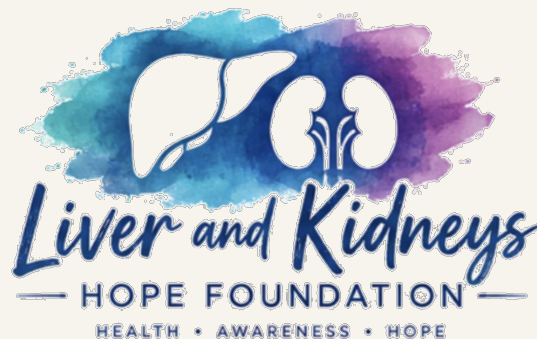




PATIENT & COMMUNITY EDUCATION SERIES

Understanding Autoimmune Hepatitis

A plain-language, comprehensive guide to autoimmune hepatitis — a chronic condition where the immune system attacks the liver, how it's diagnosed, and how it's managed for the long term.

Covering diagnosis, treatment, remission, and living well with AIH

Health Education Series · EDU-LIV

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First Edition

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A NOTE BEFORE YOU BEGIN

Autoimmune hepatitis is, for most people, a very treatable condition. The large majority of patients respond well to treatment and go on to live full, normal lives. This guide aims to explain the condition clearly while keeping that genuinely hopeful outlook front and center.

SECTION 1 Your Liver: A Quiet, Hardworking Organ

Before discussing what can go wrong, it helps to appreciate just how much your liver does every day — usually without you noticing at all.

Your liver is the largest solid organ inside your body, weighing roughly 1.4 kg (about 3 pounds) in an adult. It sits just under your rib cage on the right side, tucked below the diaphragm and above the stomach and intestines. Scientists have identified more than **500 distinct functions** it performs — from processing nutrients and making bile, to filtering toxins and producing clotting proteins.

What your liver does for you

- **Processes nutrients**, storing and releasing sugar to keep blood sugar steady.
- **Manages fats**, making bile to help digest dietary fat.
- **Filters and detoxifies**, neutralizing alcohol, medications, and natural waste products.
- **Makes essential proteins**, including albumin and most blood-clotting factors.
- **Stores vitamins and minerals**, such as vitamins A, D, E, K, B12, and iron.

A remarkable ability to heal — and a vulnerability to the wrong kind of attention

The liver can regenerate after injury, and it normally coexists peacefully with the immune system, which patrols the huge volume of blood passing through it looking for genuine threats like bacteria and viruses. In autoimmune hepatitis, something goes wrong with this usually well-calibrated relationship, and the immune system begins treating the liver's own cells as a threat — the subject of this entire guide.

DID YOU KNOW?

The liver has very few pain-sensing nerves and a large amount of spare capacity, which is part of why autoimmune hepatitis can be present for some time before it's noticed — either through vague symptoms or, sometimes, through an abnormal blood test found for an unrelated reason.

KEY POINT

Autoimmune hepatitis is fundamentally different from the metabolic, viral, and alcohol-related conditions covered elsewhere in this guide series — here, the liver's own immune environment is the problem, which is why its treatment looks so different too.

SECTION 2

What Is Autoimmune Hepatitis?

Autoimmune hepatitis (AIH) is a chronic condition in which the immune system mistakenly attacks the liver's own cells, causing inflammation and, if untreated, progressive liver damage.

"Autoimmune" describes any condition where the immune system, which normally defends the body against outside threats like bacteria and viruses, mistakenly identifies the body's own tissue as a threat and attacks it. In autoimmune hepatitis, this mistaken attack is directed at liver cells (hepatocytes), causing ongoing inflammation — "hepatitis" simply means inflammation of the liver, regardless of cause.

A chronic, but highly treatable, condition

Unlike a viral infection that the body eventually clears, autoimmune hepatitis is generally a long-term condition requiring ongoing management. The encouraging news is that it responds well to treatment in the large majority of patients, and many people achieve long periods of quiet disease activity (remission), covered in Section 14.

KEY POINT

Autoimmune hepatitis is not caused by anything you did — it isn't linked to diet, alcohol, or lifestyle in the way some other liver conditions are. It results from a misdirected immune response, and it responds to treatments that calm that immune response.

DID YOU KNOW?

