

# UNDERSTANDING IRON OVERLOAD



A Patient Guide






# UNDERSTANDING GROWTH HORMONE THERAPY

## A Patient Guide

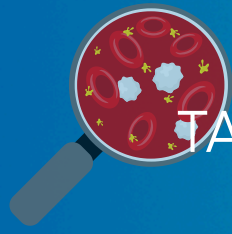


This booklet will help you learn about iron overload. You will find out what causes too much iron in your body, how it affects your health, and what you can do to manage your condition and protect your organs.

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## WHAT IS IRON OVERLOAD?



**Iron** is a mineral your body needs to make hemoglobin, the protein in red blood cells that carries oxygen. But too much iron can be harmful.

Iron overload happens when your body has more iron than it can use or safely store. The extra iron builds up in organs like the liver, heart, and pancreas, where it can cause serious damage over time.

Think of it this way: Iron is like fuel for your body - you need the right amount to function. But just like a car engine can be damaged by too much fuel, your organs can be damaged by too much iron. The body has no natural way to get rid of excess iron, so it keeps building up.

### **Key Terms to Know**

**Iron Overload:** A condition where too much iron builds up in the body.

**Ferritin:** A protein that stores iron. Blood tests measure ferritin levels to check iron stores.

**Hemochromatosis:** A genetic condition that causes the body to absorb too much iron from food.

**Transfusional Iron Overload:** Iron buildup from receiving many blood transfusions.

#### References:

1. National Heart, Lung, and Blood Institute. "Iron Overload." NHLBI, NIH. <https://www.nhlbi.nih.gov/health/iron-overload>
2. Iron Disorders Institute. "Iron Overload." [irondisorders.org](http://irondisorders.org).
3. Hemochromatosis.org. "About Hemochromatosis."



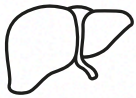
# HOW IRON OVERLOAD AFFECTS THE BODY

When iron builds up in your organs, it causes damage through a process called oxidation (similar to rusting). Different organs are affected in different ways:

## LIVER

The liver is usually the first organ affected.

- Iron deposits cause inflammation
- Can lead to fibrosis (scarring)
- May progress to cirrhosis
- Increases risk of liver cancer



## HEART

Iron in the heart is very serious.

- Can cause heart failure
- May cause irregular heartbeat (arrhythmia)
- Leading cause of death in transfusional iron overload



## PANCREAS

- Can damage cells that make insulin
- May lead to diabetes



## JOINTS

- Can cause arthritis-like pain
- Most commonly affects knuckles and joints



## ENDOCRINE GLANDS

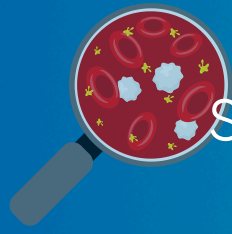
- Can affect thyroid, pituitary, and reproductive glands
- May cause hormone problems, fatigue, infertility



**Good News:** With early treatment, organ damage can often be prevented or even reversed.

### References:

1. American Liver Foundation. "Hemochromatosis." [liverfoundation.org](http://liverfoundation.org).
2. Cooley's Anemia Foundation. "Iron Overload." [thalassemia.org](http://thalassemia.org).



## SIGNS & SYMPTOMS



Iron overload often develops slowly, and many people have no symptoms in the early stages. Symptoms usually appear after iron has been building up for years.

Early Symptoms	<ul style="list-style-type: none"><li>• Fatigue and weakness (most common)</li><li>• Joint pain (especially knuckles)</li><li>• Abdominal pain</li><li>• Loss of sex drive</li><li>• Brain fog or memory problems</li></ul>
Later Symptoms (as organs are affected)	<ul style="list-style-type: none"><li>• Bronze or gray skin color</li><li>• Diabetes symptoms (thirst, frequent urination)</li><li>• Irregular heartbeat or shortness of breath</li><li>• Enlarged liver</li><li>• Swelling in legs or abdomen</li><li>• Hair loss</li><li>• Erectile dysfunction (men)</li><li>• Missed periods (women)</li></ul>

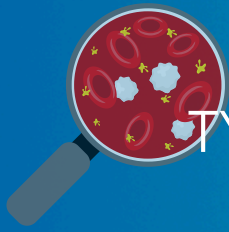
### In People Who Receive Blood Transfusions

Symptoms may appear after receiving approximately 10-20 transfusions. Regular monitoring is essential to catch iron buildup early.

