



# Hepatitis C

*Liver*  
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LIVER PATIENT SUPPORT

## **Essential facts about Hepatitis C**

Hepatitis C (Hep C) is a virus that infects the liver and can cause damage to the liver (inflammation and liver scarring).

Hep C is common, but underdiagnosed, with approximately 60,000 people in the UK currently infected and many are unaware of their infection.

About 60% of people who are exposed to Hep C do not clear the infection and develop a long-term (chronic) infection that can cause liver damage. Approximately 40% of people with Hep C will clear the infection, without treatment, within 3 months of being first infected.

Hep C is now curable with an 8 or 12 week course of antiviral tablets.

In the UK there is a plan to try to eliminate Hep C from the country by 2030.

Hep C is transmitted by blood to blood contact and the most common risk factors for Hep C are a history of intravenous drug use, sharing drug paraphernalia (pans, water, filters) or having received blood transfusions/blood products before 1996.

Hep C usually causes few symptoms. Mild tiredness is the most frequent symptom and many are unaware of having the infection.

Everyone with a previous history of intravenous drug use (even only once) or a history of blood transfusion/blood products should have a test for Hep C, otherwise there is a risk the infection will not be diagnosed and liver damage could occur.

Treatment for Hep C involves taking antiviral tablets for 8-12 weeks. The treatment has no or minimal side effects for most people and cures more than 95% of those who complete the course of treatment.

There are a few different antiviral medications for Hep C and the treatment chosen depends on the genotype and other clinical factors (See page 6 of this leaflet for further details).

Untreated Hep C can cause cirrhosis (severe liver scarring), liver failure and liver cancer after more than 20 years of infection.

People who drink excessive amounts of alcohol (more than 14 units per week) are at high risk of developing cirrhosis so excessive alcohol consumption should be avoided.

Anyone with Hep C should not share razors, toothbrushes or hair clippers otherwise there is a risk of transmitting Hep C to others.

Hep C is not transmitted by day to day contact, such as sharing cutlery with infected individuals.

What is chronic Hep C?

If the Hep C infection persists for longer than six months it can lead to long term liver damage by causing inflammation in the liver (hepatitis) and scarring of the liver (fibrosis). This is referred to as chronic Hep C.

Chronic Hep C should be treated with antivirals to reduce the risk of developing liver damage.

Currently there are an estimated 60,000 people living with chronic Hep C in the UK.

Over the last decade more than 90,000 people have been treated and cured of their chronic Hep C.

How is Hep C spread?

The Hep C virus is mainly transmitted through blood to blood contact. Injecting drug users and people who have had blood transfusions prior to January 1996 are most at risk.

Blood donations have been screened for Hep C in the UK since that time.

Some people who have previously received blood products, for example haemophiliacs, or those having a blood transfusion abroad where blood is not screened, may be at risk of infection.

Hep C is common in some other countries of the world (for example, Africa, South Asia, Eastern Europe and Egypt) so people who were born in these countries or who have had medical procedures in these countries may also be at risk of Hep C.

Hep C infection is not acquired through normal social contact. For example, you cannot catch it from sharing a toilet seat, crockery, cutlery or just touching an infected person.

Hep C can be transmitted sexually but this is relatively uncommon unless there are high risk sexual activities or blood contact during sex. Over the last few years in the UK, there have been some outbreaks of Hep C among men who have sex with men. Safe sexual practice and a barrier method of contraception is advised e.g. condoms to reduce onward transmission.

Hep C can be transmitted from a mother to baby, although the risk is relatively low (2-5%). Therefore to reduce the risk of infection, it is important that Hep C is treated, whenever possible, before individuals or their partners get pregnant. When babies born to mothers with Hep C reach the age of 1 year old they should have a Hep C test done to check if they have become infected.

### **What are the symptoms?**

Hep C can affect people quite differently. The majority of people have no symptoms and are often unaware they have been infected, while others experience extreme tiredness and often feel unwell.

Symptoms, when present, may be vague and include: mild to severe fatigue, anxiety, weight loss, poor

appetite, nausea (sickness), joint pains, pain in the area of the liver and concentration problems.

People who have had Hep C for many years and develop cirrhosis can have symptoms of liver failure including ascites (fluid in the abdomen), gastrointestinal bleeding for varices (varicose veins in the gullet) or hepatic encephalopathy (toxins affecting the brain).

### **Preventing transmission of Hep C**

- Clean up blood spills with undiluted bleach.
- Carefully clean cuts and wounds and cover with a dressing.
- Do not share personal items such as toothbrushes, razors, scissors, hair clippers, vapes, crack pipes, rolled paper notes or straws to snort drugs.
- Make sure sterile needles are used for ear piercing, tattooing and acupuncture.
- Do not share any injecting equipment including syringes, filters and water or straws etc used for snorting.
- Do not donate blood.
- We advise that your regular sexual partner is also tested for Hep C as there could be a risk of reinfection.