Autoimmune hepatitis was first clearly described in the 1950s, and for decades was sometimes called "lupoid hepatitis" because of some shared features with lupus, another autoimmune condition. This name is no longer used, since we now understand it as its own, distinct disease.

SECTION 3

How It Develops: The Immune System Turns on the Liver

Understanding the immune process behind autoimmune hepatitis helps explain why treatment focuses on calming the immune system, rather than on the liver directly.

A case of mistaken identity

In autoimmune hepatitis, specific immune cells (T-cells) mistakenly recognize proteins on the surface of liver cells as foreign, triggering an inflammatory attack against them. This is

thought to require both a genetic predisposition and some kind of triggering event, though the exact trigger is often never identified in an individual person (Section 5).

Ongoing inflammation and injury

Once triggered, this immune attack tends to persist, causing ongoing inflammation and injury to liver cells. Left unchecked over time, this repeated injury can lead to fibrosis (scarring) and, eventually, cirrhosis — which is why identifying and treating the condition matters, even when symptoms are mild or absent.

Why suppressing the immune response works

Because the fundamental problem is an overactive, misdirected immune response, medications that calm the immune system (Section 13) directly address the root cause — reducing inflammation, allowing the liver to heal, and, in many people, preventing further scarring.

KEY POINT

This immune basis is the single most important thing to understand about autoimmune hepatitis — it explains both why the condition develops and why the mainstay treatments work the way they do.

DID YOU KNOW?

Researchers believe certain genetic markers, particularly specific variations in immune-related genes, make some people more susceptible to developing autoimmune hepatitis — though having these markers doesn't mean someone will definitely develop the condition.

SECTION 4 Types of Autoimmune Hepatitis

Autoimmune hepatitis is generally classified into subtypes based on specific antibodies found in the blood — a distinction that can carry some clinical meaning, though it doesn't change the overall treatment approach dramatically.

Type	Key antibodies typically present	General notes
Type 1	Anti-smooth muscle antibodies (ASMA) and/or antinuclear antibodies (ANA).	The most common type, affecting people across a wide age range, including adults and children.
Type 2	Anti-liver kidney microsomal antibodies (anti-LKM1) and/or anti-liver cytosol antibodies (anti-LC1).	Less common; tends to present more often, though not exclusively, in children and younger people, and can sometimes present more severely at diagnosis.

KEY POINT

These antibody patterns help confirm the diagnosis and occasionally hint at a somewhat different disease course, but the overall treatment principles — calming the immune system with medication — apply broadly across both types.

DID YOU KNOW?

A small number of people with autoimmune hepatitis test negative for all of the commonly checked antibodies — sometimes called "seronegative" autoimmune hepatitis. In these cases, diagnosis relies more heavily on other findings, including liver biopsy appearance (Section 9) and ruling out other causes.

SECTION 5 Causes & Risk Factors

The exact cause of autoimmune hepatitis in any individual person is often never fully identified, but research points to a combination of genetic susceptibility and environmental triggers.

Genetic susceptibility

Certain inherited genetic markers, particularly within a group of genes involved in immune regulation (called HLA genes), are more common in people with autoimmune hepatitis, suggesting a hereditary component to susceptibility — though the condition itself is not directly inherited in a simple, predictable pattern.

Possible environmental triggers

In someone genetically susceptible, certain triggers are thought to potentially set off the immune misfire, though a specific trigger is often never pinpointed in an individual case:

- **Certain viral infections**, which may temporarily confuse the immune system in susceptible individuals.
- **Certain medications**, which have, rarely, been associated with triggering an autoimmune-hepatitis-like reaction.
- **Other environmental exposures** remain an active area of ongoing research.

Who tends to be more at risk

- **Women are affected considerably more often than men**, a pattern seen across many autoimmune conditions.
- **A personal or family history of other autoimmune conditions** (such as autoimmune thyroid disease, type 1 diabetes, or celiac disease) is somewhat more common in people with AIH.

- **It can develop at any age**, from early childhood to late adulthood.

KEY POINT

Autoimmune hepatitis is not something you catch, and it's not caused by lifestyle choices. If you have it, understanding this can help ease any sense that something you did brought it on.

DID YOU KNOW?

Because AIH clusters somewhat with other autoimmune conditions, your care team may ask about symptoms like fatigue, joint pain, or thyroid issues, and may check for related conditions as part of your overall evaluation.

