

# Haemochromatosis

A guide for patients, families & whānau



our mission is to care, our vision is to cure



LBC wishes to acknowledge the hard work and commitment of IRONZ, its committee and members, who up until September 2011 were the New Zealand Haemochromatosis Support & Awareness Group. IRONZ began in 1998 as a patient awareness and support group and have paved the way for support and information about haemochromatosis in New Zealand. IRONZ merged with LBC in 2011 and the production of this booklet has been made possible using financial contributions from previous IRONZ members.

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## Introduction

This booklet has been written to help you and your family or whānau understand more about haemochromatosis.

If you or someone in your family has been diagnosed with haemochromatosis, you may feel that you need more information. We hope that the information contained in this booklet is useful in answering some of your questions. It may raise other questions, which you should discuss with your doctor or specialist nurse.

You may not feel like reading this booklet from cover to cover. It might be more useful to look at the list of contents and read the parts that you think will be of most use at a particular point in time.

Some people may require more information than is contained in this booklet. We have included some internet addresses that you might find useful. In addition, you may also receive written information from the doctors and nurses at your treatment centre.

For further information or specific queries, you can email us at [iron@leukaemia.org.nz](mailto:iron@leukaemia.org.nz); or contact our Support Services team by phoning 0800 15 10 15.

It is not the intention of this booklet to recommend any particular form of treatment or management to you. Please discuss the management of your condition with your doctor and treatment team.

We hope that you find this booklet useful. There is a feedback form in the back of this booklet, please feel free to fill this in and return it to us to assist in the production of future editions.

Leukaemia & Blood Cancer New Zealand (LBC) supports people affected by a wide range of blood conditions, including haemochromatosis.

## Acknowledgements

Leukaemia & Blood Cancer New Zealand acknowledges the support of Haemochromatosis Australia for granting us permission to use shared material within this booklet.

Leukaemia & Blood Cancer New Zealand also gratefully acknowledges Dr Hilary Blacklock (Middlemore Hospital) and Dr Bart Baker (Palmerston North Hospital) for their assistance with the development of this booklet.

## Leukaemia & Blood Cancer New Zealand

Leukaemia & Blood Cancer New Zealand (LBC) is the only organisation in New Zealand dedicated to the provision of information and support to New Zealanders and their families living with blood cancers, and blood conditions such as haemochromatosis.

Since 1977, our work has been made possible through our fundraising events and the generous support we receive from individuals, companies, trusts and grants. We do not receive government funding.

### Patient Support

Leukaemia & Blood Cancer New Zealand's Support Services provide personalised support programmes for patients and their families. This can include regular visits, phone or email contact, as well as face to face education and support programmes and an online information forum. We also provide a toll free number for advice, empathy and support.

### Research

Research plays a critical role in building a greater understanding of blood cancers and other blood conditions. LBC supports and funds investigation into these disorders. Improved treatments for patients are those that lead to better outcomes.

### Information

We provide vital information to patients, families, health professionals and the community to improve understanding about blood cancers and blood conditions.



## Awareness

We work to increase public knowledge of blood cancers and conditions. This is achieved through specifically focused campaigns for the public, health professionals and health agencies.

## Advocacy

We represent the needs of patients and their families to the government, related agencies and other relevant organisations.

## Contacting us

Leukaemia & Blood Cancer New Zealand provides services and support throughout New Zealand. Every person's experience of living with a blood cancer or condition is different. Living with a blood disorder may not be easy, but you do not have to do it alone.



Call **0800 15 10 15** to speak to a local Support Services Coordinator or to find out more about the services offered by LBC. Alternatively, contact us via email by sending a message to [iron@leukaemia.org.nz](mailto:iron@leukaemia.org.nz) or by visiting [www.leukaemia.org.nz](http://www.leukaemia.org.nz).

We welcome visitors to our offices in Auckland, Wellington and Christchurch. Please phone for an appointment.

## Learning about your condition

Many people lack specific information when they are diagnosed with haemochromatosis. This booklet is designed to provide information about this condition, including the necessary investigations, family testing and the long-term management of iron overload when necessary.

Before going to see a specialist doctor, it may be helpful to make a list of the questions you want to ask. It may help to bring a family member or a friend along who can write down the answers to your questions or prompt you to ask others.

Your doctor will spend time with you discussing the disorder, the recommended investigations and a treatment or management plan. Feel free to ask as many questions as you need to.

