Children's Liver Disease Foundation
fighting childhood liver disease

Hepatitis B – Parents and Guardians

A Guide

Information for parents and guardians who would like to know more about hepatitis B in children.

This leaflet is designed for parents and guardians who would like to know more about hepatitis B in children. The leaflet includes information on:

- The hepatitis B virus
  – acute hepatitis B
  – chronic hepatitis B
- How children and young people get hepatitis B
- Blood tests results
- Treatment
- Who you should tell about your child's hepatitis B infection?
- Prevention of transmitting the hepatitis B virus to others
- Fostering and adoption

Other leaflets:

- An Introduction to Liver Disease

If you have any questions about anything discussed in this leaflet you can talk to the medical team looking after your child or you can get in touch with CLDF's Families Team for further advice and support.

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 the liver is inflamed or damaged 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. The virus is present in blood and bodily fluids. The body's immune system responds to the virus and this response can damage the liver cells.

Acute hepatitis B

It 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.

Symptoms of acute hepatitis B:

- Tiredness
- General aches and pains
- A high temperature (fever)
- A general sense of feeling unwell
- Loss of appetite
- Feeling and being sick
- Diarrhoea
- Tummy (abdominal) pain
- Yellowing of the skin and eyes (jaundice)
- Dark urine and pale, grey-coloured stools

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

Chronic hepatitis B

This 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. When hepatitis B is acquired at a younger age, it is more likely to become chronic (long-term).

Symptoms of chronic hepatitis B:

Most children with chronic hepatitis B have no symptoms. However, some children may experience symptoms if they have a 'flare' of the hepatitis B infection. A flare can occur when the liver enzymes become raised (see leaflet "An Introduction to Liver Disease"). 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 children are referred to a specialist children's liver centre where their liver function and hepatitis B virus can be closely monitored, assessed and treatment provided if necessary.

How did my child 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 the person doesn’t have any symptoms.

It **cannot** be spread by casual contact such as sharing utensils, cups, cuddling, hand holding or by breastfeeding (unless nipples are cracked or bleeding). Hepatitis B cannot be spread through casual kissing but there may be a risk if there are cold sores, ulcers, bleeding gums, cuts or abrasions in the mouth of the infected person.

Hepatitis B can be transmitted from mother to child or by person-to-person transmission.

Mother to child (vertical transmission)

The main way children in the UK contract hepatitis B is at birth from their mothers who have hepatitis B infection.

Pregnant women in the UK are tested for hepatitis B as part of their antenatal routine during pregnancy. If a pregnant woman tests positive for hepatitis B and she has been told that she is at high risk of transmitting the infection, she should receive oral antiviral treatment in the 28th week of the pregnancy.

This helps to reduce the risk of her child also contracting the infection. Babies born to mothers who have hepatitis B are considered high risk infants. These babies should receive the accelerated hepatitis B vaccination course as stated on page 14.

Person to person (horizontal transmission)

Hepatitis B is highly infectious and can be spread when blood from an infected person enters another person's body. Ways this can happen include, contact with open wounds or a bite that breaks the skin, sharing toothbrushes, razors, shavers and equipment for cutting hair, injecting drugs and sharing drug taking equipment and sexual intercourse. Hepatitis B can also be spread through receiving contaminated blood during a medical procedure. Blood donations in the UK are screened for hepatitis B to remove the risk but it is possible to receive contaminated blood in other countries.

You may not see any blood on an item but this doesn't mean there isn't any blood or virus present. The hepatitis B virus can last up to a week on dry surfaces.

How can I prevent my child passing the infection to other people?

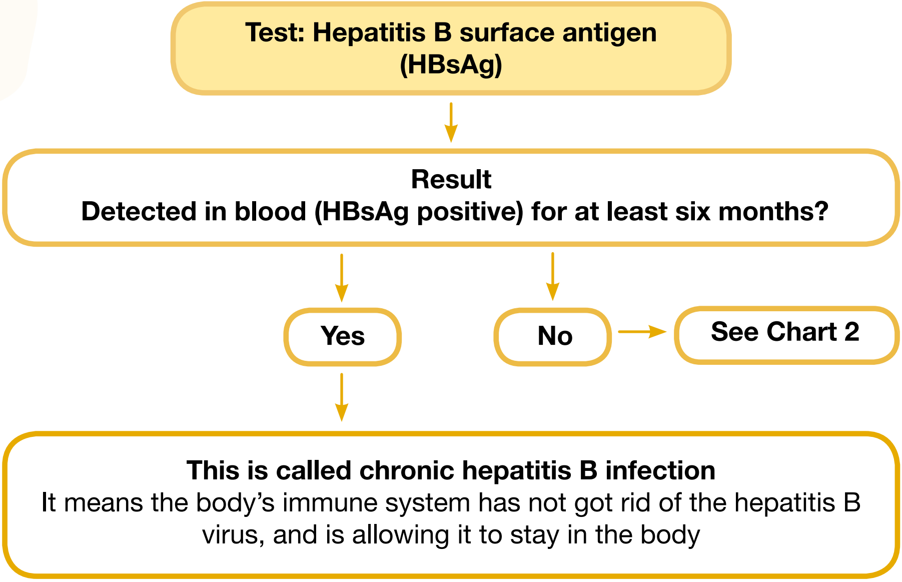
Ensure your child knows what they need to do:

