

Autoimmune hepatitis



BRITISH
LIVER
TRUST

Fighting liver disease

Autoimmune hepatitis

The British Liver Trust works to:

- support people with all kinds of liver disease
- improve knowledge and understanding of the liver and related health issues
- encourage and fund research into new treatments
- lobby for better services.

All our publications are reviewed by medical specialists and people living with liver disease. Our website provides information on all forms of adult liver disease and our Helpline gives advice and support on general and medical enquiries. Call us on **0800 652 7330** or visit **www.britishlivertrust.org.uk**

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The liver

Your liver is your body's 'factory' carrying out hundreds of jobs that are vital to life. It is very tough and able to continue to function when most of it is damaged. It can also repair itself – even renewing large sections.

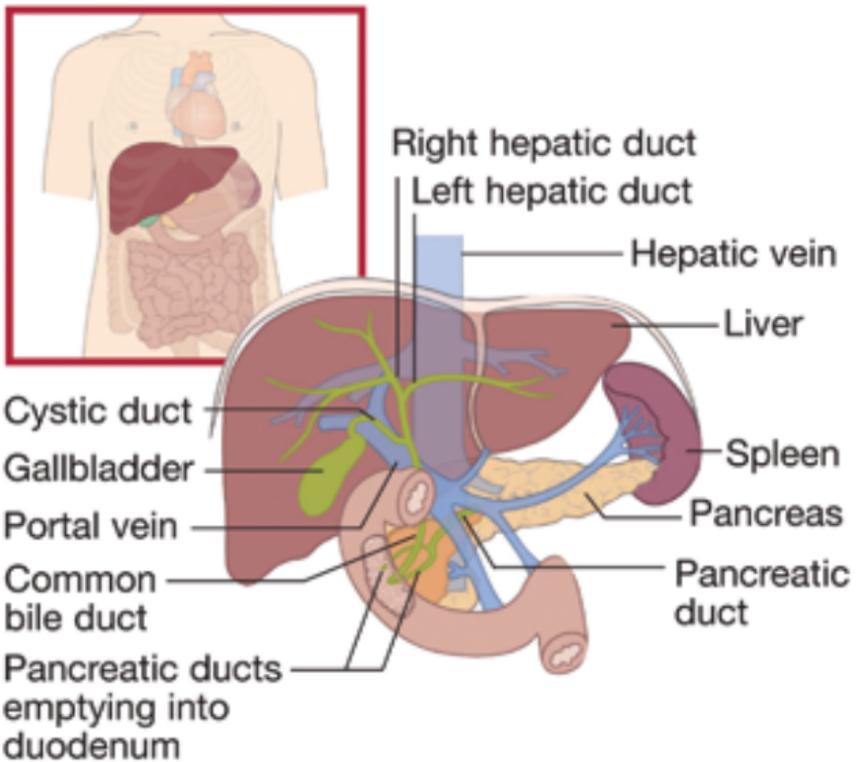
Your liver has around 500 different functions. Importantly it:

- fights infections and disease
- destroys and deals with poisons and drugs
- filters and cleans the blood
- controls the amount of cholesterol
- produces and maintains the balance of hormones
- produces chemicals – enzymes and other proteins – responsible for most of the chemical reactions in the body, for example, blood clotting and repairing tissue
- processes food once it has been digested
- produces bile to help break down food in the gut
- stores energy that can be used rapidly when the body needs it most
- stores sugars, vitamins and minerals, including iron
- repairs damage and renews itself.

How liver disease develops

Liver damage develops over time. Any inflammation of the liver is known as hepatitis, whether its cause is viral or not. A sudden inflammation of the liver is known as acute hepatitis. Where inflammation of the liver lasts longer than six months the condition is known as chronic hepatitis.

Fibrosis is where scar tissue is formed in the inflamed liver. Fibrosis can take a variable time to develop. Although scar tissue is present the liver keeps on functioning quite well. Treating the cause of the inflammation may prevent the formation of further liver damage and may reverse some or all of the scarring.



Cirrhosis is where inflammation and fibrosis has spread throughout the liver and disrupts the shape and function of the liver. With cirrhosis, the scarring is more widespread and can show up on an ultrasound scan. Even at this stage, people can have no signs or symptoms of liver disease. Where the working capacity of liver cells has been badly impaired and they are unable to repair or renew the liver, permanent damage occurs.

This permanent cell damage can lead to liver failure or liver cancer. All the chemicals and waste products that the liver has to deal with build up in the body. The liver is now so damaged that the whole body becomes poisoned by the waste products and this stage is known as end stage liver disease. In the final stages of liver disease the building up of waste products affects many organs. This is known as multiple organ failure. Where many organs are affected, death is likely to follow.

What is autoimmune hepatitis?