It's worth being clear about what genetic susceptibility does and doesn't mean here: having a close family member with autoimmune hepatitis does modestly raise the statistical likelihood of developing it yourself, but the condition is not inherited in a simple, predictable pattern the way some single-gene disorders are. Most people diagnosed with AIH have no known family history of it at all, and most family members of someone with AIH never develop the condition themselves.

SECTION 6 How Common Is It? Who Is Affected

Autoimmune hepatitis is considered a rare disease, though it's increasingly recognized, partly thanks to more routine liver blood testing catching cases that might once have gone undiagnosed.

Estimates of how many people are affected vary by region and study, generally suggesting somewhere in the range of roughly 10 to 25 people per 100,000 in many populations — making it far less common than the metabolic and viral liver conditions covered elsewhere in this guide series, but not vanishingly rare.

Who tends to be affected

- **Women, particularly**, are affected considerably more often than men — by some estimates, roughly three to four times as often.
- **It can develop at any age**, with some research suggesting two broader peaks — one in childhood to young adulthood, and another in midlife to older adulthood.
- **People with other autoimmune conditions** or a family history of them may have a somewhat higher likelihood of developing AIH.

DID YOU KNOW?

Rates of AIH diagnosis appear to have risen in recent decades in some studies — likely reflecting, at least in part, increased awareness and more routine liver blood testing, rather than necessarily reflecting a true rise in how often the condition occurs.

KEY POINT

Autoimmune hepatitis is uncommon enough that many people have never heard of it before their own or a loved one's diagnosis — but it is well-studied, well-understood by specialists, and, importantly, well treated.

SECTION 7 Signs & Symptoms

Autoimmune hepatitis presents quite differently from person to person — some people have no symptoms at all, while others experience a sudden, severe onset. Understanding this range helps set realistic expectations.

Common, general symptoms

- **Fatigue**, often significant and one of the most commonly reported symptoms.
- **Joint pain or aches**, without necessarily any joint swelling.
- **Nausea and reduced appetite.**
- Discomfort in the **upper right abdomen.**
- **Itching (pruritus).**

More specific liver-related signs

- **Jaundice** — yellowing of the skin and eyes.
- **Dark urine and pale stools.**
- **Spider-like blood vessels** visible on the skin, in more established disease.

A wide range of presentations

Some people are diagnosed after a routine blood test happens to show abnormal liver enzymes, with no symptoms at all. Others experience a more gradual onset of fatigue and vague symptoms over months. A smaller number present with a sudden, more severe flare, sometimes resembling acute hepatitis, which requires more urgent evaluation and treatment.

SEEK MEDICAL CARE PROMPTLY

Rapidly worsening jaundice, confusion, or significant abdominal swelling can indicate a severe flare or complication and warrants prompt medical attention.

KEY POINT

Because symptoms are so variable — including sometimes being completely absent — autoimmune hepatitis is often found through blood tests rather than through symptoms alone, which is part of why it's worth discussing any unexplained, persistently abnormal liver enzymes with your clinician.

SECTION 8 How Autoimmune Hepatitis Is Diagnosed

Diagnosing autoimmune hepatitis involves combining blood tests, ruling out other causes, and often a liver biopsy, since no single test can confirm it on its own.

Blood tests

- **Liver enzymes (ALT, AST)** — typically elevated, sometimes significantly, reflecting active liver-cell inflammation.
- **Autoantibodies**, including ANA, ASMA, anti-LKM1, and anti-LC1, as discussed in Section 4 — their presence and pattern help support the diagnosis and identify the type.
- **Immunoglobulin G (IgG) levels** — often elevated, and a useful supporting marker.
- **Tests to exclude other causes**, including viral hepatitis panels, and screening for other conditions that can mimic or overlap with AIH (Section 10).

Scoring systems

Because no single test is definitive, clinicians often use a standardized scoring system — the simplified AIH score is common in practice — that combines autoantibody results, IgG level, biopsy findings, and the exclusion of viral hepatitis into an overall score suggesting the diagnosis is probable or definite.

Imaging

Ultrasound or other imaging may be used to assess the liver's general appearance and rule out other structural causes, though imaging alone cannot diagnose autoimmune hepatitis.

KEY POINT

Diagnosing AIH is a process of building a consistent picture from several pieces of evidence together — not any single test. This is completely normal and doesn't reflect uncertainty about whether you have a real condition.

