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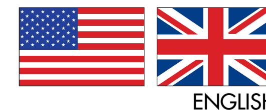

Anemia, Blood Transfusions, Iron Overload, & Myelodysplastic Syndromes:

A Handbook for Adult MDS Patients

Published by The Myelodysplastic Syndromes Foundation, Inc.

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TABLE OF CONTENTS

Introduction 2

Why Are Blood Transfusions Necessary? 2

What is Iron Overload? 5

How Serious is Iron Overload? 7

How is Iron Overload Diagnosed? 7

How Are Iron Levels Monitored? 9

Is Iron Overload Treatable? 9

What Treatments Are Available for Iron Overload? 10

What Are the Side Effects of Iron Chelating Drugs? 13

What Practical Measures Can I Take to Help Reduce Iron Overload? 14

Appendix

- Glossary 15
- Resources 17
- Additional Readings 18
- Financial Assistance 18
- Patient Tracking Chart 19

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Introduction

This handbook contains information about the accumulation of iron in the body that occurs after repeated blood transfusions and the treatments available for transfusion-dependent iron overload for patients with myelodysplastic syndromes (MDS). *Transfusion-dependent iron overload* is quite a mouthful. The language of medicine can be intimidating, but your doctor, nurse, and others on your health care team want you to know about your condition and possible treatments that may improve your quality of life.

This patient handbook also contains tools, including a simple form to help track your transfusions and laboratory results, a list of resources and additional readings for those who are more curious, and a glossary to help you understand the medical terms.

Roughly 80% of MDS patients have anemia (low red blood cell counts and corresponding low hemoglobin levels) when they are initially diagnosed with MDS. Blood transfusions are often used to treat the symptoms of anemia in patients with MDS. Although chronic anemia is seldom life threatening, it can reduce a patient's quality of life.

This patient handbook is intended to help you understand transfusion-dependent iron overload.

Why Are Blood Transfusions Necessary?

Myelodysplastic syndromes are a group of blood and **bone marrow** disorders in which the marrow does not produce enough mature red blood cells, white blood cells and platelets. *(See "Blood and Its Components" box.)* Most patients with MDS receive regular transfusions of **red blood cells** because their body cannot produce an adequate number of these cells to meet the needs of various tissues in the body.

Red blood cells contain **hemoglobin**, a rather large iron-containing protein that gives blood its red color and that carries oxygen from the lungs to all body tissues. Oxygen is needed by all of the body's cells to grow, carry out their specific functions, and divide. When the number of red blood cells falls below a certain level, the amount of oxygen also falls, such that cells and tissues do not receive enough oxygen. Without oxygen to provide the energy to carry out specific functions, cells become less efficient and fatigued.

You are considered to have **anemia** when your red blood cell count and hemoglobin (a marker for oxygen) fall below the normal range to a certain level. The symptoms of anemia vary depending on how low the red blood cell count is and how low the

hemoglobin level is. The level of anemia may affect each person differently depending on their age and general health. Some of the symptoms you may notice when you are anemic include a pale complexion, fatigue, weakness, and sometimes shortness of breath.

Symptoms of Anemia

- Weakness and fatigue
- Shortness of breath (especially during exercise)
- Rapid heart rate
- Lightheadedness or dizziness (especially when standing or on exertion)
- Headache
- Chest pain
- Difficulty concentrating
- Pale skin
- Mental confusion

There are treatments that may improve red blood cell production in some MDS patients, but these treatments are not effective in all patients with MDS and some patients may not be able to tolerate them. Blood transfusions are a common way to provide temporary relief of the symptoms of anemia. Thus, blood transfusions are sometimes referred to as symptomatic or supportive care. It's important to note that there is a downside to receiving red blood cell transfusions—red blood cells carry iron and after repeated transfusions, a patient may end up with elevated levels of iron in the blood and other tissues. There are other possible side effects associated with blood transfusions, which your health care provider will discuss with you.