### **What is cirrhosis?**

Cirrhosis is scarring of the liver caused by long-term liver damage. This scarring leads to loss of liver cells, which can result in reduced liver function. Any long-term condition or disease that affects the liver can cause cirrhosis. Hep C is one of the most common causes of cirrhosis.

Cirrhosis causes the liver to become firm and knobbly because of a build-up of scarring in the liver. This can reduce blood flow through the liver, which in turn can cause a build-up of pressure in the portal vein. This is the main vein that takes blood from the intestines to the liver. High pressure in the portal vein is called portal hypertension and this causes many of the symptoms associated with cirrhosis.

- Ascites - a build-up of fluid in the abdomen.
- Bleeding varices - internal bleeding from blood vessels in the gullet (oesophagus) or stomach.
- Encephalopathy - confusion from the build-up of toxins in the blood that can affect brain function.
- Liver Cancer – Hep C cirrhosis is a risk for the development of hepatocellular carcinoma (cancer that originates from the liver).

## **What tests may be done in patients with suspected Hep C?**

### **Hep C tests**

1. Your first Hep C blood test will probably be an antibody test. A positive test only shows that you have been exposed to the Hep C virus. A further blood test is needed to confirm whether you have the virus or not.
2. If the Hep C antibody test is positive, a Hep C RNA (ribonucleic acid) test by PCR (polymerase chain reaction) is required to confirm infection and to measure the amount of virus in the blood.
3. A positive Hep C RNA test means an individual currently has active Hepatitis C infection and may need treatment. Before starting antiviral treatment, this test is sometimes repeated to confirm active infection. This is especially important if it is a very recent infection as some individuals can clear the infection without any treatment.
4. Hep C blood tests can be performed using standard blood tests or sometimes using a finger prick blood test. If a finger prick test is used then a standard blood test is usually done to confirm the finger prick test.
5. Hepatitis genotype - There are six recognized strains of Hep C, known as genotypes, with numerous sub-types. The most common strains in the UK are genotypes 1 and 3. In most cases the genotype is measured to determine which antiviral treatment to prescribe because some of the antivirals don't work for certain genotypes. Knowing the genotype is also helpful, if treatment fails, to determine whether there has been treatment failure or reinfection.

Other tests.

1. For individuals who have a positive Hep C test, blood is usually taken to test for other blood borne viruses including Hepatitis B and HIV (human immunodeficiency virus) because sometimes these viruses are also present in patients with Hep C.
2. Liver blood tests are also usually taken to assess the function of the liver. These tests measure enzymes and other chemicals in the blood to give an indication of the damage and function of the liver.
3. Other tests may be undertaken to assess the amount of liver fibrosis (scarring in the liver) including:
  - a. FIB-4 score - this is calculated from the liver blood tests. A low FIB-4 score of less than 1.3 excludes any significant damage in the liver. A FIB-4 score greater than 1.3 could indicate some damage in the liver and a test called a fibroscan will be conducted to assess this further.
  - b. Fibroscan – this is an ultrasound-based test that measures the elasticity of the liver. This is an accurate and painless test to measure liver scarring. Several readings are taken by placing a probe over your liver between your ribs. The test takes approximately 5 minutes to complete.
4. For patients with suspected significant scarring of the liver, an ultrasound of the liver may be performed.

### **Treatment for Hep C**

If you have Hep C you will need to be referred to a specialist who has expert knowledge of hepatitis. This could be a hepatologist (liver specialist), a gastroenterologist, a specialist in infectious disease or a specialist nurse.

When you are referred to a specialist for Hep C treatment, the specialist will take a medical history and arrange the appropriate tests for you. They will discuss the treatment options with you and arrange for you to start treatment once all the relevant information is known.

Treatment for Hep C has been revolutionised in the last 10 years with the development of direct acting antiviral

drugs (DAAs). These medications stop the Hep C replicating in the blood leading to a rapid drop in virus levels in a few days, curing the infection in most cases.

Antiviral treatment for Hep C is taken in tablet form once daily for 8 or 12 weeks. Overall cure rates are greater than 95% for those who complete the course of antivirals. There are several DAAs that are used and the specific treatment given will depend on your genotype and other clinical parameters. Treatment decisions are made at a regional multidisciplinary meeting in line with NHS England recommendations. First line treatments include Epclusa, Harvoni, Maviret, and Zepatier.

Once your treatment has been agreed, you may commence the treatment at a face to face appointment or the medications will be delivered to you and you will have a telephone consultation to start the treatment.

Once you start the treatment it is extremely important to complete the whole course exactly as prescribed. This will maximise your chance of a cure. The effects of treatment in pregnancy are not known therefore you or your partner are advised not to become pregnant for the duration of your treatment. If you have any questions about your treatment you should contact your consultant or specialist nurse.

The outcome of Hep C infection is determined 3 months after completion of the course of DAAs.

If your Hep C RNA is NOT DETECTED 3 months after completion of the DAA treatment course then you will have achieved a sustained virological response, which is considered a cure of the infection. Patients often have another Hep C RNA test 6 months after completion of their treatment to confirm this result. More than 95% of those completing the DAA treatment achieve cure.