- Cover cuts and any wounds with a water proof dressing
- Don't let anyone touch your blood if you cut yourself or have a nose bleed
- Do not share toothbrushes with others
- Clean up any blood spills you may have
- Do not share razors or hair clippers
- Do not share any equipment used to inject, snort or smoke drugs e.g. needles, syringes, spoons, water, filters, straws, notes, crack pipes.

What do the blood test results mean?

Blood tests will be done to find out if someone has hepatitis B. If a child is found to be positive for hepatitis B their condition will be assessed and monitored by undertaking blood tests and other investigations. The tables below explain what the different blood test results mean.

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)

↓

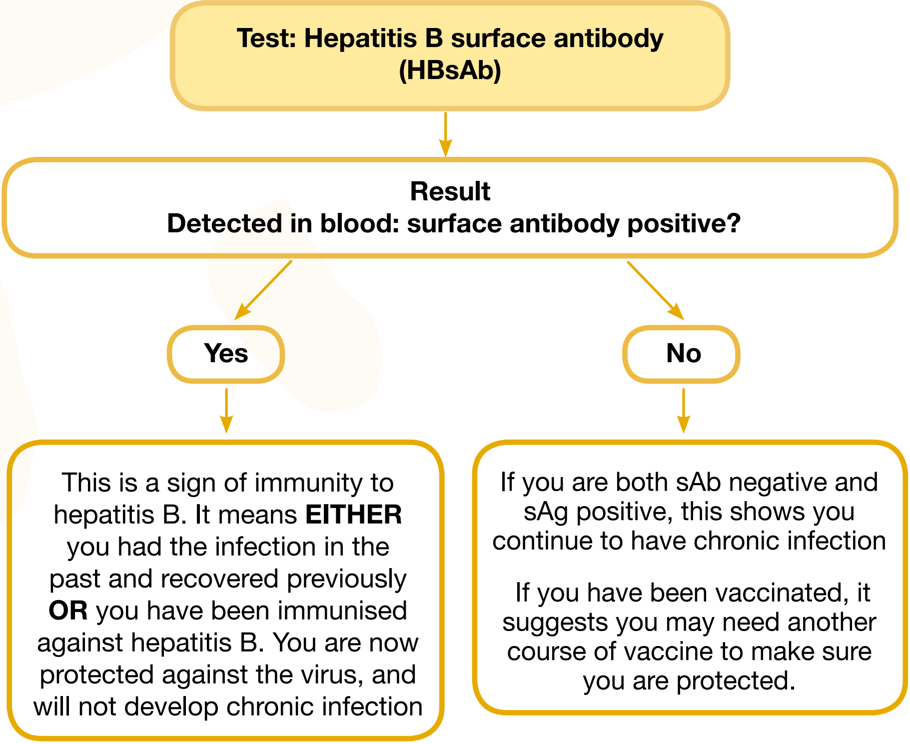
Result
Detected in blood (HBeAg positive) or not (HBeAg negative)?

↓

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?

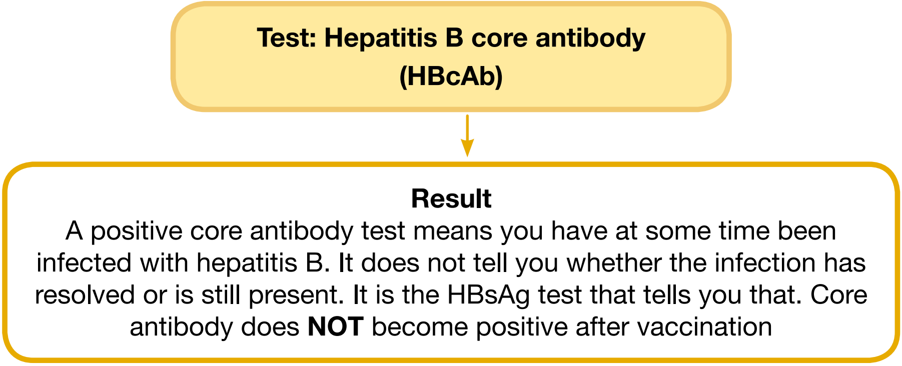
Yes

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 both 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 whether your child needs closer monitoring, further tests such as a liver biopsy, or may need to start treatment.

What treatment is available?

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

Who should I tell about my child's hepatitis B infection?

You should inform healthcare professionals treating your child including their dentist.

