



Children's Liver
Disease Foundation

fighting childhood
liver disease

Hepatitis B:

A Guide for Young People

Introduction

This leaflet has been written for teenagers (13+) who have hepatitis B and would like to know more about it.

You will find out about:

- The hepatitis B virus
 - acute hepatitis B
 - chronic hepatitis B
- How you got hepatitis B
- What the blood tests mean
- Treatments
- How to prevent passing hepatitis B to other people
- Who you should tell
- Going to clinic and taking medication
- Playing sports
- Career options

If you would like to talk to someone about your condition you can contact the Young People's Team at CLDF.

 youngpeople@childliverdisease.org

 0121 212 6024

 CLDFyoungpeople

Other leaflets you may find useful:

– An Introduction to Liver Disease

The hepatitis B virus

Hepatitis means inflammation of the liver. The liver is an organ which carries out lots of important jobs in the body. If it is inflamed or damaged, then it may not work properly. You can find out more about the liver and the jobs it does in the leaflet “An Introduction to Liver Disease”.

Hepatitis B is a virus that causes an infection in the liver. The virus is present in blood and bodily fluids. If the body’s immune system responds to the virus this response can damage the cells in the liver.

Acute hepatitis B

Hepatitis B can cause a sudden illness. This is called acute hepatitis B.

Acute hepatitis B can occur in both adults and children, although it is less common in children. Sometimes there may be no symptoms but in other cases it can cause someone to become very ill.



Acute hepatitis B can, in rare cases, lead to acute liver failure. This is when the liver is badly damaged over a short period of time and stops working properly. If this happens then a liver transplant may be needed. This complication is very rare in children and young people and only happens in around 1 out of 100 (1%) people diagnosed with a hepatitis B infection. For more information see CLDF's leaflet "Acute Liver Failure".

Chronic hepatitis B

Chronic hepatitis B is when the hepatitis B virus does not clear from the body within six months. This is more common in children but can occur in adults as well.

Symptoms of chronic hepatitis B:

Most children and young people with chronic hepatitis B have no symptoms. They grow and develop normally. It tends to be in later years that the virus can cause problems.

Some children and young people may experience symptoms. This is usually known as having a 'flare' of the hepatitis B infection. A flare can occur when liver

enzymes are raised (see CLDF leaflet "An Introduction to Liver Disease"). The symptoms may be the same as those for acute hepatitis B but they are milder and tend to come and go.

It's important that you are referred to a specialist liver centre where your liver function and hepatitis B virus can be monitored, assessed and treatment provided if necessary. This is important even if you feel well.

How did I get hepatitis B?

Hepatitis B is spread when blood from an infected person enters another person's body. The virus can be spread even if you don't have any symptoms. It cannot be spread by casual contact such as sharing utensils, cups, cuddling, or hand-holding. It is unlikely that hepatitis B spreads through casual kisses but there may be a risk if the infected person has cold sores, ulcers, bleeding gums, cuts or abrasions in their mouth.

There are several ways blood from an infected person can enter another person's body:

- From their mother during birth. This is the most common way young people in the UK have been infected with hepatitis B
- Contact with open wounds or a bite that breaks the skin
- Sharing toothbrushes and razors, shavers and equipment for cutting hair
- Getting a tattoo or piercing from a premises without good hygiene standards. It is essential that you ensure they are registered or have a licence.
- Receiving contaminated blood during a medical procedure. Blood donations in the UK are screened for hepatitis B to remove this risk but it is possible to receive contaminated blood in other countries.
- Using intravenous drugs and sharing drug taking equipment
- Sexual intercourse

How do I prevent passing hepatitis B to other people?

There are a number of things you can do to make sure you do not transmit the virus to other people:

- Cover cuts and wounds with a waterproof dressing.
- Don't let anyone touch your blood if you cut yourself or have a nose bleed, unless they are wearing gloves.
- Clean up all blood spillages appropriately.
- People who are menstruating (having periods) should dispose of sanitary toiletries appropriately.
- Don't share toothbrushes, razors, hair clippers or similar equipment with others.
- Don't share needles or drug snorting equipment with other people.
- Inform your partner of your hepatitis B if you are sexually active so they can be tested and if negative get vaccinated.
- Use a condom when you have sex to prevent transmission of the virus.
- Avoid contact sports such as boxing or rugby due to the risk of bleeding.

What do my hepatitis blood tests mean?

Blood tests will be done to find out if someone has hepatitis B. They are also used to monitor the condition of people who are positive for hepatitis B. The following flow charts explain what the different blood test results mean.

