nam aidsmap

HIV & hepatitis

2010 Sixth edition

Acknowledgements

Written by **Michael Carter**
Sixth edition 2010
Due for review in 2012

NAM is grateful to the funders of this booklet series:
Department of Health
NHS Pan-London HIV Prevention Programme

Awards
Previous editions of this booklet were commended in the British Medical Association's Patient Information Book Awards, 2004 and 2008.

Thanks to the following people for their assistance:

Dr Mark Nelson
Chelsea and Westminster Hospital, London

Dr Sanjay Bhagani
Royal Free Hospital, London

Duncan Scott
Clinical Nurse Manager, Graham Hayton Unit, Royal London Hospital

Garry Brough

Professor Janet Darbyshire
Joint Director of NIHR Clinical Research Network

HIV & hepatitis

This booklet is for people with HIV who want to know more about hepatitis A, B and C. These are viruses that can damage the liver and make you very unwell. There is information in this booklet about how you can prevent yourself from becoming infected with these viruses, and how they are treated if you have become infected. This booklet is not intended to replace discussion with your doctor, but should help you to think about questions you would like answering.

A summary is provided on page 31 and a glossary on page 33.

Contents

The liver

'Hepatitis' means inflammation of the liver.

The liver is the largest internal organ in your body. It is located at the upper right-hand side of the abdomen. Having a healthy liver is important for everybody, but it is especially important for people with HIV. The liver plays a vital part in processing medicines used to treat HIV and other conditions. Viral infections that affect the liver, such as hepatitis A, hepatitis B and hepatitis C, can make you ill and also mean that the liver is unable to process medicines properly.

What your liver does

Your liver has four major functions:

- It stores and detoxifies your blood, filtering out unwanted substances.
- It makes a substance called bile, which is released into your gut and helps you digest fat.
- It processes nutrients from foods, releasing energy into your bloodstream, and storing vitamins and minerals.
- It manufactures proteins and certain vitamins.

What can go wrong with your liver

Drinking a lot of alcohol over a long period of time can damage your liver, leaving it

permanently scarred and unable to work properly.

Certain recreational drugs, such as heroin, cocaine and ecstasy can also damage your liver.

Medicines used to treat illnesses and infections, including some HIV drugs, can also affect your liver, causing inflammation. Inflammation of the liver is known as hepatitis.

Viruses can also cause this inflammation, and therefore damage to, the liver. This booklet gives detailed information on these viruses – chiefly hepatitis B and hepatitis C – which can cause serious long-term or chronic illness. Information is also included on hepatitis A, which can make you unwell, but only in the short term.

Liver disease: fibrosis and cirrhosis

You'll have regular blood tests to monitor the health of your liver as part of your routine HIV care. Increases in certain enzymes can indicate that the liver isn't working properly, or is being damaged. You can find out more about the type of tests that will be done to monitor the health of your liver in NAM's patient information booklet, *CD4, viral load and other tests*.

Excessive drinking, drug use, and having hepatitis B or hepatitis C can all damage the tissue in your liver. Two terms are used to describe this – fibrosis and cirrhosis.

If your liver has fibrosis, this means that part of it has been hardened and scarred. Fibrosis can be

reversed if the cause is identified and dealt with early enough.

Cirrhosis is severe scarring of the liver, leaving it in danger of no longer being able to work properly. This can be serious, causing jaundice, internal bleeding and swelling of the abdomen. Damage caused by cirrhosis is often permanent.

Liver disease: liver cancer

Cirrhosis from long-term infection with hepatitis B and hepatitis C significantly increases the chances of liver cancer developing.

Liver cancer is difficult to treat and surgery, involving the removal of part of the liver or liver transplantation, is often the only option. Small tumours can be removed, but the chance of a new tumour developing within five years is high. Chemotherapy has no proven benefit for survival in liver cancer but can relieve symptoms.

Vaccinations against hepatitis

Vaccinations are available against hepatitis A and hepatitis B. Unless you already have immunity to hepatitis A or B as a result of clearing a previous infection with the virus, you should have these vaccinations. Your HIV clinic can check if you have immunity to one or both, with a blood test.

The chance that the vaccination won't induce immunity the first time is greater in people with HIV, particularly if you have a low CD4 count, so you might need to repeat the vaccination course. Some clinics may choose to use a double dose of the vaccination against hepatitis B to improve

the chances of the vaccine working. As with any other treatment you might receive elsewhere it's important that your HIV doctor knows you're having the vaccinations.

