Autoimmune hepatitis

Your guide to understanding and living with autoimmune hepatitis

BRITISH LIVER TRUST

Raising awareness, transforming lives

Contents

"There are often no signs that you have autoimmune hepatitis and symptoms can be vague. Blood tests and a liver biopsy are used to help confirm that you have it. Once you are diagnosed, we can help treat it."

Dr Vikki Gordon, Consultant Gastroenterologist and Hepatologist, University Hospitals Coventry and Warwickshire NHS Trust

This booklet will help you understand more about autoimmune hepatitis, and give you help and advice to improve your condition.

Your doctor is the best person to speak to about your treatment, as they know your medical history.

What is autoimmune hepatitis?

Autoimmune hepatitis is a life-long and rare liver disease. It is when your body's immune system causes damage to its own healthy liver cells. This leads to inflammation in the liver.

Treatment involves very effective medicines that suppress the immune system and reduce inflammation. It also reduces the likelihood of your condition getting worse.

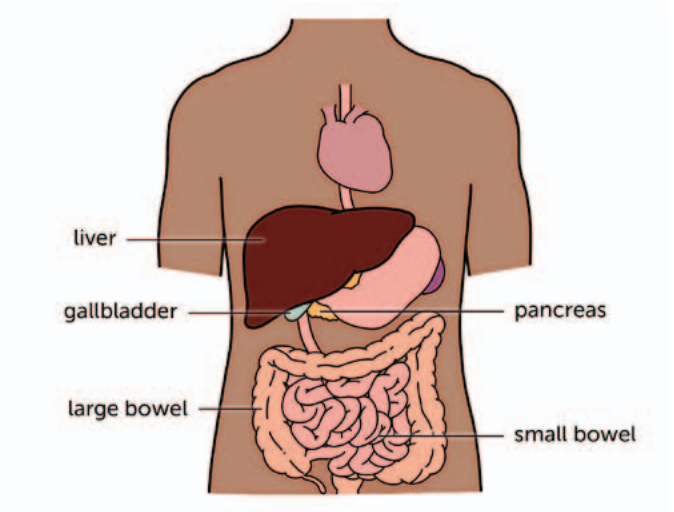
If left untreated it can lead to serious scarring of the liver (cirrhosis). This can then lead to liver cancer or liver failure.

It is not entirely clear what causes autoimmune hepatitis, and it is not known whether anything can be done to prevent it.

- Around 4 out of 5 people who have autoimmune hepatitis are women
- A third to a half of people who are diagnosed have a personal or family history of other autoimmune conditions. These include thyroid disease, rheumatoid arthritis, ulcerative colitis or type 1 diabetes
- About 1 in 3 people with autoimmune hepatitis will have cirrhosis when they're diagnosed.

The role of the liver

Your liver is on the right side of your tummy, just under your ribs. It works like your body's factory and carries out hundreds of jobs that help keep you alive and well.



Your liver:

- turns digested food from your gut into all the different chemicals your body needs
- breaks down toxins, alcohol, drugs and other harmful substances
- helps control the amount of sugar in your blood
- makes the chemicals that help your blood clot

The immune system

The immune system protects you from infections. Its main goal is to identify and kill things in your body that should not be there.

All the cells in your body carry markers called antigens. Different cells have different antigens. Bacteria, viruses, and other things that can cause infections carry antigens too. Your immune system uses these antigens to check if something should be in your body or not. Like checking an entry ticket.

The main defenders in a healthy immune system are white blood cells. These include B cells and T cells, together these are called lymphocytes.

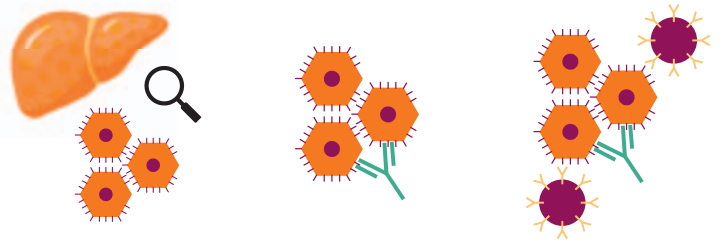
B cells look for antigens that should not be there. If they find one, they produce antibodies that will lock on to the antigens. This is like putting up a flag. It tells T cells to kill the cell or virus with the antigen and antibody flag. Some T cells are called ‘killer cells’.