Remember, you also have the right to request a second opinion if you feel this is necessary.



## Interpreting services

If patient and doctor do not speak the same language, family or friends may help to translate. However, the doctor can also arrange for a trained interpreter if using a family member or friends is inappropriate. New Zealand's Health and Disability Code states that everyone has the right to have an interpreter present during medical consultations.

## What is haemochromatosis?

Haemochromatosis is a genetically inherited blood condition affecting iron metabolism, causing a person to absorb too much iron. The stored iron levels may potentially become high enough to cause damage to major organs especially the liver, but also the heart, joints, pancreas and sex organs. Haemochromatosis is a blood condition which is not cancer and will not develop into a blood cancer.

### What is iron?

Iron is a mineral found in plants, soil and animals. Plants absorb iron through their roots, animals then eat these plants, which humans then consume in their diet as fruit/vegetables and meat. All foods contain iron, some more than others.

Iron is essential to many normal human body functions. As our bodies do not produce iron, we need to consume it in our diet. The body has no means of excreting excess iron, except through blood loss. When we consume iron under normal circumstances, we absorb just the right amount that our bodies require to function. In people with haemochromatosis the body absorbs too much iron over a long period of time and when a high level has accumulated, damage to body organs may occur.

### What is ferritin?

Ferritin is an iron-storage protein which keeps your iron in a dissolvable and usable state, which helps to prevent iron toxicity to the cells. The serum ferritin value reflects the amount of stored body iron – this is why serum ferritin levels are used to monitor and measure body iron levels through a standard blood test.

## How common is it & who gets it?

Haemochromatosis is an inherited condition, that is, a mutation or change in a gene in the cellular DNA is passed down to the person affected from their ancestors.

Although haemochromatosis is most common in people of northern European descent, it can occur in other ethnicities. Approximately 1 in 10 New Zealanders of northern European descent are carriers of one mutation, and one in 200 may have a mutation inherited from each parent and, as a consequence, are at risk of developing genetic haemochromatosis.

Parents of a person with haemochromatosis will at least be carriers of a genetic mutation, if not affected themselves. This is explained in further detail later on this booklet, including the chances of your siblings and/or children. See the section on genetic inheritance.



## What are the symptoms?

Haemochromatosis is usually a silent condition, which in many cases displays no symptoms. As a person ages and iron accumulates, some signs and symptoms may become evident.

These may include:

- tiredness, fatigue, lethargy
- abdominal discomfort
- joint pain
- low libido (loss of sex drive)
- Occasionally a person may develop a 'bronzed' complexion if the ferritin levels are very high (this is rare)

Signs and symptoms will vary from person to person, may not be present at all, or may be attributed to other issues, causing the condition to go unrecognised for some time.

For many people a regular check-up with their GP for other conditions, or as part of health insurance examination, often reveals the first indication of haemochromatosis through routine blood tests. However, serum iron studies are not always done routinely as most patients with haemochromatosis have a normal or slightly high haemoglobin.

Some undiagnosed iron overload sufferers, who have fatigue, have been known to take iron tablets for years without medical advice - these supplements are a serious danger to people with haemochromatosis. It is recommended that iron tablets are not taken for a prolonged course by anyone without a blood test.

## What are the risks?

Iron overload takes time to occur and consequently severely high iron levels and the potential to cause organ damage may develop over a series of years, often decades. However, diagnosis and treatment before the iron levels reach a dangerous level can prevent these complications.

There are different genetic sub-types of haemochromatosis and it is important to point out that not all people who have the gene mutations will accumulate iron to seriously high levels. The amount of iron accumulation will also depend on age, diet, iron supplements, whether a person has had blood transfusions, episodes of bleeding, heavy periods and/or pregnancies (women), whether they are overweight, have diabetes, hyperlipidaemia, and/or a heavy alcohol intake.

Those individuals without permanent organ damage can expect to have a normal life span. The small group with significantly damaged organs can have more serious problems and will need on going monitoring and treatment.

