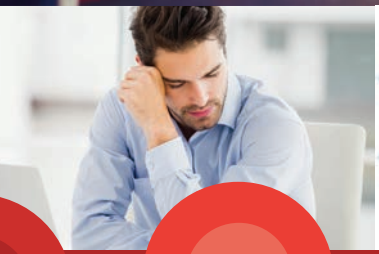
Haemochromatosis

Your questions answered

Haemochromatosis Australia
Inherited Iron overload disorder



Haemochromatosis
Some fast facts

- Haemochromatosis is the most common genetic disorder, affecting approximately 1 in every 200 Australians of European origin.
- Symptoms tend to occur after the age of 40, but may be earlier or later. Early symptoms may include fatigue, abdominal pain and joint aches.
- A person with haemochromatosis, if untreated, is at risk of absorbing too much iron from their food. This 'iron overload' builds up in various parts of the body and causes damage in adults.
- Early iron overload might have no symptoms, even though organ damage is occurring.
- Organs that may be damaged by iron overload include the liver, heart, pancreas, joints and sex organs.
- Iron overload can be detected by a blood test.
- The genetic condition of haemochromatosis is also detected by a blood test.
- Haemochromatosis is easily treated. Excess iron is removed from the body by taking blood in the same way as donating blood at a blood bank.
- Early diagnosis and treatment prevents complications and results in normal health and life expectancy.
- Haemochromatosis cannot be treated by diet alone.

Frequently Asked questions

These questions are answered in the following pages by some of Australia's foremost experts on the subject:

Professor Lawrie Powell AC, MD, PhD, FRACP, FRCP (Lond.)
Director, Royal Brisbane Womens Hospital Centre for the Advancement of Clinical Research
Professor Emeritus The University of Queensland Brisbane

Professor Martin Delatycki MBBS, FRACP, PhD.
Director, Clinical Genetics - Austin Health
Director, Bruce Lefroy Centre - Murdoch Childrens Research Institute

Professor John Olynyk BMedSc, MBBS, FRACP, MD.
Director of Gastroenterology, Fremantle Hospital

Dr Barbara Bell,
National Blood Services Manager, Australian Red Cross Lifeblood

Assisted by- Dr Katie Goot MBBS, BSc, FACRRM
GP Liaison Officer for Haemochromatosis Australia

How do I know if I have haemochromatosis?

Quick answer

Your doctor can order blood tests (known as iron studies) to check your iron levels. If there is a reason to suspect haemochromatosis you can be tested for the genes by another blood test.

More information - Contributed by Professor Lawrie Powell

Regular check ups

Many cases of haemochromatosis are now diagnosed when a person attends a GP for a "check up". In doing the standard laboratory tests the GP will notice a raised serum iron level and follow this up with more specific tests for haemochromatosis.

You should be tested for haemochromatosis in the following situations

You have some symptoms that suggest haemochromatosis

General symptoms relating to increased levels of stored iron in the whole body include fatigue, weakness, lethargy, apathy, weight loss, abdominal pain and joint aches – in particular, aches within the joints of the fingers.
If you have these symptoms, are Caucasian (of European racial origin) and over the age of 30, then haemochromatosis should be suspected.
If you have any of the complications that can be caused by haemochromatosis (including liver disease, liver cancer, heart failure, diabetes, impotence, loss of libido, early menopause, pigmented skin, arthritis), then you should be tested for haemochromatosis.

You have family members who have haemochromatosis

If your brother, sister, child, parent or grandparent has haemochromatosis, then you should be tested as your risk of having the same condition is much increased.
If your cousin, aunt or uncle has haemochromatosis then you should also be tested, although the risk is not as great as in the list above.

You should be tested if a relative died from one of the following conditions which might have been caused by haemochromatosis

- liver disease but did not have hepatitis B or hepatitis C and did not drink alcohol
- liver cancer at a young age (under 60 years old)

- heart failure where the cause of heart failure was not known
- "bronze diabetes" (pigmented skin and diabetes)

Blood tests

If you have ever had a blood test which shows that you have increased iron levels or that you have abnormal liver function then you should be tested for haemochromatosis.

Iron levels test name	Threshold to consider haemochromatosis for females	for males
Serum Iron	Above 30 µmol/L	Above 30 µmol/L
Serum Ferritin (SF)	Above 200 µg/L	Above 300 µg/L
Transferrin Saturation (TS%)	Above 45%	Above 50%

µmol/L = micromoles per litre and µg/L = micrograms per litre

There are a number of reasons apart from haemochromatosis that can lead to increased iron levels and abnormal liver function. These include hepatitis B infection, hepatitis C infection, alcoholic liver disease and fatty liver (also called Non-Alcoholic Fatty Liver Disease or NAFLD).

Who gets haemochromatosis and how?