There are lots of different tests which can be confusing. If you need help to understand what each of them means then take this leaflet along with you to your next appointment where your doctor or specialist nurse will be able to explain each of the tests to you.



Chart 1: What do my hepatitis B blood results mean?

Test: Hepatitis B surface antigen (HBsAg)

Result
Detected in blood (HBsAg positive) for at least six months?

Yes

No

See Chart 2

This is called chronic hepatitis B infection.

It means the body's immune system has not got rid of the hepatitis B virus, and is allowing it to stay in the body.

Test: Hepatitis B viral load (HBV DNA)

Result
HBV DNA levels can vary over time
The doctors and nurses will explain your results

This result tells you the amount of virus in the blood

It is very common for the level to be high. It may get lower if the body's immune system tries to control the virus and makes antibodies against the virus.

Test: Hepatitis B e antigen (HBeAg)

Result
Detected in blood (HBeAg positive) or not (HBeAg negative)

A positive result means there are high or medium levels of virus in the blood.

A negative result is usually seen when the body's immune system has made antibodies against the virus (e antibody or eAb) and usually means that the viral load is getting lower. However, sometimes the viral load can become medium or high again, even when eAb is present. This is because the virus can find ways of overcoming any attempt to control it.

Chart 2: What do my antibody tests mean?

Test: Hepatitis B surface antibody (HBsAb)

Result

Detected in blood: surface antibody positive?

Yes

This is a sign of immunity to hepatitis B. It means **EITHER** you had the infection in the past and recovered previously **OR** you have been immunised against hepatitis B. You are now protected against the virus, and will not develop chronic infection

No

If you are sAb negative and sAg positive, this shows you continue to have chronic infection.

If you have been vaccinated, it suggests you may need another course of vaccine to make sure you are protected

Test: Hepatitis B core antibody (HBcAb)

Result

A positive core antibody test means you have at some time been infected with hepatitis B. It does not tell you whether the infection has resolved or is still present. It is the HBsAg test that tells you that. Core antibody does **NOT** become positive after vaccination

Chart 3: How do I know if my liver is inflamed?

If you have chronic hepatitis B infection, you will be monitored in several ways:

Test: ALT level in blood

ALT is a protein released from liver cells. Normal ALT value depends on your age and whether you are male or female. A high ALT is seen when the liver is becoming inflamed, but also may be seen when the body is fighting the virus and trying to control it

Result

Normal level – Mildly raised level – Raised level

Levels may differ between laboratories, age groups and gender

Test: FibroScan or ARFI scan

These are special scans, like an ultrasound, that measures how stiff the liver is and may give an indication as to whether the liver is becoming scarred

The results of these tests will help your doctor decide how often you need monitoring, whether any further investigations are required and whether you need treatment.

What treatment is available for hepatitis B?

At the moment, there is no cure for hepatitis B but more research is taking place. Treatment is aimed at reducing the amount of hepatitis B virus in the blood and improving the immune system response. This will lower the risk of spreading the infection and prevent damage to the liver.

There are a number of different treatments for children and young people which are constantly changing and improving. Your healthcare team will talk to you about the treatments if you need them.

What if I forget to take my medication?

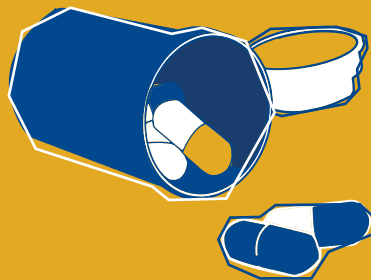
If your doctor has prescribed treatment for your hepatitis B, it is important that you take your medication **even if you feel fine**. If you forget to take your medication you should take your normal dose as soon as you remember.

If you keep forgetting to take your medication over a long period of time, you could become unwell.

Tell your doctor or nurse as soon as possible. They may want to arrange a blood test or see you in clinic before your next planned appointment.

If you find it difficult to remember to take your medication it can be helpful to set a reminder on your phone that repeats daily at the same time. You may want to consider a medication reminder app on your phone such as the DrugStars app. You can find further information at drugstars.com.

You can talk to your doctor or nurse if you are still finding it difficult to take your medication for any reason. They will be able to offer you some advice and support.



Why is going to clinic so important, even if I feel fine?

When you're young hepatitis B is normally mild so you may not have any symptoms or feel ill at all. However, as you get older the virus can start to damage your liver. If your hepatitis B isn't monitored and treated properly, it can lead to liver damage.

This is why it is so important to go to all of your clinic appointments.

