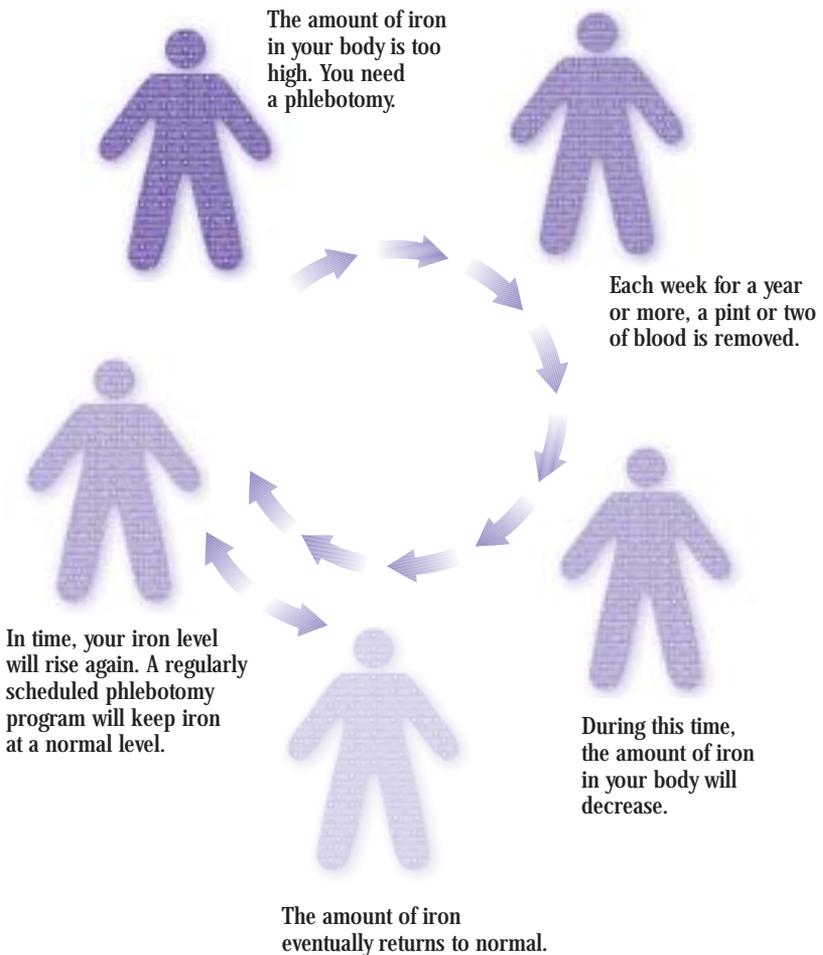
Most people feel just fine, but others feel tired afterwards and like to rest for an hour or so. It's a good idea to drink liquids (water, milk, or fruit juices) before and after a phlebotomy.

Where can I get a phlebotomy?

You can get a phlebotomy at many blood donation centers (for example, hospitals, clinics, and bloodmobiles).

Getting your iron level back to normal

Without phlebotomies, hemochromatosis can cause death.
Treatment is worth the effort.



My family and hemochromatosis

Hemochromatosis runs in families. So, your blood relatives—your parents, grandparents, sisters, brothers, or children—may also have it.

How can I help my family?

You can help by telling your blood relatives that you have hemochromatosis and they could have it too. Urge family members to get their iron levels checked by their doctors. The sooner they know whether they have hemochromatosis, the better. People who start treatment early can stay healthy.

Why does hemochromatosis run in families?

Hemochromatosis runs in families because the genes that we are born with typically cause it. We inherit genes from our parents, and our children inherit genes from us.



“I am one of the lucky ones—I got treatment in time. But my brother and sister were not so lucky—both died of liver disease due to iron overload. If their disease had been diagnosed earlier, they might be alive today. Please get checked if you think there’s any chance you might have the disease.”

Jack C.

How likely are my children to have hemochromatosis?

This is impossible to answer because children inherit genes from both parents. Talk with your children's pediatrician about your family history of hemochromatosis. Ask if your children should be tested to make sure their iron levels remain normal.

Indeed, it's important for all close family members to get their iron levels tested (parents, grandparents, sisters, brothers, and children) if anyone in the family has hemochromatosis.

The earlier family members find out if they have hemochromatosis, the better their chances of leading long, healthy lives.

