

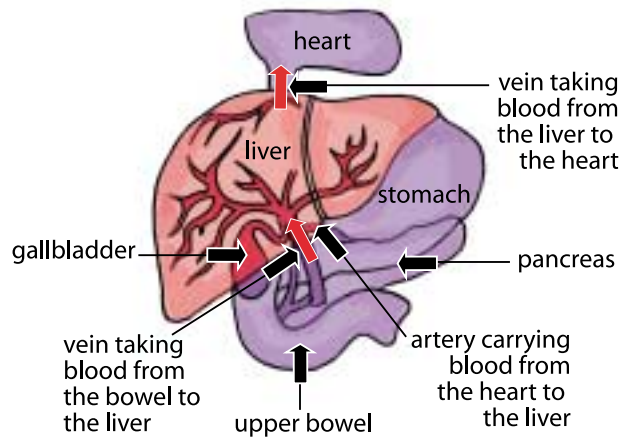
English

# Hepatitis C

**TACKLING  
DRUGS  
CHANGING  
LIVES**

## The liver

The liver is your body's chemical factory performing hundreds of complex functions that are vital for life. It is a very uncomplaining organ and has the ability to carry on its many functions with only a small portion actually working.



### The liver:

- produces quick energy when needed
- stores sugars, vitamins and minerals including iron
- aids the digestive process by producing bile
- neutralises certain poisons
- controls the production of cholesterol
- maintains hormone balance
- helps the body resist infection by producing immune factors
- regenerates its own tissue.

### This leaflet is for information only.

Professional, medical or other advice should be obtained before acting on anything in the leaflet as no responsibility can be accepted by the British Liver Trust as a result of action taken or not taken because of the contents.

## What does hepatitis mean?

Hepatitis means inflammation of the liver. The commonest cause is infection with a virus, but inflammation can be caused by drinking too much alcohol, the side effects of some drugs and chemicals, and a liver disease called autoimmune hepatitis, in which the body's immune system malfunctions and attacks the liver.

There are several different viruses that affect the liver, primarily hepatitis A, B, C, D and E. The main difference between the viruses is how they are spread, the way they cause liver damage and the effects they can have on your health.

For information on [hepatitis A, C, D and E](#), visit the British Liver Trust website at [www.britishlivertrust.org.uk](http://www.britishlivertrust.org.uk) (not currently available in Portuguese).

## What is hepatitis C?

Hepatitis C, sometimes referred to as hep C or HCV, is a liver disease caused by the hepatitis C virus.

### Symptoms

Hepatitis is commonly described as either an **acute** or **chronic** illness. An acute illness means a short, sharp illness that may be severe, but most people recover within a few weeks with no lasting effects. A chronic illness is one that lasts a long time, possibly for the rest of a person's life.

Hepatitis C remains chronic in most, but it affects people quite differently. Many have no symptoms and are often unaware they have the virus. Symptoms, when present, can be vague. Some people experience extreme tiredness and feel unwell.

A few have a short 'flu-like illness, occasionally with nausea, vomiting and jaundice, but this is unusual.

**Symptoms can include:**

- mild to severe fatigue
- anxiety
- weight loss
- loss of appetite
- alcohol intolerance
- pain in the area of the liver
- concentration problems ("brain fog")
- feeling sick
- flu-like symptoms such as fever, chills, night sweats and headaches
- jaundice.

Some of the symptoms may come and go and it has not been unusual for people to be diagnosed as having ME, or chronic fatigue syndrome. The liver is a very uncomplaining organ and most people do not know that it is not working properly until advanced disease has developed.

Approximately 20% of infected people get better completely; it is not known why some people are successful at fighting off the infection. The rest remain infected, which means in these people the liver stays inflamed. Many will have mild inflammation only, which may never develop further. Others will go on to get cirrhosis, some 20, 30 or even 40 years after being infected.

**Chronic hepatitis C**

Hepatitis C is described as chronic when the infection lasts longer than six months. The liver remains inflamed and, over time, the inflammation damages the liver cells. The damage may be serious for some people, but for others it causes no problems. Unfortunately, the degree of liver injury bears little relationship to the severity of the symptoms. In most cases the infection will not be apparent for a long time. Doctors cannot predict who will or who will not go on to develop serious liver disease.

