LIVER UK

The new name for the British Liver Trust and Children's Liver Disease Foundation

Haemochromatosis

A guide for adults with inherited haemochromatosis

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Contents

Welcome

Welcome to your guide to understanding haemochromatosis. It provides information on causes, diagnosis, symptoms, treatment and living with haemochromatosis.

This information has been written for:
adults with hereditary haemochromatosis that started in adulthood

Others who may also find this information useful:
- family and friends of adults with haemochromatosis
- healthcare professionals

Visit our website to read and download all our information on haemochromatosis.

Including information about:
- neonatal haemochromatosis in newborn babies
- juvenile haemochromatosis in teenagers and young adults

Use this QR code to view our resources or visit **liveruk.org/haemochromatosis**

How to say it:
Haemochromatosis
Hee-moh-crow-muh-TOH-sis

Key facts about haemochromatosis

1. Haemochromatosis is a common genetic condition.
2. Around 1 in 160 people in the UK have it.
3. It means you absorb too much iron from your food.
4. The extra iron can build up causing iron overload.
5. It is diagnosed with blood tests.
6. Having the genes does not mean you will definitely become unwell.
7. Symptoms usually start in middle age.
8. Common symptoms include joint pain and fatigue.
9. Untreated iron overload can damage your organs, particularly the liver.
10. Treatment reduces iron in the body and lowers the risk of organ damage.
11. With treatment as needed, people with haemochromatosis have a normal life expectancy.

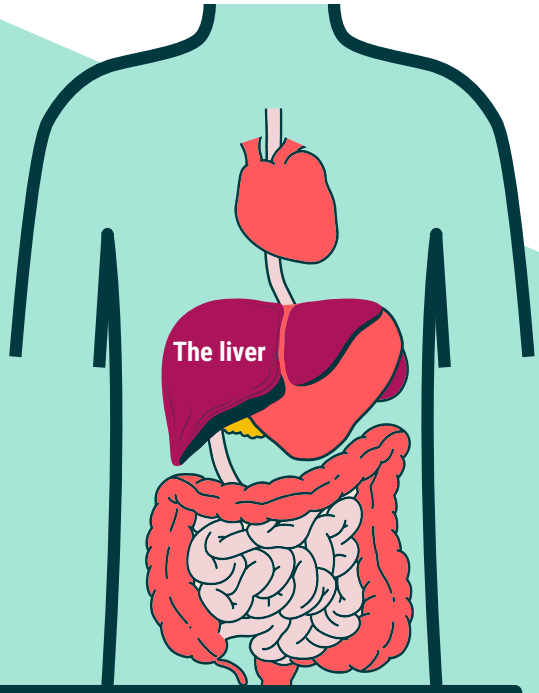
About the liver

The liver is one of the most important organs in the body. It is on the right side of the tummy, just under the ribs. It works like the body's factory and carries out hundreds of important jobs every day.

The liver is a dark reddish-brown colour.

It is divided into two main sections called "lobes". There is a right lobe and left lobe. The right lobe is a bit bigger.

The liver is joined up to some important arteries and veins that bring blood into and out of the liver.



The liver has over 500 jobs. These include:

- digesting food
- producing and storing energy
- storing vitamins, iron and other nutrients
- fighting infections
- breaking down toxins and other harmful substances
- helping you heal

About haemochromatosis

Few people know much about haemochromatosis, unless it runs in their family. This section explains what it is, what causes it and how it may affect you.

What haemochromatosis is

The name haemochromatosis is used for a few different conditions. They all have different causes. But they share a name because they can all lead to iron building up in the liver. Each type usually starts in a different age group. This information is about haemochromatosis that starts in adults, usually in mid-life. You can find information about juvenile haemochromatosis (teens and young adults) and neonatal haemochromatosis (newborn babies) on our website.

It's important to remember that these are separate conditions. People don't progress from one type to another as they get older.

If you have haemochromatosis your body doesn't process iron in the same way as other people. Iron can build up in your body and cause problems in the long term. But haemochromatosis can be managed by your doctor once you know you have it. The sooner you have treatment, the less likely you are to have any serious effects.

Haemochromatosis runs in families and can be passed on through your genes. If a close relative has it, you may be tested before you have any symptoms

As with other genetic conditions, how haemochromatosis is passed on is complicated. Some people have the genes but don't develop the disease.