A few patients relapse after completing their course of antivirals. A second course of antivirals, using an alternative antiviral treatment, is often offered to those



who relapse. The multidisciplinary team will decide on the most appropriate second line treatment.

In order to maximise your chances of achieving a cure of Hep C it is important to remember to take the antiviral tablet every day exactly as recommended by your consultant or specialist nurse. A detailed explanation of how to maximise your chances of a cure will be given to you when you start treatment.

Successful treatment of Hep C reduces the risk of developing progressive liver disease and cirrhosis in the future. Studies have also shown an improvement in quality of life in many patients. Patients who already have cirrhosis usually have an improvement in their liver function following treatment and there is a reduced risk of developing complications of cirrhosis such as liver cancer and varices.

#### Follow up after treatment

Patients without cirrhosis who have achieved sustained virological response (cure) usually have a good long-term prognosis and are often discharged from the Hep C clinics.

Some damage in the liver can still persist in patients with cirrhosis following successful antiviral treatment. While the risk of liver-related complications, such as liver cancer, reduces after treatment, they can still occur in patients with cirrhosis. Therefore, individuals with cirrhosis need long term follow up in liver clinics to monitor for complications like liver cancer and varices.

It is important to know that patients who have had Hep C treatment can be re-infected if they are exposed to Hep C again, so if individuals are engaging in injecting drug use they must ensure they use clean needles and equipment every time.

Patients who have had Hep C will have antibodies to Hep C in their blood for life. In order to determine if the infection is active then a Hep C RNA test is needed.

## **Acknowledgement:**

We are very grateful to Professor Stuart McPherson Consultant Hepatologist at The Newcastle upon Tyne Hospitals NHS Foundation Trust for writing this LIVErNORTH leaflet for the benefit of liver patients.

## **LIVErNORTH can help you.**

We have access to extensive information on all liver diseases and treatments - more on the back cover.

### Our website

[www.livernorth.org.uk](http://www.livernorth.org.uk)

### Our email address

[info@livernorth.org.uk](mailto:info@livernorth.org.uk)

Other contacts:

British Liver Trust

[www.britishlivertrust.org.uk](http://www.britishlivertrust.org.uk)

Haemophilia Society

[www.haemophilia.org.uk](http://www.haemophilia.org.uk)

The Hepatitis C Trust

<http://www.hepctrust.org.uk>

Addaction

<http://www.addaction.org.uk>

National Hepatitis C resource centre

<http://www.hepccentre.org.uk/>

### useful websites

[www.hivandhepatitis.com](http://www.hivandhepatitis.com)

[www.gastrohep.com](http://www.gastrohep.com)

[www.doh.gov.uk/drugs](http://www.doh.gov.uk/drugs)

[www.nice.org.uk](http://www.nice.org.uk)

[www.nhs.uk](http://www.nhs.uk)

## LIVERnORTH Information Leaflets:

1. Liver Patient Support
  2. Accommodation for patients & families
  3. Autoimmune Hepatitis (AIH)
  4. Alcohol and Liver Disease
  5. Looking After Your Liver
  6. Primary Biliary Cholangitis (PBC)
  7. Coping With Stress
  8. Primary Liver Cancer (HCC)
  9. You and Your Consultant
  10. Primary Sclerosing Cholangitis (PSC)
  11. Lifestyle and your Liver (MASLD/NAFLD)
  12. Liver Disease
  13. Skin Care for Liver Patients
  14. Diet and Liver Disease
  - 14a. Nutrition in Liver Disease
  15. Hepatitis C (HEPC)
  16. Travel Insurance for Liver Patients
  17. Hepatitis E (HEPE)
  18. Fatigue in Liver Patients/A Patient's Journey
  19. Scanning - a short guide (*aka Understanding Tests*)
  20. Liver Cirrhosis Self Management Toolkit \*
  21. Exercise & Osteoporosis in Liver Patients
  22. Hepatic Encephalopathy (HE)
  23. Our Livers, Our Lives
  25. Allowances (DLA & PIP)
  26. Compensated Liver Cirrhosis (CLC)
  27. Hepatitis B (HEPB)
  30. Wellness Walks - several available
- \* only from your doctor or healthcare professional

### **To access LIVERnORTH information leaflets:**

- **Download from our website:**  
(<http://www.livernorth.org.uk/pages/factsheet.htm>)
- **Collect from our display boards:**  
(Various Hospitals & Clinics)
- **Email us:** [info@livernorth.org.uk](mailto:info@livernorth.org.uk)
- **Phone/FAX:** 0191 3702961
- **Write to us:** *freepost LIVERnORTH*
- **Facebook direct message us:**  
<https://www.facebook.com/livernorth/>



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**LIVERNORTH**

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[Info@livernorth.org.uk](mailto:Info@livernorth.org.uk)

[www.livernorth.org.uk](http://www.livernorth.org.uk)

Registered Charity Number 1087226

LIVERNORTH is a national liver patient support charity  
and has provided this leaflet free of charge

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