### Cirrhosis is...

Cirrhosis is the medical term describing excessive development of scar tissue (fibrosis) within a liver, irrespective of the underlying cause. Usually when the liver is acutely damaged, some of the liver cells die and the organ regenerates itself without scarring.

If a chronic or repeated disease process damages the liver, then scarring develops. This process usually starts slowly and progresses over many years without causing any symptoms. Eventually excess scar tissue builds up and this begins to interfere with some of the liver's vital functions. At this point, the liver is no longer able to regenerate itself sufficiently. Symptoms can develop at any stage, but usually occur relatively late on in the scarring process. Many of the symptoms are caused by the complications of cirrhosis when the liver is failing.

Cirrhosis is irreversible, although recent research has started to identify how cirrhosis occurs, leading to the possibility of developing new drugs to fight the process of scarring of the liver.

For more information, see the British Liver Trust leaflet [Cirrhosis](#) or go online at [www.britishlivertrust.org.uk/content/diseases/cirrhosis.asp](http://www.britishlivertrust.org.uk/content/diseases/cirrhosis.asp) (not currently available in Portuguese).

### Late effects of cirrhosis

#### Internal bleeding

Blood that comes from the intestines to feed the liver, before passing back into the general circulation, cannot get through the hardened liver. This obstruction to the flow of blood causes back pressure down the system, leading to enlarged (varicose) veins in the lining of the gullet and stomach because the blood is trying to find a way round the scarred liver. The varicose veins can burst, causing severe internal bleeding, which shows itself as vomited blood or altered blood in the stools (black, tarry bowel motions). Either of these symptoms must receive urgent medical treatment.

### Effects on the brain

The liver normally breaks down waste products that would otherwise affect the brain. With severe liver disease the liver cannot remove these waste products and they are carried by the blood to the brain. Symptoms can range from minor lapses in memory to slurred speech, confusion and unconsciousness. With treatment these effects can be reversed.

### Fluid retention

Severe liver disease alters the way the body handles fluid - excess water is retained in the body and may be obvious as swelling of the legs and/or the abdomen (due to fluid in the cavity which surrounds the bowel). The accumulation of fluid is called ascites.

### Liver cancer

In a few people liver cancer may develop as a late result of cirrhosis. Liver transplantation can be done when someone has developed primary liver cancer, so long as it has not progressed too far and beyond the liver to other sites in the body.

## How is hepatitis C passed on?

### Contact with blood

A tiny amount of blood - too small to be visible to the naked eye - from someone who has the virus, will transmit the infection if it gets into someone else's bloodstream, for example, through an open wound, cut or scratch.

Blood donations in the United Kingdom have been screened for hepatitis C since September 1991.

Some people who received blood or blood products before then may be infected, e.g. haemophiliacs (and pregnant women who received anti D as a treatment for rhesus incompatibility in the Republic of Ireland). Blood and blood products may not be screened for the virus in some overseas countries.

### Sex

Sexual transmission of hepatitis C is thought to be unusual, but probably does occasionally occur. Doctors are unsure whether the infection that occurs between partners is because of sexual exposure or because of other reasons, for example, sharing a personal item such as a toothbrush or razor.

People with more than one sexual partner are advised to use condoms, as there is some evidence that those with many sexual partners have an increased risk of being infected. Condoms may reduce the risk of infection, and all other sexually transmitted infections.

Naturally, couples are often worried about infecting each other, but when one partner is positive and the other negative after many years, it seems reasonable to advise that it is unnecessary to change to using condoms for protection.

Penetrative sex during a period is best avoided when a woman is hepatitis C positive.

### Normal social contact

Infection is not acquired through normal social contact, for example, from a cup or by touching an infected person. However, it is a sensible precaution if you are HCV positive to use your own personal items such as a nailbrush, scissors or razor and to be meticulous about cleaning up any blood, for example from cuts or scratches. Undiluted household bleach should be used to clean up blood from floors and work surfaces. Scratches, cuts and wounds should be carefully cleaned and covered with a waterproof dressing or plaster.

