



HBV

A guide for patients

JUSTRI is a UK-based not-for-profit organisation, which provides resources and education for those with and working with HIV and viral hepatitis.

See what we do at **www.justri.org**

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Written and compiled by Dr Mike Youle and Dr Sanjay Bhagani

Design by Geoff Sheridan, **www.premonition.co.uk**

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Section 1: Introduction

Welcome to this JUSTRI guide written for someone diagnosed with active hepatitis B virus (HBV) infection, to help them to live a long and healthy life with this condition.

It provides information about medical and other services, tests and treatments and has been developed using our experience at the Royal Free Hospital, London UK, which currently provides care for over 5000 HBV and 650 human immunodeficiency virus (HIV) and HBV co-infected patients.

Over 250 million people world-wide have HBV infection which if untreated can cause serious liver disease. It represents a significant public health problem in many countries and contributes to 60% of deaths from liver **cirrhosis** and 75% of cases of liver cancer (**hepatocellular carcinoma [HCC]**) globally. A small proportion of people with HBV are also infected with HIV, and liver disease is the single biggest cause of non-**AIDS** death in these individuals.

Nowadays, hepatitis B infection is easy to treat with drugs given to suppress the virus, which helps to maintain the health of your liver and reduce progression to cirrhosis and liver cancer. However, at present there is no cure for HBV, so regular monitoring of your condition by using blood tests and scans is a vital part of keeping you well.

The main aim of this guide is to make sure that you understand what tests and other investigations, such as scans, you need and why, and to support you in making sure that your HBV is monitored regularly, as directed by your doctor.

How to Use this Guide

We hope that this guide will give you a better understanding of your HBV infection and how it is monitored and treated by your doctors and nurses. There is a **glossary of medical terms**, (pages 13-14) which have been **highlighted** the first time they occur in the text and a section on page 15 to note down your appointments for clinic visits, monitoring bloods and scans, that are a vital part of your long-term care.

Medicine is a constantly changing field and there are many online sources in the **Further Information** section of this guide that provide a wealth of scientific and general information about HBV infection. Don't be afraid to use the internet to find things out – we all do! However, information on the internet is of varying quality and sometimes should be read with caution, although the sites we have suggested are all quite reliable. As with all printed information, please check for updates to this guide, especially if reading it after December 2020; the latest version is always available at www.justri.org.

Many people, some living with HBV, with and without HIV, have helped write this guide and we welcome any comments, corrections or ideas and suggestions for inclusion in future editions; please send these to home@justri.org.

JUSTRI and the authors welcome you to contact them if you have any questions or need help in accessing treatment and care for viral hepatitis of any type. Please get in touch at home@justri.org.

Basics of the Liver and Viral Hepatitis

Your liver performs many jobs in the body and is vital for life.

It responds to injury by becoming inflamed - this is called hepatitis, whatever its cause. Sudden liver inflammation is called acute hepatitis, but if it lasts over six months it is known as chronic hepatitis. This continued

inflammation leads to scarring of the liver called **fibrosis**. Your liver can still function when this happens, but over time the damage increases, although you may have no symptoms to suggest that this is occurring.

Hepatitis B Virus (HBV)

Hepatitis is usually caused by excess alcohol or several types of virus, each of which is very different and unrelated to each other. Hepatitis B virus (HBV) is very common worldwide and can be infectious to others unless treated.

Transmission of HBV only occurs between humans. It can be passed from mother to child during pregnancy or between individuals, either during sex, or within households, through the sharing of toothbrushes, razors and towels, or by sharing of chewing gum or partially eaten sweets amongst children. It is not thought to be transmitted by cooking and eating utensils, or by sleeping in the same room.

In Africa and Asia, transmission is mainly from mother-to-child and in early childhood. In the rest of the world, sexual transmission in adult life or by sharing or re-using needles is commonest. If infection is from the mother, or acquired as a child, most individuals develop chronic HBV infection. If you are infected in adult life, and you have a normal immune system, it is likely that you will clear the infection and therefore not need treatment. Between two and ten percent of people infected as adults will become

chronic carriers of HBV, which means they will be infectious to others, until they are treated, and may go on to develop chronic liver damage.

HBV infection, if not cleared, is life-long. The liver damage it causes results from the interplay between the virus and the **immune system**. For many patients, the immune system can effectively control the virus and these people will develop very little liver damage. However, in some people this continued liver damage eventually leads to cirrhosis and liver cancer. Progression to **end-stage liver disease** and cancer occurs over a period of many years, although it appears to be faster if you also have HIV infection. If your immune system is suppressed, such as with anti-rejection medication after a transplant, or with treatment for cancer, you may get a re-activation of HBV infection which will then need treating.