Iron overload can cause damage to the following organs:

- Liver: fibrosis, which is reversible with venesection. Very high iron levels can progress to cirrhosis, which is a known factor in the development of liver cancer.
- Heart: palpitations, breathlessness, fatigue, swollen ankles.
- Pancreas: diabetes, with symptoms of thirst, increased urination and tiredness.
- Joints: pain in the hands, wrists, shoulders, hips, knees and ankles, associated with arthritis.
- Skin: grey or bronze discolouration of the skin.
- Sex organs: in women – irregular periods, early menopause, loss of libido. In men – impotence, loss of libido, testicular atrophy, gynaecomastia.

## How is haemochromatosis diagnosed?

There are a number of blood tests which are required to confirm a diagnosis of haemochromatosis. Some of these blood tests include specific tests measuring iron levels, tests to assess any damage to other organs, and also tests to exclude other causes for increased iron/ferritin levels.

### Blood tests

Most people who are affected have an increased iron saturation of greater than 55% and/or a raised serum ferritin.

#### Iron tests

- Serum iron: the amount of iron circulating in the blood. This can vary during a 24 hour period and with food intake.
- Serum ferritin: the level of the serum ferritin generally reflects total iron body stores. However the result can be falsely elevated during an infection, and/or with inflammation, liver disease, heavy alcohol intake and when the serum cholesterol is raised.
- Serum iron binding capacity or transferrin: this test measures the amount of transferrin protein which binds to and transports the iron in the blood.
- Iron or transferrin saturation: the ratio of serum iron to iron binding capacity gives the percentage of iron which is firmly bound to the transport proteins. This does not reflect the saturation of the overall body in iron.

#### Liver function tests (LFTs)

A group of blood tests used to assess the general state of the liver by indicating a degree of damage or inflammation. Abnormal LFT blood results may be a result of a wide range of causes (some of them temporary and reversible), including viral infections, excess alcohol intake, fatty liver from obesity/high cholesterol and do not necessarily indicate permanent damage.

## Alpha fetoprotein (AFP)

This is a protein present in the liver which rises significantly if a cancer develops. A gradual increase in a person with haemochromatosis may indicate the development of liver cancer in its early stages. Therefore it is an important tool in monitoring patients with cirrhosis and may be tested every 6 to 12 months by your doctor.

## Genetic testing

Currently only a small number of genetic mutations responsible for haemochromatosis have been identified, usually in people of northern European descent. Therefore, genetic testing for the common European mutations, which are expensive, should not be carried out on other ethnicities (e.g. Asian), as they will return false negative results.

Genetic testing should only be done once; because haemochromatosis is an inherited disorder, the results will not change with time. If the results of this test are negative, it does not mean that the person does not have haemochromatosis, only that they do not have one of the genetic mutations that can currently be tested for.

## Other blood tests

Other blood tests may include: blood glucose, fasting lipids (including cholesterol) and infection markers.

## **Radiology tests**

### Ultrasound scan

A non-invasive and painless scan using sound waves (similar to a pregnancy scan) which can detect changes/cancers in the liver. This may be done every 6 or 12 months in the small group of people with cirrhosis.

### Ferri-scan®

A special kind of magnetic resonance imaging (MRI) technique which is able to accurately quantitate the amount of iron in the liver tissue using sophisticated computer software at the time of testing. This test is only performed for diagnosis in rare situations.

## **Liver biopsy**

A needle is passed into the liver to obtain a sample which is then analysed under the a microscope in the laboratory. This is only done in a small number of cases where the cause of an abnormal liver is not clear; it is particularly useful to check whether the iron is in the liver or storage cells and to provide diagnostic information where the doctor wants to exclude other causes of liver damage and/or cirrhosis. The need for this test has lessened with the availability of non-invasive investigations.

## Which doctor?

If your General Practitioner (GP) suspects that you might have haemochromatosis you may be referred on to other specialist doctors for further tests and consultation. These may include the following:

**Haematologist:** a doctor who specialises in the care of people with conditions arising from the blood, bone marrow and lymphatic system.

**Gastroenterologist or Hepatologist:** a doctor who specialises in the care of people with conditions of the liver, stomach and bowel.

Iron is absorbed in the gut and complications of haemochromatosis can affect the liver, this is why patients are sometimes under the care of a gastroenterologist or hepatologist.

You may be managed primarily through your GP, or a combination of GP and specialist doctor.

## Monitoring & treatment

It is important to note that not everybody diagnosed with haemochromatosis will need treatment. However, all diagnosed with the condition should have regular blood tests with their doctor to monitor their iron stores and to detect early iron overload.