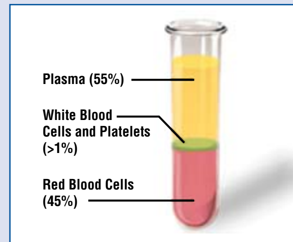
The majority of patients with MDS develop symptomatic anemia at some time over the course of their disease. Nearly 90% of adult patients with MDS are treated with red blood cell transfusions at regular intervals over months or years.

Most often, two units of packed red blood cells are given during each transfusion. How frequently transfusions need to be administered will vary depending upon the severity of symptoms and the **hematocrit** or hemoglobin level. *(See "Hemoglobin & Hematocrit" box.)* Transfusion intervals (the time between one transfusion and the next) may vary from every few months in lower risk MDS to every 2 to 6 weeks in higher risk disease. In some MDS patients, the transfusion interval may be as often as once every 1 to 2 weeks.

Blood and Its Components

The body contains about 5 liters (5.3 quarts) of blood. Blood is composed of cells and liquid in nearly equal amounts. The liquid portion of blood is called **plasma**. About half of the volume of blood is plasma, which is made up of mostly water that contains salts (electrolytes), hormones, and proteins such as antibodies and albumin. Blood **serum** is identical in composition to plasma but does not contain the clotting factor fibrinogen.

The cells found in blood are identified as red blood cells (also called erythrocytes), five types of **white blood cells** (also called leukocytes), and **platelets** (cell-like blood elements involved in blood clotting). All of these cells are produced in the bone marrow from precursor stem cells. Millions of mature blood cells and platelets are produced and released into the blood every day to replace older decaying and dying cells, which are removed. In adults, the bones that are the major sites of blood cell production are the spine, ribs, breastbone, pelvis, shoulders, and the skull.



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Hemoglobin and Hematocrit

Hemoglobin is an iron-containing protein in red blood cells that carries oxygen to the tissues. Hemoglobin is measured from a blood sample and the amount present is expressed in units of grams per deciliter, abbreviated g/dL.

The normal value for hemoglobin varies by age and gender. Anemia occurs when hemoglobin concentrations fall below 12 g/dL for women and 13 g/dL for men. The severity of anemia is categorized by the following hemoglobin concentration ranges:

- Mild anemia, hemoglobin between 9.5–13.0 g/dL
- Moderate anemia, hemoglobin between 8.0–9.5 g/dL
- Severe anemia, hemoglobin below 8.0 g/dL

Like hemoglobin, hematocrit is measured from a blood sample. The hematocrit is the fraction of blood composed of red blood cells and is expressed as a percentage. People with a high volume of plasma (the liquid portion of blood) may be anemic even if their blood count is normal because the blood cells have become diluted. Like hemoglobin, a normal hematocrit percentage depends on age and gender. In adults, anemic ranges for hematocrit generally fall below 39% in men and below 36% in women.

What is Iron Overload?

Red blood cell transfusions may provide temporary relief from the symptoms of anemia, but they also add extra iron to the body. And while there are a few therapies that can restore the production of red blood cells so that patients can become transfusion-independent, they are not appropriate for all MDS patients. In fact, for approximately 40% of MDS patients, transfusions are the only option to treat the symptoms of anemia. Supportive therapy with repeated red blood cell transfusions can lead to elevated levels of iron in the blood and other tissues. Thus, MDS patients who receive transfusions for their anemia are at risk for excess iron or iron overload. *(See "Transfusions and Excess Iron" box.)*

As a general rule, iron overload occurs after you receive 20 units of red blood cell transfusions. In addition to developing iron overload as a result of multiple transfusions, MDS patients with **sideroblastic anemia** may develop iron overload as a result of excessive absorption of iron from food. You may not know that excess iron is building up in your body because there may be no symptoms.