Quick answer

Haemochromatosis is an inherited condition. To be affected you must receive a faulty gene from each parent

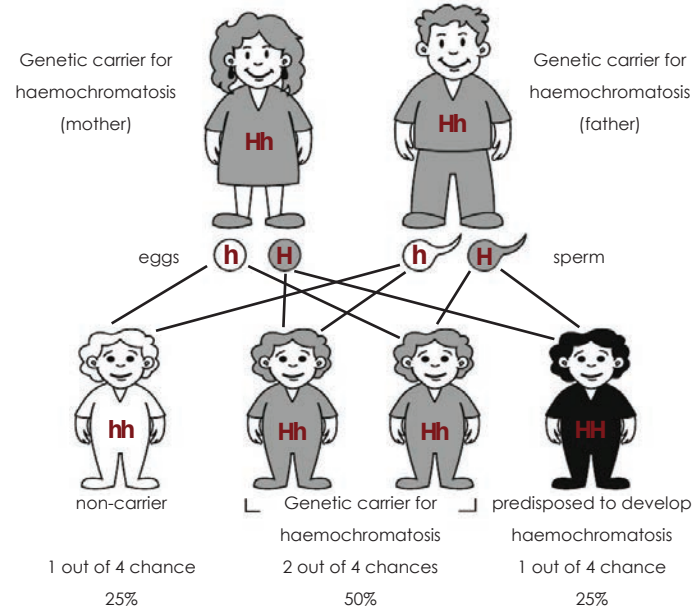
More information - Contributed by Professor Martin Delatycki

Genes and haemochromatosis

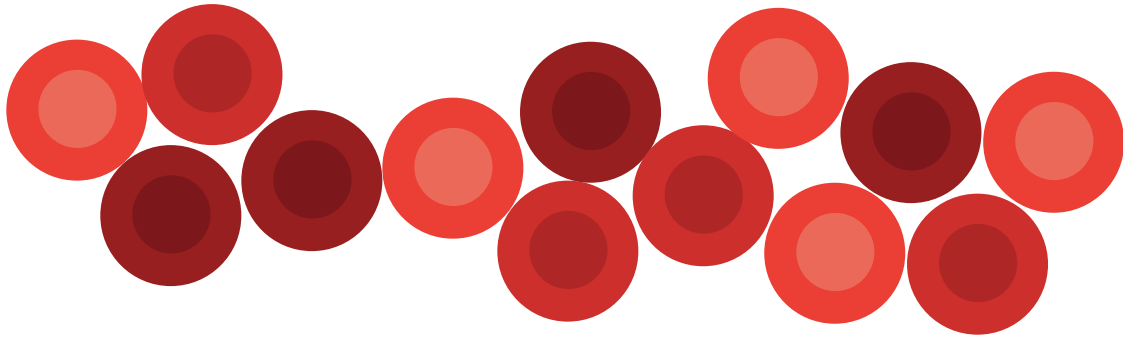
We have about 25,000 pairs of genes in each cell. Haemochromatosis occurs due to a person inheriting gene faults which are technically called mutations.

Faults in a number of different genes can cause haemochromatosis, but in Australia most people with the condition have it due to faults in the HFE gene.

Our genes come in pairs, one inherited from each parent. To have haemochromatosis a person needs to have a fault in both of their HFE genes (see figure). This is known as autosomal recessive inheritance.



h = normal HFE gene
H = faulty HFE gene



There are two common faults in the HFE gene. These are called C282Y and H63D. Almost all people with severe haemochromatosis have two copies of the C282Y gene fault.

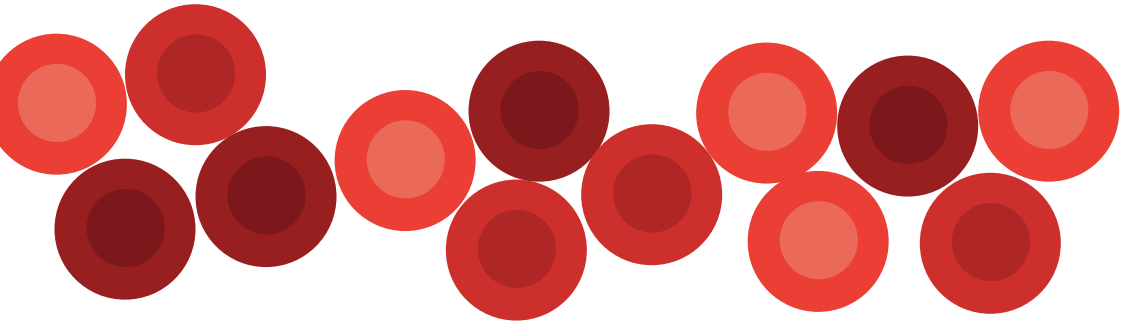
Around 80% of men and 60% of women with the double dose of the C282Y gene fault will have raised iron levels in their body. It is estimated that up to 45% of men and 10% of women who have a double dose of the C282Y gene fault will develop significant problems from this such as liver cirrhosis. An unknown percentage will have less severe problems. The reason why some have very high iron levels and severe medical problems whilst others have milder or even no problems is not well understood.

If a person has two copies of the H63D gene fault it is very unlikely that they will have any problems at all. If a person has one copy of C282Y and one copy of H63D they may get raised iron levels, but it is very unlikely that they will have severe problems such as liver cirrhosis.

There are some rarer forms of haemochromatosis that are due to faults in different genes. If a person is diagnosed with haemochromatosis but has normal test results for the HFE gene, testing of other genes can be arranged. Testing for faults other than HFE C282Y and H63D is complex and is generally done through a clinical genetics department. Clinical genetics departments exist in all Australian states.

How many people are at risk of haemochromatosis?