A complete vaccine course can provide long-term protection. You should have annual tests to make sure that your levels of immunity are high enough to protect you. You can have a booster injection if the level isn't sufficient to protect you.

There is currently no vaccine against hepatitis C.

Hepatitis A

Hepatitis A can cause a short-term (or acute) illness, which normally lasts 10 to 14 days. It has no long-term, or chronic, phase. You can normally expect to get better without any special treatment, and once you have had hepatitis A you cannot get it again.

Hepatitis A is spread by contact with infected human faeces (shit). Contamination of food, drinking water and ice cubes is a common route of transmission, but it can also be passed on during sex, particularly by rimming (oral-anal contact).

You might be sick because of hepatitis A for longer if you have HIV, and having hepatitis A

may also mean that you have to stop taking your HIV drugs or other medicines for a time. This is because many medicines are broken down by the liver. When the liver is inflamed because of hepatitis A, it is unable to process medicines properly, meaning that the chance of experiencing side-effects is increased.

Hepatitis B

Hepatitis B virus (often known as HBV, but to avoid possible confusion with HIV, this abbreviation isn't used in this booklet) is an infection that can cause severe damage to your liver, sometimes resulting in death.

It is a very common infection around the world, particularly in Africa, the Indian sub-continent, and throughout the rest of Asia. Many gay men with HIV are also infected with hepatitis B. Hepatitis B infection is also common in people who inject drugs. Between 5 and 10% of people diagnosed with HIV are also infected with hepatitis B or hepatitis C. This is often called co-infection.

Transmission

The reason why so many people with HIV have hepatitis B is because it can be spread in a similar way to HIV, by contact with infected body fluids like blood, semen and vaginal fluid, and from a mother to her baby during pregnancy or delivery.

Although small amounts of hepatitis B virus can be found in saliva, saliva is not likely to spread the infection, unless saliva from an infected person gets into a cut or sore.

In richer countries, such as the UK, hepatitis B has mainly affected gay and bisexual men, and injecting drug users. Increasing numbers of cases are being seen in people who have come to the UK from Africa and India.

Hepatitis B is more infectious than HIV. Like HIV, it is possible to reduce the risk of becoming infected with the hepatitis B virus.

It is important that people with HIV are vaccinated against hepatitis B unless they are already immune. Using a condom for anal, vaginal and oral sex reduces the chances of hepatitis B being passed on during sex. Similarly, you should never share needles or other injecting drug equipment.

Blood products in the UK are routinely screened for hepatitis B.

Symptoms

The majority of adults who are infected with hepatitis B have no symptoms to suggest that

they have the infection, and it is often only diagnosed by routine blood tests and monitoring of the health of the liver. Even if you have no symptoms at all, you can still pass on the virus to others.

However, symptoms may occur soon after infection. These can include some of the following:

- A yellowing of the skin and whites of the eyes (jaundice).
- Loss of appetite.
- Pain in the stomach.
- Nausea and vomiting.
- High temperature.
- Joint and muscle aches and a general feeling of being unwell.

These symptoms can be severe and, in some rare cases, can cause death.

Stages of infection

There are four stages of hepatitis B infection.

Stage 1 – Immune tolerance At this stage the hepatitis B virus is able to reproduce freely in the body but does not cause any symptoms or liver damage. In adults, this stage tends to last for several weeks after infection with hepatitis B. In babies and small children, it can last for several years after infection.

Stage 2 – Immune response During this stage the immune system (the body's natural defences), attacks the hepatitis B-infected cells in the liver and starts to clear the infection from the body. In some people, this phase may last for just a few weeks. However, in people whose immune system cannot clear the infection, it can last for years. The immune system attacks those cells in the liver that are infected with hepatitis B virus. This causes liver damage and many people develop symptoms and become unwell at this time.

Stage 3 – Viral clearance This stage is often also known as 'seroconversion'. The body produces antibodies in response to a substance on the surface of the hepatitis B virus called the e-antigen. During this stage, hepatitis B stops reproducing.

Stage 4 – Immunity to hepatitis B This is when the immune system produces a full antibody response to hepatitis B, and clears the body of hepatitis B virus. Hepatitis B genetic material (DNA) may, however, remain inside the liver cells and can, on rare occasions, reactivate at a later date.