Haemochromatosis is primarily monitored with blood tests. Depending on how your body is affected by the condition and your rate of iron accumulation, selected people may require ultrasounds and sometimes liver biopsies at infrequent intervals, if organ damage is suspected.

If your blood levels of ferritin are very high, then treatment will likely be required in order to prevent damage from prolonged iron overload.

Treatment for haemochromatosis is therapeutic venesection; this involves taking an amount of blood from a vein in the arm, similar to giving a blood donation. Some people with haemochromatosis never need venesection; others may require an initial course of venesection after diagnosis and then there may be a period when venesection is not needed. At different times in your life, your body uses iron at different rates, which is why venesection may occur at irregular intervals.



The frequency of venesection required for a person varies greatly. Typically when a person is newly diagnosed they require more regular venesections – this could be anywhere from weekly, fortnightly to monthly, depending on the initial ferritin level and the ability to cope with regular venesections without causing significant anaemia. When blood is removed, the excess iron in the body is used to replace that lost. This intensive phase is to deplete the iron stores as quickly as possible to an acceptable level.

Once a person has their excess iron stores depleted – which can take up to 12 months, they then usually enter a maintenance phase of venesection. At this point, the frequency of venesection is decreased to maintain the iron levels at an acceptable level. Again, this varies between individuals but may be 3-6 monthly.

Furthermore many individuals who have their iron stores depleted may never again accumulate iron to a level as to require further venesection treatment. Their bodies may not re-accumulate iron as before and/or simply their age precludes this being a problem in future years.

## Target blood test values

Target parameters can vary depending on several factors and are determined by your treating doctor or specialist nurses as the best target for you. Your age, other medical history, medications and general health are all considered when planning the best course of treatment for you.

- Management is based on serum ferritin levels which reflect the amount of stored iron in the body. If venesection is clinically indicated, a serum ferritin of 50-100ug/l may be a reasonable target – however this is subject to individual patient factors.
- Transferrin saturation levels can fluctuate throughout the day depending on the diurnal variation of serum iron levels and are not used routinely to determine the frequency of venesection.
- Organ damage is unlikely until the serum ferritin exceeds 1000ug/L. However a few people may experience symptoms at levels less than this. The most common of these is the rarer complication of arthritis especially in the joints of the hands and feet.
- Furthermore factors such as diabetes, cardiac conditions, age, and liver function will all be considered when your doctor advises you of the most appropriate management plan for your condition.

## What is therapeutic venesection?

Therapeutic venesection is the taking of blood as treatment for medical reasons. This involves taking an amount of blood from a vein in the arm, similar to giving a blood donation. The person reclines in a lazyboy chair or on a bed, and a needle is placed into a vein in their arm and approximately 450mls of blood (more or less depending on body weight) is collected in a blood bag or vacuum bottle over 10-15 minutes. The person is then encouraged to rest for at least 10 minutes following the procedure and to have a drink to help replace the blood volume lost, before leaving the clinic or practice where this has been performed. Some patients with heart conditions may need to be more carefully monitored.

### Tips for venesection:

- Do not have a venesection while fasting. Ensure you drink plenty of fluids prior to having a venesection, particularly in the warmer summer months. This aids in recovery by preventing hypotension (low blood pressure) and enhances nice full veins for easy needle access. If your veins are not very accessible, putting your arm in warm water can help.
- Listen to your body – take the time to rest 10 minutes after the procedure. Have a juice, a cup of tea and a snack. If you feel tired, then rest.
- Avoid heavy lifting from the affected arm for 24 hours following venesection. The arm may be tender and you do not want it to start bleeding again. Leave the dressing on overnight for this reason also.
- If you are anxious or have other significant health issues – tell the nurse your concerns. She/he will do their best to reassure and explain things to you and may even be able to schedule your appointment at a time of the day where a support person can accompany you and drive you home.
- Patients who have dangerous jobs or operate heavy machinery should not work on the day of venesection.
- Top athletes should avoid venesections for four to six weeks prior to an elite event such as a cycle race, rowing event or marathon as lowering the haemoglobin can affect sport performance (reduces  $VO_2$  max).

Treatment takes place in New Zealand in a variety of settings depending on which region you live in. These include: hospital outpatient clinics, the New Zealand Blood Service (NZBS), community laboratories and occasionally in some GP practices.