About iron in the body

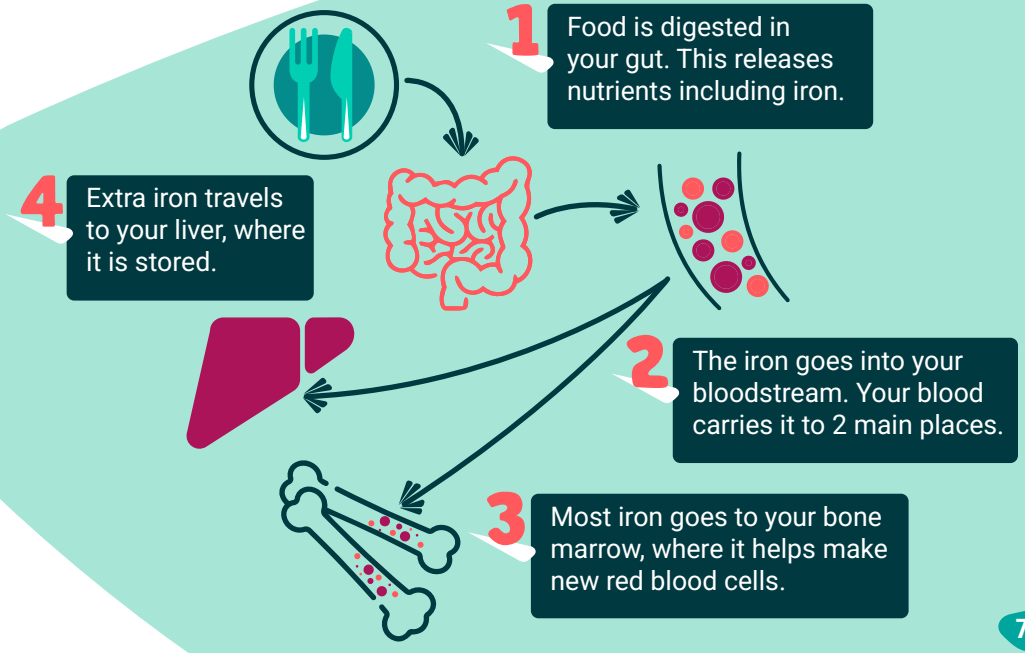
Iron is a chemical element that is found in many foods. It's a very important part of haemoglobin – a protein found in red blood cells. Your body also stores extra iron in the liver, for when it's needed.

Haemoglobin in red blood cells carries oxygen from the lungs around your body. It's then released to body tissues that need it.

Iron is absorbed in the gut from the food you eat and passes into the bloodstream. A protein called transferrin picks up the iron in the blood and carries it to the liver for storage or to your bone marrow, where new red blood cells are made.

How haemochromatosis affects iron in the body

If you have haemochromatosis, your body doesn't produce enough of a protein called hepcidin. This hormone limits how much iron your body absorbs from your gut when you don't need it. Without it, your body absorbs too much iron and can't get rid it. So, over time, it builds up. This is mostly in the liver. If haemochromatosis isn't diagnosed and managed, iron build up can eventually damage your liver and other body organs.



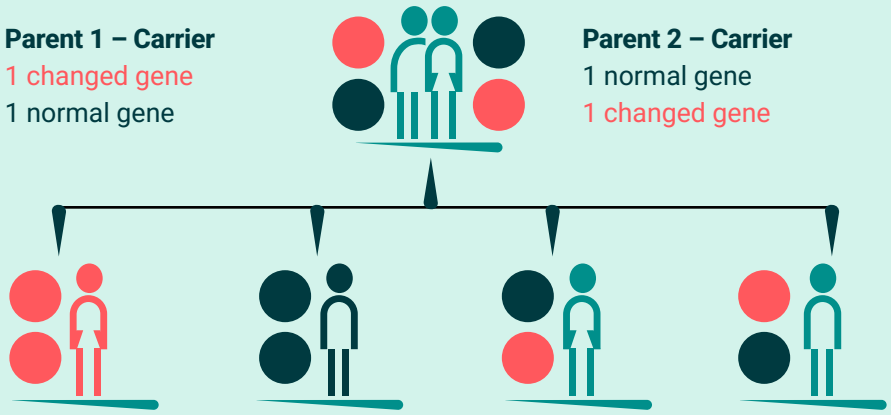
The cause of haemochromatosis

Haemochromatosis is a genetic condition that runs in families. Genes come in pairs. We inherit one from our mother and one from our father. Haemochromatosis is a recessive condition. That means that you must inherit the gene from both parents to be at risk of developing it.