After they are made, antibodies will stay in your body in case you have to fight the same thing again. The most common antibody is immunoglobulin G (IgG).

When you have autoimmune hepatitis, your immune system can also be triggered by your own cells. Your B cells also produce antibodies that stick to antigens on your own cells. These are called autoantibodies. This makes your T cells attack your own healthy liver cells. And this damages your liver and causes inflammation.

You will usually have more IgG in your body if you have autoimmune hepatitis. You will be tested for this when you are being diagnosed and to monitor how your body is responding to treatment.

Autoimmune hepatitis and the immune system



Liver cells

Antibodies latch on and wrongly mark the liver cells as foreign

Immune cells attack and destroy the liver

When you’re being treated for autoimmune hepatitis, your medicines act as a shield against your body’s immune system. This reduces the inflammation and protects your liver.

What causes autoimmune hepatitis?

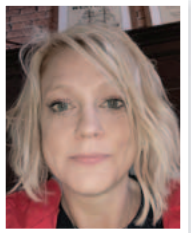
The causes of autoimmune hepatitis are not always clear. They are thought to be a combination of:

- **Autoimmunity** – when your immune system makes autoantibodies, which attack and damage your body's own cells and organs
- **Genetics** – it can run in families, which may make it easier for a trigger to set it off
- **External triggers** – causes outside your body, such as getting a virus or taking certain medicines

What is hepatitis?

Hepatitis is the medical term used to describe inflammation of the liver. There are lots of causes of hepatitis and some of them are more well-known than others. Some people think autoimmune hepatitis is the same as other types of hepatitis, such alcohol-related hepatitis or viral hepatitis. However, you cannot catch autoimmune hepatitis and it is not related to drinking alcohol.

If you would like help and advice about dealing with stigma, please visit our website:
www.britishlivertrust.org.uk/help-with-stigma



"I've struggled to get people to understand my condition at work. It's helped to frame it slightly differently by saying 'I've got an autoimmune condition that attacks my liver' rather than saying 'liver disease' or using the word 'hepatitis' – terms some people associate with drinking too much alcohol and having a virus, which isn't always the case."

Louise was diagnosed with autoimmune hepatitis in 2017

Some people with autoimmune hepatitis will have another type of liver disease: an overlap syndrome. The most common are primary biliary cholangitis (PBC), primary sclerosing cholangitis (PSC) and non-alcohol related fatty liver disease (NAFLD).

Your liver specialist can help you understand what an overlap syndrome means for you and your condition.

What are the symptoms of autoimmune hepatitis?

Nearly a quarter of people with autoimmune hepatitis will have no symptoms. Or you might get symptoms after you have been diagnosed. For some people these can develop quickly over a few days (acute hepatitis).

Early symptoms can include an overwhelming sense of tiredness (fatigue), feeling generally unwell, itching, and yellowing of the skin and eyes. As the liver struggles to work more serious symptoms can develop. **If you have any of these symptoms, tell a doctor straight away:**

- Yellowing of the skin and whites of the eyes (jaundice)
- Swelling in the legs, ankles and feet caused by a build-up of fluid (oedema)
- Swelling in your tummy caused by a build-up of fluid (ascites)
- Periods of confusion, forgetting things, mood changes or poor judgement (hepatic encephalopathy (HE) or brain fog)
- A tendency to bleed and bruise more easily, such as frequent nosebleeds and bleeding gums.

Even if you have no symptoms, if you have another autoimmune condition and are worried, tell your doctor.

Read more about the symptoms of liver disease on our website: www.britishlivertrust.org.uk/symptoms

How is autoimmune hepatitis diagnosed?

You might find out you have autoimmune hepatitis during tests for other health problems. If your GP suspects you have autoimmune hepatitis they will do some blood tests and then refer you to a liver specialist. This will either be a hepatologist (a doctor who specialises in liver disease) or a gastroenterologist (a doctor who specialises in the digestive system). They will try to find out what the problem is and how damaged your liver is.

This will include a thorough medical history, physical examination, special blood tests and scans. Most people also need a liver biopsy. Blood tests, scans and biopsies are usually carried out at a hospital.