Other MDS patients considered to be at risk for iron overload are transplant recipient candidates who have already received more than 20 to 30 red blood cell transfusions, those with a serum **ferritin** level greater than 1000–2500 ng/mL (see below), and those with an IPSS risk of "Low-Intermediate-1" who require continued transfusions. The International Prognostic Scoring System (IPSS) estimates the risk of disease progression and survival for patients with MDS based on a number of disease variables. *(See www.cancer.org/cancer/MyelodysplasticSyndrome/OverviewGuide/myelodysplastic-syndromes-overview-stage.)*

Keeping track of the number of transfusions you have received and certain laboratory results, such as hemoglobin and ferritin levels, can help you in a number of ways. You will be able to see how often you need transfusions and the level of hemoglobin that causes symptoms requiring you to need a transfusion. Knowing how many transfusions you've had will help in talking with your doctor, nurse, and other health care providers about your risk for iron overload. The simple form below helps to track transfusions. *(See the Appendix for full page tear-out chart.)* Regardless of whether or not you're receiving treatment for iron overload (available treatments are discussed below), you should keep a record of all transfusions, your blood type, and any antibodies in the blood.

Transfusion Tracking Chart

Date of Transfusion	Location	Contact Number	Number of Units Received
mm/dd/yy			

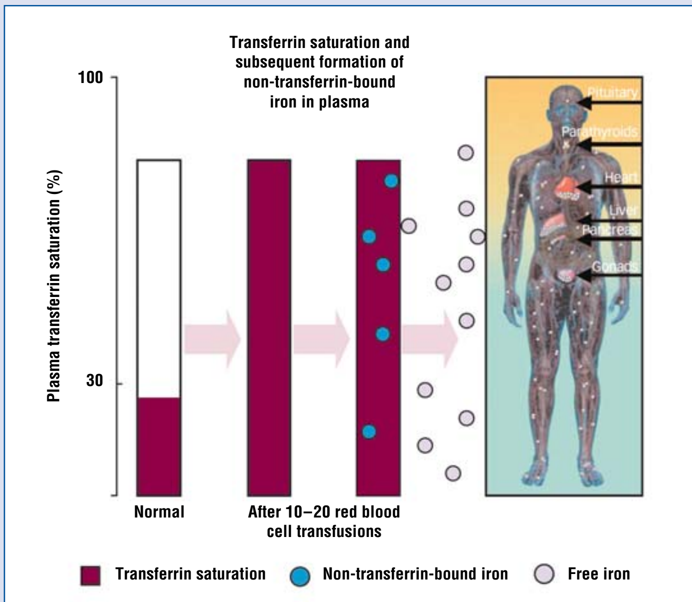
Total number of units received →

Transfusions and Excess Iron

Your body contains about 3 to 4 grams of the element iron (Fe). Nearly two-thirds of the body's iron is found in the oxygen-carrying protein in the blood called hemoglobin. The remainder is found in myoglobin (found in muscle cells) and other proteins. The amount of iron in the body is tightly controlled and most of it is recycled. The very small amounts that are lost daily (1 to 2 milligrams) are balanced by absorption from the diet. The body has no normal way to rid itself of excess iron.

Each unit of packed red blood cells contains about 250 milligrams of iron. Over the course of therapy with repeated blood transfusions, iron builds up in the body's tissues and organs. After approximately 20 transfusions, a patient will receive an additional 5 grams of iron, nearly doubling the amount of iron in their body.

Normally, iron binds to plasma protein called **transferrin**, which circulates in the body, accumulating within cells in the form of ferritin. Iron overload occurs when transferrin becomes saturated, increasing the concentration of non–transferrin-bound iron—a toxic substance to cells. As levels of non–transferrin-bound iron accumulate in the blood, they are absorbed into the surrounding tissues, leading to increased levels of unbound iron in the liver, heart, pancreas, pituitary gland, and other glands.



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How Serious is Iron Overload?

Iron overload is a potentially dangerous condition because excess iron can damage tissues. Excess iron may accumulate in the heart, liver, lungs, brain, bone marrow, and endocrine organs putting you at risk for a number of conditions. Many of these are not reversible and may be life-threatening, including heart failure, **cirrhosis** and **fibrosis** of the liver, gallbladder disorders, diabetes, arthritis, depression, impotence, infertility, and cancer. Much of the data on the damaging effects of iron overload are from other transfusion-dependent anemias in patients with blood disorders such as **sickle cell anemia** and **thalassemia**.