In Australia, around 1 in 5 people have a single copy of the H63D gene fault and 1 in 9 a single C282Y gene fault. Around 1 in 200 will have a double dose of the C282Y gene fault and around 1 in 50 has one copy of each of the C282Y and H63D gene faults.



Who should be tested?

If a person has haemochromatosis due to faults in the HFE gene then their relatives are at increased risk of also having haemochromatosis. Brothers and sisters have at least a 1 in 4 chance of having the gene faults and should be encouraged to be tested. Children of one parent who has haemochromatosis have around a 1 in 20 chance of having the condition.

Children

It is recommended that, rather than testing young children directly, the partner of the parent with haemochromatosis is tested in the first instance. This has two purposes. Firstly, the partner can know whether or not they are at risk of haemochromatosis themselves. Secondly, if they have neither C282Y nor H63D then their children are at very low risk of having haemochromatosis and do not need to be tested. If the partner has one or two copies of these gene faults then the children can be tested.

It is recommended that the children should be tested in late teenage years or early adulthood so that they can understand the issues that are relevant to them and make an informed choice about testing and its consequences. There is no evidence that haemochromatosis due to faults in the HFE gene results in significant problems before adulthood and therefore there is no need to test young children.

Other relatives

Because the gene faults for haemochromatosis are so common, more distant relatives, including aunts, uncles and cousins, should also be encouraged to be tested.

Some genetic mutations give humans an advantage. It is thought that the mutation that causes haemochromatosis was an advantage 2000 years ago where iron in the diet was scarce. The mutation first occurred in the Celts and Vikings and spread around the world when Celts and Vikings moved to different parts of the world.

Our genes are in our body even before we are born and are there in our body until we die.
We can't change the genes that we get from our mother's egg cell and our father's sperm cell.
Assuming normal conception, we cannot control the genes which we pass on to our children.

What is the risk of developing haemochromatosis in my lifetime?

Genotype*	Risk of iron overload	How many caucasian Australians have this genotype?
Normal genotype	no increased risk	2 in 3
Heterozygous H63D	probably no increased risk	1 in 5
Heterozygous C282Y	probably no increased risk	1 in 9
Homozygous H63D	very slightly increased risk	1 in 100
Compound Heterozygous C282Y / H63D	increased risk	1 in 50
Homozygous C282Y	greatly increased risk	1 in 200

* See **Explaining some words** inside the back page for the meaning of genotypes

What might haemochromatosis do to me?

Quick answer

If you have the genetic faults for haemochromatosis you are at risk of overloading iron. Too much iron can damage various parts of your body. Depending on the level of iron in your body you may develop one or more symptoms including chronic fatigue, joint pain, liver and heart problems

More information - Contributed by Professor John Olynyk

Developing iron overload

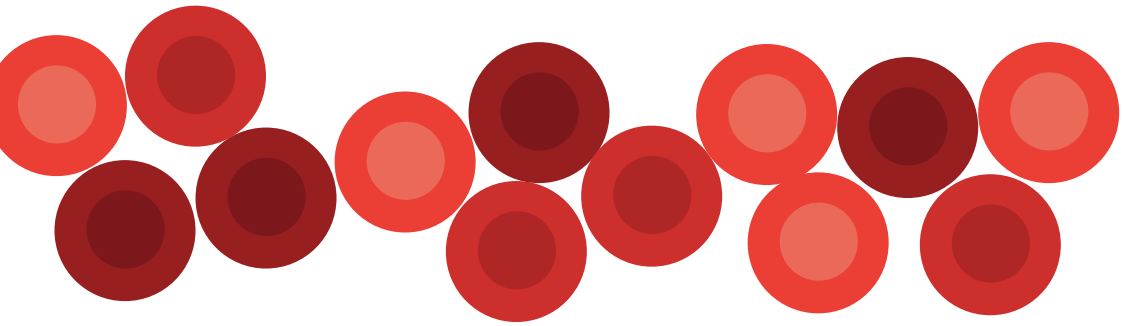
The degree of iron overload which is present in haemochromatosis is influenced by many things. These may be thought of broadly as factors which positively (+) enhance or reduce (-) the degree of iron loading, including:

+ a person's age (increased age provides a longer time to develop iron overload)
+ the amount of iron in a person's diet
+ the amount of iron a person takes in vitamin pills and medications
+ the amount of alcohol a person drinks
+ unidentified other factors including other genes
– the number of times a person has donated blood
– bleeding for any reason such as accidents and operations
– for menstruating women, the amount of blood lost in their periods
– number of children (pregnancy uses up stored iron)
– unidentified other factors including other genes

Symptoms of iron overload

Symptoms of haemochromatosis do not necessarily appear in a particular order and not every person with haemochromatosis will have symptoms. Many individuals, especially those who are younger, may have no symptoms at all. Each person has their own individual level at which they might feel symptoms of iron overload.

Generally symptoms develop as iron levels increase. However, some people can have high levels of stored iron with no symptoms. The absence of symptoms does not necessarily indicate that there is no significant body tissue damage occurring.



General symptoms of iron overload

Fatigue, weakness, lethargy, apathy, weight loss, abdominal pain and joint aches.