It is important to give your doctors as much information as you can. This includes other autoimmune diseases or health conditions you have. This will help them to diagnose your condition correctly and give you the right care. An early diagnosis can often mean your treatment will be more effective.

Blood tests

You could learn you have a liver problem from your doctor. This is usually the result of routine blood tests, which include liver blood tests (or liver biochemistry tests).

If you have autoimmune hepatitis, you will have more liver enzymes in your blood. These are alanine aminotransferase (ALT) and aspartate aminotransferase (AST).

If your liver blood tests keep being abnormal, you will have further blood tests to identify autoantibodies. Autoantibodies include:

- Anti-mitochondrial antibodies (AMA)
- Anti-nuclear antibodies (ANA)
- Anti-smooth muscle antibodies (ASMA).

You will also be tested for another type of antibody, called immunoglobulin G (IgG).

If you have autoimmune hepatitis, you will most likely have higher levels of these autoantibodies and IgG in your blood. IgG is used as a marker to monitor the effectiveness of your treatment.

Blood tests are an important guide to who might have liver disease. But they aren't accurate enough to rule out liver disease by themselves. If your liver blood tests are abnormal it is important that your doctor investigates. This could include more blood tests, a scan and often a liver biopsy.

Scans

If liver disease is suspected, scans can give doctors a more detailed picture of what is going on.

These can include the following:

- An **ultrasound scan** looks at the surface and general shape of your liver, as well as any changes from its normal appearance.
- **Transient elastography** eg FibroScan®, measures the stiffness of your liver and helps your doctor judge how much liver scarring (fibrosis) there might be.
- **CT** and **MRI scans** can look at your liver in more detail.

Liver biopsy

Blood tests and scans are not usually enough to make a diagnosis. If there is any doubt your doctor will recommend a biopsy. This can check for inflammation and scarring of the liver (fibrosis) to find out how advanced your liver disease is.

Your doctor should explain the risks and why they think having a biopsy is a good idea. This will help you decide for yourself if you agree (consent) to have one.

A liver biopsy might be an option if you are not responding to treatment, or your doctor wants to stop it at a later date. They might suggest a liver biopsy to make sure your liver inflammation has improved or gone away (remission).

"To confirm you have autoimmune hepatitis, you will usually have a liver biopsy. As well as a medical history, blood tests and scans – it's one more piece of a jigsaw puzzle that fits together to show us the whole picture. As there is no one single test to diagnose autoimmune hepatitis, it can take some time."

Dr Vikki Gordon, Consultant Gastroenterologist and Hepatologist, University Hospitals Coventry and Warwickshire NHS Trust

For more information about liver biopsy visit our website.

Other tests if you have cirrhosis

Advanced liver disease is called cirrhosis. If you have or develop cirrhosis your clinical team will monitor your condition. You will be offered a clinical check-up every six months. They will also talk to you about any other tests or care you might need.

Endoscopy

You might have an endoscopy to look inside your food pipe (oesophagus) and stomach to check for swollen veins (varices). If the varices are large and at risk of bleeding, your liver specialist can place rubber bands around them to cut off their blood supply (banding).

You can read detailed information about cirrhosis on our website.

Surveillance scan for liver cancer

Liver cancer is more common if you have cirrhosis. Finding it early means it can often be cured. Doctors use regular checks (surveillance) every six months. This is to check for a type of liver cancer called hepatocellular carcinoma.

To find out more about liver cancer, visit our dedicated website: www.livercanceruk.org

Treating autoimmune hepatitis

Most people with autoimmune hepatitis need treatment. This is called immunosuppression and uses a combination of medicines: corticosteroids and another immunosuppressant.

Immunosuppression reduces how active your immune system is. This stops it attacking your liver and reduces the inflammation.

The main aim of treatment is to improve your symptoms and your blood tests. It will also prevent or reduce scarring and long-term liver damage and failure.

You are likely to take medicines for at least two years. For many people this could be for life. It might be possible to stop treatment completely, but some people can become ill again (relapse) and need further treatment.

These decisions should be made carefully between you and your clinical team. If your treatment changes, or is stopped completely, you will be checked more closely.