Studies in patients with MDS have shown that iron overload resulting from regular red blood cell transfusions is associated with a poorer overall survival and a higher risk of developing leukemia. This negative effect on survival depends on the number of red blood cell transfusions received per month. The negative effect on survival is also related to the severity of MDS (low-risk versus high-risk disease using the IPSS and WPSS risk categories).

Management of iron overload and treatment of iron toxicity by iron **chelation** *(pronounced key-LAY-shun)* therapy in patients with MDS and transfusion-dependent anemias has been shown to reduce iron burden and may improve survival in some patients with MDS.

How is Iron Overload Diagnosed?

Although many tests are available to assess iron overload, the most commonly used one today is a simple blood test called a ferritin test. The ferritin level indirectly estimates iron overload. Ferritin is a protein in the serum that binds iron and helps to store iron in the body. Because it is a simple blood test, it is easy to perform repeatedly to obtain ferritin readings over time, and a trend can be observed and monitored. Serum ferritin levels are generally checked in MDS patients at the time of diagnosis and repeated every 3–4 months when regular blood transfusions are required (transfusion-dependent MDS). Keeping track of your serum ferritin level along with your transfusions and hemoglobin levels can help you understand your risk of iron overload. *(See Appendix for full page tear-out chart.)*

Normal values for serum ferritin are usually in the range of 12–300 ng/mL for men and 12–150 ng/mL for women. A low serum ferritin level typically means reduced iron stores. Lower than normal levels of ferritin are a sign of iron-deficiency anemia, whereas higher than normal levels may indicate hemolytic anemia, megaloblastic anemia, or iron overload.

Tests for Iron Overload

Test	Advantages	Disadvantages
Ferritin test *(Most Common Method)*	– Noninvasive – Widely available – Useful in deciding when to initiate therapy – Useful in monitoring treatment effectiveness	– Measurement values are altered by inflammation, infection, and ascorbic acid (vitamin C) deficiency – Does not correlate well with total body iron
Liver biopsy (liver iron concentration) *(Limited use due to risk)*	– Correlates well with total body iron burden – Allows for assessment of liver histology – High levels predict risk for cardiac disease, endocrine complications, and death	– Invasive – Accuracy affected by sample size – Sampling errors due to fibrosis and uneven distribution of iron – Cardiac disease may be present when liver iron is low
MRI (**M**agnetic **R**esonance **I**maging) *(Used to evaluate abnormal liver enzymes in patients with elevated ferritin)*	– Noninvasive – More widely available – Correlates well with liver iron concentration by biopsy	– Expensive – Variety of techniques and analytic programs may limit comparability – Cardiac disease may be present when liver iron is low
Cardiac iron loading by MRI *(Used primarily to evaluate cardiac symptoms in patients with elevated ferritin)*	– Noninvasive – Correlates with risk for cardiac disease	– Expensive – Difficult to validate with biopsy specimen

Serum ferritin levels greater than 1000–2500 ng/mL indicate iron overload. In MDS patients, serum ferritin levels have been shown to be related to the number of red blood cell units received. A serum ferritin value of 1000 ng/mL may be reached after as few as 20 units of red blood cells have been transfused. One disadvantage to the ferritin test is that the results are affected by inflammation, infection, and ascorbic acid (vitamin C) deficiency. Therefore, the trends in the ferritin levels over a period of time are most useful in monitoring iron overload.

How Are Iron Levels Monitored?

Before you begin chelation therapy and while you are on therapy, a number of tests may be used to monitor your iron levels. Some of these tests are used to assess the amount of iron in your blood and organs, whereas other tests are used to monitor possible side effects of chelation therapy.

