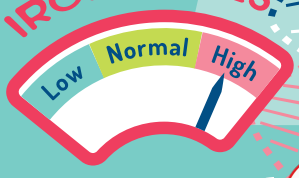
GENETIC HAEMOCHROMATOSIS

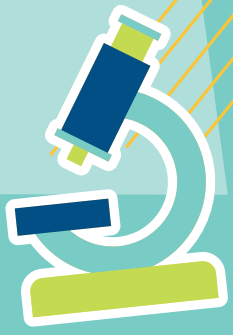
EXPLAINED

Also known as 'GH'

FIND OUT:

- What is GH?
- What are the symptoms?
- How is it treated?
- Can I be tested?
- And other helpful information





Haemochromatosis • UK +Fe

Saving lives and preventing ill-health

WHAT IS GENETIC HAEMOCHROMATOSIS?

Genetic Haemochromatosis is mostly referred to as...

"GH"

If left untreated, people can become unwell.

The good news is that treatment is available and if diagnosed early, serious symptoms can usually be prevented before they begin.

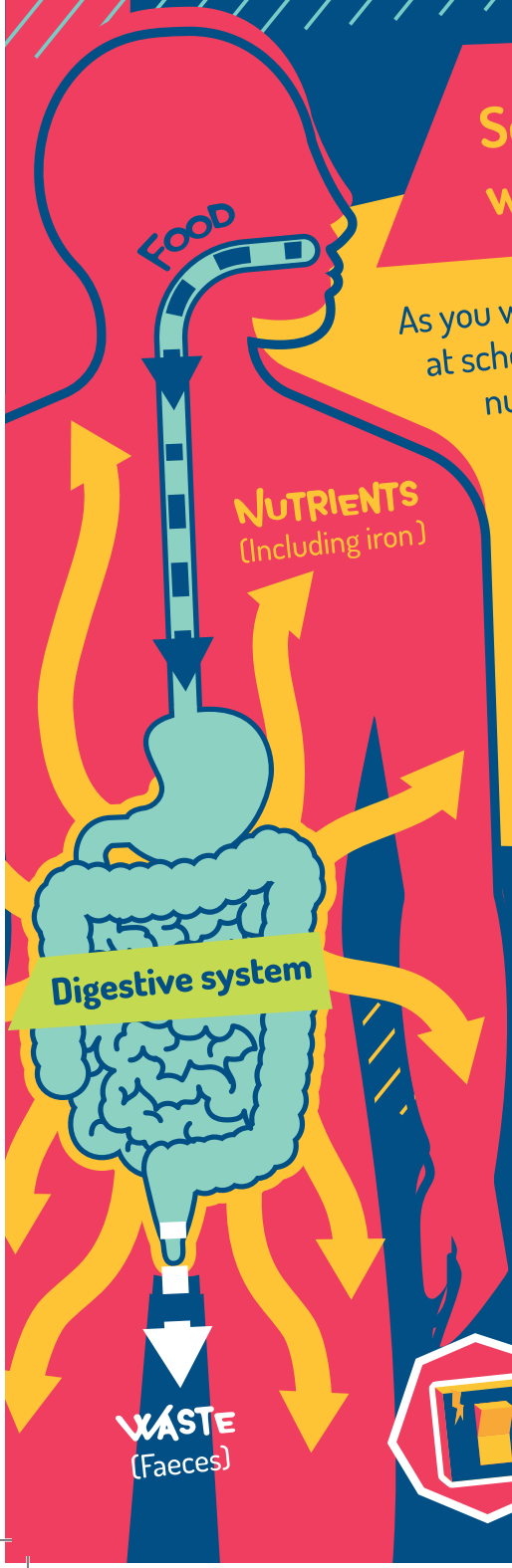


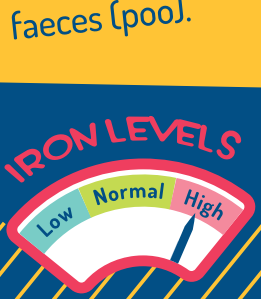
So...what happens when someone has GH?