Most adults infected with the hepatitis B virus recover fully and develop lifelong immunity. However, up to 10% of people infected as adults will become chronic carriers of the virus. This means that they will continue to be infectious to others and can develop serious, long-term liver damage. Infected children, especially newborn babies, are much more likely to become chronic carriers. People with HIV are also less likely to clear the virus.

Monitoring

There are a number of tests you can have to see if you are infected with hepatitis B, or if you have been infected and have managed to clear the infection.

If the tests find fragments of the hepatitis B virus (called surface antigens) over a period longer than six months, then you are a chronic carrier of hepatitis B and continue to be potentially infectious to other people.

People who test positive for the hepatitis B e-antigen as well have higher rates of replication of hepatitis B and are also more likely to be infectious.

If you have antibodies, but no surface antigen, after six months of infection, then your immune system has cleared hepatitis B infection.

If infected, you should also have regular tests to see if your liver has been affected by hepatitis B. These are called liver function tests and they look at levels of certain chemicals, proteins and enzymes, which give an indication of how well your liver is working and whether there is ongoing damage to the liver. They should be performed at least every six months. You can find out more about the type of tests that will be done to monitor the health of your liver in NAM's patient information booklet, *CD4, viral load and other tests*.

Ultrasound examinations are sometimes used to see how much damage has been done to the liver, but in some cases it may be necessary

to perform a liver biopsy. This is when a tiny sample of tissue from the liver is extracted (using a hollow needle) for examination under a microscope (see p.19 for more information).

Treatment

Treatments are available if your body does not clear infection with hepatitis B itself. The aims of hepatitis B treatment include reducing liver inflammation and the amount of hepatitis B DNA. Ideally, treatment will also remove all hepatitis B antigens from the body and produce antibodies.

Several drugs are currently available for the treatment of hepatitis B. These are adefovir (*Hepsera*), interferon alfa, entecavir (*Baraclude*), and telbivudine (*Sebivo*).

A number of anti-HIV drugs have good activity against the hepatitis B virus:

- 3TC (lamivudine, *Epivir*, called *Zeffix* when used to treat hepatitis B without HIV therapy)
- FTC (emtricitabine, *Emtriva*)
- tenofovir (*Viread*, also available in a combined pill with FTC called *Truvada*).

Many HIV doctors will use these drugs to treat both HIV and hepatitis B in co-infected patients.

The type of treatment you receive will depend on how both hepatitis B and HIV are affecting your health. It's very important that the drugs that also work against HIV aren't taken unless

they are part of an HIV treatment combination. This is because otherwise they may be taken in a way that causes your HIV to become resistant to them. You can find out more about resistance in the *Adherence & resistance* booklet in this series.

Before starting any course of treatment, you'll be intensively monitored to check the health of your liver, and your CD4 cell count and viral load.

As a general rule, your choice of hepatitis B treatment will be guided by your CD4 cell count.

If you have a CD4 cell count below 350: HIV treatment is recommended at this level. Therefore, the combination of drugs you are given should work against both HIV and hepatitis B. The most widely used option is a pill combining FTC and tenofovir called *Truvada*, also available in the combination pill *Atripla*.

If you have a CD4 cell count between 350 and 500: People with hepatitis B are one of the groups of patients for whom earlier HIV treatment may be appropriate. Therefore, a combination of drugs that are active against both viruses (for example, a combination that includes *Truvada*) should be used.

CD4 cell count above 500: Early HIV treatment is an option. An alternative is the use of hepatitis B drugs that do not work against HIV: either pegylated interferon or adefovir. Entecavir should not be used without antiretroviral drugs because it can cause cross-resistance to the HIV drug, 3TC (lamivudine, *Epivir*).

HIV treatment and hepatitis B

HIV treatment can be used safely and effectively if you have hepatitis B.

However, when some people infected with HIV and hepatitis B start taking HIV treatment, they may experience a short-term flare-up of liver inflammation.

This is usually the consequence of the HIV treatment restoring the immune system, which then becomes better at responding to infections such as hepatitis B. This improved immune response can lead to active liver inflammation as a result of hepatitis B disease.

People with hepatitis B appear to be at greater risk of experiencing the increases in liver enzymes which some anti-HIV drugs can cause. The drugs particularly associated with liver side-effects include lopinavir/ritonavir (*Kaletra*), darunavir (*Prezista*) and ddI (didanosine, *Videx, Videx EC*).

