

Hepatitis C Information Pack

The information in this pack is designed to give an overview of hepatitis C. It is not intended to be taken as medical advice and therefore we advocate that all those found to be positive should be referred to a consultant by their GP for assessment, further diagnosis and treatment of hepatitis C. Please also note that although we can answer general queries via the advice line or email, it would be inappropriate or unsafe for us to give individualised advice without full medical assessment. For individual medical questions please refer back to your medical team.

What is hepatitis?

The term 'Hepatitis', means inflammation of the Liver. This can be caused by alcohol, autoimmune disease (when the body's own defences attack healthy body tissues), specific liver diseases or viruses.

Hepatitis C

Hepatitis C (HCV) is a virus which was discovered in 1989 but a blood test to diagnose it was not developed until 1991.

It is estimated that approximately 0.5 % of the UK's population are infected with hepatitis C. That's about 250,000-400,000 people. Worldwide there are estimated to be 170 million people chronically infected with the hepatitis C virus.

About 10% of those infected will go on to develop serious liver damage after 20 to 30 years. The virus infects the liver; the body's immune system tries to fight off the infection and causes inflammation in the liver as a result. This inflammation can lead to fibrosis (scarring) of the liver tissue and in some cases may cause the development of **cirrhosis**. However this process may take up to 20 or 30 years in some individuals. Those who develop cirrhosis are at risk of developing liver cancer and or liver failure which may require a liver transplant.

How is hepatitis C passed on?

Hepatitis C is a blood borne virus which is passed on via blood to blood contact. Most people will not have symptoms at the time of infection and therefore won't realise they have been infected. If symptoms are experienced it may be in the form of a short flu-like illness including jaundice (yellow skin).

- Many people have become infected by receiving blood transfusions or blood products (e.g. haemophiliacs), before adequate blood screening was introduced in 1991. Blood transfusion in this country is now safe; however this may not be the case in the developing world where adequate screening procedures are absent or there is poor sterilisation of medical equipment which comes into contact with blood e.g. renal dialysis.
- The most common route of transmission is via sharing of needles and syringes and injecting drug paraphernalia. This means that anyone who has ever injected drugs-even if only once- is at risk of being chronically infected with hepatitis C.
- Tattooing, body piercing or any invasive procedure where inadequate sterilisation occurred may have put individuals at risk.
- Healthcare workers may be at risk through needle-stick injuries in their place of work.
- The risk of the virus being passed on through sexual contact is thought to be very low, at only about 3% risk for the duration of the sexual partnership, but many experts still dispute whether this occurs.
- A mother may pass the virus on to her baby but again the risk is very low at about 5%. This is called vertical transmission. Breast feeding is thought to be safe provided bleeding does not occur from chapped nipples.
- Other risks are thought to be sharing of straws when snorting cocaine, or through sharing of household items such as razors and toothbrushes.
- There are some people who have become infected and the route of transmission remains unknown.

Vaccine

There is no vaccine available for hepatitis C although there is ongoing research into this. Due to the ability of the virus to mutate and the different strains of the virus, this has proved difficult to develop.

This is not to be confused with hepatitis A & B (HAV & HBV) which do have vaccines. HAV is spread through infected food or water and people who are infected recover completely after a short illness. HBV is also a blood borne virus which is transmitted in a similar ways to HCV ...but much higher risk of sexual transmission.

Preventing hepatitis C infection

Sharing of any injecting equipment (including spoons and filters) must be avoided at all times.

Ensure any invasive procedures (such as acupuncture) are carried out using disposable or sterilised equipment.

Do not share household items such as toothbrushes, razors, nail files or clippers if blood may be present.

Clean up blood spillages with household bleach and wear gloves if possible.

As sexual transmission is considered to be low risk, it is not usually recommended for long term sexual partners to change their practices but both partners need to discuss if they are concerned about the risks, and make informed choices. For new sexual partners, safer sex should always be practiced to ensure protection against other infections as well as the low risk of contracting hepatitis C.