As you will probably know from biology lessons at school, our bodies regulate the amount of nutrients we absorb from our food.

This includes the mineral **iron**. Iron is needed to keep the body healthy and is important in making red blood cells, which carry oxygen around the body.

When the body has enough iron it usually stops absorbing it, getting rid of any that it doesn't need through faeces (poo).





The chemical symbol for iron is **'Fe'**

Someone who has GH cannot control the amount of iron they absorb. Even when their body has enough iron they still continue to absorb it. **It is like the off-switch is broken!**

This is sometimes referred to as:

iron overload.

WHAT ARE THE SYMPTOMS?

In someone with **iron overload**, this excess iron needs to be stored somewhere in the body. It often builds up in places like the **joints, liver and other organs**.

This build-up of iron can affect how these organs or tissues work.

This can cause **PROBLEMS** such as...

Extreme tiredness and weakness (also known as chronic fatigue)

Pain in the joints and/or arthritis

(often in the **hands**, **knees**, **hips**, and **shoulders**)

Heart problems

Liver problems

Diabetes (late onset type)



People can have these symptoms without having GH.

Problems with memory

Mood swings

Skin appears bronzed, like a permanent tan

Decrease in body hair

Abdominal pain (near the stomach region)

Irregular or absent periods in women

People with GH will not always have the same symptoms and may be affected at different ages.

It is not possible to predict how and when a person may be affected. **Most people with GH don't have any symptoms until they are adults** (usually in their 30s or 40s).

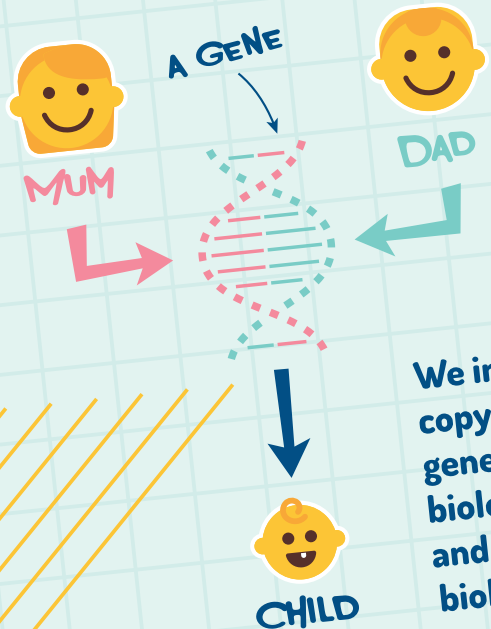
Both men and women can have GH but men normally get worse symptoms than women.

This is because women have periods and so lose blood containing iron naturally every month.

WHAT CAUSES GH?

Genetic Haemochromatosis, as the name suggests, is **genetic!**

We each have 2 copies of every **gene** (a set of genetic instructions). These carry information that help decide how we look and how our bodies grow and develop.