The health of your liver will be closely monitored after you start treatment. You can find out more about the type of tests that will be done to monitor the health of your liver in NAM's patient information booklet, *CD4, viral load and other tests*.

Hepatitis C

Hepatitis C, although unrelated to hepatitis B, often causes similar symptoms. Estimates of the number of people in the UK who are chronically infected vary, but range from just under 200,000 people to nearly 450,000. The majority of those living with hepatitis C do not know they are infected.

Transmission

Hepatitis C is mostly transmitted by direct blood-to-blood contact. The most common route of transmission in the UK is by sharing equipment for injecting drug use, mainly via blood-contaminated needles and syringes, but sexual transmission does occur. The virus can survive in syringes and in tubs of lubricant for weeks. Sharing drug sniffing equipment (straws or banknotes) has also been shown to be a risk.

Many people also contracted hepatitis C from being given blood products in a medical procedure before screening and sterilisation processes were introduced (September 1991 in the UK).

Sexual transmission of hepatitis C is less common but does occur. It is more likely to happen if you also have another sexually transmitted infection. Also, anal or rough sex is more likely to pass on the infection. Oral sex is of low risk. The virus is present in saliva, but kissing is not usually a risk unless both partners have cuts in the mouth or bleeding gums.

In recent years, there has been a large increase in the number of HIV-positive gay men who have

also become infected with hepatitis C through sexual transmission. There seems to be an association with rougher sex, with risk factors such as fisting, group sex and using recreational drugs during sex, but sometimes the only identifiable risk factor is unprotected anal sex.

There is also evidence that some of the infections in HIV-positive gay men may be as a result of injecting drug use and other shared routes of drug taking.

There is little evidence of sexual transmission of hepatitis C in heterosexuals.

Mother-to-child transmission of hepatitis C is uncommon, but the risk is increased if the mother is also infected with HIV. A high hepatitis C viral load also increases the chance that a mother will pass on hepatitis C to her baby. As with HIV, a caesarean delivery reduces the chance of mother-to-child transmission of hepatitis C.

Unlike hepatitis A and B, having hepatitis C once does not mean you are then immune from getting it again. It is also possible to be reinfected with a different strain of hepatitis C.

Preventing hepatitis C

When used correctly, condoms can reduce the risk of sexual transmission of hepatitis C, as well as HIV and other sexually transmitted infections.

Some HIV-positive gay men try only to have unprotected sex with men who are also HIV-

positive ('serosorting'). However, because of the risk of contracting other sexually transmitted infections and hepatitis C, it is recommended that condoms should still be used even when a sexual partner is also HIV-positive.

The use of gloves for fisting is also an effective method of prevention. In group sex situations, neither sex toys nor lubricants should be shared. Gloves and condoms should be changed between partners.

Needles, syringes and other equipment used to inject drugs, and equipment used to sniff drugs such as straws or banknotes, should never be shared.

Some studies have found a risk of passing on hepatitis C by breastfeeding, but the evidence is inconclusive. However, in the UK and other countries where safe alternatives to breast milk are available, all mothers with HIV should avoid breastfeeding.

Sharing household items that may have any contact with blood, such as razors, toothbrushes and nail scissors, should be avoided. The hepatitis C virus can live outside the body much longer than HIV can. There is no risk of transmission through normal social contact, such as sharing crockery or cutlery, or touching someone with hepatitis C.

Blood spills from someone with hepatitis C should be cleaned up using undiluted household

bleach. Scratches, cuts and wounds should be carefully cleaned and covered with a waterproof dressing or plaster.

Using non-sterile needles for piercings, acupuncture and tattooing is a transmission risk; new, sterile needles should be used.

Symptoms

Less than 5% of people experience symptoms when they are first infected with hepatitis C. When they do occur, symptoms can include jaundice, diarrhoea and feeling sick. Even if you do not have any symptoms, you can still pass the virus on to others.

In the longer term, about half of people with hepatitis C will experience some symptoms. The most common ones are feeling generally unwell, extreme tiredness, weight loss, intolerance of alcohol and fatty food, and depression. (You can find more information on the link between depression, hepatitis and hepatitis treatment, and on managing depression in NAM's booklet, *HIV, mental health & emotional wellbeing*, in this patient information series.)

Disease progression

Only about 20% of people who have been infected with the hepatitis C virus appear to clear the virus naturally from their blood, whilst about 80% will develop chronic hepatitis C. Those with chronic infection will continue to be infectious and can pass on the virus to others. If a person continues to be infected over a number of years with the hepatitis C virus, they could develop the

following complications:

- Chronic liver inflammation.
- Liver cirrhosis.
- Liver cancer.