Frequency of Testing During Iron Chelation Therapy

Test	Every Month	Every Three Months	Once a Year
Auditory testing			✓
Granulocytes	✓		
Serum ferritin		✓	
Serum transaminase	✓		
Serum creatinine	✓		
Liver iron stores (T2 MRI)			✓
Myocardial iron stores (T2 MRI)			✓
Ophthalmic testing			✓

Is Iron Overload Treatable?

Fortunately, iron overload can be treated with chelation therapy using iron-chelating drugs. The goal of therapy is to keep the body's iron level low enough to prevent the development of organ damage. Even after organ toxicity has developed, chelation therapy can reverse some of the complications of iron overload. Drugs called chelating agents that bind to iron so that it can be removed from the body are the most common way to treat iron overload in patients with transfusion-dependent MDS.

Chelation therapy is continued until your serum ferritin level is less than 1000 ng/mL. This may take several months to several years.

After beginning iron chelation therapy, your iron level will be monitored every 3–4 months. The ferritin test is used to evaluate your response to iron chelation therapy. If you are receiving therapy, your health care provider will monitor the number of red blood cell transfusions you receive as well as your serum ferritin level.

If your serum ferritin level falls below 500 ng/mL during the course of treatment or if you are no longer receiving transfusions, chelation therapy may be discontinued. However, your iron level will continue to be monitored.

Some MDS patients who no longer require red blood cell transfusions as a result of treatment for their MDS may be candidates for phlebotomy *(pronounced fla-BOT-a-me)*. Phlebotomy involves removing a unit of blood — similar to donating blood — which, like iron chelating agents, removes the iron carried in red blood cells as well as unbound iron in the blood.

What Treatments Are Available for Iron Overload?

Currently there are two iron chelating drugs available for MDS patients: Desferal® (generic name, deferoxamine) and Exjade® (generic name, deferasirox) are available in the United States and have been approved by the U.S. Food & Drug Administration (FDA). Another iron chelating drug — Ferriprox® (generic name, deferiprone) — is commercially available for the treatment of iron overload in patients with thalassemia in Europe and about 50 other countries around the world, including China and Australia. Ferriprox is not currently approved for treatment of iron overload in patients with MDS, but is being studied in clinical trials. All three drugs chelate, or bind, to iron and promote iron removal from the body.

Desferal® (Deferoxamine)

Note that the spelling of the generic name of Desferal appears variably in the medical literature as deferoxamine, desferoxamine, and deferroxamine.

Desferal is administered by injection anywhere from 3 to 7 times a week. Some patients receive twice-daily subcutaneous (beneath the skin) injections. Others receive slow intravenous infusion by way of a portable, battery-operated pump worn over a period of about 8 hours, often overnight. Desferal can also be given by injection into muscle (intramuscular administration.) The most effective route of administration is different for each patient. Less frequent injections (1–2 times per week) may be possible when the ferritin level is reduced.

Image courtesy of DRE, Inc. (Louisville, KY). Reprinted with permission.

Patients receive up to two grams of Desferal for each unit of blood transfused. Typically, a physician will initiate treatment with one gram, gradually adjusting the dose upward until it reaches no more than three grams a day.

Desferal is slow acting, removing only 6 to 10 mg of iron per infusion; however, it can maintain negative iron balance even when blood transfusions continue.

Iron Chelating Drugs: A Comparison

Property	**Deferoxamine (Desferal®)**	**Deferasirox (Exjade®)**	**Deferiprone (Ferriprox®)**
Route of administration	Subcutaneous, intramuscular, or intravenous	Oral	Oral
Typical daily dosage	25–50 mg/kg	20 mg/kg starting dose	75 mg/kg
Schedule	Administered for a period of 8–24 hours, 3–7 days per week	Once daily	Three times daily
Main route of excretion	Urine/feces	Feces	Urine
Special monitoring	Annual ophthalmology and auditory exams	Monthly blood urea nitrogen, creatinine, hepatic transaminases, and urinalysis; annual ophthalmology and auditory exams	Weekly complete blood count with differential Annual ophthalmology and auditory exams

Exjade® (Deferasirox)

Exjade is an oral treatment for iron overload that is taken once daily at a dose of 20 milligrams per kilogram of body weight per day. For a patient weighing 150 lbs, the daily dose is 1350 milligrams (mg). Exjade should be taken once-a-day on an empty stomach, at least 30 minutes before food, and preferably at the same time every day.