Some people with haemochromatosis may be eligible to become a blood donor through the New Zealand Blood Service (NZBS). There are certain criteria which a person must meet – your doctor can complete a referral form to the NZBS to see if you are eligible.

There is a Venesection Record Book available from Leukaemia & Blood Cancer New Zealand, to keep track of your blood tests and treatment. Contact us on 0800 15 10 15, [iron@leukaemia.org.nz](mailto:iron@leukaemia.org.nz), or ask your doctor or nurse for a copy.

## Genetic inheritance

Genes contain the information the body needs to develop from the first cells to the grown adult body. There are about 300,000 genes in the body and research continues to map these genes and understand how they affect our health and well-being. Genes come in pairs with one from the father and one from the mother.

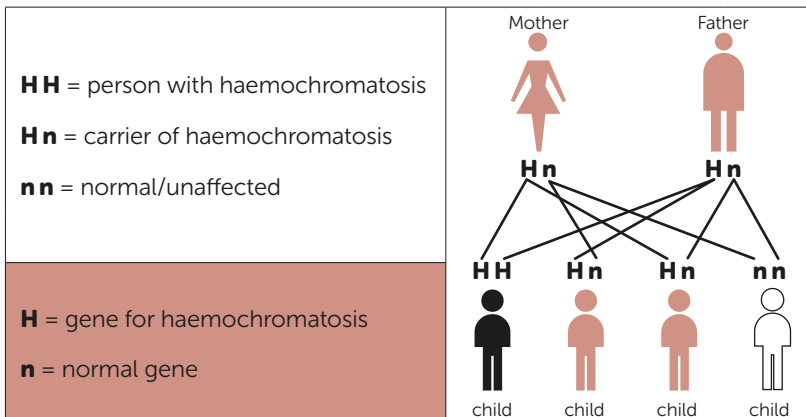
Inherited disorders are caused by specific genes that have changed or 'mutated' and have been passed down through generations. You have no choice in the genes you inherit.

The most common abnormal gene for haemochromatosis occurs frequently in the population; 1 in 10 people of northern European descent are carriers and 1 in 200 people in New Zealand may be affected.

Gene inheritance occurs when a particular family characteristic is passed on from one generation to another, such as blonde hair or blue eyes. The gene for haemochromatosis is recessive; this means that people with haemochromatosis have inherited two separate genes, one from their mother and one from their father, to have the condition.



If a person only inherits one haemochromatosis gene – they are a carrier, and do not have the condition itself, but possess the ability to pass it onto their offspring. The diagram below shows the possible outcomes for offspring from two parents who are carriers:



## Types of haemochromatosis

**HFE haemochromatosis:** The gene that controls haemochromatosis has been identified and is known as HFE. While several different mutations in this gene have been discovered, there are two main mutations or faults that cause hereditary haemochromatosis in people of European descent; these are referred to as C282Y and H63D. The C282Y mutation is associated with most cases of hereditary haemochromatosis. The H63D mutation (and some other rarer mutations) only cause problems when inherited together with the C282Y gene (see compound heterozygote below).

**Homozygous haemochromatosis:** the person has two copies of the C282Y mutated gene. This person has hereditary haemochromatosis, and may be at risk of absorbing excess iron from the diet and developing iron overload.

**Heterozygous haemochromatosis (carrier):** the person has one copy of a faulty gene and one unaffected gene. This person is known as a carrier; it is uncommon for them to have significant issues with iron overload.

**Compound heterozygote:** the person has one copy of the C282Y gene and one copy of the H63D gene. This person is at less risk of accumulating excess iron stores, although to a lesser degree than that of a homozygote. This sub-type is sometimes referred to as a milder form of haemochromatosis.

**Non-HFE haemochromatosis:** 1 in 700 Europeans with haemochromatosis have no mutation in the HFE gene. This non-HFE haemochromatosis is due to mutations in other genes that are rarely tested, or are as yet unidentified. It is important to perform iron studies on close relatives of a person with significant iron overload and no identifiable gene mutation, to ensure that another family member does not have the same condition.

**Non-European haemochromatosis:** very rarely haemochromatosis occurs in people of non-European descent. As these mutations are as yet largely unidentified and are therefore unable to be tested for, genetic testing in people without European ancestry is not appropriate.