When you go to clinic you will have different tests which measure how much hepatitis B virus you have in your blood and how well your liver is working. By having regular checks your doctors can tell if your liver is affected by the virus and they will try to prevent your liver becoming more damaged by prescribing medication.

If the hepatitis B infection does not clear you will be seen by the liver transition team to support you to move from paediatric to adult services for ongoing appointments.

Key things to consider

Who should I tell about my hepatitis B infection?

Choosing whether to tell people about your hepatitis B status is a very personal decision.

There can be a stigma associated with hepatitis B. This means sometimes family and friends don't fully understand what it is and may have negative thoughts about it. However, some people find that support from family and friends is important and helps them to cope.

Telling other people that you have hepatitis B can be scary because you may fear that people will judge you. This isn't always the case but you should be 100% happy and comfortable with whom you choose to tell because once you have told them, you can't take it back.

Before deciding whether you should tell someone ask yourself these questions:

- How well do I know them?
- Why do I want to tell them?
- Do I trust them to keep anything I tell them private?
- What will I do if they don't react how I expect them to?

You don't have to tell anyone about your hepatitis B infection unless you want to. It is completely your choice but you should tell the healthcare professionals who are treating you including your dentist. You should also tell those providing you with tattoos, piercings and invasive beauty treatments e.g. acupuncture.

It can also be difficult to decide whether or not you should tell your teachers. Again, this is **your choice**. You don't have to tell your school but if you do they should ensure confidentiality at all times.

If you are sexually active, you should tell any sexual partners so they can be tested and vaccinated against the hepatitis B virus.

Can I still take part in sport with hepatitis B?

Having hepatitis B doesn't mean you have to stop playing sports. Contact sports such as boxing and rugby are not advised because of the risk of injuries that may cause bleeding. This increases the risk of passing the infection to other people. You don't have to tell people that you have hepatitis B if you aren't comfortable in doing so but you should know how to deal with injuries properly when blood is involved. Remember:

- If you are bleeding you should stop playing
- First aiders should always wear gloves
- Any blood should be cleaned up immediately and properly
- Clothes with blood on them should be changed and washed appropriately

Can hepatitis B affect my career options?

Having hepatitis B may mean you can't work in some careers.

Medical school

If you are applying to medical school you will need to tell the university about your condition. As a medical student and as a doctor you will not be allowed to perform exposure prone procedures (EPPs). These are procedures that have a higher risk of you passing hepatitis B to a patient. You can qualify with a full medical degree and become provisionally registered as a doctor without undertaking EPPs but this will limit which areas you can work in. You can visit the British Medical Association (BMA) website for further guidance.

Dentistry

Only people classed as hepatitis B surface antigen negative can apply to dentistry school. Dentistry students have to perform exposure prone procedures (EPPs) in order to qualify and graduate.

Armed forces

If you have hepatitis B you are unable to join the British Army, RAF and the Royal Navy.

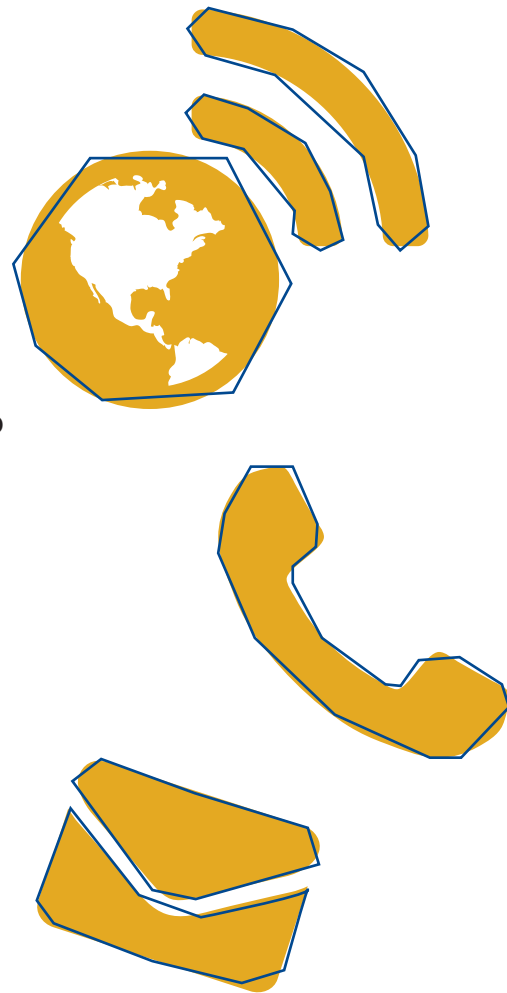
There may be other restrictions in certain careers but it is always worth discussing any concerns you have with the occupational health team at the organisation you would like to work for before making your decision.