**Important:** Many of these symptoms are vague and can be caused by other conditions. The only way to know if you have iron overload is through blood tests.

#### References:

1. Mayo Clinic. "Hemochromatosis - Symptoms." MayoClinic.org.
2. Iron Disorders Institute. "Symptoms." irondisorders.org.



# TYPES OF IRON OVERLOAD

## HEREDITARY HEMOCHROMATOSIS

A genetic condition that causes the body to absorb too much iron from food.

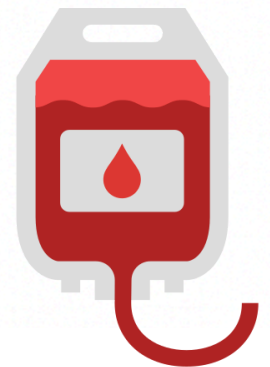
- Most common genetic disease in people of Northern European descent
- Caused by mutations in the HFE gene (most commonly C282Y)
- Must inherit the gene from both parents
- Symptoms usually appear in adults (ages 30-50)
- More common and more severe in men
- Women often protected until menopause (monthly blood loss)

## TRANSFUSIONAL IRON OVERLOAD

Iron buildup from receiving many blood transfusions.

Occurs in people with conditions requiring regular transfusions:

- Thalassemia
- Sickle cell disease
- Myelodysplastic syndromes (MDS)
- Aplastic anemia
- Other blood disorders



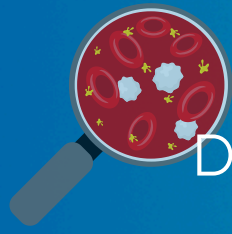
Each unit of blood contains about 200-250 mg of iron. After 10-20 transfusions, iron begins to accumulate in organs.

## OTHER CAUSES

- Excessive iron supplements
- Chronic liver disease
- Rare genetic conditions

References:

1. Hemochromatosis.org. "Types of Hemochromatosis."
2. Cooley's Anemia Foundation. "Transfusional Iron Overload." thalassemia.org.



## DIAGNOSIS



### How is Iron Overload Diagnosed?

Iron overload is diagnosed with blood tests and sometimes imaging:

#### Blood Tests

##### Serum Ferritin

What It Measures: Iron stores in the body

Normal Range: 20-200 ng/mL (women), 20-500 ng/mL (men)

In Iron Overload: Often greater than 1,000 ng/mL

##### Transferrin Saturation

What It Measures: How much iron is bound to transferrin (iron-carrying protein)

Normal Range: 20-50%

In Hemochromatosis: Often greater than 45%

##### Genetic Testing

- Tests for HFE gene mutations (C282Y, H63D)
- Confirms hereditary hemochromatosis
- Family members may also be tested

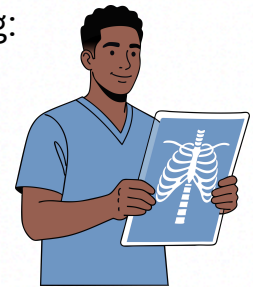
#### Imaging

##### MRI (Magnetic Resonance Imaging)

- Can measure iron in the liver and heart
- Non-invasive way to monitor iron levels
- T2\* MRI especially useful for heart iron

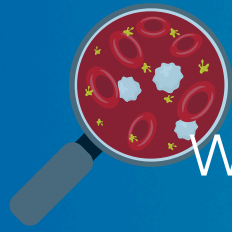
##### Liver Biopsy

- Sometimes used to check for liver damage
- Less common now with improved MRI techniques



#### References:

1. AASLD. "Hemochromatosis Guidelines." [aasld.org](http://aasld.org).
2. Mayo Clinic. "Hemochromatosis - Diagnosis." [MayoClinic.org](http://MayoClinic.org).



## WHAT TO EXPECT

### Disease Course

With treatment, most people with iron overload can live normal, healthy lives. Here's what to expect:

#### Iron Overload is Treatable

- Treatment can remove excess iron from the body
- Organ damage can often be prevented
- Some existing damage may improve with treatment

#### Treatment is Ongoing

- For hereditary hemochromatosis: lifelong phlebotomy
- For transfusional iron overload: chelation therapy as long as transfusions continue
- Regular monitoring is essential

#### Treatment Goals

- Reduce ferritin to safe levels (usually below 50-100 ng/mL for hemochromatosis)
- Maintain safe iron levels over time
- Protect organs from damage

#### Prognosis

- If caught early (before organ damage): normal life expectancy
- If liver damage has occurred: increased risk of complications
- Heart iron is reversible with chelation therapy

#### Family Screening

If you have hereditary hemochromatosis, your family members should be tested. Early detection prevents complications.

