



## HEPATITIS

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CARING FOR PEOPLE WITH HAEMOPHILIA ...

Revised 1993

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### Please note

*The medical information in this leaflet has been checked with medical experts in the UK during April 1993.*

*It should be noted that the publication is intended to provide basic information about hepatitis for people with bleeding disorders and that it should not be regarded as a substitute for the personal advice and information available from Haemophilia Centre Directors or other relevant medical staff.*

**PLEASE CONSULT YOUR HAEMOPHILIA CENTRE FOR  
MORE DETAILED PERSONAL ADVICE AND  
INFORMATION**

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### What is hepatitis and how is it caused?

*Hepatitis is an inflammation of the liver. This is detected in most people by changes in the liver enzymes in the blood. In the vast majority of cases the liver continues to function properly making the proteins, including coagulation proteins, that it normally produces. At present hepatitis C is a cause for concern for people who received treatment with clotting factor concentrates before 1988. Since 1988 the risk that blood products could transmit hepatitis has been minimised. Therefore, those only treated after 1988 should be safe from infection with this virus.*

*In people with haemophilia and other bleeding disorders hepatitis is usually caused by viral infection. A number of viruses have been identified as causes of hepatitis. These viruses are called hepatitis A, hepatitis B, hepatitis C or hepatitis D. Hepatitis B and C can definitely be carried in blood products, and recent evidence indicates that there is a possibility that the A virus may also be transmitted in this way. Recently the Regional Centre Directors' Organisation has recommended that vaccination against hepatitis A should be offered to all people with haemophilia and related bleeding disorders who have not been exposed previously to hepatitis A.*

*Hepatitis in patients with bleeding disorders is most usually caused by the hepatitis C virus, although it is sometimes caused by the hepatitis B or D virus. Hepatitis B causes 5 - 10 % of the liver disease found in people with haemophilia. In the UK the figure is lower than this.*

*The hepatitis D virus is a defective virus and is only found in people who have been infected with the hepatitis B virus. In a few cases it can be serious. If you are protected against infection with hepatitis B you will also be protected against hepatitis D.*

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## How is hepatitis C infection spread?

*This virus has been transmitted in blood products in the past and some evidence now exists indicating that it can be transmitted, albeit rarely, sexually. Because this risk exists use of a condom during sexual intercourse is recommended for some people who have been infected with the hepatitis C virus. It is most important that you should discuss this with your Centre Director.*

*It was first cloned in 1989 and before this it was known as non A non B hepatitis. It is responsible for more than 90% of cases of hepatitis caused by infected blood or blood products.*

## What will happen to me if I have been infected with hepatitis C?

*Many of those with hepatitis C have a mild form of hepatitis that is unlikely to give problems. All people who have received unsterilised blood product can be assumed to have been exposed to the C virus and in most cases the virus is present in the body. 90% of people with haemophilia, in different populations around the world, show a positive test result for hepatitis C virus (HCV) antibodies.*

*Current opinion is that 40% of those people with haemophilia who have hepatitis C virus may develop chronic liver disease. This means that they will have abnormalities in their blood test but for most people their liver will function well and they will feel well.*

*In some people chronic liver disease may become a serious matter which could, potentially, lead to liver failure. One potentially serious form of liver disease is cirrhosis. In the majority of cases progression is slow, over decades.*

*Detection of cirrhosis may be difficult in people with haemophilia because a liver biopsy may be required and this may lead to serious complications. Hepatitis C virus can also cause liver cancer but this is rare and takes many years to develop.*

## Vaccination and treatment for hepatitis C

*There is good evidence that Interferon may be of value in selected patients. It is a naturally occurring material which can be produced commercially. Injection of Interferon three times a week improves liver function in about 50% of patients but it has to be given for 6 - 12 months for benefit to be seen and may be required for life. If treatment with Interferon is stopped about half of those whose liver function improved will relapse!*

*Clinical trials of Interferon are in progress and the Working Group on Chronic Liver Disease and Haemophilia has recommended that people with haemophilia who have chronic hepatitis C should be offered Interferon on the basis of clinical trial. They do not recommend Interferon for people with auto-immune chronic active hepatitis or uncomplicated cirrhosis. Trials are needed to establish the dosage, frequency and length of treatment. Side effects consist of flu-like symptoms in some patients.*

*The Centre Directors Working Party on Chronic Liver Disease in Haemophilia is surveying all Haemophilia Centre Directors to find out what is happening at present. At present there is no vaccine against hepatitis C. However a vaccine against hepatitis C would be very valuable and research to produce one continues.*

*Testing blood donations for hepatitis C began in September 1991. The Blood Transfusion Service screens blood donors and those people infected with hepatitis viruses are excluded.*

## Testing of sexual partners

*The testing of sexual partners for the hepatitis C virus should be available to anyone who is hepatitis C virus positive (HCV+). It is important that you should discuss this with your Centre Director if you are HCV+.*