A change in a gene that you inherit is called a genetic variant (because it 'varies' from the gene that most people have.)

If you inherit one copy of a haemochromatosis gene variant, you are a carrier and can pass it on to your children. But you won't have haemochromatosis yourself. Nor will your children, unless their other parent is also a carrier. Even then, there is only a 1 in 4 chance (25%) that a child will inherit the gene variant from both parents.

Only people with 2 gene changes can develop haemochromatosis



Around 1 in 10 people in the UK carry the most common haemochromatosis gene variant. But only around 300,000 people have inherited the gene from both parents and have haemochromatosis (1 in 156 people).

Even if you do inherit the haemochromatosis gene variant from both parents, you may never actually develop it. This is because of something called 'incomplete penetrance'. You can find out more about this on page 10.

Types of haemochromatosis

Several different genetic variants can cause haemochromatosis. The commonest is a change in the HFE gene called C282Y. It causes 8 out of 10 cases of haemochromatosis and is known as HFE haemochromatosis. Haemochromatosis caused by other gene variants is generally called non-HFE haemochromatosis.

In HFE and non-HFE haemochromatosis, you nearly always have to inherit a gene variant from both parents to have the condition.

Gene variants and risk

There are differences in the risk of developing haemochromatosis with different gene variants. C282Y carries the highest risk overall. A doctor or specialist nurse will investigate the gene variants you have. They can then talk through the risk of developing haemochromatosis, how likely you are to need treatment, and your risk of future complications.

A doctor or specialist nurse may also look at other possible causes of liver problems. These include alcohol use and a build-up of fat in your liver (a condition called fatty liver).

The risk of iron overload in haemochromatosis

Whichever gene variants you have, it doesn't necessarily mean you will develop haemochromatosis. This is the case with most genetic conditions.

The difference between the number of people having a genetic variant (the genotype) and the condition it can cause (the phenotype) is known as 'penetrance'. This may make more sense if you think of it as how much the disease breaks through - or penetrates.

Haemochromatosis has 'incomplete penetrance' meaning that not everyone with the genes will develop it. Doctors can't predict who will develop the actual condition and who won't.

Gene penetrance is likely to be affected by other genes that influence the same processes in the body and things in daily life (environmental factors). Several other genes help to control how your body takes in and uses iron (iron metabolism). These genes may take over all or part of this job in some people who have a haemochromatosis genotype.

Haemochromatosis is rarely affected by the amount of iron in the diet, but liver damage may be made worse by the effect of alcohol and fat accumulation in the liver.

If I have the gene variants, what are the chances I'll have iron overload?

Haemochromatosis is more likely to develop as you get older. The chances are higher in men than in women (although exact figures vary between research studies).

- Some people with the necessary gene variants have no sign of haemochromatosis at all.
- Some people have signs of haemochromatosis in blood tests. This means that blood tests are showing that their iron levels are beginning to rise. But they have no other signs or symptoms of haemochromatosis. Doctors call this 'biochemical penetrance'.
- Other people have biochemical penetrance and also have symptoms of iron build up in the body. Doctors call this 'clinical penetrance'.

If you have the gene variant for haemochromatosis on both copies of the gene, you will need to have regular blood tests throughout your life to check for iron building up (iron overload).

Having signs in your blood tests (biochemical penetrance)

At least half of those with the gene variants will have signs of haemochromatosis in blood tests at some point. This may be up to 8 out of 10 in men (80%) and just over half (55%) of women. It's lower for women because they lose iron each month during a period. This naturally lowers their iron levels until they reach menopause.

If your blood tests are showing signs of biochemical penetrance, your doctor will continue to monitor you. But they may not suggest treatment if there is no sign that the amount of iron stored in your body is too high.

Having symptoms of iron build up in your body (clinical penetrance)

If you have iron build up, your doctor may call this 'iron overload'. Signs of iron overload in blood tests will mean you need to start treatment. Your doctor will also monitor you for symptoms.

Having symptoms of iron overload is much less common than showing signs in a blood test. Most people with haemochromatosis genes will never develop any clinical signs or symptoms other than possibly fatigue and joint pain (which are relatively common). Symptoms are more common with age and in men.

Symptoms of haemochromatosis

Symptoms are caused by extra iron in your body. Your doctor will regularly check your iron levels with blood tests. But even if these are raised, you may still not have any physical signs because there is not enough iron to cause problems.

Don't assume that any symptoms are due to haemochromatosis – you're just as likely to have other causes of aches and pains as anyone else. See your GP or ask your specialist.