Symptoms of higher levels of iron overload in certain organs

Liver

Iron overload in the liver causes fibrosis, which generally repairs when iron stores are reduced. Higher levels of iron lead to cirrhosis (irreversible scarring and the death of liver cells).

Symptoms include:

- Pain in the liver (under your right ribcage) due to liver damage
- Enlarged liver, which doctors call hepatomegaly
- Fatigue and weakness
- Jaundice (yellowness of the skin and whites of the eyes)
- Reduced body hair, itching, easy bruising

In the most serious cases iron overload leads to liver cancer.

Heart

Iron overload in the heart leads to:

- Irregular heartbeat or palpitations due to heart muscle damage
- Shortness of breath, breathlessness with physical activity
- Fatigue
- Swollen ankles

In the most serious cases iron overload leads to heart failure.

Pancreas

Iron overload in the pancreas causes diabetes. The symptoms of this are:

- Thirst
- Increased need to urinate
- Tiredness

- Skin infections that don't heal well
- Blurry vision
- Dizziness
- Always feeling hungry, weight gain or weight loss

Diabetes, if untreated, may cause severe illness including blindness, kidney failure, heart attack and death.

Joints

Haemochromatosis is associated with arthritis. The most commonly affected joints are the hands, wrists, shoulders, hips, knees and ankles.

Skin

Iron overload may cause grey or bronze discolouration of the skin.

Sex organs

Iron overload may cause:

- In women, irregular periods, early menopause, loss of libido
- In men, impotence (inability to get or maintain an erection), loss of libido, shrinking testicles (which doctors call testicular atrophy), development of man boobs (which doctors call gynaecomastia).

Will it happen to me?

Not every person with the commonest genetic mutations linked to haemochromatosis will develop iron overload.

In Australia about 1 in 3 males and 1 in 30 females who are aged between 40 and 70 years and are homozygous C282Y will, at some stage, develop clinical features of iron overload disease.

It is difficult to predict if and when someone with genetic mutations linked to haemochromatosis will develop iron overload, so life-long monitoring of iron levels is crucial. Most men and women who will develop clinical problems related to iron overload will have done so by the age of 55-60 years.

It is important to remember that many of the symptoms that are associated with haemochromatosis may have other causes. If a new, unusual or worrying symptom develops, it's a good idea to get a check-up with your doctor.

Do I need to see a specialist?

Quick answer

Every GP has their own level of experience in looking after people with haemochromatosis.

Your GP might have lots of experience and feel very comfortable in looking after you. However, your GP might not have much experience in looking after people with haemochromatosis and might wish to ask for the advice and input of a specialist.

More information - Contributed by Professor Lawrie Powell

The following are some reasons for a person who has haemochromatosis to be referred to a specialist:

- Serum Ferritin (SF) more than 1000µg/L at the time of diagnosis
- Iron overload without typical genotype (Homozygous C282Y or Compound Heterozygous C282Y/ H63D)
- Abnormal liver function tests at the time of diagnosis
- Enlarged liver at the time of diagnosis
- Alcohol dependency.

Sometimes, further tests are needed to get a better idea of whether there are any complications of haemochromatosis.

The organ most directly affected by this condition is the liver. Therefore the specialists most often used are gastroenterologists or hepatologists. Other specialists will advise on heart, joint and other matters as required.

In any case, you always have the right to seek another opinion from a different GP or from a specialist.

How is haemochromatosis treated?

Quick answer
Keep iron stores at a safe level.
Have blood tests to check your level and have blood taken as necessary to unload iron.