Hepatitis C cannot be transmitted by touching, sneezing, kissing, hugging or by sharing eating utensils or drinking from the same cup.

Normal detergent washing for cleaning of these items is ample.

Symptoms of hepatitis C

Not everyone with chronic hepatitis C infection experiences symptoms, and in those that do experience symptoms they can be vague and non-specific which often means that people go undiagnosed.

The most common symptoms are fatigue, joint pains, pains in your liver, irritable bowel symptoms, headaches, brain fog or memory loss and lack of concentration, depression, mood swings, itching, night sweats and loss of appetite.

However this list is not intended to be absolute as there may be other symptoms that people experience and which may be linked with hepatitis C.

Viral Tests

Hepatitis C is diagnosed by a blood test which you must be asked to consent for. You should always be offered pre and post test discussion or consultation to ensure that you are provided with the right information, in order to help you make the decision whether to be tested at that time.

Confidential testing is usually available through GUM (Genitourinary Medicine) clinics and GP's and some drug services are also able to provide testing.

The first test which is usually performed is an **antibody test**. This is a blood test which will determine whether you have ever been exposed to the hepatitis C virus. Not all individuals will develop chronic infection with the virus as about 15% of people will get over the infection. We do not yet know why some peoples immune systems are able to do this.

If the **antibody test** is positive this means that at some time you have been exposed to hepatitis C and a further blood test is required to see if you have chronic (ongoing) infection. This

is called a **PCR (Polymerase Chain Reaction) or HCV RNA test**. This test will confirm whether you actually have hepatitis C. The test result is either Positive or Negative. If the test is negative this should be re-checked at least once, as sometimes if the levels of virus in the blood are very low, the test may not pick it up. Also, if you may have been exposed recently (in approximately the past 6 months) to the virus, the test may not show this until later.

There is another test which can show the amount of virus present in your blood, called **Viral Load** test but this is not always routinely available. This may be due to the expense but also because the significance of the test was not agreed until more recently. This test can now be used to assess the response to treatment.

There are different strains of the hepatitis virus which have been identified. These are called **Genotypes** and types 1, 2 & 3 are common in the UK and types 4, 5 & 6 in other parts of the world. There are also subtypes e.g. type 1a or 1b. The significance of the genotype is that some respond better to treatments. Genotype testing should be done prior to starting treatment to plan the length of treatment.

Other Tests

For some people, the reason the doctor has suggested a blood test for hepatitis C may have been that the **Liver Function tests (LFT's)** were already found to be abnormal. **LFT's** (ALT and AST or Alanine Aminotransferase and Aspartate Transferase) are a measurement of enzymes produced in response to inflammation, and are used as a rough guide of the level of inflammation present. In hepatitis C the LFT's will often fluctuate between normal and abnormal. If the tests are high one month and low the next month this does not mean that there has been a fundamental change in the condition of the liver, these tests results do go up and down, and this is expected in someone with hepatitis C.

Further tests which may be done are **Liver Ultrasound** which gives information about the size, shape and texture of the liver, and a **Liver Biopsy**. This involves a small piece of liver being taken out through the skin by a needle, using a local anaesthetic, then this is looked at under a microscope, and the level of scarring, if any, and ongoing inflammation in the liver tissue is assessed. The risk of serious complications such as bleeding after this procedure are very low, (1 in 10000) but you will be kept on bed rest for at least 6 hours after the procedure to minimise this risk. You should also be given painkillers as this can be a painful procedure.

Alcohol

Many studies have shown that if you drink alcohol when you have hepatitis C that liver disease will develop much more rapidly. Therefore this is the most important thing someone with hepatitis C can do:

Either stop drinking alcohol, or if you can't or don't want to stop, reduce alcohol intake as much as possible.

You may be able to access specialist help for alcohol issues if you need this via your GP.