TALK WITH YOUR CLINICIAN

It's reasonable to ask: "What specific findings support this diagnosis?" and "Which type of autoimmune hepatitis do I have, if that's been determined?"

SECTION 9 The Role of Liver Biopsy

Unlike some other liver conditions where biopsy has become less central, a liver biopsy plays an important, often essential role in confirming autoimmune hepatitis and guiding treatment decisions.

Why biopsy matters so much here

Autoimmune hepatitis has a characteristic appearance under the microscope — including a specific pattern of inflammation (interface hepatitis) and particular immune cells infiltrating the liver tissue — that helps confirm the diagnosis, distinguish it from other causes of hepatitis, and assess how much inflammation and fibrosis are currently present.

What it involves

A thin needle, usually guided by imaging, removes a small sample of liver tissue, typically under local anesthesia. A pathologist examines the sample, looking for the specific features associated with autoimmune hepatitis alongside grading inflammation and staging any fibrosis present.

When it's used again later

Beyond the initial diagnosis, a repeat biopsy is sometimes considered before stopping or significantly reducing treatment, since it can help confirm that inflammation has genuinely resolved — information that blood tests alone don't always fully capture.

DID YOU KNOW?

Normal liver enzyme levels don't always mean inflammation has fully resolved at the microscopic level — this is part of why some specialists consider a repeat biopsy valuable before making significant changes to long-term treatment.

KEY POINT

If a biopsy is recommended — whether at diagnosis or later in treatment — it's because the specific information it provides genuinely changes how your care is managed, not as a routine or arbitrary step.

For many patients, a biopsy at diagnosis also provides a useful baseline: knowing exactly how much inflammation and scarring were present at the start makes it much easier for your care team to judge, over time, whether treatment is working as intended, and to compare against any future biopsy if one becomes relevant later in your treatment course.

SECTION 10 **Related & Overlapping Conditions**

Autoimmune hepatitis can sometimes occur alongside other autoimmune liver conditions, or share features with them — situations collectively known as "overlap syndromes."

Overlap with primary biliary cholangitis (PBC)

Some people show features of both autoimmune hepatitis and PBC, a condition that primarily affects the small bile ducts within the liver. This overlap can affect the specific treatment approach, sometimes combining medications used for each condition.

Overlap with primary sclerosing cholangitis (PSC)

Less commonly, features of autoimmune hepatitis and PSC — a condition affecting the larger bile ducts, often associated with inflammatory bowel disease — can occur together, particularly in younger patients.

Other autoimmune conditions

Because autoimmune hepatitis clusters with other autoimmune conditions, your care team may ask about or screen for related conditions, including:

- **Autoimmune thyroid disease.**
- **Type 1 diabetes.**
- **Celiac disease.**
- **Rheumatoid arthritis and other autoimmune joint conditions.**

KEY POINT

If you're diagnosed with an overlap syndrome, it doesn't mean your situation is more complicated to manage in a discouraging sense — it means your care team has identified the full picture, allowing treatment to be tailored more precisely to address everything that's actually happening.

DID YOU KNOW?

Because of this clustering, being diagnosed with one autoimmune condition sometimes prompts screening for others, even without specific symptoms — a proactive, rather than reactive, approach to your overall health.

SECTION 11 Possible Complications

With effective treatment, most people with autoimmune hepatitis do very well. Understanding what can happen without treatment, or in a minority of cases despite it, helps explain why ongoing management matters.

Progression to fibrosis and cirrhosis

Without treatment, ongoing immune-driven inflammation can lead to progressive scarring (fibrosis) and, eventually, cirrhosis — covered in depth in our companion cirrhosis guide. This is precisely why treatment is generally recommended for anyone with active disease, even when symptoms are mild.

Complications of cirrhosis, if it develops

For the minority who do progress to cirrhosis — often because the condition wasn't caught early, or was difficult to control — the same complications covered in our cirrhosis guide can apply, including portal hypertension, ascites, and an increased risk of liver cancer, which then requires regular surveillance.

A severe, acute presentation

In a smaller number of cases, autoimmune hepatitis can present suddenly and severely, occasionally progressing toward acute liver failure, covered in our companion guide on that topic — a reminder that a severe presentation always warrants urgent evaluation.