You have the right to choose which hospital your doctor refers you to. There is a list of hospitals with specialist liver departments on our website, to help you find one near you.

Your care will be managed by a hepatologist or a gastroenterologist. Speak to your clinical team about whether you can be supported by a liver nurse specialist.

Corticosteroids

Corticosteroids are a type of steroid, used to reduce inflammation in the liver.

They are also an immunosuppressant. They are different from anabolic steroids, used by some people to increase their muscle mass.

Common types of corticosteroids are prednisolone and budesonide. **Prednisolone** is the main steroid used to treat autoimmune hepatitis.

If you have jaundice when you are diagnosed, you will usually only have corticosteroids. When your symptoms improve, you will also start taking an immunosuppressant.

Read more about budesonide on our website:
www.britishlivertrust.org.uk/AIH

When you take prednisolone (or other steroids) for more than three weeks, you should have a steroid treatment card. Carry it with you and keep it up to date. You will need it in an emergency, or if you are having any medical or dental treatment. These days, it might also be helpful to take a photo of it on your phone.

How to take prednisolone

Prednisolone comes in tablets. Take it with food to help reduce tummy problems.

How much will I need and for how long?

How much medicine you need (the dose) will be different for each person. Generally, you will start with a higher dose and gradually reduce this over time. Once the inflammation is under control, you might stop taking steroids completely and continue with a long-term immune suppressant to stop your condition getting worse (flaring). You might need to continue taking a low dose of steroids.

If you have had symptoms, these can improve within days. For some people it can take longer.

Steroids can interact with other medicines. Let your liver specialist know about all the medicines you are taking.

Do not eat liquorice or products containing glycyrrhizin (liquorice extract) when you are taking prednisolone. This might increase the amount of the steroids in your body and your side effects.

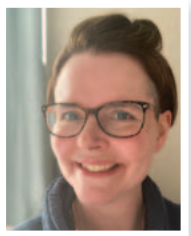
Managing side effects

Some side effects can happen straight away. Others can happen after weeks or months. If you tell your clinical team they can sometimes help by changing your treatment. Common side effects include:

Weight gain

Prednisolone can make you hungrier, and also can make you hold more water in your body (water retention). Try to eat well without increasing your portion sizes. Regular exercise will also help to keep your weight stable. When you stop taking prednisolone, your appetite and the way your body holds water should return to normal.

A common side-effect of taking prednisolone over a long period of time can be "moon face". You can help the swelling around your face by reducing your salt intake, drinking more water and getting enough sleep. Your doctor might be able to help you reduce your medicine (tapering) or stop taking it.



"My face shape has changed quite a bit, so I've treated myself to a new hairstyle and I'm saving up for new glasses. This has definitely helped me cope."

Anna was diagnosed with autoimmune hepatitis in December 2022

Indigestion

Take prednisolone with food to reduce the chances of tummy problems. It may also help if you avoid rich or spicy food while you are taking it. If symptoms continue, ask your doctor or liver specialist about taking another medicine to protect your tummy.

Problems sleeping (insomnia) or feeling restless

Take prednisolone in the morning so levels are lowest at bedtime.

A small number of people have more serious side effects. You might also have withdrawal symptoms if your dose is reduced or you stop taking prednisolone. Tell your doctor if you feel unwell or if you notice anything unusual about your health.

Taking steroids over a long period of time can affect your health in several ways. Your doctor will offer you a bone density scan (DEXA scan) every 1 to 2 years to check your bones aren't thinning (osteoporosis). They will also prescribe calcium and vitamin D supplements to help your bones stay strong.

Immunosuppressants

The most common immunosuppressant used with corticosteroids is azathioprine. Immunosuppressants:

- Moderate how active your immune system is
- Help prevent inflammation and cell damage
- Reduce your symptoms.

Mercaptopurine (6MP), mycophenolate mofetil (MMF) and tacrolimus (TAC) are other types of immunosuppressant. They can be used instead of azathioprine. For example, when you have serious side effects or when your autoimmune hepatitis has not responded to azathioprine.

Immunosuppressants can interact with other medicines. Let your liver specialist know about all the medicines you are taking.