### Injecting drug use

Current evidence suggests that 50% - 80% of past and present users may be infected with hepatitis C. They become infected by sharing any equipment used in the process of injecting because it is likely to have invisible contamination with blood. Only one occasion of sharing injecting equipment is needed

to be exposed to the virus - and that may have been years previously. An increasing number of people, who injected a few times many years ago, are now being diagnosed as having hepatitis C. Recently there has been some concern about sharing straws for snorting cocaine because the practice may be a route of infection through nosebleeds. For more information on injecting drug use, please ask for a copy of the British Liver Trust booklet [Injecting Drug Use and Hepatitis C](#) (not currently available in Portuguese).

#### Acupuncture, tattoos, body piercing

A few people have become infected by unsterile needles being used for ear and body piercing, acupuncture and tattooing. The best way to protect yourself is to ensure disposable needles are used and that they come straight out of a sterile packet.

#### Saliva

The virus has been detected in saliva, but it is unlikely that it can be transmitted by kissing. It is advisable to reduce the possibility of infection by not using someone else's toothbrush and by maintaining good oral hygiene.

#### Mother to baby

The risk of a mother with hepatitis C infecting her baby during pregnancy or during the birth is about 6%. When it does occur, it is not known whether this is in the womb, during delivery or immediately after the birth, but it is not during conception. Babies are sometimes found to have antibodies to the virus, but these usually disappear by the time the baby is 12 to 18 months old, which shows that the antibodies are acquired from the mother and that the baby has never been infected with the virus.

Since the usual test is for antibodies, it may not be possible to determine if a baby is infected until it is over a year old, but there is a test for the virus itself ("PCR test") that may detect it in the first few months. Doctors do not yet know if the disease

that occurs when a baby is infected will go on to become serious.

Infected mothers are often concerned about passing the virus on to their other children. As long as all the precautions listed below are taken, household transmission is a low risk. Kissing and cuddling a child is safe.

#### Breastfeeding

Most doctors consider breastfeeding to be safe if the mother has no symptoms. In theory infection could be possible if a mother has cracked nipples that bleed and the baby has a cut in the mouth.

#### Unknown

In some cases doctors don't know how people became infected.

### Preventing infection

- clean up blood with undiluted household bleach from floors and work surfaces
- carefully clean cuts and wounds and cover with a waterproof dressing
- use your own toothbrush, razor, scissors and other personal items
- consider practicing safer sex if you have multiple partners
- if HCV positive, do not register as an organ donor or donate blood or semen
- ensure disposable sterile needles are used for acupuncture, tattooing, body or ear piercing
- use sterile injecting equipment including syringes, filters, spoons and water if you inject drugs - never share anything you use for injecting with anyone, whatever the circumstances
- wash your hands after any incident involving blood - yours or anyone else's
- wear rubber gloves if handling anyone else's blood or any articles that might be contaminated with blood.

## Tests

There are many different tests performed on people who are suspected of having hepatitis C infection or in whom hepatitis C is diagnosed. These are to help in the diagnosis of the disease, or as a means of following its progression, or to see the response to treatment.

### Blood tests

Hepatitis C antibodies are detected by a blood test. The test that is freely available, called an anti HCV test, looks for antibodies to hepatitis C that are produced by the body's immune system in response to the virus. This is not a test for the virus itself. There are several antibody tests which tell the doctor slightly different things.

A positive antibody test will usually be confirmed on the same sample by a second antibody test and then by a later test on another sample. A positive result, known as anti HCV positive, shows that a person has been exposed to the virus at some time. It does not detect whether the virus is still present or whether the person is infectious.

It may take a long time, sometimes a few months, for antibodies to appear in your blood after being infected. It is usually 8 to 12 weeks after exposure to the virus, but occasionally can be up to six months or more. This means that an antibody test taken too early may not detect hepatitis C.

If it is thought necessary by your specialist, there are other blood tests that may be taken to indicate a continuing infection ("PCR" or "viral RNA" test). A negative test for a continuing infection does not necessarily mean that the virus has disappeared. The virus may still be present elsewhere in the body, but not detectable in the blood.

As mentioned, these tests are not always conclusive and must be interpreted by your specialist.

### Liver function tests (LFTs)

Liver function tests (LFTs) are blood tests that measure substances in the bloodstream that indicate that the liver is damaged. However, they are not always good indicators of liver damage and do not detect the presence of the virus. LFT levels can fluctuate throughout the course of the disease. Sometimes they are normal, but this does not prove that liver damage is absent.