Autoimmune hepatitis, often referred to as AIH, is one cause of chronic hepatitis and can be, if untreated, one of the most severe forms.

For a long time AIH was known as chronic active hepatitis. AIH is just one of the causes of chronic active hepatitis but it is now recognised as a specific disease.

What causes AIH is not well understood. It is believed the cells that do the damage are circulating blood cells known as lymphocytes. They behave as though the hepatocytes (the liver cells) are foreign and start to destroy them. This leads to chronic hepatitis which, if untreated, will progress to cirrhosis and eventually to liver failure.

How common is autoimmune hepatitis?

Fortunately, AIH is relatively uncommon although it occurs in both males and females.

Between the ages of 15 and 25, it is women who are mostly affected. Around the ages of 45 and 55, both men and women are affected.

What are the signs and symptoms of autoimmune hepatitis?

The most common signs of AIH are:

- fatigue
- a general feeling of ill-health
- lack of energy
- a tendency to tire easily
- an inability to finish a full days work
- the need to have more sleep
- joint pains (arthralgia) which are an indirect effect of chronic hepatitis and are usually mild and intermittent, noted mostly in the mornings.

Less common symptoms may be:

- nausea
- decreased appetite
- weight loss
- abdominal pain or bloating
- indigestion
- jaundice
- abnormal blood vessels on the skin on the face, arms and chest
- bruising.

If the disease is very active or advanced, jaundice (yellowing of the skin and whites of the eyes and darkening of the urine) may occur.

If cirrhosis develops as a result of chronic AIH there may be muscle wasting, weight loss, ascites (swelling of the abdomen with fluid) and vomiting blood.

In many cases the condition develops almost secretly, with no factor pointing to the liver as a cause of ill-health.

Diagnosis

This is usually made by taking a careful medical history, performing a physical examination, arranging of blood tests and a liver biopsy.

People with AIH may have other autoimmune diseases at the time of diagnosis of AIH, before the diagnosis is made or after. Some of the conditions associated with autoimmune hepatitis include:

- thyroid disease (either over or under active)
- pernicious anaemia (a deficiency of vitamin B12)
- vitiligo (pale patches on the skin).

Testing for AIH

Liver function tests (LFTs) are blood tests that measure substances in the bloodstream that indicate that the liver is damaged.

Other blood tests used in AIH include those that identify immunoglobulins and autoantibodies. These are antibodies in the blood that react with the body's own cells and include antinuclear antibodies (ANA) or smooth muscle antibodies (SMA). To assess the

amount of liver damage, confirm the diagnosis and to exclude other causes of liver disease, a liver biopsy is usually done. In this procedure a fine hollow needle is passed through the skin to the liver and a small sample of tissue is withdrawn.

This is usually done under local anaesthetic and may mean an overnight stay in hospital.

Prevention

The cause of AIH as yet remains unknown. You will not develop AIH by exposure to someone else with the disease. It is not thought to be due to a virus and has nothing to do with alcohol. Although there is a genetic link to AIH, at present there is nothing that can be done to prevent the condition occurring.

Treatment

Once the diagnosis has been made, treatment is almost always required.

The treatment used is called immunosuppression. This therapy uses a type of steroids, known as corticosteroids, to reduce (suppress) the ability of your immune system to fight infection.

It is usual to start treatment with a relatively high dose of steroids, usually prednisone or prednisolone. When the inflammation is brought under control, the dose can be reduced. Usually other drugs are added to allow for a lower dose of steroids.

Another immunosuppressant, azathioprine, is most commonly used in combination with steroids. This drug is slower acting and has fewer side effects than steroids.

If AIH is well controlled, steroids may be withdrawn completely so that you are maintained on azathioprine only, although this is not always possible.

Autoimmune hepatitis appears more often to be a controllable rather than a curable disease, therefore most patients need long-term maintenance therapy. It may be possible to completely withdraw the immunosuppression but this is not without risk as relapse can occur months, or even years after withdrawal.

Other drugs such as cyclosporin, tacrolimus, mycophenolate and D-penicillamine may also be considered.

You should not stop taking any of these drugs without first consulting your doctor or specialist.

Liver transplantation

For a few people who eventually develop advanced cirrhosis, a liver transplant may be necessary.

This is a major operation and you will need to plan it carefully with your medical team, family and friends.

Side effects of treatment

Unfortunately, corticosteroids have a number of side effects which your doctor should discuss with you. These are often seen when a high dose is given for a long time. They can:

- increase appetite
- cause weight gain
- induce diabetes or make diabetes worse
- cause fluid retention (which can lead to puffiness of the face and legs)
- cause indigestion.

They may also cause:

- thinning of the skin and bones. For most people who take steroids, additional treatment may be required to reduce the risk of bone loss
- a tendency to bruise more easily.