Your liver specialist or doctor might talk to you about a 'shared care agreement' when you have been prescribed medicine to control your condition. This means that the medicine the hospital has started can be continued by your GP, so you will not have to visit the hospital to collect your medicine. There might be certain medicines that can only be prescribed by a hospital.

How to take azathioprine

Azathioprine usually comes as tablets. Take it with plenty of water, after eating a meal or with a snack, to help reduce tummy problems.

How much will I need and for how long?

Doses will vary and could change during the course of your treatment. It will depend on your weight and how serious your autoimmune hepatitis is.

The length of treatment depends on each person. It is likely to be for several years, and longer (sometimes for life). For some people treatment can be stopped if your signs and symptoms improve a lot or go away (remission). In this case, you might be offered a liver biopsy to check it is safe to stop taking the medicine.

This type of medicine can act slowly, so it may be up to three months before you feel any benefits.

Do not drink milk or eat dairy products at the same time as taking your azathioprine tablets. Dairy products contain an enzyme which can break down the medicine, making your treatment less effective. Take your medicine at least one hour before, or two hours after, having milk or dairy products.

Managing side effects

You are more likely to experience side effects when you first start taking azathioprine or when your dose is increased. You will usually feel better within a month or so. Common side effects include:

Fatigue

Fatigue is a common symptom of having autoimmune hepatitis. It is also a common side effect of taking azathioprine. This will improve as the inflammation in the liver improves. Eating well, being physically active and getting enough sleep can help.

Feeling sick

Stick to simple meals and do not eat rich or spicy food. It might help to take azathioprine after you have eaten. If you keep feeling sick after a couple of weeks speak to your clinical team. Your medication could be changed to mercaptopurine.

If you are struggling with other side effects or they are not going away, speak to your doctor, liver specialist or specialist nurse. They can sometimes adjust your treatment to help.

Staying healthy on immunosuppressants

- You will be at higher risk from COVID-19, so you are eligible for antiviral treatment. This will stop you getting severe symptoms and will also reduce the risk of you needing to go to hospital. Keep some NHS COVID-19 tests at home, as you will need to test and confirm you have the virus to apply for treatment.
- There is a slightly increased risk of developing some cancers. It is important to reduce the risk of skin cancer by not using sunbeds and protecting your skin from strong sun with clothes, hat, and sunscreen with at least SPF30. It is also a good idea to take part in cancer screening when you are invited. Especially screening for cervical cancer as it is caused by a virus.
- It is important to avoid anyone who has or may have measles, shingles or chickenpox. If you become ill, you should make an appointment to see your doctor as soon as possible.
- Do not take ‘live’ vaccines while taking these medicines, and for three to six months after you stop treatment. If you are living with anyone planning to have one, ask your GP whether it is safe.

If you have liver disease you are more vulnerable to infections. And if you do get ill, you are more likely to become severely ill. It is important to have your Hepatitis A and B, flu and COVID-19 vaccinations.

Liver transplants

If your liver is very badly damaged, a liver transplant could be life-saving. It is usually only recommended if other treatments are no longer helpful, and your life is threatened by end stage liver disease.

Anyone with liver disease can have a transplant assessment if they meet certain conditions. This will be carried out at a liver transplant unit. The process usually takes a few days. You may need to stay in hospital during this time, or you may be able to go home at the end of each day.

The assessment involves talking to liver transplant specialists and having tests to check your liver and general health, including the strength of your heart and lungs.

As surgery is very technical, people who have a transplant will need to spend some time in the Intensive Care Unit (ICU) after their operation.

Liver transplants are very successful. They are a major operation so it can take up to a year to recover, most people are able to leave hospital around 10 days after surgery.

Once you have had a transplant you will need lifelong treatment with medication to control your immune system. This is managed by your transplant specialist or hepatologist.

If you have later stage liver disease it is really important to ask your liver specialist about having a transplant.

Visit our website for information about liver transplants:
www.britishlivertrust.org.uk/transplants

Monitoring your condition

It is important to have regular appointments with your doctor or liver specialist so they can monitor your condition. They will be able to provide you with more information on how often these should be, who with, and what to expect.

As you start your treatment, you might have more blood tests to monitor how you are responding. As your condition becomes more controlled, you will have less.