#### References:

1. Hemochromatosis.org. "Prognosis and Outlook."



## TREATMENT OPTIONS

Treatment depends on the cause of iron overload:

### PHLEBOTOMY (Blood Removal)

The main treatment for hereditary hemochromatosis.

#### How It Works:

- Similar to donating blood
- About 1 pint (500 mL) of blood is removed
- Each session removes about 250 mg of iron

#### Schedule:

- Initially: weekly or every 2 weeks until iron levels normalize
- Maintenance: every 2-4 months for life

### IRON CHELATION THERAPY

The main treatment for transfusional iron overload.

Chelation medications bind to iron in your body and help remove it through urine or stool.

#### Medications:

- Deferasirox (Exjade, Jadenu) - once daily tablet or granules
- Deferoxamine (Desferal) - given by injection/infusion
- Deferiprone (Ferriprox) - oral tablets, three times daily

### DIETARY CHANGES

Supportive therapy (not a replacement for medical treatment):

- Avoid iron supplements and multivitamins with iron
- Limit vitamin C supplements (increases iron absorption)
- Avoid raw shellfish (risk of bacterial infection)
- Limit alcohol (damages the liver)

#### References:

1. AASLD. "Treatment of Hemochromatosis." [aasld.org](http://aasld.org).



# IRON CHELATION THERAPY

If you receive regular blood transfusions, chelation therapy helps remove the extra iron.

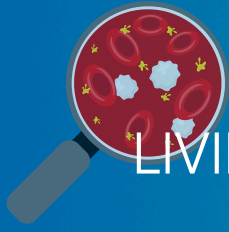
Deferasirox (Exjade, Jadenu)	<ul style="list-style-type: none"><li>• Most commonly used chelator</li><li>• Taken once daily by mouth</li><li>• Jadenu tablets can be swallowed whole with water</li><li>• Exjade tablets are dissolved in liquid</li><li>• Removes iron through stool</li></ul>
Deferoxamine (Desferal)	<ul style="list-style-type: none"><li>• Given by slow injection under the skin or into a vein</li><li>• Usually given over 8-12 hours (often overnight)</li><li>• Requires an infusion pump</li><li>• Very effective for heart iron</li></ul>
Deferiprone (Ferriprox)	<ul style="list-style-type: none"><li>• Taken three times daily by mouth</li><li>• Especially good at removing heart iron</li><li>• Sometimes used with other chelators</li></ul>
Monitoring During Chelation	<ul style="list-style-type: none"><li>• Regular blood tests (kidney and liver function)</li><li>• Hearing and vision tests (some chelators can affect these)</li><li>• Ferritin levels every 1-3 months</li><li>• MRI to monitor liver and heart iron</li></ul>

### Common Side Effects

- Stomach upset, nausea, diarrhea (deferasirox)
- Injection site reactions (deferoxamine)
- Joint pain

#### References:

1. Cooley's Anemia Foundation. "Iron Chelation." [thalassemia.org](http://thalassemia.org).



# LIVING WITH IRON OVERLOAD

With proper management, you can live a full and healthy life:

## Dietary Guidelines

- Avoid iron supplements and vitamins with iron
- Limit vitamin C supplements (they increase iron absorption)
- You do NOT need to avoid iron-rich foods (treatment handles excess iron)
- Avoid raw or undercooked shellfish (risk of Vibrio infection)
- Limit alcohol (or avoid completely if liver damage is present)

## Protect Your Liver

- Avoid or limit alcohol
- Get vaccinated for hepatitis A and B
- Tell your doctor about all medications and supplements
- Maintain a healthy weight

## Stay on Track with Treatment

- Keep all phlebotomy or chelation appointments
- Take chelation medication exactly as prescribed
- Don't skip doses
- Get regular monitoring tests

## Family Matters

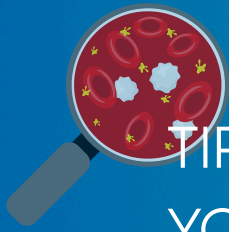
- If you have hereditary hemochromatosis, tell your family
- Parents, siblings, and children should be tested
- Early detection prevents complications