## How is hepatitis B infection spread?

*The hepatitis B virus is found in blood, saliva and semen. It has been transmitted to people with bleeding disorders in blood products. It can be transmitted from mother to child through the placenta and between individuals by sexual contact. All blood spills should be cleaned up promptly and carefully. Infection with hepatitis B is preventable and it rarely gives rise to long term (chronic) problems.*

## What will happen to me if I have been infected with hepatitis B?

*People can be affected by the hepatitis B virus in very different ways. In most cases the infection causes acute hepatitis and usually the symptoms are very mild. Most people (about 75%) have no symptoms or may feel tired or depressed. People in this group are infectious even though they have no symptoms.*

*About 25% of adults suffer from jaundice which may last between 1 - 4 weeks and sometimes as long as six months. The recovery period can take as long as another six months. Very rarely liver failure can happen in the absence of jaundice in this group of people.*

*About 95% of healthy adults who become infected do not have the virus in their blood after six months, they are not infectious after six months and should not suffer further problems.*

*Approximately 5% of healthy adults will become chronic carriers of hepatitis B; they continue to have the virus in their blood six months after infection. All those in this group are infectious and liver disease may progress in one of two ways.*

*Firstly the patient may have Chronic Persistent hepatitis. This is a very mild type of chronic hepatitis. There are no symptoms but the person is infectious. Secondly some people with Chronic Persistent hepatitis may develop Chronic Active hepatitis.*

*In this case liver damage is progressive and may lead to cirrhosis. Rarely hepatic cancer may also develop in chronic carriers many years after infection.*

*If children are infected they are more likely than adults to become chronic carriers of hepatitis B.*

## Vaccination for hepatitis B

*All people who are treated with clotting factor concentrates should be vaccinated against hepatitis B unless their blood already contains antibodies against the virus. In this case they already have immunity against the hepatitis virus. Antibodies occur in those who have received large amounts of unsterilised blood products containing the B virus in the past.*

*The vaccine is safe and has a high success rate although the success rate of vaccination is lower amongst those who are HIV+. The Haemophilia Centre Directors' Organisation is concerned to ensure that all people with haemophilia are vaccinated.*

### It is generally agreed that:

- ~ newly diagnosed children who are likely to be exposed to blood products should be vaccinated as soon as possible, usually as soon as they are born;*
- ~ partners of those who have chronic hepatitis B (carriers of the virus) should either be vaccinated or use condoms;*
- ~ the vaccine should be given to all who handle needles or glassware contaminated with blood products;*

*Vaccination against hepatitis B may become, in the future, a standard childhood procedure for the whole population.*

*Blood donations have been tested for hepatitis B since the early 1970s. The Blood Transfusion Service selects blood donors and people who might pass on hepatitis viruses are excluded.*

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## How can infection with hepatitis B or C be prevented?

*Since 1986 clotting factor concentrates have been treated to inactivate viruses. There is now a large body of evidence indicating that viral inactivation is effective in currently available concentrates.*

*Viral inactivation through solvent detergent or heat treatment should ensure that hepatitis B does not occur in people with haemophilia who have only received treated factor VIII or IX since 1988.*

*Since 1988 blood products have not transmitted hepatitis C viruses and those who have only been treated since that time should be safe from infection with this virus. However it cannot be stated with absolute certainty that all blood products are safe in this respect and it is important those people with haemophilia should attend clinics regularly.*

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## How can I find out if I have been infected with a hepatitis virus?

*Tests are available to find out if a person has been infected with hepatitis A, B or C. Your Centre Director may ask you if you wish to have such tests carried out on a sample of your blood and you may ask your Centre Director to discuss with you whether or not tests should be carried out. Many people with haemophilia will already know if the tests have been done, in many Centres the tests are part of the six monthly review clinic. Tests are recommended for all people with haemophilia who have received blood products. Although earlier tests were unreliable recent improvements have made the tests used to confirm the presence of hepatitis C antibodies much more reliable.*

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## Liver Transplants

*These should be considered for selected patients with either hepatitis B or C. A transplant may be appropriate for some with end stage liver failure. If a patient with hepatitis C receives a transplant the new liver can be infected by hepatitis C virus present in the patient. People who are HIV sero-positive cannot be offered a liver transplant because of the immunosuppression used during this treatment.*

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## What should I do if I have hepatitis?

*Attend clinics regularly so you can keep up to date with hepatitis A or B vaccination and with treatment for hepatitis C.*

*Apart from making sure that you attend your clinics regularly you should avoid too much alcohol and large doses of paracetamol.*

*People with liver disease should not take any medication without speaking to their Centre Director or Physician. Drugs used in the treatment of HIV may affect the way the liver functions. Your Haemophilia Centre Director will discuss this with you.*

**Alcohol**      *less than 40g daily. A pint of beer will contain about 20g of alcohol, a single measure of whisky or gin about 10g and a glass of red wine also about 10g.*

*10g of alcohol is equivalent to one unit. You should not consume more than 21 units (for men) or 14 units (for women) per week and the less you consume the better it is for your liver. Excessive alcohol consumption appears to increase the risk that chronic liver disease or hepatic cancer may develop.*