## Family testing

If you have been diagnosed with hereditary haemochromatosis, you should explain to your family what it is and the importance of being tested. If their tests are positive they will have the chance to take control of their condition and if the test is negative they will be reassured that they do not need treatment or monitoring.

Your doctor will help you work out a plan to inform and discuss the impact of your diagnosis with your family.

### Children

If a parent tests positive for haemochromatosis the most logical step is to genetically screen the other parent. If that other parent does not carry a mutated HFE gene then testing of the children is not required.

Because it is unlikely haemochromatosis will cause damage through excessive iron stores in children (iron stores take years to accumulate), it is widely recommended that genetic testing of children is delayed until late teenage years /early adulthood.

If a young child is suspected to be positive for haemochromatosis, it is very important not to restrict foods which contain higher levels of iron which is a vital requirement for normal childhood growth, brain development and academic performance as well as immune function.

There may be exceptions to this and testing of children should be discussed in full with your doctor, so a plan which is appropriate for your family can be undertaken.

### Other family members

Testing all the population is not possible or sensible, but once a person is found to have a haemochromatosis gene, other family members may be advised to also be tested. These can include parents or children, brothers and sisters, aunts, uncles, and first cousins. The aim of family testing is to identify any other individual with iron overload before permanent organ damage occurs.

## Pregnancy

Considerable iron is required to meet the requirements of the pregnant woman and the developing baby during pregnancy. Thus iron stores are actively depleted as a result – this is why iron supplementation is often required during pregnancy.

However, indiscriminate use of iron supplementation during pregnancy may be harmful in women who have haemochromatosis, unless iron deficiency is determined through blood tests.

It is recommended that women have iron studies performed in early pregnancy. Those women who have haemochromatosis should consult their doctor regarding the management of their individual iron status during pregnancy.

In some instances it may still be necessary to have iron supplements during pregnancy, due to increased body requirements for iron during this time.

## Looking after yourself

### Nutrition

A healthy and nutritious diet is important in helping your body maintain normal body function. Do not unnecessarily restrict or cut out the intake of any food groups from your diet, as this could lead to deficiencies in certain nutrients. Talk to your doctor or nurse if you have any questions about your diet or if you are considering making any radical changes to the way you eat. You may wish to see a nutritionist or dietician who can advise you on planning a balanced and nutritious diet. Just remember that all foods contain iron to a varying extent, and that if you are on maintenance venesections with a relatively normal monitored serum ferritin level, restrictions are unwarranted.



A low iron diet will not on its own prevent or reduce iron accumulation. In general a balanced nutritional diet is recommended. However there are some specific recommendations for people with haemochromatosis:

- Avoid iron supplements
- Consume red meats in moderation
- Eat a balanced diet
- Consume alcohol in moderation<sup>1</sup>
- Limit vitamin C supplements to 500mg/day and preferably take at a time away from your regular meals
- Use mineral supplements for specific deficiencies only<sup>2</sup>
- Do not consume raw shellfish<sup>3</sup>
- If you are known to have a fatty liver or diabetes, seek advice on specific dietary restrictions

Notes:

1. People who already have liver abnormalities should abstain from alcohol.
2. Some minerals (zinc, cobalt, manganese and chromium) share absorption pathways with iron and may also be retained in the liver.
3. People with haemochromatosis at the stage when the serum ferritin is very high are at risk of developing an infection from the organism *Vibrio vulnificus* which can contaminate shellfish. As this is very rarely found in New Zealand waters, the risk of severe infection/sepsis is very rare. Cooked shellfish are fine to consume, and eating shell fish can resume when iron levels are normal.

If you wish to take a multivitamin, there are formulations on the market which do not contain iron. You can visit your local health supplement store for more information on these products.

## Complementary therapies

Complementary therapies are therapies which are not standard medical therapies. Many people find that they are helpful in coping with their treatment and general well being. There are many different types of complementary therapies. These include yoga, exercise, meditation, prayer, acupuncture, relaxation and herbal and vitamin supplements. Please ensure that such supplements are safe and are produced by reputable firms; also that they do not include iron.

Complementary therapies 'complement' or assist with recommended medical treatments. They are not recommended as an alternative to medical treatment.

It is important to let your doctor or nurse know if you are using any complementary or alternative therapies in case they interfere with your condition and/or the effectiveness of the treatment you may be having.

