



The Informed Patient

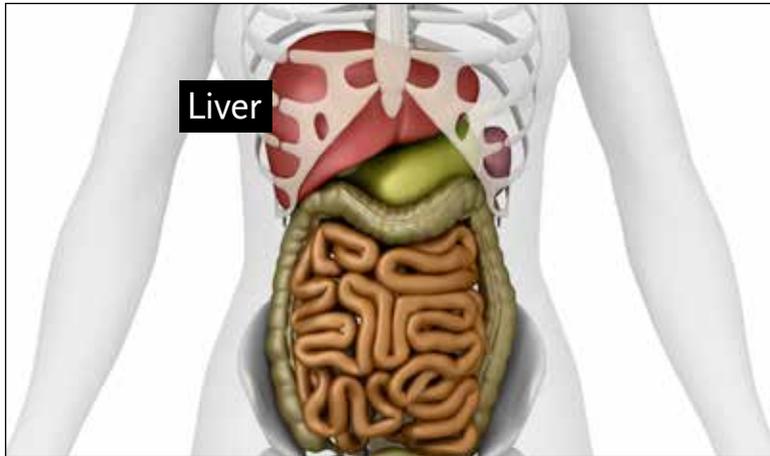
AUTOIMMUNE HEPATITIS AND ITS TREATMENT

This booklet aims to answer questions you may have about autoimmune hepatitis (AIH), with a particular focus on steroids, the primary treatment for AIH.

Hopefully you'll find the information it contains helpful, but it isn't meant to take the place of your doctor or nurse. So, if you do have any worries about your AIH or its treatment, do talk them through with a member of your healthcare team.

AIH is a liver disease

The liver is the biggest and one of the most important organs inside your body. In an adult, it's about the size of a rugby ball and it sits just behind the ribs on the right-hand side.



The liver carries out hundreds of jobs that are vital to life, from helping food digestion and fighting infection, to getting rid of waste products from the blood. If your liver becomes badly damaged and starts to fail, almost every part of your body can be affected.

Hepatitis is the name given to inflammation of the liver. The symptoms of inflammation; pain, swelling, redness and heat – are the body's natural response to injury or irritation. When it comes to AIH, we are not absolutely sure what the trigger is. The body's immune system seems to turn against itself, mistaking liver cells for intruders, which it then attacks.

AIH is uncommon. It only affects 1 or 2 people in every 10,000 in the UK. It is up to 4 times more common in women than men, and it can affect any age group.

AIH is typically chronic, meaning it can last for years. If it isn't treated, the persistent inflammation can lead to scarring and hardening of the liver known as cirrhosis. Eventually, liver failure can result.

With treatment, the outlook for people with AIH is good

People with AIH almost always need treatment. Not only does it improve symptoms, it also reduces the risk that the disease will progress and that they will suffer complications.

Most people with AIH will be looked after by a hepatologist, a doctor who specialises in liver diseases.

Generally speaking, people with AIH will need long-term treatment with medications that control the immune system. These are called immunosuppressants and they include steroids and a drug called azathioprine.

Steroids are the mainstay of AIH treatment

The first thing you need to know is that not all steroids are the same.

You may have heard about steroids in connection with disgraced sports people. But steroids are also naturally produced in the body in response to injury. That's why they are commonly used in medicine for a variety of illnesses including inflammation in the lung (asthma), or in the joints (rheumatoid arthritis), or in the skin (eczema).

Steroids are normally the first treatment given to people with AIH. So the chances are you will be prescribed either a drug called prednisolone (or prednisone) or a newer treatment called budesonide.

Prednisolone and budesonide are both corticosteroids, but they work in different ways. Prednisolone enters the bloodstream and travels around the body to reduce inflammation. Budesonide works locally in the gut and liver to reduce inflammation before it enters the bloodstream. Both have been used successfully for many years to treat Crohn's disease – an immune disease of the gut.

If your doctor prescribes you prednisolone, you may start on a fairly high dose. But as your condition improves, the amount of medicine you take is gradually reduced to the lowest possible dose that controls the disease.

Side-effects considered

Like all medicines, steroids for AIH may cause side-effects. Because everybody is different, it isn't possible to say which, if any, you'll experience, or how serious they might be. That said, corticosteroid side-effects can be troublesome, particularly when a high dose is given for a long time.

Some of the more frequently encountered side-effects are mentioned below, but it is always important to read the patient information leaflet within the product pack for a full list of side-effects.

What are the short-term side-effects?

The most common side-effects include weight gain due to fluid retention and increased appetite, altered mood such as feeling depressed or tearful, and increased irritability. Difficulty in sleeping, spots (acne) and facial hair can also occur.

What are the long-term side-effects?

Long-term side-effects include thinning of the bones called osteoporosis, diabetes, a round swollen face and a thinning and bruising of the skin.

How can I minimise side-effects?

Osteoporosis can be minimised by taking tablets such as calcium and vitamin D3, which helps protect the bones. If your doctor prescribes you these extra tablets as well as your steroid, it is very important that you take them as directed.