Rarely, haemochromatosis can cause other medical conditions to develop.

The symptoms of these other conditions are covered in "Complications and related conditions" on page 21.

Early symptoms of haemochromatosis

The commonest early symptoms of haemochromatosis are:

- feeling very tired (fatigue)
- arthritic pains in your joints, most often in the ankles, hips, or wrists and hands.

Joint pain in haemochromatosis is similar to osteoarthritis in the pain it causes and how it affects your joints. But it usually starts at a younger age than you'd expect with arthritis.

The most common symptoms of iron overload in haemochromatosis are joint pain and fatigue. They can both start quite early on, sometimes years before any other symptoms or signs develop.

Diagnosing Haemochromatosis

Your doctor may suggest tests for haemochromatosis after a close family member has been diagnosed. Or you may have signs of having too much iron and your doctor wants to confirm or rule it out.

It may be a shock to find out that there is a genetic condition running in your family. It will take time to take this in. Having some basic knowledge about genes and how genetic conditions run in families will help you come to terms with what it means.

If only one of your parents has a gene variant, you could carry it and pass it on to your children but are not at risk of having haemochromatosis yourself.

Having a test – or not

You can have a genetic blood test for the specific gene variants that cause haemochromatosis. Because haemochromatosis only affects adults, the genetic test is not usually offered to anyone under 18.

People have different views about being tested for any potential illness. Some people think straightaway that they would like to know for sure whether they have an illness or a gene that causes it. Others know straightaway that they don't.

Neither of these views are right or wrong. It's a personal decision. Most people are somewhere between and need time to weigh up the arguments for and against.

Even if you inherit two copies of a haemochromatosis gene variant, you may never have any symptoms. You may show signs in blood tests, but haemochromatosis may never develop any further.

Pros and cons

NHS genetic counselling services are available for anyone considering having a gene test. If you are struggling with your decision, speak to your doctor. They can refer you.

If you have a test, you will know whether you have any risk of developing haemochromatosis. If you don't have a test, you may be worrying about it unnecessarily.

Some people find the prospect of having any medical tests makes them very anxious. Just the idea of having any type of blood test may cause anxiety. Only you can know what's best for you.

These days, haemochromatosis is very well controlled with regular blood tests and treatment. If you don't know you have it, you may only find out because you develop symptoms that could have been avoided.

You may worry about a genetic test affecting insurance applications. But your insurance company is not allowed to ask you whether you have had any genetic tests for a medical condition.

What will happen if I have inherited haemochromatosis gene variants?

You will have blood tests from time to time, to see if you are developing iron overload. If you aren't, that'll be all you need.

If you do show signs of iron overload on your blood tests, your doctor may suggest more frequent blood tests and sometimes other tests such as scans. Depending on test results, your doctor will also discuss whether you need to start treatment.

Blood tests for haemochromatosis

You will need to have blood tests to check your iron levels if you have the gene variants or if your doctor suspects haemochromatosis. Monitoring your iron levels can help your doctor to make sure you don't develop any future health problems from excess iron.

There are two main blood tests that you will have:

- Transferrin saturation (TSat)
- Serum ferritin

Your doctor is also likely to do a complete set of liver blood tests for a general check of your liver health. Symptoms are more likely if there are other problems with your liver. It also gives your doctor a baseline for the future.

Transferrin saturation (TSat) measures the amount of iron you're absorbing. The normal TSat level is around 30%. If your TSat level is higher than 45%, you may have too much iron in your body.

TSat levels can vary through the day. Your doctor may ask you to have this checked at different times, or before you've eaten that day.

Having raised TSat doesn't mean that you have iron overload. It takes years for the iron to build up to a level that starts to cause problems.

Serum ferritin shows how much iron is stored in your body. Doctors measure this in micrograms per litre. They will compare this to the normal reference range for the lab that did your test, to see if it is higher than usual.

Ferritin can go up if you have other causes of liver damage, such as inflammation, fatty liver or drinking too much alcohol. If this is the case, your TSat level will be normal. A combination of both elevated ferritin and TSat are very suggestive of haemochromatosis.

If your results are normal

Your blood test can be normal at a young age, but you could be at risk of high iron levels in the future. Your doctor is likely to ask you to have the blood tests repeated at intervals. How often this happens may vary but it could be once a year. As long as the results are normal, this is all you'll need to have done.

If your results are raised

It's quite common for people to have raised blood test results but never develop any clinical signs of haemochromatosis. Depending on your TSat and ferritin blood test results, your doctor will talk through with you whether or not you need to start treatment.