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Exjade tablets should be dissolved in a glass of orange juice, apple juice or water and taken as a drink. The tablet(s) should be dropped into a glass of orange juice, apple juice, or water, and then stirred until dissolved and the solution is evenly mixed. (The solution may have a thick consistency and this may take several minutes) It is important to finish any of the remaining Exjade in the glass by adding a little more liquid to the glass and stirring. Exjade should not be chewed or swallowed whole, and should not be taken at the same time as antacids medicines that contain aluminum, such as Maalox®.

Clinical trials in patients with beta thalassemia, sickle cell disease, other anemias as well as MDS have shown that Exjade significantly reduced liver iron concentration (LIC), an indicator of iron content in the body, and led to the maintenance or reduction of iron burden in transfused patients. Because Exjade may cause certain adverse reactions that impair kidneys or liver function, its use is closely monitored by blood tests every month or more frequently if a patient is at increased risk for these complications. You should not receive Exjade if you have impaired kidney or liver function, have platelet counts less than 50×10^9/L, or have a hypersensitivity to deferasirox, or any component of Exjade.

Clinical Trials

Clinical trials are carefully designed and conducted studies that evaluate medical treatments and interventions for diseases. Several clinical trials are evaluating the treatment of iron overload caused by repeated red blood cell transfusions in MDS patients. A description of these studies can be found online at the U.S. National Institutes of Health clinical trials website *ClinicalTrials.gov*. This website is a registry of all the clinical trials that are supported by the U.S. government and by private organizations in the United States and around the world. For a current listing of trials for the treatment of iron overload in MDS, go to http://clinicaltrials.gov/ct2/results?term=iron+overload+AND+MDS.

For each clinical trial, information about study eligibility requirements, trial locations, and contact information can be found by clicking on the link to the study. The *ClinicalTrials.gov* website also contains background information on understanding clinical trials, a glossary, and links to other useful resources.

Ferriprox® (deferiprone)

Ferriprox® is not licensed for use in MDS patients, although the manufacturer is seeking approval for iron overload in MDS in several countries. Ferriprox is currently used to treat iron overload in patients with thalassemia who are unable to use Desferal because of intolerability or lack of effectiveness. It is taken by mouth as a tablet or as an oral solution. The usual dose is 25 mg/kg, three times per day, or a total daily dose of 75 mg/kg/day. In clinical studies and in clinical practice, Ferriprox has been shown to be effective in removing iron from the body. Ferriprox has a side effect profile similar to that of Desferal.

Ongoing clinical trials are evaluating the use of Ferriprox® alone and in combination with Desferal® in patients with transfusion-dependent iron overload. The use of combination chelation therapy would allow Desferal® to be infused less frequently, and help facilitate medication adherence (taking both therapies as prescribed at recommended doses on time every time).

What Are the Side Effects of Iron Chelating Drugs?

The common side effects of iron chelators are listed in the *"Iron Chelating Drugs: Common Side Effects"* table. Some, but not all, patients experience side effects while on iron chelation therapy. Most side effects can be prevented or effectively managed by working closely with your health care team. In some cases, the side effects can be managed by a dose adjustment or dose interruption. Such medication changes should only be made after talking with your health care provider.

The most common reported side effects of Desferal include rash, hives, itching, pain or swelling at the infusion site, vomiting, diarrhea, stomach or leg cramps, bloody urine, blurred vision, fever, rapid heart beat, and dizziness. Potential long-term adverse reactions include kidney or liver damage, loss of hearing, or cataracts.

The most common side effects associated with Exjade use include diarrhea, nausea, vomiting, headache, abdominal pain, fever, cough, and mild nonprogressive increases in serum creatinine. Potential long-term adverse reactions to Exjade include kidney or liver damage, loss of hearing, or cataracts.