Treatment for chronic hepatitis C

History & update

Interferon

Interferon is a protein which occurs naturally in the body and plays a part in fighting off infections. Interferon alpha has been used since the mid 1980's to treat nonA/non BHepatitis (which was later found to be caused in most cases by chronic

hepatitis C infection). The success rate or Sustained Virological Response (SVR) was low at around 15-25%, and this treatment was licensed in the early 1990's. There are two main versions of interferon called Viraferon (Interferon alpha 2b) and Roferon (Interferon alpha 2a), both licensed for hepatitis C.

How is Interferon taken?

Interferon is taken by injection subcutaneously (into the fat under the skin similar to the type of injection a diabetic would take) in the stomach or top of leg three times per week, and has a number of significant **side effects**.

Treatment is usually taken for 6 or 12 months depending on the genotype you have.

Side effects

Most commonly experienced are flu-like symptoms and chills -especially after dosing- tiredness or fatigue, headaches, nausea, loss of appetite and muscle aches and pains. The symptoms vary considerably during treatment from person to person, but many people are advised by their doctor or nurse specialist to take 2 tablets of Paracetamol which often helps. Always check with your medical team before self medicating. The side-effects are usually worse at the very beginning of treatment, and then become less severe as your body becomes used to the interferon. There are other side effects which may also occur later into treatment, such as mood changes, hair loss, or even depression. Rarely, thyroid problems (either under or over active thyroid) may occur, but this is usually reversible. Your medical team should provide you with strategies for coping with, and reducing certain side effects.

You or a family member/partner will be taught how to give yourself the injections by the nurse. You should be monitored very carefully and frequently by your doctor and nurse while you are on Interferon treatment and after stopping. They will check your tolerance, side-effects and response to the treatment and blood tests are performed regularly as part of this assessment. Occasionally the dose of your medication may need to be altered if your blood counts drop.

If unsure about any aspect of your treatment always refer back to your medical team.

Combination Treatment

In 1999 treatment results were improved to around 40% when a drug called **Ribavirin** (Rebetol) was licensed (a nucleoside analogue). This is taken every day in tablet form alongside the Interferon injections and is known as **combination therapy**. However the side effects are often much worse with the addition of Ribavirin and it commonly causes anaemia.

Pegylated Interferon

The latest form of interferon now available is called **Pegylated Interferon**. This newer treatment is now also licensed to be taken in combination with Ribavirin. Pegylated Interferon plus Ribavirin has shown much better sustained response rates at over 50% which is an obvious improvement, but patients should discuss their individual case with their clinician. It is taken by injection like standard Interferon but the difference is that it is only taken once per week. This is because it has been made to act by slow release and stays in the body for longer, therefore the results are better. The side-effects although not so much of a 'roller-coaster' experience as with the three times a week dosing, unfortunately are still quite significant, but there is definite convenience of only having to self inject every 7 days. There

have been reports of an increase in skin problems and depression occurring. There are two licensed versions of Pegylated interferon; called Viraferon Peg (Pegylated Interferon Alpha 2b) and Pegasys (Pegylated Interferon Alpha 2a).

Complementary or Alternative Treatments

Not surprisingly due to the side-effects and length of conventional treatment, some people with chronic hepatitis C infection prefer to use Alternative or Complementary treatments to try to manage their illness. Therapies used can be varied such as Traditional Chinese Medicine, Herbal supplements, Acupuncture, Massage, Aromatherapy, Meditation, Reiki Healing, vitamins/dietary supplements as well as changing lifestyle factors, such as diet, stress levels and routines.

While many people do claim benefits from these therapies and changes in lifestyle, it is important to remember that there has not been enough adequate research yet conducted to show that any of these treatments will actually cure hepatitis C. Therefore you may help yourself to feel better and cope more easily with side effects and symptoms, which is an obvious benefit, but without affecting the virus.

Also remember that stringent regulations which prevent just anyone from practicing Alternative to Complimentary therapies are not in place in the UK, and **that some herbs may actually be harmful or dangerous to the liver.**

So please always ensure that you tell any potential practitioner about your liver condition and check with your doctor first.