Deciding if and when to start treatment is very individual. If you have raised TSat but ferritin is not raised, you are absorbing more iron than is normal but don't yet have iron overload. Some people want to start treatment then, but others prefer to wait until their iron level needs to be reduced. Your doctor will talk this over with you.

You will have further tests to make sure your iron levels won't cause symptoms or damage to body organs if not treated. This may also be to check for other causes of abnormal blood test results, such as fatty liver or damage from alcohol.

Further tests for haemochromatosis

Your initial blood test results give your doctor a general idea of your iron levels.

You may hear your doctor talk about tests called FIB-4 or ELF (Enhanced Liver Fibrosis test), which can give a more accurate picture of liver damage.

Everyone with haemochromatosis needs to have a liver assessment. Storing too much iron can damage and scar your liver – doctors call this fibrosis. As well as FIB-4 or ELF, you may have a special ultrasound called transient elastography (a FibroScan) or an MRI of your liver. Both of these are painless and take about half an hour. You have them as an outpatient.

Treating haemochromatosis

The aim of treatment is to reduce your iron levels and stop them from getting any higher. This prevents damage to your body, particularly your liver. If you already have some damage, treatment may even help your liver recover.

Removing excess iron

The most commonly used treatment for haemochromatosis is to have blood removed regularly. Doctors call this venesection (pronounced veen-a-section) or therapeutic phlebotomy. You might also hear the term 'blood letting'. You have around a pint (500ml) of blood taken each time. This takes out around 250mg of iron.

The treatment is very similar to giving blood. The nurse (or blood technician) will put a rubber strap around your upper arm. This is called a tourniquet (torn-ik-ay). It helps your veins stand out and makes it easier to put in a needle.

The nurse will connect the needle to a storage bag, to collect your blood. Once it's full, the nurse will take the needle out and put a cotton wool ball and some surgical tape over the site to apply pressure.

Preparing for venesection

Some people feel faint when they give blood. Eating a light meal an hour or two beforehand can help. Drink plenty before and after you have the blood taken, to make up for the fluid you've lost.

Some people like to warm up with a bit of light exercise before they go to the blood donation centre. This can help the technician to find a vein to put the needle into. Squeezing a stress ball can help the blood to flow during the procedure.

You may feel tired for a couple of days afterwards, so it's worth remembering that when planning your treatment.

How does venesection treat haemochromatosis?

When you have blood removed, your bone marrow steps up the production of red blood cells to make up for what's been lost. As the bone marrow needs iron to do this, your body moves iron from the stores in the liver. So, each time you have venesection, your liver iron stores will be reduced.

How often you have blood taken

The timing of your treatment depends on your test results. At first, you may have blood taken every one or two weeks. How long this goes on for varies. If you have very heavy iron overload, you may need weekly treatment for a year or more.

When your blood results are back to normal, you have treatment less often. Again, how often varies. It may be as often as every 2 months, up to every 6 months.

You'll have blood tests to check your ferritin and transferrin saturation (TSat) every few months. This makes sure you are having venesection often enough to keep your iron levels within a normal range.

What happens to my blood?

This depends on the stage of your treatment. Initial treatment is called “induction” venesection. This continues until your iron levels are back to normal. You usually have this as an outpatient in hospital. The blood that’s taken will be discarded.

Once your iron levels are normal, your treatment is called “maintenance” venesection. As long as you meet all the conditions for donating blood, you may be able to have your maintenance treatment as a blood donor. Then your blood can be used to help others in the same way as all donated blood. It’s perfectly healthy – as a genetic condition, haemochromatosis can’t be passed on to anyone else.

If you are donating your blood, you’ll go to a Blood Transfusion Service (BTS) donation centre to have your treatment. The BTS will register you as a haemochromatosis blood donor as you’ll be giving blood more often than is usual.

The BTS will not monitor your treatment, so it is important to still go for your regular tests and appointments as well.

Complications and related conditions

If it isn’t controlled, iron overload in haemochromatosis can cause a number of health problems.

Apart from fatigue and joint pain (arthritis), you are very unlikely to be at risk from these problems if:

- you are diagnosed before you have any damage from iron overload
- you have regular venesection to keep your iron levels normal.

There are also measures you can take to minimise the risk of complications. These are covered in our living with haemochromatosis page.