## Emotional Support

- Connect with support groups
- Talk to others who understand
- Seek help if you feel anxious or depressed

### References:

1. Hemochromatosis.org. "Living with Hemochromatosis."



## TIPS FOR TAKING YOUR MEDICATION



### DO:

- Take chelation medication exactly as prescribed
- Take deferasirox on an empty stomach or with a light meal
- Swallow Jadenu tablets whole with water
- Take deferiprone with or without food
- Keep all monitoring appointments
- Stay hydrated (drink plenty of water)
- Report any side effects to your doctor

#### For Deferoxamine Users

- Rotate injection sites
- Check infusion equipment regularly
- Report any injection site problems

#### If You Miss a Dose

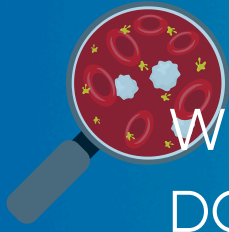
- Take it as soon as you remember (same day)
- If it's almost time for the next dose, skip the missed dose
- Never double up



### DON'T:

- Skip doses - consistency is essential
- Take antacids containing aluminum with deferasirox
- Stop medication without talking to your doctor
- Take iron supplements or multivitamins with iron
- Take high-dose vitamin C supplements
- Drink alcohol excessively

**Common Side Effects:** Nausea, diarrhea, stomach pain, rash, headache. Many improve over time. Tell your doctor if they persist.



## WHEN TO CALL YOUR DOCTOR

### ! CALL 911 OR GO TO THE EMERGENCY ROOM IF:

- Chest pain or pressure
- Severe shortness of breath
- Irregular or racing heartbeat
- Severe abdominal pain
- Vomiting blood or blood in stool
- Signs of severe allergic reaction

### ! CALL YOUR DOCTOR'S OFFICE IF:

- Persistent nausea, vomiting, or diarrhea
- Stomach pain that doesn't go away
- Dark urine or decreased urination
- Yellowing of skin or eyes
- Unusual fatigue or weakness
- Changes in hearing or vision
- Rash or skin changes
- Signs of infection (fever, chills)
- Joint pain
- Side effects that concern you

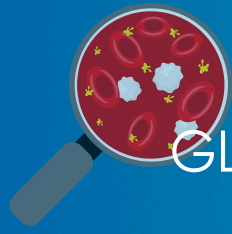


*Keep Your Monitoring Appointments!*

*Regular blood tests and imaging help track your iron levels and protect your organs.*

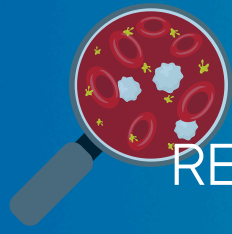
References:

1. Cooley's Anemia Foundation. "When to Seek Help." [thalassemia.org](http://thalassemia.org).



# GLOSSARY

CHELATION	Treatment that uses medication to remove excess iron from the body
CIRRHOSIS	Severe scarring of the liver
FERRITIN	A protein that stores iron; blood levels indicate iron stores
HEMOCHROMATOSIS	Genetic condition causing the body to absorb too much iron
HFE GENE	The gene most commonly mutated in hereditary hemochromatosis
IRON OVERLOAD	Too much iron in the body
MRI	Imaging test that can measure iron in organs
PHLEBOTOMY	Blood removal treatment for hemochromatosis
TRANSFERRIN	Protein that carries iron in the blood
TRANSFERRIN SATURATION	Percentage of transferrin that is carrying iron
TRANSFUSIONAL IRON OVERLOAD	Iron buildup from receiving many blood transfusions



## RESOURCES



### **Learn More:**

- Iron Disorders Institute: [irondisorders.org](http://irondisorders.org)
- Hemochromatosis.org: [hemochromatosis.org](http://hemochromatosis.org)
- American Hemochromatosis Society: [americanhs.org](http://americanhs.org)
- Cooley's Anemia Foundation: [thalassemia.org](http://thalassemia.org)
- American Liver Foundation: [liverfoundation.org](http://liverfoundation.org)
- National Heart, Lung, and Blood Institute: [nhlbi.nih.gov](http://nhlbi.nih.gov)
- Mayo Clinic - Hemochromatosis: [mayoclinic.org](http://mayoclinic.org)
- MedlinePlus - Iron Overload: [medlineplus.gov](http://medlineplus.gov)



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