



Understanding autoimmune hepatitis

What it is and how it's treated



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

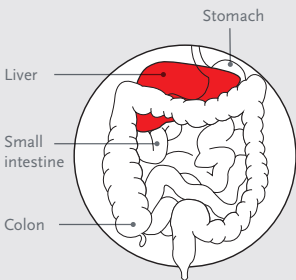
Hopefully you'll find the information it contains helpful, but it isn't meant to take the place of your doctor or nurse. So, if you do have any worries about your AIH or its treatment, do talk them through with a member of your healthcare team.



What is AIH?

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 is like a chemical processing factory. It 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.

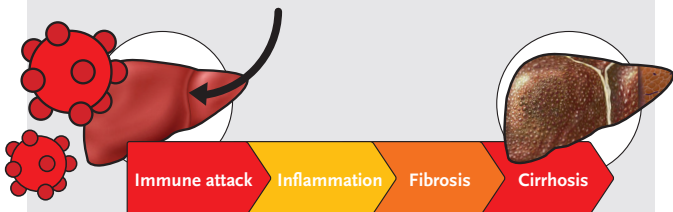
Hepatitis is the name given to inflammation of the liver. The symptoms of inflammation – pain, swelling, redness and heat – are the body's natural response to injury or irritation. When it comes to AIH, we are not absolutely sure what the trigger is. The body's immune system normally fights off infection from foreign pathogens without harming healthy cells. In AIH, the immune system mistakes liver cells for intruders and attacks them, leading to chronic inflammation and damage. AIH is one of many diseases of the immune system, also called autoimmune diseases.

How common is AIH?

AIH is relatively 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 a lifelong condition. If it isn't treated, persistent inflammation can lead to a build-up of scar tissue in the liver (fibrosis) that eventually replaces healthy liver tissue and stops your liver from working normally (cirrhosis).

The immune system mistakes the liver for something foreign



How is AIH treated?

People with AIH almost always need treatment, but with it, the outlook is good. 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 hospital doctor who specialises in liver diseases, such as a hepatologist or gastroenterologist.

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

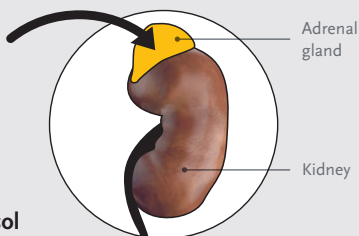
What are corticosteroids?

Corticosteroids are the mainstay of AIH treatment. They're called steroids for short, but they're not the same as the anabolic steroids you may have heard about in connection with bodybuilders.

Steroids, such as cortisol, are naturally produced in the body in response to injury, and they're actually the most effective anti-inflammatory treatment we have. That's why they're used to treat lots of different inflammatory conditions including inflammation in the lung (asthma), or in the joints (rheumatoid arthritis), or in the skin (eczema).

Cortisol is a hormone made naturally in your adrenal glands in response to injury

Corticosteroids used for treating AIH are drugs made to resemble cortisol



Steroids are normally the first treatment given to people with AIH, but not all steroids are the same. Chances are, you will be prescribed either a steroid called prednisolone or a second generation steroid called budesonide. Both have been used successfully for many years to treat Crohn's disease – a disease of the gut.

If your doctor prescribes you budesonide, you may start on a dose of around 9mg per day. If you're prescribed prednisolone, you may start on a fairly high dose of around 40 or 50mg a day. But the amount of medicine you take will be gradually tapered to minimise any side effects.



What are the side effects?

Steroids can act on most of the cells in your body. So while they work really well, the main drawback of systemic steroids is that they can have side effects if they get to places where they're not needed.

Because everybody is different, it isn't possible to say which side effects, if any, you'll experience, or how serious they might be. That said, steroid 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 increased risk of infections, 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. These effects are reversible once you stop taking steroids.

What are the long-term side effects?

Long-term side effects include increased blood pressure, a round swollen face, and a thinning and bruising of the skin. There is also the potential for irreversible problems like diabetes, glaucoma and a thinning of the bones called osteoporosis.

How can I minimise side effects?

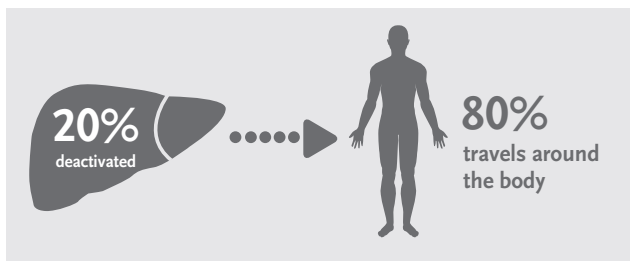
Osteoporosis can be minimised by taking tablets such as calcium and vitamin D3 which help protect the bones. If your doctor prescribes you these extra tablets as well as your steroid, it is very important that you take them as directed.

Budesonide is a treatment option that may help reduce side effects by limiting the steroid concentration in the bloodstream.

Why do side effects for prednisolone and budesonide differ?

Although budesonide and prednisolone are both steroids, there's a key difference: the amount of drug that's broken down and deactivated in the liver.

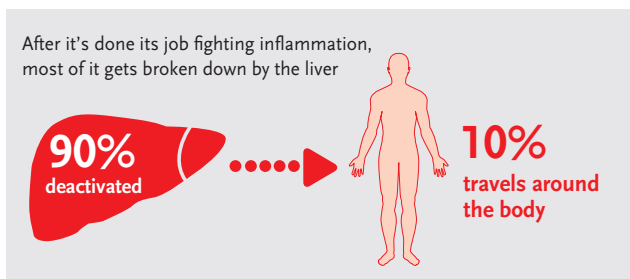
With drugs like prednisolone, lots of the drug enters the circulation



This means most of it is free to travel around the body, which may cause unpleasant and serious side effects

With budesonide, it's a different story

After it's done its job fighting inflammation, most of it gets broken down by the liver



So a lot less reaches the rest of the body, and it's much less likely to cause unwanted steroid side effects

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?

Once in remission your doctor may prescribe you a low dose of budesonide or an immunomodulator called azathioprine to help keep you in remission. 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.

How long do I need to take 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. But 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 for those whose liver is already seriously damaged by the time they are diagnosed, a liver transplant may be an option.

What else can I do to look after myself?

While there aren't any specific diet recommendations for AIH, the best advice is to eat a healthy, balanced diet with plenty of fruit and veg.

If you're taking steroids, weight-bearing exercise like walking is excellent for maintaining your bone health. Your doctor might also recommend taking supplements that help protect your bones.

And remember, you're not on your own. Lots of people find it helpful to talk to others facing similar challenges through groups like AIH Support.



Eat as well as you can



Keep yourself active



Talk things through

aihsupport.org.uk



Listen to Hazel's story about how she manages her AIH by scanning this code with the camera on your smartphone or tablet.

Visit drfalk.co.uk/diseases-treatments/liver-diseases to find more about AIH and how it's treated

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at www.mhra.gov.uk/yellowcard for UK residents and via <http://www.hpra.ie/homepage/about-us/report-an-issue> for residents of the Republic of Ireland. By reporting side effects you can help provide more information on the safety of medicines.

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