Choosing whether to tell people about your/your child’s hepatitis B status is a very personal decision and there is no right or wrong answer. There can be a stigma associated with hepatitis B and sometimes family and friends don’t fully understand what it is. Some people, however, find that support from family and friends is important and helps them to cope with the diagnosis better.

It is also up to parents when to tell children about their health. It is helpful that even young children receive some information about what they can do to prevent passing the infection on to others.

Whether or not to tell a child’s school is also a difficult decision for some parents. There is a worry that the school may stigmatise or treat a child with hepatitis B differently but they should ensure confidentiality at all times. **It is your choice.**

Prevention and vaccination for hepatitis B in low risk newborns

All babies born to mothers who have had a negative hepatitis B surface antigen blood test result during antenatal care are known as low risk babies.

Routine vaccination

From 1st August 2017 **all** babies born in the UK are offered the hepatitis B vaccine as part of the universal vaccination which is given at 8, 12 and 16 weeks of age.

Prevention and vaccination for hepatitis B in high risk newborns

There are different vaccines available to try to stop hepatitis B developing in babies born to mothers with hepatitis B. These differ from the routine vaccinations given to all babies when they are born. Babies who are born to mothers with hepatitis B have an accelerated course (see page 14). These babies should receive the first vaccine as soon as possible after birth, and definitely within the first 24 hours of life.

Sometimes the blood test can show that a mother is highly infectious. If this is the case the child may be given another injection of specific hepatitis B immunoglobulin (HBIG) at birth, as well as the vaccine, to help them to fight the infection. This provides temporary immunity whilst waiting for the vaccine to work. HBIG should be given at the same time as the first vaccine or as close as possible to the vaccine within 24 hours of birth.

Vaccination timings for a child at risk of hepatitis B:

- At birth – within 24 hours of birth
- 4 weeks
- 8 weeks
- 12 weeks
- 16 weeks
- One year of age

Children require ALL of these vaccinations on time and as scheduled in order to give the infant the best chance of being protected.

Babies born to mothers with hepatitis B should have a blood test at 12 months old to find out if the vaccine has worked and whether the child has developed immunity against the virus. This can be done at your GP surgery, local community clinic and, in some cases, at home.

Vaccination is more than 95% effective in protecting babies from long-term hepatitis B infection.

All mothers in the UK are offered hepatitis B screening during antenatal care. It's important to speak to a midwife so that the appropriate vaccinations can be organised.

Breastfeeding is not thought to have an effect on passing hepatitis B onto a child. It is recommended that mothers can breastfeed once the infant is vaccinated as long as they don't have bleeding or cracked nipples.

Other individuals who require hepatitis B vaccination:

- Family members, siblings and carers living in the same house as a person who has been diagnosed with acute or chronic hepatitis B
- All household contacts
- Sexual partners of people with hepatitis B
- Those involved in fostering or adoption

Fostering and adoption

Families adopting from countries where hepatitis B infection is common or at high levels are advised to have the hepatitis B vaccination. The vaccine will reduce their risk of contracting the virus.

A baby born to a mother with hepatitis B won’t be tested for hepatitis B until they have completed all vaccinations for hepatitis B at 12 months old.

If you adopt or foster an infant whose mother has or may have had hepatitis B you will need to make sure they receive their hepatitis B vaccinations as scheduled (see page 14).

Foster carers, and their families, should also be immunised against hepatitis B if they are looking after children with hepatitis B. When a child is fostered there should be a medical exam and a health assessment of the child during the process. Carers should be advised about any infection risks and whether they need to be immunised.

Carers should check the child's red book (if available) to see if the hepatitis B vaccination has been given and to check whether the child has had a blood test for the hepatitis B surface antigen, hepatitis B core antibody and hepatitis B surface antibody. These results will inform the doctor or nurse if the child has a good response to the vaccinations (immunity) or not (see section 'What do the blood test results mean?').

CLDF produces a wide variety of information resources for children and young people up to the age of 25 with liver disease, their families and the healthcare professionals who look after them. This information can be downloaded or ordered from CLDF's website childliverdisease.org. For further enquiries regarding CLDF's information please contact the Information and Research Hub Manager by email at irhm@childliverdisease.org or call 0121 212 6029.

Thanks

This 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/your child's 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.

Notes

Notes

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 up to the age of 25 with a liver condition? CLDF's Families and Young People's teams are 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.

If you are a parent/carer or family member then get in touch with CLDF's Families Team:
Phone: 0121 212 6023 **Email:** families@childliverdisease.org

If you are a young person and want to find out more about CLDF's services you can contact CLDF's Young People's Team:
Phone: 0121 212 6024 **Email:** youngpeople@childliverdisease.org

CLDF have 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 www.childliverdisease.org/get-involved. Alternatively you can email the Fundraising Team at fundraising@childliverdisease.org or call them on **0121 212 6022.**

Children's Liver Disease Foundation,
36 Great Charles Street, Birmingham, B3 3JY
0121 212 3839 info@childliverdisease.org
Main site: childliverdisease.org

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