Who can I contact for more information and support?

Your medical team are there to answer any questions you may have, no matter how silly you think they sound. It can be helpful to write your questions down before attending the appointment and take them in with you to discuss with your doctor or nurse.

You can also talk to CLDF's Young People's Team about any worries or concerns you have, whether they are related to your liver or not. You can contact the team by calling **0121 212 6024** or emailing youngpeople@childliverdisease.org.

There is also a CLDF Young People's Facebook page you can visit: [facebook.com/CLDFyoungpeople/](https://www.facebook.com/CLDFyoungpeople/)



Here are some helpful links for further information:

Smoking, Alcohol and Drugs

drinkaware.co.uk

This website has useful facts and information on current drinking guidelines, alongside offering expert advice and tips on how to drink more responsibly. You can also download helpful apps and order factsheets and leaflets to take steps to limit your alcohol intake.

nhs.uk/smokefree

Smokefree provides expert support information and advice on quitting smoking.

talktofrank.com

Talk to Frank gives you essential information on the side-effects, risks and law concerning different types of drugs and gives you the opportunity to receive friendly, confidential drugs advice in the form of live chat, personal stories and FAQs.

Sexual Health

brook.org.uk

Brook offers free and confidential sexual health services to young people, as well as education and support. There is information on a variety of sexual health topics such as pregnancy and contraception as well as the opportunity to ask for advice via their web and textchat services.

Education and Work

<https://nationalcareers.service.gov.uk/>

The National Careers Service gives you a wide range of support and advice about the world of work by offering personalised help from careers advisers, course and job searches to find career opportunities that are right for you, and essential help with CVs, personal statements and interviews.

Emotional and Mental Health

youngminds.org.uk

A charity committed to improving the emotional well-being and mental health of young people. Their website provides accessible, down-to-earth information on everything you may want to know about mental health through online resources and personal stories along with a link to their HeadMeds website which focuses on mental health medication and the issues this can have.

mind.org.uk

A charity which provides advice and support to empower anyone experiencing a mental health problem. On their website you can access information on mental health alongside advice and tips on everyday life, and a confidential helpline to speak with an adviser via phone, email or text.

General Support

childline.org.uk

Childline is a free and confidential helpline available for young people where you can contact an adviser via message board, email, telephone or online chat to ask for help with a range of issues.

Essential information on topics like peer pressure, bullying and self-esteem and how to deal with this are also available, along with interactive games and videos.

Thanks

The booklet has been written, edited and reviewed with the help of staff at each of the specialist paediatric liver centres: Birmingham Women's and Children's NHS Foundation Trust, King's College Hospital and Leeds Children's Hospital. Thank you to all of the staff involved who have made the production of this leaflet possible.

Disclaimer

This leaflet provides general information but does not replace medical advice. It is important to contact your medical team if you have any worries or concerns.

Feedback and Information Sources

Information within this leaflet has been produced with input from the three specialist paediatric liver centres in the UK. To provide feedback on this leaflet, or for more information on the content of this leaflet including references and how it was developed contact Children's Liver Disease Foundation: info@childliverdisease.org.

This leaflet has been reviewed in May 2019. It is due to be reviewed by May 2022.

What is Children's Liver Disease Foundation (CLDF)?

CLDF is the UK's leading organisation dedicated to fighting all childhood liver diseases.

CLDF provides information and support services to young people up to the age of 25 with liver conditions and their families, funds vital research into childhood liver disease and is a voice for everyone affected.

Are you a young person with a liver condition?

CLDF's Young People's team is here for you, whether you want to talk about issues affecting you, meet and share with others, or just belong to a group which cares, knows what it's like and is fighting to make a difference. You are not alone.

Get in touch:

Phone 0121 212 6024

Email youngpeople@childliverdisease.org

CLDF has a social media platform called HIVE for young people with a liver disease/transplant to make new friends, connect and share stories childliverdisease.org/young-people/hive.

Would you like to help us support the fight against childhood liver disease?

All of CLDF's work is funded entirely through voluntary donations and fundraising. Please help us to continue to support young people, families and adults diagnosed in childhood now and in the future. To find out more about fundraising and how you can join the fight against childhood liver disease you can visit: childliverdisease.org/get-involved. Alternatively, you can contact the Fundraising Team by email fundraising@childliverdisease.org or call 0121 212 6022.

Children's Liver Disease Foundation

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