If someone has diabetes or hypertension (high blood pressure) these problems may become worse.

Corticosteroids may also increase the severity of glaucoma (increased pressure in the eye) or cataracts.

Looking after yourself

Diet and exercise

Some people who are prescribed steroids for autoimmune hepatitis may find their appetite increases and that they gradually gain weight. If this happens, it is still important to eat a varied and well balanced diet. However, if you are gaining too much weight you should try to reduce calorie-rich foods such as sugar, sweets, cakes, biscuits, fried food, pasties and pies, crisps and chocolate. Use low-fat versions instead and fill up on fruit and vegetables.

If weight gain is a problem, your doctor may suggest specialist help from a dietician.

Some people who are more severely affected by AIH may need to consider making changes to their lifestyle, such as giving up work or a particular activity. Others find that pacing their daily activities helps to preserve stamina and energy.

Daily walking (or swimming if preferred) is encouraged to keep your muscles in good shape. However it is advisable to talk to your doctor or health professional before undertaking any strenuous activity.

Alcohol

Anyone with autoimmune hepatitis should not drink alcohol, or as little as possible. If you choose to drink, the Department of Health currently offers the following guidelines for sensible drinking:

- Women should not regularly drink more than two to three units of alcohol in a single day (no more than 14 units in a week)
- Men should not regularly drink more than three to four units of alcohol in a single day (no more than 21 units in a week)

A unit of alcohol is 10 millilitres (ml) of pure alcohol.

However, these guidelines are for people without a liver condition. Drinking alcohol can speed up or worsen the impact of liver disease. If you have cirrhosis caused by AIH you should not drink at all.

There is still a lot of ignorance about hepatitis in all its forms outside of medical circles. AIH is not an infectious disease and may have a good prognosis when properly treated. However, people with AIH report being subjected to unnecessary caution and have encountered difficulties when applying for employment or insurance where medical records are requested. If this happens, it is worth talking to your doctor or consultant as many are willing to write to a mortgage or insurance company describing your health and life expectancy.

Useful words

Acute – short, sharp illness that may be severe, but most people recover within a few weeks without lasting effects.

Antibodies – special proteins made by the body's defence (immune) system to fight and neutralise a foreign substance.

Autoimmune disease – a type of disease where the immune system mistakenly attacks another part of the body.

Chronic – an illness that lasts a long time (more than six months), possibly for the rest of a person's life.

Immunoglobulin – specific protein substance (antibody) that is produced by plasma cells to help fight infection.

Immunosuppression – a therapy that suppresses the ability of your immune system to fight an infection or disease when it enters the body.

Inflammation – the first response of your immune system to infection or injury, usually noticeable by pain, swelling or tenderness.

Steroid – natural or synthetic compounds sharing the same four-ring molecular structure. The steroids we refer to in this leaflet are corticosteroids – drugs used to reduce pain, swelling and other symptoms of inflammation.

Thyroid – a butterfly-shaped endocrine (hormone-secreting) gland in your neck that is found on both sides of the trachea (windpipe).

Who else can help?

AIH Support Group

12 Seaward Walk

Great Yarmouth

Norfolk NR30 5NS

Tel: 0845 370 0997

Email: matt@autoimmunehepatitis.co.uk

www.autoimmunehepatitis.co.uk

An online support group providing information and support for people with autoimmune hepatitis.

Further information

The British Liver Trust publishes a large range of leaflets about the liver and liver problems, specially written for the general public.

Leaflets that you may find particularly helpful include:

- *Alcohol and liver disease*
- *Cirrhosis of the liver*
- *Diet and liver disease*
- *Liver disease tests explained*
- *Liver transplantation*

Contact us for more information:

Tel: 0800 652 7330

Email: info@britishlivertrust.org.uk

Web: www.britishlivertrust.org.uk

This leaflet is for information only. Professional, medical and other advice should be obtained before acting on anything contained in the leaflet as no responsibility can be accepted by the British Liver Trust as a result of action taken or not taken because of the contents.

Special thanks

Professor James Neuberger DM FRCP
Liver Unit, Queen Elizabeth Hospital, Birmingham.

Can you make a difference?

Liver disease is increasing alarmingly and the need to do more is greater than ever before...

For the British Liver Trust to continue its support, information and research programme, we need your help. We raise funds from many sources and a large proportion is donated by voluntary contributions. If you would like to send a donation it will enable us to continue providing the services that people need.

If you can help, please fill in the form on the page opposite.

If you wish to help us further with our work by organising or participating in a fundraising event or becoming a **“Friend of the British Liver Trust”** please:

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British Liver Trust

2 Southampton Road
Ringwood, BH24 1HY

Tel: 0800 652 7330 **Fax:** 01425 481335

Email: info@britishlivertrust.org.uk

Web: www.britishlivertrust.org.uk