Other Hepatitis Viruses

Several other unrelated viruses can cause damage to the liver:

HEPATITIS A VIRUS (HAV)

This is usually spread by contact with faeces or infected food. Those at increased risk include: travellers to parts of the world with poor levels of sanitation, men who have sex with men (MSM), and people who inject drugs.

It can be unpleasant, but it's not usually serious and most people recover fully over several months. However in rare cases it can be life-threatening. A vaccine is available for people at high risk of infection.

HEPATITIS D VIRUS (HDV)

Sometimes called Delta virus, this only occurs in those already infected with HBV and affects around 5% of HBV patients globally. Transmission is the same as for HBV, but HDV leads to severe liver

damage and must always be tested for in patients with chronic HBV infection. HBV vaccination will protect against this second infection.

HEPATITIS C VIRUS (HCV)

There are over 70 million people chronically infected with HCV worldwide. Transmission is mainly by transfusion of infected blood products, sharing of needles and unsafe medical practices. Heterosexual sexual transmission and mother-to-child HCV transmission appear to be relatively rare. Recently, an epidemic of acute HCV has developed amongst

mainly MSM, thought to be linked to traumatic sexual practices, injecting drug use and sharing of implements for intranasal drug use. Curative therapy is now available and highly effective. Sometimes treating HCV leads to a reactivation of HBV infection which then itself needs treating.

Section 2: The Liver Clinic

HOW WILL THE CLINIC LOOK AFTER ME?

Your clinic should operate as a team, so that all key people, including you, are fully involved in your treatment and care decisions. This ensures good communication between everyone and better outcomes for you. Remember to ask questions - it's quite a good idea to write them down before you see the doctor or nurse, so that you can get everything answered.

Most clinics provide a range of services to accommodate the planned and unplanned nature of the condition and its treatment. These should include:

- Routine clinics with booked appointments for new patients and those on regular follow-up
- 'Walk-in' services (for problems that arise at short notice)
- Out-of-hours access for emergencies
- Virtual or e-clinics with email consultation may be available, especially for people living a long distance away

How the clinic operates varies according to local needs and resources. One method, which we use, is for the trained nurse to perform a **Fibro scan**[®] and blood tests. Then with these results, the doctor takes your medical history, examines you and discusses your care. In this way, everything can be done

efficiently, and a treatment and follow-up plan discussed with you at a single clinic visit. The frequency of clinic visits will be determined by the stage of your liver disease and whether you are treated or not.

People need different types of information when they come to clinic. Specialist nurses or your doctor can help with this and provide resources on transmission, prevention, treatment and support, as well as answer any questions you may have.

A summary of your clinic visit will be made and kept in your notes (usually electronic nowadays) and with your consent a copy sent to your general practitioner (GP), and any other specialists involved in your care. Most clinics send copies of any correspondence to you at home (with your consent) to keep you involved in decision-making. If they don't, then please ask them to do so, as it's vital that you always know what is going on with your care.

The relationship between HIV and HBV can be complex and benefits from an integrated approach to care, management and treatment. Ideally, a joint clinic should have staff with expertise in both HIV and viral hepatitis, and the complications of liver disease.

What Assessments Will I Have?

You should have the following assessments when you are first seen to determine the severity of liver disease and then some of them at regular

intervals decided on by your clinic doctor. Future investigations will depend on how your HBV progresses.

1. MEDICAL HISTORY AND EXAMINATION

Your doctor will take a detailed history from you about risk factors for infection and other medical conditions that may affect your HBV infection or its treatment. This will include:

- Any symptoms, such as muscle and joint pain, fevers, feeling and being sick, being unusually tired all the time, loss of appetite, abdominal pain; or signs such as dark urine, pale, grey-coloured stools, itchy skin or yellowing of the eyes and/or skin (**jaundice**)
- A history of jaundice or any past blood transfusion
- Likely time and source of infection to help with partner notification and to decide if your infection is acute or chronic
- Medication history, to see if any treatment you take may have caused the hepatitis

- Current medication, to assess any interaction with HBV treatment
- Other health conditions you may have, such as diabetes or heart disease
- Risk factors for progressive liver disease such as, being overweight, older, male, alcohol abuse or HIV infection
- Family history of viral hepatitis, liver disease or liver cancer
- Any psychiatric history
- Drug and alcohol history, including injecting or inhaled drug use

You will also be examined for any signs of liver disease.