"We see so many people who find out too late that they have hemochromatosis—after lots of damage is already done. It's vital that people with hemochromatosis urge family members to get tested immediately. Then, if they have the condition, they can get treatment before there's much damage."



*Prad Phatak, MD
Rochester General Hospital
Rochester, New York*

What can I do to stay healthy?

There is a lot you can do to take charge of hemochromatosis and to make sure your life is as normal and healthy as possible.



Checkups: Have the amount of iron in your blood tested regularly.



Phlebotomy: Make sure to get phlebotomies when you need them.



Food: Don't eat raw fish or raw shellfish. Cooking destroys germs harmful to people with hemochromatosis.



Alcohol: If you choose to drink alcohol, drink very little. Women should have no more than one drink a day. Men should have no more than two a day. If you have liver damage, however, do NOT drink any alcohol.



Iron pills: Don't take iron pills, supplements, or multivitamin supplements that have iron in them. Eating foods that contain iron is fine.



Vitamin C: Vitamin C increases the amount of iron your body absorbs. So, don't take pills with more than 500 mg of vitamin C per day. Eating foods with vitamin C is fine.



Exercise: You can exercise as much as you want. CDC recommends that everyone gets 30 minutes of exercise a day to stay fit and healthy.

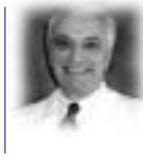
Other information

Are people with hemochromatosis allowed to donate blood?

Yes. There is no medical reason why blood from people with hemochromatosis should not be used for transfusions. The Food and Drug Administration has special guidelines about handling blood donations from people with hemochromatosis.

If you are interested in donating your blood, contact your blood bank directly to find out about its policies.

“For a year now, we’ve been using blood from the phlebotomies of hemochromatosis patients for transfusions. The patients are pleased to help others in this manner, and the practice has helped greatly in a time of blood shortage.”



*Vincent J. Felitti, MD
Southern California Kaiser Permanente
San Diego, California*

How many people have hemochromatosis?

In the United States more than one million people have the gene mutation that can cause hemochromatosis; this gene mutation is most common among people whose ancestors came from Europe. Not all people with this gene mutation develop iron overload, and not all people with iron overload develop the clinical signs and symptoms of hemochromatosis.

How to find out more

One of the best things you can do when you find out you have any type of illness is to learn as much as you can about that illness. Talk with your doctor about what to expect. Ask questions.

Sometimes it's only after you've left the doctor's office that you think of questions. After learning you have hemochromatosis, write your questions down as they come to you, and then talk with your doctor again.

“CDC is interested in teaching physicians and patients more about early diagnosis and treatment of hemochromatosis. An important step that patients can take toward good health is to keep getting phlebotomies.”



*Michele Reyes, PhD
Centers for Disease Control and Prevention
Atlanta, Georgia*

Remember, every question is worth asking.

For more information, visit these Internet sites:

www.cdc.gov/health

Information on various diseases (including iron overload and hemochromatosis) from the Centers for Disease Control and Prevention.

www.genome.gov/Health

Information on genetics from the National Institutes of Health for physicians and nurses.

***www.irondisorders.org**

Iron Disorders Institute (IDI) is a nonprofit National Voluntary Health Agency whose mission is to reduce pain, suffering, and unnecessary death by uniting resources to educate the public and medical community about iron.

You can get on the Internet free at all public libraries.

More than one million people in the United States have the gene mutation that can lead to hemochromatosis.

* Listing this Web site is solely a service to readers and does not constitute endorsement by the Centers for Disease Control and Prevention or the federal government.

Remember

You can live a long, healthy life when you take charge of your hemochromatosis.

- Have the level of iron in your blood checked regularly.
- Have a phlebotomy as often as needed.
- Don't eat raw fish or raw shellfish.
- Stay away from alcohol.
- Don't take pills with iron in them.
- Limit vitamin C pills to 500 mg or less per day.
- Follow your doctor's recommendations.

Begin treatment as soon as possible.

The earlier you get treatment, the better your chances of staying healthy.

Urge your family members to have their iron levels tested.



"I have hemochromatosis, so I had my son tested to see if he has it too. I'm glad I did because he does have the disease, and we found out early. The doctor says if my son watches what he eats and gets phlebotomies when he needs them, he'll probably never suffer any bad effects."

Carol S.