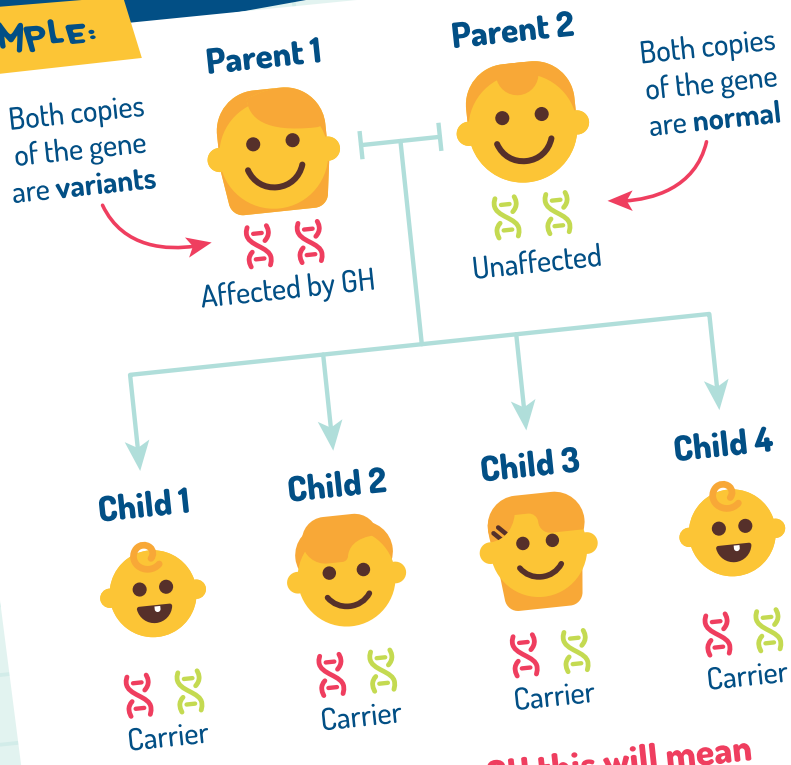


The human body has **tens of thousands** of different genes

We inherit one copy of each gene from our biological mother, and one from our biological father.

For a person to have GH they need a mistake in their genetic code (called a variant) in **both copies** of their genes. When someone has one variant copy and one normal copy, they are called a **carrier**.

EXAMPLE:



If one of your parents has GH this will mean that you are a carrier.

The normal copy of the gene is usually enough to keep carriers healthy.

AM I GOING TO GET GH?

There are other possible scenarios:

2

1 If both parents are carriers...





a quarter of their children may develop GH — 1/4

half may be carriers — 1/2

a quarter may be unaffected — 1/4

3 If both parents have GH, which is rare...



all children will have GH and are at risk of symptoms

ALL

If one parent has GH and one is a carrier...



half may develop GH

½

half may be carriers

½

These are averages and can differ. The best way to know for sure is to be **tested**. This can happen from the age of 16 and it is **completely up to you** if you want to be tested or not.

CAN I BE TESTED FOR GH?

GH usually affects people when they are adults so healthy children don't need to be tested.

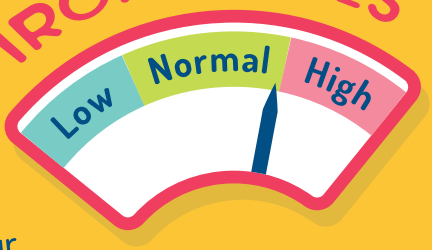
16 YEARS

It is completely up to you whether to have genetic testing or not. When you reach **16** you are considered old enough to think carefully about your options and decide for yourself if genetic testing is right for you.



A genetic test can tell you if you have GH and if you are at risk of iron loading. It is a good idea to talk to your family and your doctor if you want to understand more about genetic testing.

IRON LEVELS



If you have GH, your doctor will recommend that your iron levels are checked every year. **Regular monitoring of your iron levels can help your doctor to manage any symptoms and may prevent them from starting.**



Some people reduce their iron levels by donating their blood regularly (you need to be 17 years old to become a blood donor!).

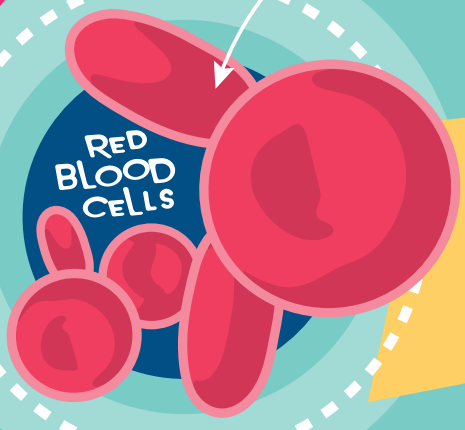
Making decisions about your personal health can be challenging. But, you should never feel under pressure or alone. It is up to you whether you want to be tested for GH. If you are tested and are diagnosed with GH, your doctor will support you and answer any questions you might have. With the right treatment you should be able to continue to do everything you usually enjoy.

IS THERE A CURE FOR GH?

Although GH cannot currently be cured, it can be treated.