2. BLOOD TESTS

When you are seen for the first time, a series of blood tests will be taken to evaluate your HBV infection, as well as other potential causes of liver damage and to assess any you already have. A full explanation of all the tests that you

might have can be found at www.hepb.org/prevention-and-diagnosis/diagnosis/other-tests/. If you are in any doubt about what the tests mean then discuss them with your doctor or nurse.

3. ASSESSMENTS OF LIVER DAMAGE

A **liver ultrasound** should be performed, when you are first seen, as well as a Fibro scan® and/or a specific set of blood tests, which can be used to estimate how much damage there is in your liver. Follow-up scans are vital in the assessment of treatment and the monitoring of your liver. Some people will be screened for liver cancer every 6 months with a liver ultrasound and an **alpha-fetoprotein (AFP)** blood test.

In anyone with a normal ultrasound but a high index of suspicion for cancer (for instance with a high AFP >200ng/mL) a second type of imaging – either an **MRI scan** or a **triple-phase CT scan** of the liver will be performed.

A **liver biopsy** is taken less frequently nowadays, but can be useful where there is doubt about the cause of the liver damage, or where ‘non-invasive’ tests give unclear results.



Here is a link to a video showing how a Fibro scan® is performed. Have a look and see how simple it is. justri.org/minimally-invasive-liver-assesment-techniques-training-london-17-9-16/

What Other Services Might I Be Referred To?

You may be referred to any of the following services, depending on what your own specific needs.

1. IMAGING AND ENDOSCOPY

Liver imaging forms a crucial part of viral hepatitis monitoring. In the clinic you will have a Fibro scan®, but the imaging department will provide all the other means of looking at your liver. All patients with cirrhosis should have 6-monthly liver ultrasounds to assess their risk of liver cancer, as well as an **endoscopy** every 1–2 years to look for **oesophageal**

varices, which could bleed. There is a handy appointments diary for you to use on *page 15* to make sure these scans are done on time. The imaging department also organise ultrasound-guided liver biopsies to assess changes in liver disease progression that can help to decide when you need to start drug treatment.

2. LIVER CANCER

Cancer of the liver is one of the serious consequences of cirrhosis, affecting 4% of patients each year. If your doctor tells you that you do have cirrhosis, it is vital that you are regularly screened, by ultrasound, to try and identify any cancers early

and if one is found, you will be linked to a specialist liver cancer team. Early cancers are curable by surgery and even with later presenting cancers, a good quality of life may be achieved with local treatments and chemotherapy.

3. LIVER TRANSPLANT

If you have very severe liver damage you may be considered for a liver transplant, even if you also have HIV. You will be

referred to the specialist liver transplant team who can discuss all the options with you.

4. DRUGS AND ALCOHOL

Some patients with HBV have drug and alcohol problems with current or past injecting drug use being a significant reason to have acquired both viral hepatitis and HIV. Drinking will further damage your liver and is not advisable. The FAST Screening tool, assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/684828/Fast

[alcohol_use_screening_test_FAST_.pdf](#), takes a few minutes to complete to check your alcohol intake and identify if you are drinking too much or have problems with alcohol. Drugs and alcohol services can offer risk-reduction counselling, information on safer use (including access to needle-exchange services) and management of drug and alcohol misuse.

5. PSYCHOLOGY AND PSYCHIATRY

Some people have mental health problems that may pre-date their diagnosis of HBV and which could have made them more vulnerable to acquiring

viral hepatitis. These problems may be worse in those with HIV co-infection or advanced liver disease.

6. SEXUAL HEALTH

Most patients with HBV will have acquired their infection sexually. You should be supported in maintaining good sexual health, including advice on avoiding acquiring new sexually transmitted infections (STIs). STI screening and treatment should be offered to all

new patients as part of their medical assessment and annually thereafter, and at other times when you want. Higher-risk populations, such as MSM, may benefit from using easy-to-use self-swab kits for STI screening and importantly from risk-reduction counselling.

7. GENERAL PRACTITIONERS

With your consent, your general practitioner (GP)/primary care team will be informed of treatment and management decisions by letter or

secure email. Chronic HBV infection is a long-term condition, so it's important to keep your GP up to date.