### Liver biopsy

The only way to assess the amount of liver damage is a liver biopsy (although a liver ultrasound may be useful). The biopsy involves taking a small sample of liver tissue for examination under a microscope. The test is usually performed under a local anaesthetic. A hollow fine needle is passed through the skin into the liver and a small piece of tissue is withdrawn inside the needle.

In most people the procedure is uncomfortable, but occasionally some people find it very uncomfortable. In many hospitals the procedure is performed as a day case, in others an overnight stay is necessary. The results of the biopsy are graded and staged according to the degree of inflammation and scarring.

### Strains of Hepatitis C

Hepatitis C virus is not a single type of virus. There are different genotypes ('strains') of hepatitis C with numerous subtypes. How common the different genotypes are varies from country to country. The most common in the UK, Europe and USA are types 1, 2 and 3. Subtypes are labelled a, b and c, etc.

It is possible to be infected again with a different genotype, or be infected with two genotypes at the same time. The different genotypes do not appear to result in different patterns of disease, but they do differ in their response to treatment; genotype 1 is the most resistant.

As a result of this, a test is usually performed to determine the genotype before treatment is advised. The results of the various tests can be confusing and require specialist interpretation. It is important that people who have hepatitis C are referred to a specialist who should be a hepatologist or a gastroenterologist with knowledge of liver disease.

### Treatment

Currently, hepatitis C is treated with a combination of two drugs, interferon and ribavirin. This is known as combination therapy. Previously interferon alpha was used on its own, but this treatment was only successful in a very small proportion of people. Now pegylated alpha interferons - a modified version of standard interferon alpha that results in a 'longer-acting' version - are available. It may work slightly differently in the body as a consequence. In treating hepatitis C, pegylated alpha interferons in combination with ribavirin will replace non-pegylated alpha interferon and ribavirin therapy.

Experience now shows that a combination of drugs improves the response rate. Response rates using pegylated alpha interferon plus ribavirin are in the order of 55% (with genotype one results of 45% and genotype two and three results of about 80%). For the few people unable to tolerate combination therapy, alpha interferon on its own is sometimes beneficial.

However, not everyone is considered suitable for treatment. Some people need only regular assessment to detect if damage to their liver is occurring or progressing. Factors such as age, gender, genotype of hepatitis C, duration of infection, degree of liver damage and whether cirrhosis has developed are important in deciding if treatment is likely to be effective.

#### Interferon is...

Interferon is a man-made drug that mimics the

naturally occurring interferon produced as part of your body's immune response to a viral infection.

The aim of the drug is to prevent the virus from multiplying and causing any further liver damage. A newer form of interferon alpha, known as pegylated, is now available, which in clinical trials of different types showed greater benefit, particularly when used in combination with ribavirin.

Non-pegylated interferon alpha is given by injection usually three times a week, with pegylated interferon injected once a week, for 6 to 12 months. People learn to inject themselves after being carefully trained, using a similar technique to that used to treat diabetes.

#### Ribavirin is...

Ribavirin is also a man-made drug used against a range of different viruses. For hepatitis C treatment it is used with interferon (non-pegylated or pegylated), never on its own. The drug is taken orally twice daily.

Whilst taking ribavirin, and for six months after stopping treatment, it is vitally important for both men and women to use contraception. This is because ribavirin may affect a child conceived whilst taking it.

#### Side effects of treatment

Both non-pegylated and pegylated alpha interferons and ribavirin produce side effects in most people, especially in the early stages of treatment, although the severity varies from person to person. Side-effects include 'flu-like symptoms, fatigue, headaches, nausea, anaemia and depression. Occasionally there may be other side effects. The 'flu-like symptoms can often be helped by taking paracetamol before and many people find that they feel better after a few weeks.

Some people who experience particularly bad effects may be unable to tolerate a full dose or a full course of treatment. Because of the range of

side effects, in particular anaemia, blood tests of various kinds are needed during treatment.

It is important that regular appointments at the clinic are kept so that side effects and progress can be carefully monitored. Being treated with this combination therapy requires significant commitment and support during the period that someone is receiving it.

Everyone with hepatitis C should be seen regularly by a specialist whether treatment is considered appropriate at present or not.

