

# Information about **hepatitis C** for patients and carers

## What is hepatitis C?

Hepatitis C is an illness caused by a virus which can be passed through blood from one person to another. It mainly affects the liver, causing swelling (inflammation) and scarring (fibrosis and cirrhosis), sometimes leading to cancer of the liver (hepatocellular carcinoma). You can have the hepatitis C virus for 20 to 30 years before the liver is seriously damaged and symptoms begin to show. A liver transplant may be an option for people who develop advanced liver disease.

## How does it affect people?

It is a potentially life-threatening condition that can affect you physically and emotionally. It can affect your quality of life. Treatment is available which can cure hepatitis C in many cases.

## What are the symptoms of hepatitis C?

Some people have no symptoms at all for many years while others may feel extreme tiredness, have sweats (especially at night), aches and pains, loss of appetite and concentration problems. People may even be thought to have myalgic encephalomyelitis (**ME**) or chronic fatigue syndrome. Symptoms may come and go. In the later stages of the infection when the liver is more seriously damaged, there may be symptoms such as jaundice, itchiness and a swollen abdomen.

## Have I been at risk?

Risk factors where blood from someone infected with hepatitis C may get into the bloodstream of another person include:

- injecting or snorting drugs while sharing any equipment;
- sharing items such as razors, toothbrushes or any item that can scratch the skin;
- piercing or tattooing if any equipment is reused;
- sexual activity, although the risk is low except where there is a risk of bleeding;
- being exposed to blood at work, for example, a needlestick injury, cuts, cleaning up blood, and dealing with violent incidents where blood is involved;
- transmission from mother to child around the time of birth (this is quite rare and happens about five times in 100);
- receiving a blood transfusion or surgical treatment abroad or in the UK before 1991, or blood products in the UK before about 1987 (transfusions and blood products are now safe from HCV infection in the UK); and
- receiving medical or dental treatment in countries where hepatitis C is common and infection control may be poor.

## Should I be tested?

You should have a pre-test consultation with a health professional if you are considering having a test. **This is very important so that you are well informed before deciding on a test. Ask yourself whether you could cope with a positive result at this time.**

## What does the test tell you about being positive or negative?

There are two types of test. The first type of test (HCV antibody test) tells you if you have ever had the virus (some people get rid of the virus naturally without medical help) while the second type (PCR test) tells you if you still have the virus in your body (infected with hepatitis C).

## What about confidentiality?

If you go to your GP for a test, in certain circumstances they may be asked to give the test result to others, for example, insurance companies or mortgage lenders. This information should not be given out without your permission. You can have an anonymous test elsewhere, such as genitourinary medicine (GUM) clinics, some liver clinics, other community settings (see the UK Hepatitis Services Directory for more information, [www.hepccentre.org.uk/tools](http://www.hepccentre.org.uk/tools)).

## Are my family and friends at risk? Should I tell them?

The support of family and friends is crucial, but it is important to tell only people you are sure you can trust with the information. To avoid infecting others, do not share household items such as toothbrushes or razors. Consider using condoms for sexual intercourse.

## How will it affect my job or my job prospects?

Many people with hepatitis C remain well enough to work but you may have to learn to listen to your body and pace yourself if you are suffering from extreme tiredness or other symptoms. You do not usually have to tell your employer that you have HCV. Side effects of treatment may mean that you feel ill and not able to work for a period of time. Depending on your employer, it may be helpful to tell them that you are having treatment. For example, they may support you by changing your working hours or any physical activities associated with your job during the treatment period.

## How will it affect my life insurance cover?

If you are diagnosed with hepatitis C, you will still be able to take out life insurance but it may be more expensive. Your medical history, symptoms, liver function and treatments will be assessed to work out what premium rate you will need to pay. If you have insurance already, you should tell your insurance company about your diagnosis. If you do not give accurate information about your health on an insurance application form, any claims you make are likely to be refused and the policy will not be valid.

## What happens during testing?

If you decide to go ahead with testing, you will be asked to give blood samples which will be sent to a laboratory for testing. Anyone who has recently been exposed to hepatitis C will need to repeat the test to make sure any negative result is accurate. This is because there is a 'window period' immediately after exposure until the test becomes positive.

If you are not infected, the healthcare team will explain how to take precautions so you don't put yourself at risk again. If you do have hepatitis C, they will explain what this means and refer you to a specialist clinic for more help and liver assessment.

To find out how your liver is being affected by hepatitis C, you will need to go to a specialist clinic. Assessment will include blood tests such as liver function tests (LFT), a genotype (strain of hepatitis C virus) test, an examination, discussions about lifestyle, other medical conditions and medicines you take, ultrasound scan, and possibly a liver biopsy. A liver biopsy means taking a small piece of the liver for laboratory analysis. This is done under local anaesthetic.

## What happens during treatment?

When these results are available, your doctor and nurse will be able to discuss treatment with you. The treatment involves an injection of a drug called pegylated interferon once a week, and ribavirin capsules or tablets taken every morning and night. Treatment lasts for either six months or a year. You will be given lots of information and advice to help you through the treatment.

Treatment is not suitable for everyone and depends on other medical conditions or complications. Avoid pregnancy while you or your partner is on treatment, and for seven to 12 months afterwards, because these drugs may be harmful to an unborn baby.

Treatment can be very effective but the drugs can have side effects. These can be managed with appropriate care and support. Your clinic should help you to access support as part of your care while on treatment. You will be expected to avoid alcohol or drugs (except prescribed drugs) for the whole time you are on treatment.