8. COMMUNITY AND PEER SUPPORT

The usefulness of being able to talk through problems, treatment and other issues with people who have undergone treatment themselves, and who are

experts in managing their own condition, cannot be over-estimated. These services may be available as one-to-one support or in a group setting.

WHAT TREATMENT MAY I BE GIVEN?

Treatment for HBV, and other hepatitis viruses, with antiviral drugs is now very effective in preventing and even reversing the damage to the liver. The type of treatment you need will be

discussed with you by your doctor or specialist nurse. Not everyone is treated immediately, especially if there is no damage to the liver, but once you start drug therapy it is currently lifelong.

IT IS **VERY IMPORTANT** THAT YOU **DO NOT STOP YOUR ANTIVIRAL HBV DRUGS** AS YOUR LIVER MAY BECOME VERY INFLAMED, LEADING TO SERIOUS ILLNESS.

Section 3: Glossary of Medical Terms

AIDS (Acquired Immune Deficiency Syndrome)

Describes the potentially life-threatening infections and cancers that may occur if your immune system has been severely damaged by HIV infection

Alpha-fetoprotein (AFP)

Blood test used to screen for liver cancer

Cirrhosis

Severe scarring of the liver which makes the liver function less well

Endoscopy

A procedure where the inside of your body is examined using an endoscope. This is a long, thin, flexible tube that has a light source and camera at one end

End-stage liver disease

This comes after the other stages of liver damage which include inflammation (hepatitis) and increased stiffness and scarring of your liver (fibrosis)

Fibro scan®

Non-invasive scan that measures the stiffness of the liver, a marker of scarring

Fibrosis

A less severe scarring than cirrhosis

HBV vaccination

This vaccine is 95% effective in preventing infection and chronic inflammation and liver cancer due to hepatitis B infection

Hepatocellular carcinoma (HCC)

This is the commonest type of liver cancer in adults and is the most frequent cause of death in people with cirrhosis

HIV (human immunodeficiency virus)

A virus that damages the cells in your immune system and weakens your ability to fight everyday infections and disease. It can lead to severe illness if not treated

Immune system

The body's defence against infections which also has a role in preventing some cancers

Jaundice

Also known as icterus, this is when your skin and whites of the eyes become yellow. It is associated with skin itchiness, dark urine and pale stools and is due to liver damage

Liver biopsy

Taking a small sample of liver for examination and testing in the laboratory. It can be taken through the skin or more commonly now by inserting a wire into a neck vein and sampling through this, which is less painful

Liver imaging

The different techniques used to look at your liver by various scans

Liver ultrasound

A scan that uses high frequency sound waves to create a picture of the liver

MRI scan

This machine uses a magnetic field and radio waves to produce detailed pictures of the liver

Oesophageal varices

Swollen veins in the oesophagus (gullet), the tube that carries food from the throat to the stomach. If you vomit blood, or have dark blood in your stool, these veins may be swollen and leaking blood. They are known as oesophageal varices and usually need urgent medical attention to prevent serious bleeding

Triple-phase CT scan

This technique scans your liver at three different time points, after you have an injection to highlight structures in the liver, which gives a more accurate scan

Virus

A small infectious agent that reproduces itself (replicates) only inside the living cells of other organisms

Further Information

NHS: www.nhs.uk/conditions/hepatitis-b/

World Health Organisation: www.who.int/news-room/fact-sheets/detail/hepatitis-b

British Liver Trust: www.britishlivertrust.org.uk

Path B: www.britishlivertrust.org.uk/our-work/campaigns/hepatitis-b-path-b/

Blood Test Information: www.hepb.org/prevention-and-diagnosis/diagnosis/other-tests/

Hepatitis Drug Interactions: www.hep-druginteractions.org

Drug and alcohol advice services:

- Antidote: londonfriend.org.uk/get-support/drugsandalcohol/
- Drink Aware: www.drinkaware.co.uk
- Fast alcohol screening test (FAST): assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/684828/Fast_alcohol_use_screening_test_FAST_.pdf

Current guidelines for the management of HBV mono-infection and HBV/HDV co-infection:

www.aasld.org/practiceguidelines/pages/guidelinelisting.aspx

www.easl.eu/medias/cpg/management-of-hepatitis-B-virus-infection/English-report.pdf

Management of viral hepatitis with HIV co-infection: www.bhiva.org/hepatitis-2013.aspx

Useful information translated into several languages are available at:

www.hepbpositive.org.uk

www.hepbandcni.net/content/hepatitis-c-public-information-leaflets

justri.
www.justri.org

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