Liver damage

Too much iron in your liver can damage liver cells, causing scarring (fibrosis). This makes the liver stiff. If your doctor is concerned that iron is causing liver damage, they will ask you to have tests to measure the degree of stiffness. You may have ELF or FIB-4 blood tests and a type of scan called transient elastography, sometimes called a FibroScan.

If liver damage continues, it can eventually develop into cirrhosis. There is so much scarring that the liver can’t work properly. Having cirrhosis increases your risk of developing a type of liver cancer called hepatocellular carcinoma (HCC). If you are at risk of HCC, your doctor will organise regular monitoring (doctors usually call this ‘surveillance’). This is so that any changes indicating cancer will be picked up as early as possible. This greatly increases the chance of successful treatment.

Contact Liver UK for more information on cirrhosis and HCC.

Liver biopsy means taking a sample of liver tissue to look at under a microscope. It is used less often these days. Other tests are as good at measuring fibrosis or checking for cirrhosis. If your test results are unclear or contradict each other, your doctor may suggest it.

Joint problems

Excess iron can damage your joints, leading to arthritis. Unfortunately, this is very common, even if you have regular treatment to control your iron levels. More than 8 out of 10 people with haemochromatosis have joint pain, most often in the hips and ankles or hands and wrists.

If you develop arthritis, your doctor will offer pain killing and anti-inflammatory medicines. Physiotherapy may also help. Some people need joint replacement surgery. On average, they need this type of surgery at a younger age than those without haemochromatosis.

Bone thinning (osteoporosis)

This means your bones are losing calcium and are not as strong as they were. It increases the risk of fractures. Even if your iron levels are controlled with treatment, you may have a higher than normal risk of osteoporosis.

A bone density scan will show if you need treatment. There are medications you can have to try and prevent any further loss of calcium. These are called bisphosphonates. They are usually tablets that you take once a week. They do have side effects, particularly irritating the lining of your stomach. Your doctor will discuss this with you if you need to take them.

Diabetes

This means your body is less able to control blood glucose levels. It can lead to many complications if it isn't diagnosed and controlled with diet, tablets or insulin.

Excess iron can collect in the pancreas, damaging the cells that produce insulin. The iron may also make your body cells less receptive to the insulin you do produce.

Your doctor will monitor your blood sugar when you have routine blood tests. But if you notice symptoms such as peeing more often, feeling very thirsty or losing weight, tell your doctor.

Controlling your iron levels will reduce your risk of diabetes. It will also help to reduce your risk if you eat healthily and manage your weight. There is more about this in "Living with haemochromatosis" on page 24.

Heart problems

These are rare in people whose iron levels are controlled with treatment. But excess iron can damage heart muscle, causing heart problems. If you have severe iron overload, your doctor may check your heart with tests such as an ECG or heart MRI. Having excess iron removed with regular venesection can help to improve heart problems.

Other hormonal changes

This is rare in adult haemochromatosis that is well controlled. But it is possible in more advanced disease.

Sex hormones and thyroid hormones may be affected. Men may have difficulty getting an erection. And women may find that their periods stop at an earlier age than normal menopause. Low levels of thyroid hormones can make fatigue worse.

Your doctor will monitor your hormone levels if they think they have been affected. Again, keeping your iron levels well controlled with treatment makes these symptoms less likely.

Skin changes

As haemochromatosis progresses, a very small number of people may develop a change in the appearance of their skin. This is actually very rare, but something that people with haemochromatosis often worry about. Iron build-up can cause the skin to look bronzed or grey. When it does happen, it's most often on the face, hands, forearms or lower legs.

Living with haemochromatosis

If you've recently found out that you have haemochromatosis genes, you may need to give yourself time and space to process all this new information. Do remember that the risk of complications is low if you've been diagnosed early and have treatment as often as your doctor recommends.

Being diagnosed with a genetic condition

Even if you have no symptoms and never actually develop haemochromatosis, being told you have the gene variants may still have an impact. Knowing that you can potentially pass this on to your children can be upsetting. There's no right or wrong way to feel. So give yourself time to take in the news and come to terms with it.

You may not have heard of haemochromatosis before. And most other people you meet won't have. That can be scary – particularly as it's lifelong. Many people who are diagnosed will have family members with it and can talk it over with them.

Liver UK is here to support you too. We have support groups and an online community to help you meet others in the same situation. You can also find comprehensive information on our website and call our nurse helpline for more advice, or when you just need to talk.

It's important to know that haemochromatosis is usually well controlled these days. If you stick to your treatment schedule, you are unlikely to develop any serious health problems because of it.