KEY POINT — THE OUTLOOK WITH TREATMENT

The vast majority of people who receive timely treatment for autoimmune hepatitis do not progress to cirrhosis or its complications. Early diagnosis and consistent treatment are the two biggest factors in achieving this good outcome.

DID YOU KNOW?

Even for people who have already developed some fibrosis by the time of diagnosis, effective treatment can still meaningfully improve, and sometimes partially reverse, the amount of scarring present.

SECTION 12

Treatment & Management: The Big Picture

Autoimmune hepatitis treatment centers on calming the immune system's attack on the liver — and the outlook, for most patients, is genuinely good.

The core treatment goal

Treatment aims to suppress the overactive immune response driving liver inflammation, allowing the liver to heal and preventing further scarring. This is achieved primarily through medications discussed in Section 13.

Why nearly everyone with active disease is treated

Because untreated autoimmune hepatitis can progress to fibrosis and cirrhosis, even in people with mild or no symptoms, treatment is generally recommended for anyone with evidence of active inflammation — this is one of the clearer, more consistent treatment recommendations across the conditions in this guide series.

A long-term, phased approach

Treatment typically unfolds in phases: an initial period aimed at inducing remission (Section 14), followed by longer-term maintenance treatment, with some patients eventually able to reduce or, in select cases, stop medication under close supervision.

A WORD OF CAUTION

Specific medication choices, doses, and treatment duration are highly individualized. **This guide cannot recommend specific treatments.** These decisions belong with a qualified hepatologist familiar with your full clinical picture.

KEY POINT

Autoimmune hepatitis is one of the more genuinely treatable chronic liver conditions — most patients achieve good control of their disease and go on to live full, normal lives.

SECTION 13

Corticosteroids & Immunosuppressive Medications

Treatment for autoimmune hepatitis has been well-established for decades and centers on a small number of medication classes, often used in combination.

Corticosteroids

Corticosteroids (such as prednisone or, in some regimens, budesonide) are typically used to induce remission — quickly calming the immune attack and reducing inflammation. Because long-term corticosteroid use carries its own side effects (Section 16), the dose is generally reduced over time once the disease is under control, often alongside a second, "steroid-sparing" medication.

Azathioprine and other steroid-sparing agents

Azathioprine is the most commonly used long-term, steroid-sparing medication, allowing the corticosteroid dose to be reduced or, in many cases, eventually stopped, while still maintaining control of the disease. For patients who don't tolerate or respond adequately to azathioprine, other immunosuppressive medications may be considered by a specialist.

Response to treatment

Most people respond well to this standard approach, with liver enzymes and other markers of inflammation improving over weeks to months. A smaller number of people have a more difficult-to-control disease course, requiring adjustment of medications or additional specialist input.

A WORD OF CAUTION

Medication choices and dosing must be individualized by your treating specialist based on your specific situation, other health conditions, and how you respond over time. **Never adjust or stop these medications on your own** — doing so can trigger a flare, sometimes a serious one.

KEY POINT

These medications have a long track record in AIH treatment, and most patients tolerate them well, especially once the initial, higher-dose induction phase is completed and doses are reduced.

During the initial weeks of treatment, blood tests are typically checked frequently — sometimes every one to two weeks — to confirm the medication is working and to catch any early side effects. As liver enzymes improve and the dose is gradually reduced, this

monitoring schedule usually becomes less frequent, though it never stops entirely, since ongoing tracking is what allows both effectiveness and safety to be confirmed over the full course of treatment.

SECTION 14 **Achieving & Maintaining Remission**

Remission — a state where disease activity is well controlled — is the central goal of AIH treatment, and it's achieved by the large majority of patients.

What remission means

Remission generally means normal or near-normal liver enzyme levels, normal or near-normal IgG levels, and, when assessed, minimal inflammation on biopsy. Achieving this state generally reflects that the immune attack on the liver has been effectively calmed.

How long it takes

Most patients who respond to treatment achieve remission within about six months to two years, though this varies by individual. Your care team will track specific markers over time to assess progress.

Maintenance treatment

Once remission is achieved, treatment generally continues at a lower, maintenance dose for a substantial period — often several years — since stopping too early carries a real risk of relapse (Section 15). Some patients remain on long-term maintenance treatment indefinitely; others, under close specialist supervision and after careful assessment, may eventually attempt to stop.