Your doctor will balance treating you effectively with reducing side effects from your medicines. They will do this by keeping the doses as low as possible. They will check your ALT, AST and IgG levels. These will show how well you are responding to treatment. The aim is to normalise these blood tests and reduce your symptoms.

The time it takes to improve the inflammation in the liver will be different for everyone. If you are well enough to stop taking medication, your doctor or liver specialist will discuss the risks and benefits. If you do stop, you will be monitored more regularly for a while.

Many people with autoimmune hepatitis get pregnant and have children.

Visit our website to find our more information about autoimmune hepatitis and pregnancy.

What is a 'flare'?

A flare can happen when you are not responding to treatment. This means your ALT and AST levels will be higher than they should be. You might have the same symptoms as before, new symptoms, or none at all.

Flares can happen because your treatment isn't working well enough. They can also happen if your treatment has been stopped due to your autoimmune hepatitis going into remission. This is called a 'relapse'. If you relapse you will need to start treatment again.

About 7 in 10 patients who go into remission and stop treatment will relapse within a year.

Anninder's story

Anninder, 34, was diagnosed with two other autoimmune conditions before she was diagnosed with autoimmune hepatitis. The treatment she is on means her condition is under control and she can now look to the future.

"In 2014 I was diagnosed with Sjogren's Syndrome and in 2020 I was diagnosed with Lupus SLE. I was put on medication and started feeling better. But a few years later, I noticed I had started to feel tired again, and my regular blood tests were showing high levels of AST, which went up and up. I was referred to hepatology, so I could have a scan of my liver. I started to feel really unwell as the weeks went on. The exhaustion was beyond anything I had ever experienced. No amount of sleep or rest could shake it off. I had lost weight and was looking after my health better than I ever had, so didn't understand why this was happening.

"The exhaustion was beyond anything I had ever experienced"

Finally, the day of the scan came, followed by my hepatology appointment. My consultant was fantastic, going through my blood tests and scans. I remember him saying "your liver is inflamed but it's still functioning. I think you have autoimmune hepatitis". He suggested I start a dose of prednisolone to bring things under control, and weekly blood tests and telephone consultations with him to see how I was doing. After three weeks of taking the prednisolone, my levels had returned to normal, and my consultant had confirmed diagnosis of autoimmune hepatitis.

"I'm now looking to the future and feel I can live my life"

I am feeling so much better now that I am on prednisolone. I also take azathioprine, which is keeping my liver levels stable. I can run around with my son, and I have energy. My liver has now recovered because of the early diagnosis.

Fatigue is one of the biggest symptoms of autoimmune conditions, so you've got to be sensible and know your limits. I'm now looking to the future and feel I can live my life. I understand more about the condition and have joined an online support group which has been brilliant."

To read about other people's experiences of living with autoimmune hepatitis, visit our website.

Living with autoimmune hepatitis

Diet

There is no special diet if you have autoimmune hepatitis. The main medicines for the condition can interact with certain foods. So you might need to avoid those (see pages 19 and 23).

Generally you should have a healthy balanced diet. Lots of vegetables, fruit, wholegrain carbohydrates (such as wholemeal bread or brown rice) and lean protein (such as chicken, fish or tofu). Cut down on highly processed foods and snacks, especially those that are high in fat, sugar, or salt.

If you have cirrhosis, as well as eating a healthy balanced diet you may need to follow special advice.

You can read more about a well-balanced diet and nutrition for people with cirrhosis on our website:
www.britishlivertrust.org.uk/diet

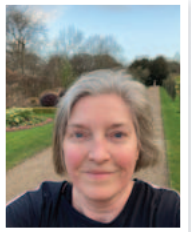
Weight

Putting on weight can be a side-effect of taking steroids. Being physically active and eating healthily will help you manage your weight. It is important to keep your weight healthy, as this helps stop more damage to your liver.

If you are struggling to keep to a healthy weight ask your doctor for advice. You might need a diet tailored to you, or a referral to a dietitian.

Keeping fit

Doing regular physical activity or exercise helps keep you strong and prevent muscle wasting. This is especially important if you have cirrhosis. Do what you can manage each day – doing something, even something small, is much better than nothing.