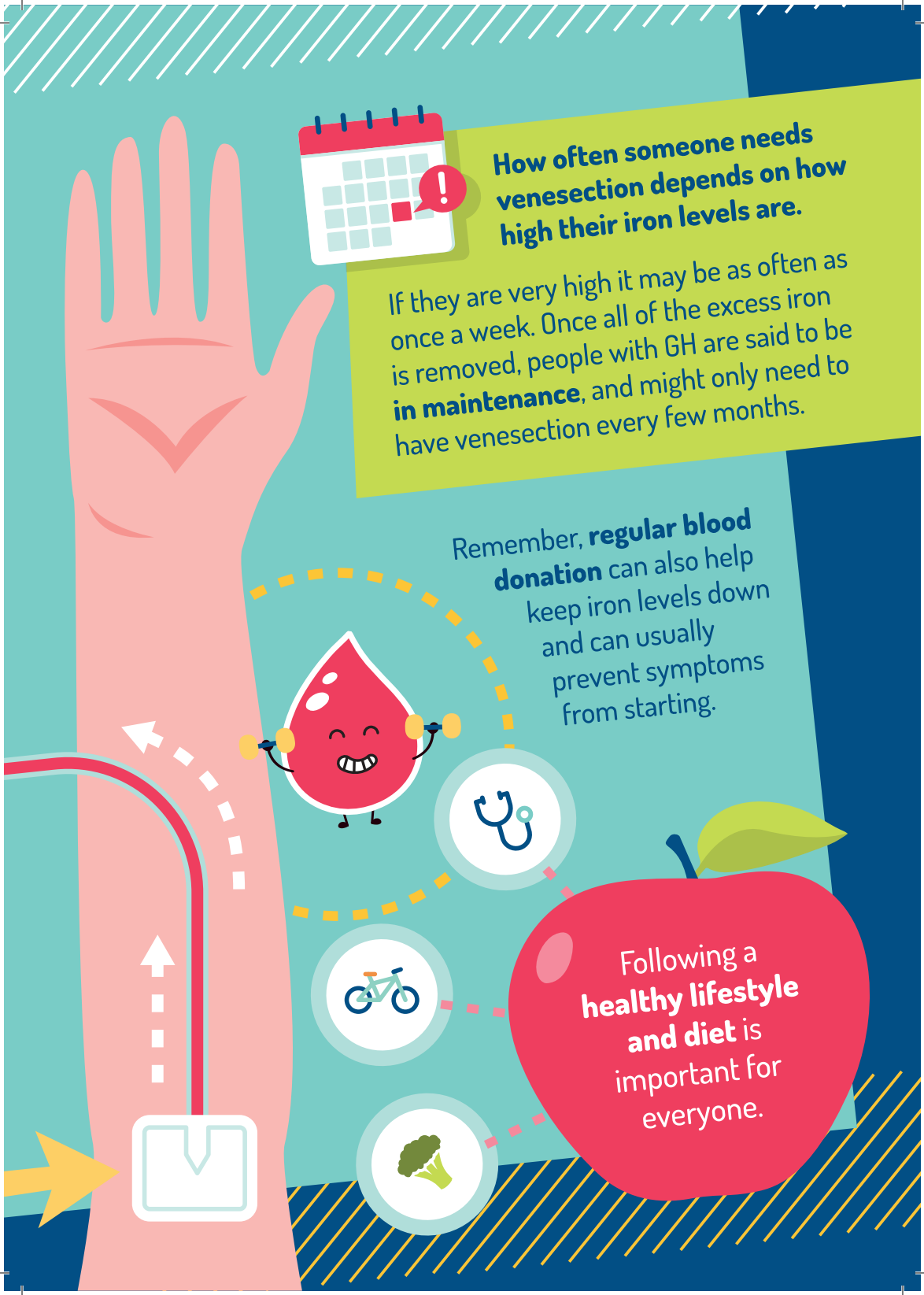
Treatment involves finding ways to remove the excess iron from the body.