Although relatively rare, hearing and eye disturbances have been reported with Desferal and Exjade use. Therefore, patients should have an auditory test and an ophthalmologic exam prior to starting therapy and annually while on therapy. Laboratory values that should be measured include your liver enzymes, kidney function, hematocrit, ferritin, and transferrin iron saturation percentage. *(See "Frequency of Testing" table)*

Discuss any symptoms you have after starting chelation therapy with your health care team and ask about when you should notify them, how to call, what phone number to call, and who you should talk to if you are having symptoms. Find out what symptoms need to be reported immediately so they can be managed promptly and the more serious side effects can be avoided.

Iron Chelating Drugs: Common Side Effects

Desferal® (Deferoxamine)	**Exjade® (Deferasirox)**	**Ferriprox® (Deferiprone)**
Local infusion site reactions	Gastrointestinal disturbances	Neutropenia (very low neutrophil count) and agranulocytosis
Neurological toxicity	Elevated liver enzymes	Musculoskeletal and joint pain
Growth and skeletal abnormalities	Elevated serum creatinine	Gastrointestinal disturbances
Allergic reactions		Elevated liver enzymes

What Practical Measures Can I Take to Help Reduce Iron Overload?

In addition to iron chelation therapy for transfusion-dependent iron overload, there are some everyday guidelines you can follow to decrease your dietary intake of iron. To decrease the absorption of iron, it helps to consume milk products, certain high-fiber foods, and tea. Avoiding alcohol and tobacco smoke might help prevent further increase of iron levels. You should also avoid eating raw shellfish, particularly oysters, because they carry bacteria that thrive in plasma containing high iron levels and therefore can increase your susceptibility to a serious bacterial infection.

If you're receiving iron chelation therapy, keep track of your transfusions and ferritin levels. *(See Patient Tracking Chart in the Appendix)* Discuss the number of transfusions you've received and your ferritin level with your health care provider. As discussed above, excess iron leads to increased risk of complications and disease associated with iron overload.

Importantly, if you're receiving iron chelation therapy, it is critical that the iron chelation drug regimen is followed as prescribed. Effective iron chelation may take several months to several years depending on the level of excess iron and continued need for transfusions. The success of treatment depends on you taking the medication as prescribed. Skipped doses or stopping the medication without talking with your health care provider can make the treatment ineffective. If you feel that the regimen is too inconvenient or you are experiencing bothersome side effects or discomfort, talk to your health care provider. They can help you choose the best chelation treatment for you and they will help manage the side effects so that you are able to take your iron chelation therapy as prescribed. Changes need to be made under the supervision of your healthcare provider.

If you're feeling discouraged, don't give up—seek outside support. Help is available. See *Resources* section... and ask anyone on your health care team. They are there to help.

APPENDIX

Glossary

absolute neutrophil count
A measure of the number of neutrophils, a type of white blood cells, in the blood; abbreviated ANC. A low ANC indicates an increased risk for serious infections.

anemia
A condition that results from not enough red blood cells; may produce a variety of symptoms and is detected by measuring RBC count and hemoglobin in the blood

antibodies
Proteins produced by certain cells of the immune system in response to the presence of foreign or "non-self" substances called antigens. Each type of antibody is unique, responds to a specific antigen, and signals other immune system cells to rid the body of the foreign substance or microorganism or aberrant cell. Also called immunoglobulins.

blood type
The four main blood types are based on the presence of two proteins on the surface a person's red blood cells—the A antigen and the B antigen. The four main blood types are A, B, AB, or O, with type A blood indicating that the A antigen is present on red blood cells and type B blood indicating that the B antigen is present on red blood cells. Type AB indicates the presence of both A and B antigens on red blood cells and type O indicates that neither A nor B antigens is present on red blood cells.

bone marrow
The spongy tissue in the center of bones that produces blood cells and platelets

cirrhosis
Scarring of the liver that results from injury or inflammation; also called liver fibrosis

ferritin
A protein in plasma that binds iron and helps to store iron in the body

fibrosis
The formation of scar tissue that results from injury or inflammation.