"Running is helping me to lose the weight I put on when the initial high dose of steroids caused me to lose control of my appetite. I've also discovered it's great for my mental health. I feel lucky that my autoimmune hepatitis is stable now and well managed so that I can enjoy exercising."

Sally was diagnosed with autoimmune hepatitis in 2019

Looking after your mental health

Living with liver disease can be hard. As well as coping with physical symptoms you may be juggling changes to your daily life, practical issues, and worrying about the future. So it is not surprising that most people will struggle at times.

Your GP will have lots of experience with mental health issues and can refer you if you need support.

Visit our website for advice and information on looking after your mental wellbeing.

Practical support for patients, family and carers

When you have been diagnosed with liver disease, there are many things for you and your loved ones to consider. As well as emotional and physical issues, there can be an impact on practical things, such as life insurance and money.

Life insurance

If you live with a long-term health condition, it can be difficult to get life insurance. Or the premium may increase.

If you can't get or afford life insurance, there might be other options. For example, you could pay into a savings account. You will need to decide if insurance is worth it, and what the best options are for you.

It is important that you tell insurance companies about any pre-existing conditions or conditions that develop while you have cover. If you don't, it could affect any claims you need to make.

Not all insurance companies are the same, so it is important to shop around. Brokers can do this on your behalf and give you advice, it is a good idea to talk to a few different ones. Some brokers specialise in insurance for people with medical conditions.

Grants and state benefits

Whether you can claim usually depends on how your condition affects you and your income and savings. Depending on your age, you may be able to claim Attendance Allowance or Personal Independence Payment (PIP). Once you are receiving a benefit, someone who helps look after you may be able to claim Carers Allowance too.

It is a good idea to ask about and apply for financial support, even if you are not sure whether you are ill enough to qualify.

Many people overestimate how ill they have to be to be eligible. You will usually need to ask your doctor for a medical certificate or to fill in a form.

Saving money on prescriptions

If you live in England and take several medicines NHS prescription costs can quickly add up. So it might be a lot cheaper to buy a prescription prepayment certificate (PPC). This is like a prescription 'season ticket' that will cover all your NHS prescriptions. No matter how many items you need.

The NHS website has a full list of who can get free prescriptions, a tool to check if you are eligible, and details of how to apply.

If you live in Northern Ireland, Scotland or Wales, you do not have to pay for your prescriptions.

There is detailed information on all these topics and more on our website, including links to help you find travel and life insurance.

How the British Liver Trust can help

A diagnosis of any kind of liver disease can be worrying and you may have a lot of questions. Speaking to one of our liver nurses and getting to know people in a similar situation can be reassuring and can really help too.

Helpline

Your clinical team are the best people to discuss the details of your treatment with. But we are here for everything else, from information and advice to simply having someone to listen.

Call our helpline and speak to a nurse on 0800 652 7330

Online community

An invaluable source of peer support, where you can post questions, share experiences and hear from others on how they or those close to them are managing their condition:
www.healthunlocked.com/britishlivertrust

Support groups

Many patients, families and carers affected by a liver condition find it helpful to speak to others and share experiences. Our support groups can be a real lifeline. The British Liver Trust hosts groups online so you can join wherever you are.

Visit our website for more information.

There are also other support groups such as AIH Support – a Facebook group dedicated to supporting anyone affected by autoimmune hepatitis (AIH) including friends, family and carers.
www.facebook.com/groups/AIHorgUK

Looking after yourself – your questions answered

Can I drink alcohol?

If you have cirrhosis you should not drink alcohol at all. Regularly drinking alcohol increases your risk of developing liver cancer.

If you don't have cirrhosis and want to drink alcohol, check with your doctor and follow the guidelines. The guidelines on low-risk drinking are the same for men and women:

- Do not drink more than 14 units of alcohol in one week
- Spread your drinking over several days
- Have 3 alcohol free days each week – it's best if these are next to each other

Can I take complementary or alternative medicines?

It is important to get your doctor's advice before trying any of these products. At the moment doctors do not generally recommend them for liver disease. Most of them are not classed as medicines so they don't go through the same strict testing for quality or effectiveness. It is possible these products have no effect or could even be harmful, including causing damage to your liver.

Does milk thistle help symptoms of liver disease?