Iron is needed to make red blood cells. When blood is removed from the body, it needs to be replaced. Replacing it uses up some of the excess iron stored in the body.



One way to remove blood from the body is:

VENESECTION


How often someone needs venesection depends on how high their iron levels are.
If they are very high it may be as often as once a week. Once all of the excess iron is removed, people with GH are said to be **in maintenance**, and might only need to have venesection every few months.
Remember, **regular blood donation** can also help keep iron levels down and can usually prevent symptoms from starting.
Following a **healthy lifestyle and diet** is important for everyone.

WHAT CAN I DO TO HELP?

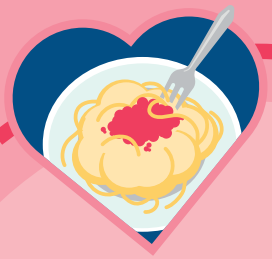
If a parent or someone in your family has GH, daily life can be more difficult for everyone. You may need to change the type of activities you do together so that they are less strenuous. Spending time together and helping support each other is important for you all.

When someone isn't feeling well they can be short tempered or withdrawn. If **you** have recently been diagnosed with GH you may also feel upset or angry, but remember there is no right or wrong way to feel.

These feelings don't mean we love each other any less.



Someone with GH can feel extremely tired and may need to sleep more often. They might not be able to keep up with jobs around the house as much as they might like or keep on top of a teenager's mess! You could help by offering to take on more household chores. Even picking up your own clothes or removing stray plates and cups from your bedroom will help.





Look out for the things that they find difficult and offer to help.

Sometimes it might just be opening a jar or packet because they have sore joints in their hands.



When caring for a loved one it might be hard to juggle all of your responsibilities with the demands of teachers, friends and homework. Talking about the situation together can be extremely helpful. It gives everyone a chance to express how they feel, **including you**.

Where can I get help or find more information?

When we learn something new about our health, it can be confusing and affect us in different ways. However, never feel like you can't talk to someone, there are always people around who can help!

You could speak to a **friend**, seek **professional support**, or another **family member** about any concerns you have about your own health. If you need help with caring for a loved one, a **doctor**, **nurse** or **social worker** could organise more support at home.

It's good to talk!



Writing down any concerns or thoughts you may have can also help you to communicate or make sense of your feelings.



HAEMOCHROMATOSIS UK (HUK):

Haemochromatosis UK has a website and a helpline (for parents, teachers and guardians).

Website: **www.ironoverload.org.uk**

Email: **helpline@huk.org.uk**

Phone: **03030 401 102**

Glossary of Words

Carrier

A person who carries one copy of the gene with a variant and a normal copy of the gene. Carriers do not usually have GH.

Gene

A single genetic instruction/code. Genes have information that tells our bodies how to grow and develop. We have two copies of each gene, one from our mum and one from our dad.

Genetic

Relating to genes and/or inherited factors (something you inherit from your mum or dad or grandparents).

Genetic Haemochromatosis (GH)

A genetic condition where a person is unable to control the amount of iron in their body causing too much iron to be present.

GH

An abbreviation for Genetic Haemochromatosis (GH).

Inherit

When your parents pass something on to you through your genes.

Iron Overload

When excess iron in the body is stored in the organs and soft tissues such as muscles.

Variant

A change in the genetic code that may or may not cause an issue.

Venesection

A form of regular blood donation used to help treat people with iron overload. This can be done at hospital or through the national blood donation service.



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ENVISION PHARMA GROUP

COMMUNITY FUND

This booklet was produced by Haemochromatosis UK in collaboration with families affected by haemochromatosis, with support from Envision Pharma Group and Ernest Hecht Charitable Foundation.

The information contained within this guide is not intended to provide clinical diagnosis and medical advice. It should not be treated as such. Always seek the advice of your doctor or a health care professional before starting any new treatment for your underlying condition.



Haemochromatosis UK is a charity registered in England and Wales (1001307) and in Scotland (SC041701) and a Company Limited by Guarantee (2541361).

Updated in 2026 by the Pass in On England Project funded by the National Lottery Community Fund.