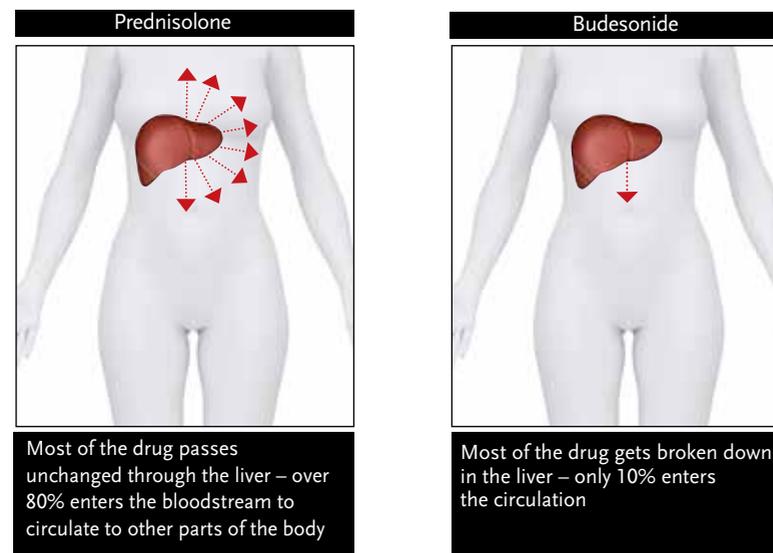
Another way that it may be possible to reduce side-effects is by the use of budesonide, which limits the steroid concentration in the bloodstream.

Why do side-effects for prednisolone and budesonide differ?

Although budesonide and prednisolone are both steroids, the way they work in the body is different – which means budesonide has a lower risk of side-effects developing.

Budesonide is called a “topical” steroid because most of the drug does not reach the bloodstream. Prednisolone, by contrast, is called a “systemic” steroid because most does enter the circulation.

Because of the lower amount of steroid reaching the bloodstream, the likelihood of side-effects is reduced with budesonide.



Your doctor will discuss the treatment options with you. It may be that if you have bone problems or are concerned about steroids, they will suggest budesonide. On the other hand, if you have cirrhosis or other systemic disorders, they are likely to suggest prednisolone. It is very important that you follow your doctor's instructions – if you are worried about something, it is always better to ask.

What is azathioprine?

Azathioprine works in a different way to steroids. If you take a steroid plus azathioprine, they tend to work better in combination than either medicine does alone. Using azathioprine may also mean that the steroid dose you need is lower. So doctors often prescribe azathioprine and a steroid together in AIH.

Side-effects of azathioprine include difficulty fighting off infections. So it is best to avoid contact with people you know have an infection. If you begin to develop symptoms of an infection, let your doctor know – particularly if you have been near people with chickenpox or shingles.

The importance of continuing treatment

Treatment works well in most cases. The inflammation usually settles and symptoms improve within a few months of starting treatment. That said, it may take a year or more to get the disease totally under control.

If your AIH completely settles, your doctor may suggest you gradually reduce the amount of medicine you take and see what happens (please note, you should not stop treatment suddenly – always discuss it with your doctor first). Unfortunately, in about 70% of cases, the hepatitis will return within 12 months of completely stopping therapy. If you do relapse, you will need to start taking medication again. Consequently, the majority of people with AIH will need to take low dose treatment for long periods of time, and sometimes indefinitely.

While you may feel a little disheartened, it is important to remember that AIH is an aggressive disease. Without treatment, AIH can result in extensive damage to liver cells making it impossible for your liver to function adequately. With treatment, most people with AIH have a normal life expectancy and feel well most of the time. That's why it is also very important you don't stop taking your treatment without consulting your doctor.

A few people do not respond well to drug treatment. For them, and those whose liver is already seriously damaged by the time they are diagnosed, a liver transplant may be an option. The long-term outlook after liver transplantation is good.

Useful words

autoimmune

When the immune system makes a mistake and attacks the body's own tissues or organs.

chronic

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

cirrhosis

Permanent scarring of the liver that occurs as a result of continuous, long-term damage.

glaucoma

Glaucoma is a group of conditions in which the nerve at the back of the eye is damaged due to changes in eye pressure.

hepatitis

The term used to describe inflammation (swelling) of the liver.

inflammation

The body's reaction to injury or infection, characterised by swelling, heat, redness and pain.

immune system

The system that defends us against attacks by organisms and substances that invade the body and cause disease.

immunosuppressant

A drug that lowers the body's normal immune response.

jaundice

Yellowing of the skin and whites of the eyes due to the abnormal presence of bile pigments in the blood.

steroids

A shortened word for corticosteroids – a group of medicines used to prevent or control the symptoms of severe inflammation due to any cause, and prevent the tissue damage that may otherwise result.

osteoporosis

A medical condition in which the bones become brittle and fragile from loss of tissue.



For more information you may like to visit
the following websites:

British Liver Trust

www.britishlivertrust.org.uk

Dr Falk

www.dralk.co.uk/index.php/patients/

PBC Foundation

www.pbcfoundation.org.uk

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