Diet and haemochromatosis

Doctors no longer recommend cutting out foods containing iron. But if you have iron overload, it makes sense not to overdo it. You can have red meat if you want to - but have it now and then, as a treat. Don't take iron tablets, or multivitamins that contain iron. And it's best to avoid foods with added iron, such as some breakfast cereals.

Like anyone else, aim for a healthy, balanced diet, with plenty of fresh fruit and vegetables, along with some protein and carbohydrates. Avoid eating too much salt and sugar. As people with haemochromatosis have a higher risk of diabetes, it's best to try to keep to a healthy weight. Being overweight also increases your risk of liver damage from a condition called fatty liver.

There is one particular risk to be aware of. You shouldn't handle or eat raw or undercooked fish or shellfish. It can be contaminated with marine bacteria that can cause serious infection in people with haemochromatosis gene variants. The bacteria is a risk because it grows more easily in iron rich environments.

Alcohol

If you've recently been diagnosed, it's best not to drink alcohol until your iron levels are back to normal. After that, there's no reason why you shouldn't drink in moderation if you want to. But it's best to stick to the UK guidelines of fewer than 14 units a week. Try to have at least 3 alcohol free days in a row each week.

Drinking too much, too often, will put extra strain on your liver. It pays to look after your liver in general if you have haemochromatosis. If you do develop iron overload, you will be more at risk of complications if you have other liver problems.

People with haemochromatosis also have a higher than average risk of thinning bones (osteoporosis). Heavy drinking can affect your bone density by decreasing the activity of cells that lay down healthy bone.

Coping with symptoms

Fatigue is a problem for many people with haemochromatosis, even if they don't have iron overload. Fatigue isn't just feeling a bit tired. You can't fight your way through it. It's more a case of learning how to manage it.

Sleeping and eating well will help to minimise fatigue. You may also find there are times of the day when you're feeling more tired or have more energy. Particular activities may make your fatigue better or worse. Once you are aware of this, you may be able to adjust your routine to suit you better. Accepting help from family and friends isn't always something people find easy. But if you ask, you're likely to find that they are only too willing to lend a hand if you're struggling.

It's proven that exercise can help to combat fatigue caused by many health conditions. It's also known to help with mental health. There are no special guidelines for exercise and haemochromatosis. Weight bearing exercise is good for keeping your bones healthy - walking, running or dancing for example. Exercising regularly will also help you to maintain a healthy weight. Don't overdo it though. You need to find a balance.

If you're struggling to cope, speak to your doctor. It may be worth having some tests to make sure there isn't anything else making fatigue worse, such as low thyroid hormone or testosterone levels.

Joint pain and arthritis are common in people with haemochromatosis. It can affect your knuckles, hips, knees and ankles.

Unfortunately, treatment with venesection doesn't seem to help with this symptom. It may not feel like it but keeping active helps to reduce pain and stiffness in the long term. Maintaining a healthy weight helps to minimise strain on your joints. Painkillers and anti-inflammatory medicines, such as ibuprofen can help you to manage pain. Always take them with food, as they can damage your stomach lining.

If you are having trouble coping, speak to your doctor. Physiotherapy may help. Unfortunately, people with haemochromatosis do tend to develop arthritis at a younger age than average and may be more likely to need physio or even joint replacement surgery later in life.

Talking about having a genetic condition

For most people, daily life won't be heavily affected by having haemochromatosis. Even so, there may be times when you have to explain your condition to someone and that can be hard. You may need to take time off work for blood tests, which will mean explaining to your employer. Of course, most employers will be sympathetic and accommodating. Haemochromatosis is a protected condition under the Equality Act of 2010. So employers have to make reasonable adjustments, including time off for tests and treatment.

Remember you can give people a copy of this booklet. Then they can read about it for themselves, without you having to repeat the same things over again. You can also download a factsheet from our website and pass it on as needed.

Your questions answered

Can I drink alcohol?

Haemochromatosis isn't caused by alcohol. But it's best to avoid it if your iron levels are high. Once they are regulated, you can drink alcohol but try to stick to the UK guidelines. Drinking too much will put a strain on your liver and with haemochromatosis, it pays to look after it. If you develop iron overload in the future, liver damage will increase your risk of further complications.

The guidelines on low-risk drinking are the same as for anyone else:

- Don't drink more than 14 units of alcohol in one week
- Spread your drinking over several days
- Have 3 days in a row without alcohol every week

Can I take complementary or alternative medicines?