More information - Contributed by Professor John Olynyk

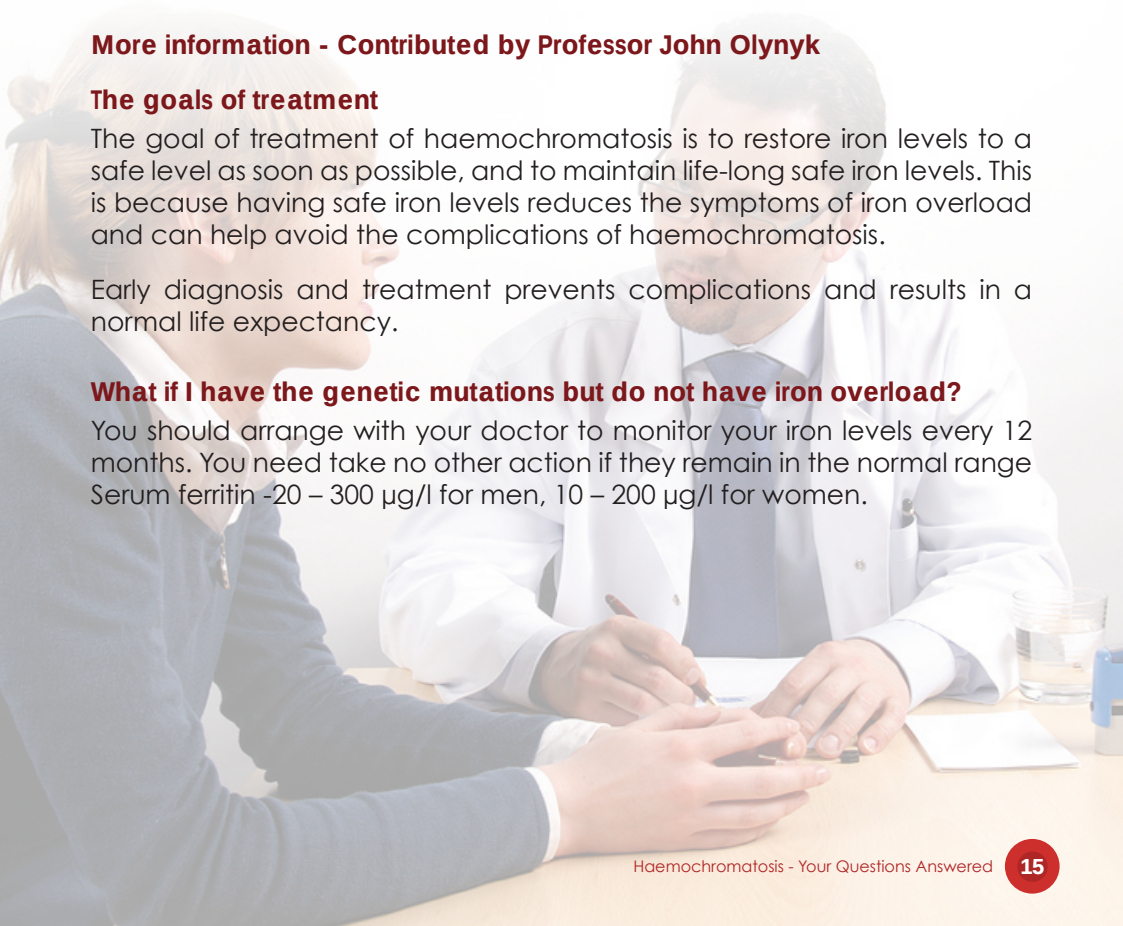
The goals of treatment

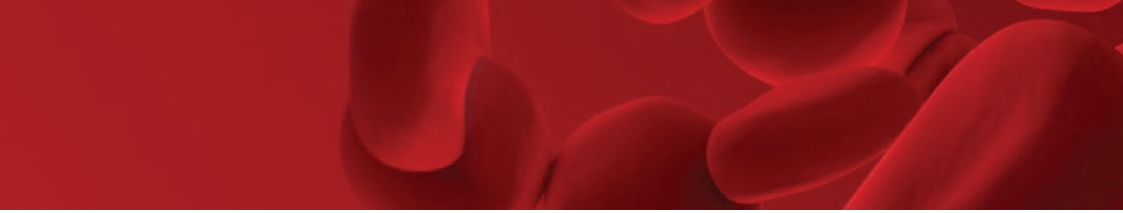
The goal of treatment of haemochromatosis is to restore iron levels to a safe level as soon as possible, and to maintain life-long safe iron levels. This is because having safe iron levels reduces the symptoms of iron overload and can help avoid the complications of haemochromatosis.

Early diagnosis and treatment prevents complications and results in a normal life expectancy.

What if I have the genetic mutations but do not have iron overload?

You should arrange with your doctor to monitor your iron levels every 12 months. You need take no other action if they remain in the normal range Serum ferritin -20 – 300 µg/l for men, 10 – 200 µg/l for women.





How can iron levels be reduced?

Venesection, or removal of 300-500mls of blood via a needle into the arm (the same method as blood donation), is the main treatment of iron overload in people with haemochromatosis.

Since the 1940s, venesections have been safely used in the treatment of haemochromatosis. This treatment is a safe, effective, and economical way of removing iron from the body. Rarely, some individuals cannot receive venesection therapy. For these people, special drugs called "iron chelators" can be administered to remove stored iron from organs such as the liver, heart, and pancreas.

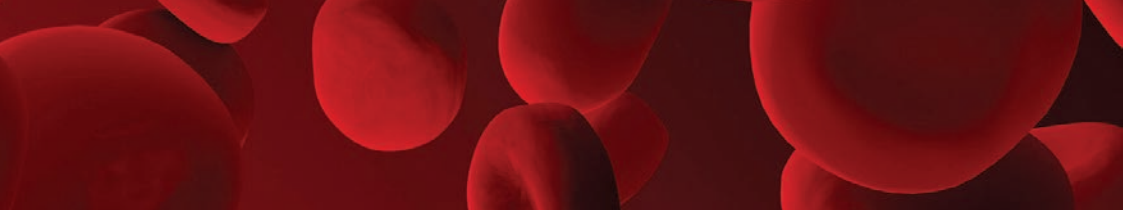
Haemochromatosis is not a blood disease. Thus the red blood cells of an individual with haemochromatosis can be safely transfused into other individuals, providing the person has no other contraindication to being a blood donor. This is the main reason why the Australian Red Cross Lifeblood provides treatment to haemochromatosis patients – they are a wonderful source of blood donors.

How can removal of blood remove stored iron?

Your body contains about 5 litres of blood. Your bone marrow is the blood cell factory of your body. Routinely in the human body, red blood cells are recycled every 3 months. If you lose blood by bleeding or donating blood, your bone marrow can replace that lost blood as long as you have enough iron, vitamin B12 and folate. This is because iron, vitamin B12 and folate are ingredients used to make new red blood cells.

After blood is removed by a venesection, some of the iron that is stored in the body moves out of storage and becomes available to help make new red blood cells.

