

Auto Immune Hepatitis (AIH)

An information guide



Auto Immune Hepatitis (AIH)

Liver damage develops over time.

Any inflammation of the liver is known as hepatitis whether it's cause is viral or not.

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

What causes AIH is not well understood. It is believed the cells that do the damage are circulating blood cells called lymphocytes. They behave as though the liver cells are foreign bodies and start to destroy them.

This leads to chronic hepatitis which if untreated will lead to cirrhosis and eventually liver failure.

Fortunately AIH is relatively uncommon. It is women between the ages of 15 to 25 who are most affected. Around the ages of 45 and 55, both men and women are affected.

What are the signs and symptoms?

The most common signs of AIH are:

- Fatigue.
- A general feeling of ill health.
- Lacking energy.
- A tendency to tire easily.
- An inability to finish a full days work.
- The need to have more sleep.
- Joint pains 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 advanced or very active, jaundice (yellowing of the whites of the eyes and skin) and darkening of the urine may occur.

If the disease has advanced to cirrhosis there may be muscle wasting, weight loss, ascites (swelling of the abdomen with fluid) and vomiting blood.

Diagnosis

This is made by arranging blood tests and a liver biopsy.

Some people with AIH may have other autoimmune diseases before, at the time of and after diagnosis for example Thyroid disease, Vitamin B12 deficiency.

Prevention

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 diagnosis has been made, treatment is almost always required.

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

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

Azathioprine is most commonly used in combination with 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.

AIH appears to be more often controllable rather than a curable disease so most patients need long-term maintenance therapy.

Sometimes it may be possible to withdraw treatment completely but this is not without risk as relapse can occur months or even years after withdrawal.

You will require regular blood testing. At first weekly then monthly and eventually 3 monthly once your condition is well controlled

YOU SHOULD NOT STOP TAKING ANY MEDICATION WITHOUT FIRST CONSULTING YOUR DOCTOR OR SPECIALIST.

Side effects of treatment

Unfortunately steroids have a number of side effects which your doctor should discuss with you.

The below side effects are often seen when a high dose is given for a long time:

- Increase appetite.
- Weight gain.
- Induce diabetes or make diabetes worse.
- Cause fluid retention.
- Cause indigestion.
- 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.

Looking after yourself

It is important to eat a varied and well balanced diet. However if you start to gain weight you should reduce calorie rich foods such as sugar, sweets, cakes, biscuits, fried food, pastry, crisps and chocolate.

Use low fat options instead and fill up with fruit and vegetables. Ask to see a dietician if you need any help or advice.

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 pacing their daily activities helps to preserve energy and stamina.

Gentle exercise such as walking and swimming is encouraged but it is advisable to talk to your doctor before taking part in any strenuous activity.

Any one with AIH should not drink alcohol

Finally

There is still a lot of ignorance about hepatitis in all its forms outside medical circles. AIH is not an infectious disease and may have a good prognosis when properly treated.

Helplines

AIH Support Group

12 Seaward Walk

Great Yarmouth

NR30 5NS

Telephone: 0845 370 0997

www.autoimmunehepatitis.co.uk

The British Liver Trust

2 Southampton Road

Ringwood

BH24 1HY

WWW.britishlivertrust.org.uk

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