Hepatitis C is one of the most recently discovered hepatitis viruses and there are some aspects of the disease that are still not fully understood.

Regular assessment is needed to be able to take advantage of new research, to detect whether liver damage is occurring or progressing and to decide if treatment is appropriate.

### **Liver transplantation**

For some people with cirrhosis who develop life-threatening complications, liver transplantation is an option. In 60-80% of people who are desperately ill, this major surgical procedure is successful. The virus does infect the new liver and can sometimes cause severe disease after some years.

### **Complementary care**

Complementary care means care that is complementary (additional) to orthodox medical treatment. Many people with hepatitis C consider complementary care in addition to orthodox medical treatment. There are many forms of complementary care such as massage, aromatherapy, reflexology, t'ai chi and meditation that people find helpful in the relief of symptoms such as tiredness and muscle aches.

These therapies help by relaxing your mind and body and by enhancing a sense of well-being.

Traditional Chinese medicine, acupuncture and medical herbalism, are other therapies that are sometimes considered by people who have hepatitis C. If you are thinking of considering complementary treatment as part of your health care, it is important to consider the benefits and risks. Not all complementary therapies are safe or effective, as is the same for orthodox medical treatment. Make sure your complementary practitioner is registered with an accredited body and is knowledgeable about hepatitis C.

Information about complementary care can be obtained from the organisations listed at the end of the leaflet.

### Diet

People with hepatitis C often ask if they should follow a special diet. For most, particularly those who are well, the answer is no. Just like anybody else, they should simply eat a well balanced diet with everything in moderation and no excesses. This means eating regular meals, including plenty of fruit and vegetables and avoiding excessive fatty and sugary meals. Also, most people need two portions of food a day which provide a good source of protein such as meat, poultry, fish, eggs, nuts, pulses, beans, cheese, milk and milk products.

Eating a variety of foods will help to ensure that meals are enjoyable as well as providing an adequate supply of vitamins and minerals. Vitamin supplements are not required by most people who are eating well, but if you are concerned, ask your doctor for guidance.

People experiencing symptoms from hepatitis C many need further advice to help them to eat well. Additional information about coping with loss of appetite and sickness are given in the British Liver Trust leaflet [Diet and Liver Disease](#) or online at [www.britishlivertrust.org.uk/content/liver/diet.asp](http://www.britishlivertrust.org.uk/content/liver/diet.asp) (not currently available in Portuguese).

If you are still concerned, ask your doctor who may refer you to a State Registered Dietician for individual advice.

### Alcohol

Ideally, anybody with hepatitis C should drink no or as minimal an amount of alcohol as possible; certainly within the recommended amount of alcohol (21 units per week for men and 14 for women). More information can be found in the British liver Trust leaflet [Alcohol and Liver Disease](#) or visit [www.britishlivertrust.org.uk/content/diseases/alcohol.asp](http://www.britishlivertrust.org.uk/content/diseases/alcohol.asp) (not currently available in Portuguese).

### Issues to consider pre-testing

If you are thinking of having a test for hepatitis C, there are some issues you may like to think about. It is best to discuss your concerns with a professional, such as your doctor, counsellor or drug worker. Also, there are clinical nurse specialists, based at some hospitals, who are trained to help people cope with hepatitis and its symptoms.

#### Insurance/mortgages

Most insurance companies ask applicants if they have been tested for HIV, hepatitis B and hepatitis C. A positive test result may mean a life insurance policy or a mortgage linked to a life policy could be refused or the premium loaded. If this happens, it is worth talking to your doctor as many consultants are willing to write to a mortgage or insurance company stating your health and life expectancy.

#### Who to tell

This is often a difficult decision. A positive result may affect the person's family and sexual partner(s). These affected people might like to consider being tested. It is worth bearing in mind that there is still a level of ignorance about the disease in the general public. There have been cases in which people have lost their jobs, been refused medical and dental treatment and children stigmatised at school. It

should always be possible to arrange for medical and dental treatment elsewhere if this happens. Simple protective measures are enough to protect healthcare workers and contacts from infection.

### Confidentiality

Confidentiality is often a concern. Most drug agencies and GUM (genito-urinary medicine) clinics offer a confidential testing service.