If you have haemochromatosis and are iron overloaded and have adequate vitamin B12 and folate available, your bone marrow will be able to make new red blood cells every time you have a venesection.



A standard 500ml venesection removes 0.25 grams of iron from the body. (That is equivalent to the amount of iron in a 40mm nail).

It takes 4 venesections to remove 1 gram of excess iron (4 nails)
A person with moderate iron overload may have between 4 and 10 grams of excess iron, which will take between 16 and 40 venesections to reduce to normal levels.

Severe iron overload may be up to 40 grams of excess iron which will require up to 160 venesections to reduce to normal levels.

This is one way of understanding the iron level test results

* not very useful in the diagnosis and monitoring of iron overload

** very useful in the diagnosis and monitoring of iron overload

Iron level test name	Explanation	If it was money, it would represent
Serum Iron*	iron in the blood stream	"loose change in your pocket"
TIBC*	ability to get even more iron	"greediness for more money"
Transferrin Saturation**	iron transported around the body	"money kept in your wallet"
Serum Ferritin**	iron stored	"the savings you have in your bank"

The treatment of haemochromatosis is in two phases:

1. Iron unloading phase

This continues until stored body iron levels are at the lower end of normal

- weekly venesections
- it may take many months to unload excess stored iron
- the aim is to have a normal haemoglobin and Serum Ferritin of about 20-50 µg/L (a low normal range value)

2. Life-long maintenance phase

- monitoring iron levels at least every 12 months, usually every 3 months
- enough venesections every year of your life to keep your iron stores at a safe level

The number of venesections required to maintain your iron stores at a safe level is highly variable between individuals. Here are some interesting facts:

- in women who menstruate, blood loss each year is about the same as 2 venesections each year
- menstruating women usually need 1-2 venesections each year
- men and non-menstruating women usually need 3-4 venesections each year

How do I know if my treatment is on track?

There are a few things to look at when interpreting your blood tests, as these test results guide how often venesections are required.

Firstly, the number of red blood cells in your blood.

this is measured by Haematocrit or Haemoglobin. You need to have a normal Haemoglobin before having a venesection. Having low haemoglobin is called anaemia – avoid this! You should not have a venesection if you are anaemic.

Secondly, the amount of stored iron in your body, or your iron levels.

The best guide of your iron stores is your Serum Ferritin Level. It is the most useful test to guide how many venesections are needed.

Venesections need to be slowed down if:

1. Your Haemoglobin is too low because your body hasn't replaced your red blood cells just yet.

2. Your Serum Ferritin is too low because you are no longer iron overloaded.

What about diet?

You should have a healthy, nutritious diet. This will include foods with the small amount of iron that you continue to need.

Haemochromatosis cannot be treated by diet.

Any excess iron absorbed by the body must be removed by venesection eventually.

A 500ml venesection removes 0.25g of iron, which is roughly equivalent to 2 to 6 months' worth of iron absorbed from your diet.

So eat what you like, as long as you participate in life-long monitoring of iron levels and you have enough venesections every year of your life to keep your iron stores at safe levels.

If you are having lots of venesections extra vitamin B12 and folate, either in your diet or taken as a supplement, can be very helpful.

What about seafood?

People with high iron levels should be careful eating raw seafood.

- Vibrio vulnificus is a bacterium that can cause rapid and life threatening septicaemia
- It is rare but not unknown in Australian waters
- It thrives in the blood of people with high Serum Ferritin
- It is found in raw seafood, particularly in raw oysters and raw clams
- Cooking the seafood destroys the bacterium
- It can be found in seafood from India, Asia and Mexico
- People with high serum ferritin should watch cuts and abrasions which occur in sea water and seek help if they do not heal well.

A healthy, nutritious diet

For good health, choose fresh, unprocessed foods that are high in nutrients and low in saturated fats.
Enjoy a wide variety of nutritious foods:

- eat plenty of vegetables, fruits and legumes (beans, baked beans, chickpeas, lentils)
- eat plenty of cereals (including breads, rice, pasta and noodles), preferably wholegrain
- include lean meat, fish, poultry or vegetarian alternatives
- include low-fat dairy foods such as milk, yoghurt and cheeses
- drink plenty of water

and take care to:

- eat only moderate amounts of sugars and foods containing added sugars
- choose lower fat foods and limit saturated fat in your diet (butter, cream, meat fats)
- choose foods low in salt
- drink within the safe limits if you choose to drink (maximum 2 standard drinks per day with two alcohol-free days each week).

Iron supplements are best avoided.

Iron fortified foods and drinks are best avoided. These include some breakfast cereals, some kinds of milk, orange juices, 'energy food drinks' and many sports energy bars and drinks.

What about alcohol?

Any alcohol consumed can increase liver problems and increase iron absorption. Limit your alcohol intake to safe drinking levels as recommended by the National Health and Medical Research Council of Australia.

If you have any liver injury then you should not consume any alcohol.

Australian Alcohol Guidelines

- For healthy men and women, drinking no more than two standard drinks on any day reduces your risk of harm from alcohol-related disease or injury over a lifetime.
- Drinking no more than four standard drinks on a single occasion reduces the risk of alcohol-related injury arising from that occasion.

Where do I go for venesection?