It's important to get your doctor's advice before trying any of these products. Doctors don't generally recommend them. Most are not classed as medicines, so they don't go through the same strict testing for quality or effectiveness. They could have no effect - or could even be harmful, including causing liver damage.

Do I need to stop smoking?

Smoking increases your risk of liver cancer and at least 50 other health conditions. If you smoke the best thing you can do for your health is quit. You don't have to do it by will power alone. Using local free stop smoking services boosts your chance of quitting by three times. Find your local free service by visiting the NHS website or speak to your GP or pharmacist.

Should I try to "detox" my liver?

You might see foods or diets being recommended to cleanse or "detox" your liver. But this isn't physically possible and won't help with haemochromatosis. Some of these diets can be dangerous.

Can I have children?

Yes, there's no reason why haemochromatosis should stop you having a family. Talk to your medical team if you are unsure of the likelihood of passing on the haemochromatosis genes to your children.

For lots more information and advice, from diet to money to mental health, visit **www.liveruk.org/living-with-liver-disease**

Useful resources

Useful websites

Liver UK
www.liveruk.org
Information and support for everyone living with a liver condition.

Arthritis UK
www.arthritis-uk.org
A UK charity that offers information about arthritis and its treatment.

Diabetes UK
www.diabetes.org.uk
A UK charity providing information about symptoms, diagnosis and managing diabetes.

Royal Osteoporosis Society
www.theros.org.uk
A UK charity dedicated to bone health and osteoporosis, providing information and support.

Association of British Insurers
www.abi.org.uk
An industry body with information about genetic testing and insurance.

NHS
www.nhs.uk
Information on haemochromatosis as well as general advice on eating well, alcohol, physical activity and stopping smoking.

How Liver UK can help

A diagnosis of liver disease can be worrying, and you may have a lot of questions. The Liver UK support team are here for you and for your family and friends.

Whether you have questions or just need someone to listen, we can help.

Find out more about our support options: **liveruk.org/support**

Call our nurse-led helpline **0800 652 7330**

Useful words

Biochemical penetrance – having signs of haemochromatosis in blood tests, but no clinical sign or symptoms.

Cirrhosis – scarring of the liver, caused by liver damage.

Clinical penetrance – having symptoms from a genetic condition.

Gene penetrance – the likelihood of a genetic condition developing if you carry the necessary gene variants.

Genetic testing – having a blood test to see if you carry particular gene variants.

Genotype – your genetic make-up; the particular genes you have inherited.

Haemoglobin – the iron-containing protein that carries oxygen in the bloodstream.

Hepatocellular carcinoma (HCC) – a type of liver cancer that may develop in people who have liver cirrhosis.

Induction venesection – early treatment to reduce iron levels.

Iron overload – having an abnormal amount of iron stored in your body.

Maintenance venesection – ongoing treatment to manage your iron levels.

Osteoporosis – loss of calcium from the bones, causing thinning and increased risk of fracture.

Penetrance – see gene penetrance.

Phenotype – the characteristics you have that are determined by your genes. In relation to a genetic condition, it means whether or not you have signs and symptoms of that condition.

Phlebotomy – having blood taken.

Serum ferritin – a blood test that estimates how much iron is stored in your body.

Transferrin – a hormone that carries iron in the blood.

Transferrin saturation (TSat) – a blood test that measures how much iron you are absorbing from your diet.

Venesection – Having blood taken as a treatment.

Follow this QR code for a full list of medical terms and useful words: liveruk.org/useful-words-glossary

How we produce information

Feedback and information services

Your feedback is important to us and will help us improve our information. To provide feedback, email **patient-info@liveruk.org**

For more information on how our information was developed, visit our website: **www.liveruk.org**

Thanks

All our information resources are reviewed by medical experts and people living with liver disease. We would like to thank:

Dr Jeremy Shearman, Consultant Hepatologist and Gastroenterologist, South Warwickshire University Foundation Trust.

Sister Kim Hicks, Medical Day Unit Haemochromatosis Nurse, Royal Cornwall Hospital, Treliske

All our patient reviewers

Disclaimer
This resource provides general information but does not replace personal medical advice. It is important to contact your medical team if you have any worries or concerns.

LIVER UK

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To make a gift in support of our work today, please scan the QR code or visit

www.liveruk.org/donate

Liver UK is the UK's leading charity dedicated to supporting adults, children and young people affected by liver disease or liver cancer. Our mission is to transform liver health by raising awareness, promoting prevention, and improving care and support for everyone affected.

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