KEY POINT

Achieving remission is genuinely good news and reflects effective treatment — but it's generally considered a reason to continue treatment at a maintenance level, not a signal to stop, at least for a substantial period of sustained, confirmed remission.

DID YOU KNOW?

Some specialists use a repeat liver biopsy to help confirm that inflammation has genuinely resolved before considering a trial off medication, since blood tests alone don't always capture the complete picture (Section 9).

SECTION 15

Relapse: What It Means & How It's Managed

Relapse — a return of disease activity after a period of remission — is common enough in autoimmune hepatitis to be considered a normal part of the disease's course for many patients, not a sign that something has gone wrong.

How common relapse is

A substantial proportion of patients experience at least one relapse, particularly after stopping medication entirely, though relapse can also occur while on treatment. This is part of why many specialists favor a cautious, gradual approach to reducing medication, with close monitoring throughout.

How relapse is recognized

Relapse is typically identified through rising liver enzymes or IgG levels on routine blood tests, sometimes before any symptoms return — which is exactly why regular monitoring continues even once someone feels completely well (Section 18).

How it's managed

Relapse is generally treated by resuming or increasing medication, following a similar approach to the original induction of remission. Most patients respond well to this re-treatment, achieving remission again.

KEY POINT

A relapse is not a failure of treatment or a sign of a worsening prognosis — it's a recognized, manageable part of this condition's natural course for many patients, and it responds to the same effective treatments used initially.

TALK WITH YOUR CLINICIAN

If you've been through a relapse before, or are considering reducing medication, ask directly: "What would relapse look like for me, and how closely will we be monitoring for it?"

SECTION 16

Living with Long-Term Immunosuppression

Because treatment involves calming the immune system, often for years, understanding what this means for daily life and overall health is an important part of living well with AIH.

Increased infection risk

Immunosuppressive medications reduce the immune system's activity, which can increase susceptibility to certain infections. Being attentive to symptoms of infection, and discussing any fever or illness promptly with your care team, is a sensible precaution.

Vaccinations

Staying current on recommended vaccinations is generally encouraged, though the timing and type of certain vaccines (particularly live vaccines) needs to be discussed with your care team given immunosuppressive treatment.

Corticosteroid-specific effects

Longer-term corticosteroid use, even at reduced doses, can affect bone density, blood sugar, weight, mood, and skin — part of why doses are generally minimized over time and why bone health monitoring (Section 17) is a standard part of care.

Routine monitoring for medication side effects

Regular blood tests also monitor for medication-related effects on blood counts and other organs, alongside tracking the AIH itself — a routine, expected part of long-term treatment.

KEY POINT

Long-term immunosuppression is a well-understood territory in medicine, with established monitoring routines designed specifically to catch and manage these effects early — this is not uncharted ground for your care team.

TALK WITH YOUR CLINICIAN

Ask specifically what infection precautions make sense for you, and what your personal vaccination plan should look like given your treatment.

SECTION 17

Diet, Lifestyle & Bone Health

While diet doesn't cause or cure autoimmune hepatitis the way it can influence some other liver conditions, several lifestyle factors genuinely support overall health during treatment.

General healthy eating

A balanced, whole-foods-focused diet — similar to the Mediterranean-style pattern described in our companion guides — supports overall health and helps manage some corticosteroid-related effects, such as weight gain and blood sugar changes.

Bone health: a specific priority

Because corticosteroids can reduce bone density over time, bone health deserves particular attention:

- **Adequate calcium and vitamin D intake**, through diet or supplementation as advised by your care team.
- **Weight-bearing exercise**, which supports bone strength.
- **Bone density scans (DEXA)**, often recommended periodically for people on long-term corticosteroid treatment.

Alcohol

Alcohol adds an additional burden to a liver already managing inflammation, and many clinicians advise minimizing or avoiding it, particularly with active disease or existing fibrosis.

Physical activity

Regular physical activity, as tolerated, supports overall wellbeing, bone health, and helps manage corticosteroid-related weight changes — check with your care team about what's appropriate for you.

TALK WITH A PROFESSIONAL

A registered dietitian can help navigate any corticosteroid-related dietary needs, and your care team can advise on an appropriate bone-health monitoring schedule.

NOTE

This section describes general lifestyle patterns for education only, not personalized medical advice. Always check with your clinician before starting new supplements, given potential interactions with your medications.