Quick answer
Talk to your doctor about the options in your area.
Haemochromatosis is not a blood condition. Subject to other illness or treatment, your blood is useful for other people.

Some options

Australian Red Cross Lifeblood

Contributed by - Dr Barbara Bell, National Blood Services Manager Australian Red Cross Lifeblood

The Australian Red Cross Lifeblood (Lifeblood) has a therapeutic venesection program for individuals who have iron overload as a result of hereditary haemochromatosis (HH), which is funded by the National Blood Authority on behalf of all Australian governments.

Many people with haemochromatosis can attend Lifeblood for venesection and Lifeblood is able to use your donation to help save lives. Even if you are not eligible to donate blood which can be used to treat patients because of medical or lifestyle considerations, Lifeblood may be able to offer a therapeutic venesection service.

It is of utmost importance that when you attend Lifeblood you always answer our questions honestly in order to ensure your safety and the safety of the patients who may receive your blood. Whilst many people with haemochromatosis and iron overload are eligible to undergo therapeutic venesection with Lifeblood, there are some people for whom this is not an option.

Because ensuring the safety of Australia's blood supply is Lifeblood's priority, people who have evidence of infection with any virus which is spread through exposure to infected blood (hepatitis B, hepatitis C or HIV infection) are not eligible for Lifeblood therapeutic venesection program. Lifeblood tests for these viruses at every attendance. If you have one of these infections, your doctor will need to organise treatment elsewhere.

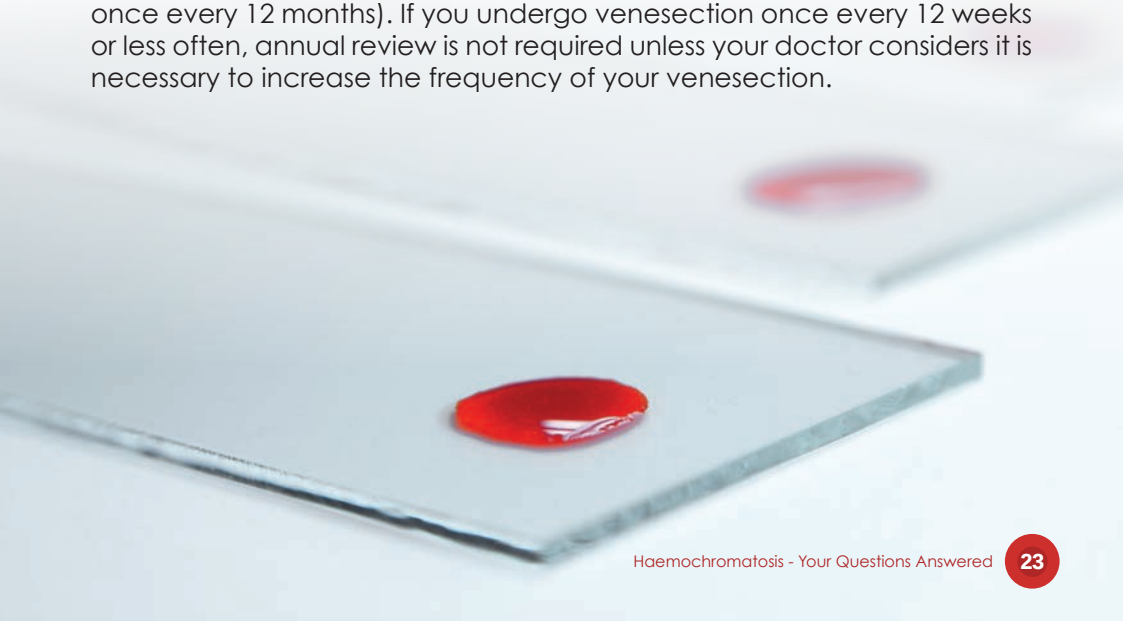
Lifeblood is committed to caring for donors' health and safety. It is not able to provide one-on-one nursing or medical supervision for donors, and because of this there are a number of medical conditions which make individuals unsuitable for venesection at Lifeblood.

People with known heart disease (heart attack, angina, heart failure, and abnormalities of heart rhythm), and those who have suffered from other vascular disease (stroke, TIA, disease of the blood vessels in the legs) are not able to undergo venesection with Lifeblood. If you have one of these conditions, your doctor will need to organise treatment in a facility where high levels of medical and nursing supervision of the procedure is possible.

Individuals who carry one gene for haemochromatosis are not eligible for the therapeutic venesection program. However, they are able to attend Lifeblood and donate as a normal blood donor, at a maximum frequency of once every 12 weeks. It is important to note that these individuals must meet all the donor eligibility criteria for blood donation. More information about eligibility as a blood donor can be found at www.donateblood.com.au.

Lifeblood does not perform any monitoring of ferritin levels for therapeutic donors and it is of utmost importance that everyone who is on Lifeblood therapeutic venesection program continues to see their treating doctor regularly.

If you need venesection more frequently than once every 12 weeks, your doctor will need to review your venesection schedule regularly (at least once every 12 months). If you undergo venesection once every 12 weeks or less often, annual review is not required unless your doctor considers it is necessary to increase the frequency of your venesection.