However, if a GP performs a test, the results will be recorded and the doctor may be obliged to divulge the information if asked, e.g. for a medical examination for a job or insurance.

### Words connected with hepatitis C

**Antibodies** - specific substances produced by the body for the purpose of neutralising a foreign substance, as part of a defence reaction

**Ascites** - large accumulation of fluid in the cavity which surrounds the bowel

**ELISA** (Enzyme Linked Immunosorbent Assay) - this describes a laboratory method used for testing antibodies

**Encephalopathy** - disturbance of the function of the brain

**Enzyme** - a substance produced by the body to do a chemical job of work (measured with liver function tests)

**Gastroenterologist** - a specialist in diseases of the gullet, stomach and bowel who has training in liver diseases

**HCV** - Hepatitis C Virus

**Hepatologist** - a specialist in liver diseases

**Jaundice** - a condition in which the whites of the eyes go yellow and in more severe cases the skin also turns yellow. This is caused by the yellow pigment (bilirubin) that is normally disposed of by the liver

**ME (Myalgic Encephalomyelitis)** - also known as chronic fatigue syndrome: a condition in which the person feels always tired without a clear cut medical reason

**Oesophageal varices** - varicose veins in the gullet

**PCR (Polymerase Chain Reaction)** - refers to a laboratory method used to test for the actual virus

**RIBA (Recombinant Immunoblot Assay)** - this describes a laboratory method for testing for antibodies

**Seroconversion** - a change in the blood test so that something related to the virus (which may be an antigen, antibody or the virus itself) appears

**T'ai chi** - a soft, slow, gentle form of exercise which can be practised by people of all ages, developed in China thousands of years ago

**TCM** - Traditional Chinese Medicine or Chinese herbal medicine that has been used by many people with hepatitis to improve or control symptoms

**Viral load** - the amount of virus in the blood

### Complementary care organisations

#### British Complementary Medicine Association

Tel: 01242 519911

Email: [info@bcma.co.uk](mailto:info@bcma.co.uk)

Website: [www.bcma.co.uk](http://www.bcma.co.uk)

#### British Holistic Medical Association

Tel: 01273 725951

Email: [bhma@bhma.org](mailto:bhma@bhma.org)

Website: [www.bhma.org](http://www.bhma.org)

Founded by doctors, provides telephone or written information on all aspects of holistic healthcare.

**For more information about Hepatitis C, or to get a test or a Hepatitis B vaccination, contact your GP or local drug and alcohol service:**

**Community Alcohol and Drugs Service (CADS)**

North House  
Goodwins Roads  
King's Lynn, PE30 5PD  
Telephone: 01553 815171

**Trust Alcohol and Drug Service**

Bure Centre  
7 Unthank Road  
Norwich, NR2 2PA  
Telephone: 01603 671900

**West Suffolk Drug and Alcohol Service (WSDAS)**

Breckland House  
St Nicholas Street  
Thetford, IP24 1BT  
Telephone: 01284 775275

The three services above are part of the **Norfolk Needle and Syringe Exchange Scheme** which aims to provide clean injecting equipment to intravenous drug users in an effort to stop the possible spread of blood borne viruses such as Hepatitis C and HIV. For a full list of needle exchange outlets please visit the Norfolk Drug and Alcohol Action Team website at [www.nordat.org.uk](http://www.nordat.org.uk)

If you would like to order copies of this booklet in Portuguese, please contact the Health Information Leaflet Service on 01603 307208 or order from the on-line catalogue at [www.heron.nhs.uk](http://www.heron.nhs.uk)

Copies of the booklet in both English and Portuguese can also be downloaded from the Norfolk Drug and Alcohol ActionTeam (DAAT) website at [www.nordat.org.uk](http://www.nordat.org.uk)

## **INTRAN**

If you would like this booklet in large print, audio, Braille, alternative format or in a different language please contact the Health Information Team on 01603 307416 and we will do our best to help.



**Norfolk Drug and Alcohol Action Team**  
This logo represents all the partner agencies of the DAAT:

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Police, Health, Prison Service,  
Youth Offending Teams,  
Connexions, Local Authorities  
and Norfolk Drug and Alcohol  
Treatment Providers.*



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**[www.nordat.org.uk](http://www.nordat.org.uk)**

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