If you are on conventional treatments, there may be interactions which we do not yet know about, so your doctor must be aware of all treatments you are taking.

Diet and hepatitis C

There is not a specific diet that is recommended for someone with hepatitis C, other than a normal healthy diet recommended for everyone. However some people may find that they have intolerance to certain foods or that a particular diet helps their symptoms. Some alternative and complementary therapies advise special diets for someone with hepatitis C, but the benefits of these are as yet uncertain. Do what feels right for you.

Other Conditions which May occur with hepatitis C

- Sjogrens Syndrome(excessively dry eyes and mouth)
- Diabetes
- Lichen Planus (a skin/gum disorder)
- Lymphoma
- Cryoglobulinaemia (immunoglobulin disorder)
- Arthritis
- Glomerulonephritis (a kidney disorder)

If you think you may have symptoms relating to any of these conditions, or you require further information on the specifics, please discuss this with your Doctor and this can be investigated.

HIV/HCV/HBV Co-infection

Co-infection with HIV/HCV and also HCV/HBV is fast becoming a big issue for patients and clinicians alike. A lot more research is required to fully understand the issues and natural history of co-infection, but we do know that two viruses tend to exacerbate each other, and that treatment decisions and management of the illnesses become extremely complex. Anyone with co-infection should be seen by a specialist with knowledge of both viruses or good referral and communication between both specialists.

Other Resources

British Liver Trust

Portman House
44 High Street
Ringwood BH24 1AG
T: 01425 463080
F: 01425 470706
E: info@britishlivertrust.org.uk
W: <http://www.britishlivertrust.org.uk>

Children's Liver Disease Foundation

36 Great Charles Street,
Birmingham, B3 3JY
T: 0121 212 3839
F: 0121 212 4300
E: info@childliverdisease.org
W: <http://www.childliverdisease.org>

Department of Health (England) National Hepatitis C Information line

T: 0800 451451
Text phone: 0800 0850859

The Eddystone Trust

36 Looe Street
Bretonside
Plymouth PL4 0EB
T: 01752 257077
F: 01752 252093
E: info@eddystone.org.uk
W: <http://www.eddystone.org.uk>

The Haemophilia Society

First Floor
Petersham House
57a Hatton Garden
LONDON EC1N 8JG
T: 020 7831 1020
F: 020 7405 4824
E: info@haemophilia.org.uk
W: <http://www.haemophilia.org.uk>
Helpline: 0800 018 6068

The Hepatitis C Trust

27 Crosby Row
London SE1 3YD
T: 020 7089 6220
F: 020 7089 6201
E: info@hepcctrust.org.uk
Helpline: 0870 2001200

PLUS VE

40 Springfield Gardens,
Ruislip,
Middlesex HA4 9TX
T: 020 8868 1441
F: 020 8868 1211
W: www.plusve.org

Other Useful Web Sites

World Health Organisation:
Health Protection Agency (England & Wales)
Health Protection Scotland (HPS):
CDSCNI (Northern Ireland):
Scottish Executive Health & Community Care:
Department of Health (England):
FACE IT Campaign web site (England):

www.who.int/mediacentre/factsheets/fs164/en
www.hpa.org.uk
www.hps.scot.nhs.uk
www.cdscni.org.uk
www.scotland.gov.uk/Topics/Health
www.dh.gov.uk
www.hepc.nhs.uk

The UK Hepatitis C Resource Centre

www.hepccentre.org.uk

276 Bath St,
Glasgow G2 4JR
T: 0141 353 6969
F: 0141 331 2552

17 Academy St,
Edinburgh EH6 7EE
T: 0131 478 7929
F: 0131 478 7928

295 New Kent Road
London SE1 4AG
T: 020 7378 5495
F: 020 7378 5489

UK Hepatitis C Information Line

0870 242 2467

info@hepccentre.org.uk