Online Referral to Australian Red Cross Lifeblood

The Australian Red Cross Lifeblood offers an online referral service for your doctor to refer you to the therapeutic donor program.
The **High Ferritin** application allows doctors to provide all necessary information required to assess your suitability for the program so that venesections can commence quickly.
Treating doctors can access the referral application at
www.highferritin.transfusion.com.au

For the details of the therapeutic venesection policy your doctor can refer to www.transfusion.com.au/high_ferritin

Public Hospitals

Some public hospitals offer venesection through gastroenterology, haematology or cancer outpatient clinics. This service is free.
Generally the blood is discarded but some hospital clinics, such as the one at the Royal Brisbane and Women's Hospital, make good use of the blood for research purposes.

Private Pathology Services

Some private pathology services offer venesection on a fee for service basis. A proportion of these will collect the full fee directly from Medicare. Others will charge the patient who then gains partial recovery from Medicare.
The blood collected is discarded or used for research purposes.

General Practice and Medical Clinics

Some General Practice and medical clinics offer venesection. Payment arrangements are the same as for private pathology services and thus free for some patients but at a subsidised cost to others.
The blood collected is discarded.

Day Surgery

Occasionally people with particular difficulties are admitted to day surgery units for venesection. In public hospitals this service is free of charge. Fees at private hospitals may be partly or fully covered by private health insurance.
The blood collected is discarded.

Further information and support
Haemochromatosis Australia

Haemochromatosis Australia is the not-for-profit support, advocacy and health promotion group for Australians affected by haemochromatosis.

- We provide support and information for people with haemochromatosis and their families.
- We promote awareness of the disorder and the need for early diagnosis.
- We encourage and foster research into haemochromatosis

For more information contact us on our Information Line 1300 019 028. Local call fee from any landline in Australia, Monday - Friday 9:00am - 5:00pm. Or visit our website www.ha.org.au

Become a member

You can join or make a donation to Haemochromatosis Australia on our website www.ha.org.au/supportus, by completing the form on the following page or by calling 1300 019 028. By becoming a member or making a donation you will help us to reduce the impact of haemochromatosis. Members receive a regular newsletter and up to date information.

Haemochromatosis Videos

View our helpful haemochromatosis videos at www.youtube.com.au/haemochromatosisaust

My Iron Manager App

Haemochromatosis Australia has developed a mobile app available from the Apple Store and Google Play Store to help people with haemochromatosis

- Find where to have a venesection using your location
- Record test results and venesection history
- Manage appointments
- Find out more about haemochromatosis.

We also have available in print a 'Venesection Record Book' to record test results and venesection history.'

More organisations providing support and information

- Arthritis Australia- *www.arthritisaustralia.com.au* 1800 011 041
- Diabetes Australia- *www.diabetesaustralia.com.au* 1300 136 588
- Heart Foundation- *www.heartfoundation.org.au* 1300 362 787
- Australian Red Cross Lifeblood- *www.donateblood.com.au* 13 14 95
- Digestive Health Foundation (Gastroenterological Society of Australia)- *www.gesa.org.au*

Join or Donate to Haemochromatosis Australia

You can join Haemochromatosis Australia or make a donation by:

- Completing the secure online form on our website at www.haemochromatosis.org.au/join and paying by credit card, PayPal or bank transfer
- Completing the form below and returning it to us with your cheque, money order or credit card details, or
- Calling our INFO LINE 1300 019 028 to pay by credit card

Please post this form to:
Haemochromatosis Australia
PO Box 6185
MERIDAN PLAINS QLD 4551

Title: .....
Given name: .....
Last name: .....
Address: .....
Suburb: .....
State: ..... Postcode: ..... Country (if outside Aus) .....
Phone (Home) ..... (Mobile) .....
Email: .....
Date of birth: .....

Membership fees:
Standard: $40.00
Concessional: $25.00 (if you are receiving government support such as age or disability pension)
Membership Fee: $_____
I would like to donate: $_____
Total: $_____

Payment:
Cheque or Money order $_____ attached.
(please make payable to 'Haemochromatosis Australia'
Or Please charge my credit card $_____
Mastercard / Visa (circle one)
Card Number: _ _ _ _ - _ _ _ _ - _ _ _ _ - _ _ _ _
Expiry date: _____ /_____ CVV: _____ (three digit number on back of card)
Signature: .....
Date: .....
All donations of $2 or more are tax deductible.

THANK YOU FOR YOUR SUPPORT

Explaining some words

Genotype- the description of a gene
Mutation- a fault in a gene
Normal genotype- no mutation
Heterozygous- one mutated gene and one normal gene
Homozygous- two mutated genes with the same mutation
Compound Heterozygous- two mutated genes with different mutations
Venesection and Phlebotomy- both words mean giving blood

Does having the genetic mutations mean that I have haemochromatosis?

Some people would say that you do not have haemochromatosis unless and until you have iron overload. They would say that if you are homozygous C282Y or compound heterozygous then you have a **predisposition to haemochromatosis.** This means you are one of the people who **may** develop iron overload.

Others would say that if you have the mutations you have got the condition.

There is no clear agreement on this use of the word.

In some places **haemochromatosis** is called **Inherited Iron Overload Disorder.**

In some places it is spelt **hemochromatosis.**

Haemochromatosis Australia
Inherited Iron overload disorder

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