Do not use milk thistle without speaking to your doctor. It could cause problems if you take certain medicines including warfarin, diazepam, the antibiotic metronidazole and sirolimus (an immunosuppressant used after liver transplant).

There is also some evidence that it could lead to low blood sugar. There is no strong evidence to support using milk thistle as a natural treatment for liver disease.

Do I need to stop smoking?

Smoking increases your risk of developing liver cancer and at least 50 other health conditions. If you smoke the best thing you can do for your health is quit. You don't have to do it by will power alone. Using local free stop smoking services boosts your chance of quitting by three times.

Find your local free service:

England	- NHS smokefree 0300 123 1044
Scotland	- Quit your way 0800 84 84 84
Wales	- Help me quit 0800 085 2219
Northern Ireland	- Stop smoking NI

Should I try to "detox" my liver?

You might see foods or diets being recommended to cleanse or "detox" your liver. But this isn't physically possible. Some of these diets can be dangerous for people with liver disease.

Visit our website for more information and advice on living with a liver condition.

Useful words

Autoantibodies – Antibodies (immune proteins) that mistakenly target and react with your own tissues or organs.

Asymptomatic – When you have an illness or condition (such as autoimmune hepatitis) but do not show any signs or symptoms of having it.

Biopsy – A medical procedure that involves taking a small sample of body tissue so it can be examined under a microscope.

Bone density scan (DEXA scan) – A scan to see how dense and strong your bones are.

Endoscopy – A test used to look inside your body, usually your food pipe (oesophagus). It uses a long, thin, bendy tube called an endoscope, which has a light and a camera on the end.

Fibrosis – The medical word for scar tissue, which can form as a result of liver damage. How much scarring there is in your liver is an important sign of how advanced your liver disease is.

Gastroenterologist – A doctor who specialises in treating diseases of the digestive system including the stomach, gut, pancreas and liver.

Hepatologist – A doctor who specialises in treating liver disease.

Immunosuppressant – Medicines that help to calm or control your body's immune system.

Inflammation – How your body responds to things that could harm it, such as germs or wounds. In autoimmune hepatitis your own immune system causes damage to its own healthy liver cells, causing inflammation in the liver.

Jaundice – When your skin or the whites of your eyes turn yellow, caused by the build-up in your body of a yellow substance called bilirubin. It can be hard to see on black or brown skin.

Osteoporosis – A condition where your bones weaken and are more fragile and likely to break. It is more common in people with autoimmune conditions and those who take steroids. **Osteopenia** is an earlier stage of osteoporosis.

Remission – When the signs and symptoms of your autoimmune hepatitis improve a lot or go away entirely. The condition itself might not be cured, but it is not causing you any problems. Biochemical remission means your blood test results are normal. Histological remission means a biopsy has shown no sign of autoimmune activity in your liver.

Transient elastography – A scan that tests how stiff your liver is, which is a sign of how much damage and scarring there is. A common type of transient elastography is called FibroScan®.

British Liver Trust information and resources

Scan the code with your phone or visit **www.britishlivertrust.org.uk/AIH** to read and download all our information about autoimmune hepatitis for patients.

Useful websites

Mind www.mind.org.uk

Advice and support to empower anyone experiencing a mental health problem.

NHS
www.nhs.uk/nhs-services/prescriptions-and-pharmacies

Advice on who can get free prescriptions and saving money with a prescription prepayment certificate (PPC).

Special thanks

All our publications are reviewed by medical experts and people living with liver disease.

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We welcome your comments on this booklet, please email: publications@britishlivertrust.org.uk

About the British Liver Trust

The British Liver Trust is the leading UK charity for all adults affected by liver disease. We are entirely funded by donations, including gifts in Wills. Our mission is to transform liver health by improving awareness, prevention, care and support.

To make a gift in support of our work today please scan the QR code or visit: www.britishlivertrust.org.uk/donate

"Try not to think too far ahead. Focus on each step, rather than the end result.

Let your family and friends know what is going on too. Living with uncertainty is tough and I really benefitted from the support.

Do more of whatever you love, as long as your doctor has okayed it and it feels right."

Anna who was diagnosed with autoimmune hepatitis in December 2022

Website: www.britishlivertrust.org.uk
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