SECTION 18

Monitoring & Your Care Team

Autoimmune hepatitis is monitored closely and continuously, even during periods of remission — because catching a relapse early, before significant liver injury occurs, is one of the most protective things ongoing care can do.

What monitoring usually involves

- **Regular blood tests**, tracking liver enzymes, IgG levels, and markers of medication side effects, more frequently during initial treatment and dose adjustments, less frequently once stable.
- **Periodic bone density scans**, given corticosteroid use.

- **Screening for related autoimmune conditions**, as relevant.
- **For those who develop cirrhosis**, the additional monitoring described in our companion cirrhosis guide, including regular liver-cancer surveillance.

Who might be on your team

Hepatologist / gastroenterologist

Primary care provider

Rheumatologist (if overlapping conditions)

Registered dietitian

Endocrinologist (for bone health, if needed)

Nurse educator

Pharmacist

KEY POINT — YOU ARE THE CONSTANT

Keeping your own simple record of lab trends, current medications and doses, and questions makes it much easier to track your own pattern over time, especially across a condition managed over many years.

MAKE THE MOST OF APPOINTMENTS

Worth asking regularly: "Are we still on track with the current treatment plan?" and "Is this a reasonable point to consider any changes to my medication?"

SECTION 19 Special Situations

Autoimmune hepatitis management looks somewhat different across certain groups and life circumstances.

Children and teenagers

AIH in children is managed with similar principles but requires pediatric-specific expertise, particularly around growth, bone development, and the emotional aspects of long-term treatment during childhood and adolescence. Type 2 AIH is relatively more common in this age group.

Pregnancy

Many people with well-controlled autoimmune hepatitis have healthy pregnancies, though careful planning with a specialist is important, since some medications require adjustment during pregnancy and disease activity can sometimes change during and after pregnancy. This is a conversation worth having well before conception, where possible.

Older adults

AIH diagnosed later in life may be managed with some adjustments to account for other health conditions and medications, and bone health monitoring becomes particularly important given baseline age-related bone density changes.

Overlap with other autoimmune conditions

As discussed in Section 10, having AIH alongside another autoimmune condition may mean coordinating care between a hepatologist and another specialist, such as a rheumatologist or endocrinologist.

TALK WITH YOUR CLINICIAN

If any of these situations apply to you, mention it directly — it may change monitoring frequency, medication choices, or which additional specialists are involved in your care.

SECTION 20

When AIH Progresses: Cirrhosis & Transplantation

For most people with autoimmune hepatitis, effective treatment prevents significant progression. For a minority, the condition can still advance to cirrhosis — and even then, options remain.

Why progression can still happen

Progression to cirrhosis is more likely when diagnosis was delayed, when the disease proves difficult to control despite treatment, or, in some cases, when a person had already developed significant fibrosis before ever being diagnosed and starting treatment.

Managing AIH-related cirrhosis

If cirrhosis develops, management follows the same principles covered in our companion cirrhosis guide — monitoring for and managing complications like portal hypertension and ascites, and regular liver-cancer surveillance — alongside continued immunosuppressive treatment for the underlying autoimmune hepatitis itself.

Liver transplantation

For those who reach decompensated cirrhosis despite treatment, liver transplantation, covered in depth in our companion guides, offers a life-saving option. Encouragingly, transplant outcomes for AIH are generally favorable, though autoimmune hepatitis can, in a minority of cases, recur in the transplanted liver, requiring ongoing monitoring and sometimes adjusted immunosuppression afterward.

KEY POINT

Progression to cirrhosis is the exception, not the rule, in treated autoimmune hepatitis — and even for those who do progress, established, effective treatment pathways, including transplantation, remain available.

DID YOU KNOW?

Because AIH can recur after transplant, some element of ongoing immunosuppression, tailored between preventing organ rejection and controlling the underlying autoimmune disease, typically continues for life in transplant recipients.

SECTION 21

Living Well, Prevention & Myths vs. Facts

A diagnosis of autoimmune hepatitis touches more than lab values — and it helps to know both how to live well with it and what's actually true about the condition.

Living well: mind, mood & community

Living with a chronic condition that requires long-term medication can bring its own emotional weight — frustration with side effects, worry about relapse, or simply the mental load of an ongoing treatment routine. These feelings are entirely understandable. Connecting with others who have AIH, whether through support groups or informal community, can help normalize this experience, and being open with your care team about how treatment is affecting your daily life and mood is a legitimate, important part of your care.