## Social and emotional effects

People cope with a diagnosis of haemochromatosis in different ways, and there is no right or wrong or standard reaction. With regular monitoring and treatment when appropriate, people with haemochromatosis can expect to live lives no different from those without haemochromatosis.

Information can often help to take away the fear of the unknown. It is a good idea for you and your family to speak directly to your doctor regarding any questions you might have about your condition and/or treatment. Some people find it useful to talk with other patients and family members who understand what it is like to live with haemochromatosis.

There is an online support and information forum run by Leukaemia & Blood Cancer New Zealand – LifeBloodLIVE. This is available at [www.lifebloodlive.org.nz](http://www.lifebloodlive.org.nz).

If you have a psychological or psychiatric condition, please inform your doctor and do not hesitate to request additional support from a mental health professional.

Support Services staff at Leukaemia & Blood Cancer New Zealand are available to provide you and your family with information and support. Please call **0800 15 10 15** to speak to a local Support Services Coordinator or to find out more about the services offered by LBC. Alternatively, contact us via email by sending a message to [iron@leukaemia.org.nz](mailto:iron@leukaemia.org.nz) or by visiting [www.leukaemia.org.nz](http://www.leukaemia.org.nz).



## Useful internet addresses

The value of the internet is widely recognised; however, not all the information available may be accurate and up to date. For this reason, we have selected some of the key sites that people living with haemochromatosis might find useful.

With the exception of our own websites, Leukaemia & Blood Cancer New Zealand does not maintain these listed sites. We have suggested sites we believe may offer credible and responsible information, but we cannot guarantee that the information they provide is correct, up to date or based on good evidence.

### **Leukaemia & Blood Cancer New Zealand**

[www.leukaemia.org.nz](http://www.leukaemia.org.nz)  
[www.lifebloodlive.org.nz](http://www.lifebloodlive.org.nz)

### **Haemochromatosis Australia**

[www.haemochromatosis.org.au](http://www.haemochromatosis.org.au)

### **Centre for Genetics Education - Australia**

[www.genetics.edu.au/factsheet/fs36](http://www.genetics.edu.au/factsheet/fs36)

### **Haemochromatosis Society - UK**

[www.haemochromatosis.org.uk](http://www.haemochromatosis.org.uk)

### **Canadian Hemochromatosis Society**

[www.cdnhemochromatosis.ca/](http://www.cdnhemochromatosis.ca/)

### **Hemochromatosis – USA**

[www.hemochromatosis.org](http://www.hemochromatosis.org)

### **Iron Disorders Institute - USA**

[www.americanhs.org/guidelines.htm](http://www.americanhs.org/guidelines.htm)

## Please send me a copy of the following patient information booklets:

Haemochromatosis

Venesection Record Book

### Or information on:

Leukaemia & Blood Cancer New Zealand's Support Services

How to make a bequest to Leukaemia & Blood Cancer New Zealand

### Newsletters:

LifeBlood

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Postcode: \_\_\_\_\_ Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Send to: Leukaemia & Blood Cancer New Zealand  
PO Box 99182, Newmarket, Auckland 1149  
Phone: 09 638 3556 or 0800 15 10 15  
Email: [info@leukaemia.org.nz](mailto:info@leukaemia.org.nz)

Leukaemia & Blood Cancer New Zealand will record your details to facilitate services and keep you informed about leukaemia and related blood disorders. We value your privacy and take all the necessary steps to protect it. You can access, change or delete this information by contacting us at [info@leukamia.org.nz](mailto:info@leukamia.org.nz)









# Haemochromatosis

We hope that you found this information booklet useful. We are interested in what you thought of the booklet – whether you found it helpful or not. If you would like to give us your feedback, please fill out this questionnaire and send it to Leukaemia & Blood Cancer New Zealand, at the address at the bottom of the following page.

## 1. Did you find this booklet helpful?

- Yes     No

Comments \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## 2. Did you find this booklet easy to understand?

- Yes     No

Comments \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## 3. Where did you get this booklet from?

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\_\_\_\_\_  
\_\_\_\_\_

## 4. Did you have any questions that were not answered in the booklet?

- Yes     No

If yes, what were they?

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**5. What did you like the most about this booklet?**

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**6. What did you like least about this booklet?**

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**7. Any other comments?**

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Thank you for helping us review this booklet. We will record your feedback and consider it when this booklet is reviewed for the next edition.

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11/2012 V1  
Charities Commission no. CC24498