granulocyte
A type of white blood cell that helps the body fight infection

hematocrit
The fraction of the blood that is composed of red blood cells

hemoglobin
The iron-containing protein in the blood that carries oxygen to the body's tissues

neutrophil
A type of white blood cell that plays a key role in protecting the body against infection. The absolute neutrophil count, or ANC, is a common blood test that is a measure of the number of neutrophils.

plasma
The liquid portion of the blood that contains salts (electrolytes), hormones, and proteins

platelet
Cell fragment found in blood that is involved in blood clotting

red blood cell
A type of blood cell that contains the protein hemoglobin that carries oxygen to the tissues of the body; also called erythrocytes; abbreviated RBC

serum
The liquid portion of the blood that contains salts (electrolytes), hormones, and proteins but not the clotting protein fibrinogen; identical in composition to plasma but without fibrinogen

serum creatinine
A blood test used to evaluate kidney function; creatinine is removed from the body by the kidneys and excreted in the urine. If kidney function is suboptimal, creatinine levels will increase in the blood because less creatinine is released in the urine.

serum transaminase
A blood test used to evaluate liver function. High levels of enzymes called transaminases are found in the liver and are released into the blood when the liver is injured.

sideroblastic anemia
An anemia in which developing red blood cells in the bone marrow (erythroblasts) do not produce enough hemoglobin and become loaded with iron (called ringed sideroblasts).

thalassemia
A blood disease caused by abnormal hemoglobin production that results in anemia

transferrin
A protein found in plasma that binds iron and circulates it throughout the body

white blood cell
A type of blood cell of which there are five subtypes, including neutrophils and granulocytes. White blood cells, or WBC, also called leukocytes, play a central role in immunity.

Resources

Aplastic Anemia & MDS International Foundation: *www.aamds.org/aplastic*

American Cancer Society: *www.cancer.org*

American Society of Hematology: *www.hematology.org*

Be Transfusion Smart. Be Iron Smart: *www.betransfusionsmart.com*

Caring Bridge: *www.caringbridge.org*

Desferal® (Deferoxamine): *www.desferal.com*

Exjade® (Deferasirox): *www.exjade.com*

Ferriprox® (Deferiprone): *www.ferriprox.com*

Iron Disorders Institute: *www.irondisorders.org*

Iron Overload Diseases Association, Inc: *www.ironoverload.org*

Medline Plus: *www.nlm.nih.gov/medlineplus/medlineplus.html*

Myelodysplastic Syndromes Foundation: *www.mds-foundation.org*

National Anemia Action Council: *www.anemia.org*

National Heart, Lung and Blood Institute: *www.nhlbi.nih.gov*

The Leukemia & Lymphoma Society: *http://www.lls.org*

The MDS Beacon: *www.mdsbeacon.com*

The Merck Manual Home Edition for Patients and Caregivers:
www.merckmanuals.com/home/index.html

Additional Reading (from the medical literature)

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Financial Assistance

Exjade® Patient Assistance and Support Services (EPASS™) Complete Care for patients residing in the United States.
http://www.us.exjade.com/patient/epass-completecare.jsp
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http://diplomatpharmacy.com/funding
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How to Contact The Myelodysplastic Syndromes Foundation:

The MDS Foundation, Inc.
4573 S Broad Street, Suite 150, Yardville, NJ 08620
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Fax: 609-298-0590
http://www.mds–foundation.org

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PATIENT TRACKING CHART

Use this tool to keep track of pertinent information, including the number of red blood cell transfusions and serum ferritin levels.

BLOOD TYPE: **ANTIBODIES:**

Date	Platelets	White Blood Cell Count (WBC)	Absolute Neutrophil Count (ANC)	Hemoglobin (Hgb)

RED BLOOD CELL TRANSFUSIONS

Date of Transfusion	Location	Contact Number	Number of Units Received

Total numbers of units received →

SERUM FERRITIN

Date	Ferritin Concentration