IF YOU ARE STRUGGLING

If you are experiencing persistent low mood, hopelessness, or thoughts of harming yourself, please reach out to a healthcare professional or a crisis line. The **988 Suicide & Crisis Lifeline** (call or text 988 in the United States) is free and available 24/7. Support is available.

Prevention

Because autoimmune hepatitis isn't linked to modifiable lifestyle factors the way some liver conditions are, there isn't a specific way to prevent it developing in the first place. The most protective step available is early recognition and treatment once it does develop — which is why unexplained, persistent liver enzyme abnormalities are always worth pursuing with your clinician.

Myths vs. facts

Myth	Fact
"Autoimmune hepatitis is caused by alcohol or poor diet."	It results from a misdirected immune response, not lifestyle factors — it is not caused by anything you did.
"It's contagious, like viral hepatitis."	Autoimmune hepatitis cannot be passed from person to person — it isn't caused by a virus.
"Once diagnosed, it always leads to cirrhosis."	With effective treatment, most people never progress to cirrhosis and go on to live full, normal lives.
"If I feel fine, I can stop my medication on my own."	Feeling well doesn't always mean inflammation has fully resolved, and stopping medication without guidance risks a relapse.
"A relapse means my treatment has failed permanently."	Relapse is common and treatable — most people respond well to resuming or adjusting treatment.
"Only women get autoimmune hepatitis."	Women are affected more often, but men and children of any gender can develop AIH too.
"Herbal supplements can replace my immunosuppressive medication."	No supplement is proven to treat autoimmune hepatitis, and stopping prescribed medication without guidance risks a serious relapse.

KEY POINT

If you remember one thing from this page: autoimmune hepatitis is a serious diagnosis, but it is also one of the more consistently treatable chronic liver conditions — the outlook for most patients, with proper treatment, is genuinely good.

CLOSING

Questions, Glossary, Resources & Disclaimer

Questions you might ask your doctor

- Which type of autoimmune hepatitis do I have, and what does that mean for my treatment?
- What is my current disease activity — am I in remission, and how is that being measured?
- What medications am I on, and what side effects should I watch for?
- Do I need a bone density scan, and how often?
- Is there any evidence of an overlapping condition I should know about?

- How and when will we re-check my liver, and what would prompt a change in my treatment plan?

Glossary

Term	Plain-language meaning
AIH	Autoimmune hepatitis — the immune system mistakenly attacking the liver.
Autoantibody	An antibody the immune system mistakenly produces against the body's own tissue.
IgG (Immunoglobulin G)	An antibody type often elevated in active autoimmune hepatitis; tracked over time.
Immunosuppressive medication	A medication that calms an overactive immune response.
Interface hepatitis	A characteristic pattern of liver inflammation seen on biopsy in AIH.
Overlap syndrome	When AIH occurs alongside another autoimmune liver condition, such as PBC or PSC.
Remission	A state where AIH disease activity is well controlled, typically reflected in normal or near-normal blood tests.

About The Liver and Kidneys Hope Foundation

The Liver and Kidneys Hope Foundation (TLHF) is a Nevada-based 501(c)(3) nonprofit dedicated to liver-health education, community support, and outreach. Through educational materials like this guide, community programming, our chapter network, volunteer efforts, and fundraising initiatives, we work to raise awareness of liver conditions and support the people affected by them, including those living with autoimmune hepatitis. The Foundation is not a medical provider and does not deliver clinical care.

A NOTE ON SOURCES AND CURRENCY

This guide reflects widely accepted, general medical understanding of autoimmune hepatitis intended for patient education. It does not cite individual studies, and treatment approaches continue to be refined. For the most current, individualized information, your healthcare team is the best resource.



Full disclaimer

PLEASE READ

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Do not use this guide to diagnose or treat a health problem or disease, and do not disregard or delay seeking professional medical advice because of something you have read here. Never adjust or stop immunosuppressive medication without guidance from your treating clinician. If you think you may have a medical emergency, contact your local emergency services immediately.

The Foundation makes no warranties about the completeness, accuracy, or currency of this information and accepts no liability for actions taken based on it. Always consult your own healthcare professional.

The Liver and Kidneys Hope Foundation · Health Education Series (EDU-LIV) · "Understanding Autoimmune Hepatitis," First Edition

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