Patterns of disease vary from person to person. Some people never experience any of these complications but about a third of those with chronic infection will develop serious liver disease after 15 to 25 years of infection.

The severity of disease can be affected by a number of factors. It is thought that it may take between 30 and 40 years for hepatitis C to cause cirrhosis – serious scarring to the liver. But men, people who drink alcohol, older people, and people with untreated HIV seem to have faster hepatitis C disease progression.

Cardiovascular (heart) disease is an increasing concern for people with HIV. Because of effective treatment for HIV, many people are living longer. But this means an increased chance for some people that they will develop heart disease. This is now known to be caused by the effect of HIV itself. In addition, some anti-HIV drugs can cause physical changes that can contribute to heart disease.

There's now some evidence that people who are co-infected with hepatitis C may have an increased risk of cardiovascular disease. Your HIV clinic should monitor your blood fats, or lipids

(cholesterol and triglycerides) to see if you are at risk of heart disease. In addition, there are higher rates of diabetes amongst people with hepatitis and HIV co-infection, a condition that may also contribute to heart disease. You can find out more about the type of tests that will be done to monitor your health in NAM's patient information booklet, *CD4, viral load and other tests*.

Diagnosing and monitoring hepatitis C

Treatment for hepatitis C has the best chance of success if it is given soon after a person is infected with the virus. So if you're at risk of hepatitis C it makes very good sense to be regularly tested for the infection. Ask staff at your HIV clinic about having these tests.

A blood test can tell if you have been exposed to hepatitis C and have antibodies to it. You should be tested for hepatitis C at least once a year, and have more frequent tests if you are especially at risk of hepatitis C.

A test is also available to measure hepatitis C viral load (called a PCR test). This can show if you are likely to clear hepatitis C naturally. Hepatitis C viral load is not an indicator of **when** to start treatment, but it can be used to indicate how long you should continue to take treatment against hepatitis C. If you have a very high hepatitis C viral load, you may require a longer course of treatment.

Liver function tests, which measure levels of enzymes produced by your liver, can give an

indication of whether or not hepatitis C has damaged your liver. However, some people with hepatitis C can have normal liver function tests, even though they have suffered significant liver damage.

If the degree of liver damage you have suffered is unclear, then you may need to have a liver biopsy. This involves using a hollow needle to remove a small sample of the liver, which is checked under the microscope for signs of liver damage.

Liver biopsies can also be used to help decide what kind of hepatitis C treatment you need and how long it should last for.

Liver biopsies can be uncomfortable for some patients (although you will be given a local anaesthetic) and, very rarely, can cause bleeding or bile to leak from the liver. If you have haemophilia you may need to receive extra clotting factor before and after the biopsy, and a very small number of people with haemophilia may not be able to have a biopsy at all because of very low clotting factor levels.

To minimise the risk of complications, some centres have started offering an alternative method called transjugular liver biopsy. This is a process by which the liver biopsy is carried out internally via a hollow wire. This wire is inserted through a large vein in the neck under X-ray guidance. The procedure reduces the risk of bleeding and other complications.

Some doctors are also exploring the possibility of using a number of different blood tests that, viewed together, can give an accurate impression of liver function and damage, rather than using biopsies. Another method for assessing liver damage is elastography (*FibroScan*), which measures liver stiffness by using a vibration probe. This is a test very much like an ultrasound scan of the liver. Many centres are now offering this as an alternative to or as well as the liver biopsy for accurate and frequent monitoring for liver damage.

How does HIV affect hepatitis C?

It seems that people co-infected with untreated HIV and hepatitis C are more likely to develop liver damage than people infected only with hepatitis C.

However, there is evidence that HIV treatment can slow hepatitis C disease progression.

The effect of hepatitis C on HIV

In countries like the UK, potent HIV treatment is widely available and people are living longer, healthier lives with HIV. However, liver disease is now a major cause of hospital admission and death among HIV-positive people because of hepatitis B and C liver-related problems.

Having hepatitis C does not appear to significantly alter your chances of becoming ill due to HIV, developing AIDS, or dying of an AIDS-defining illness.

HIV treatment if you have hepatitis C

HIV treatment can be used safely and effectively if you have hepatitis C. It's possible to treat both HIV and hepatitis C at the same time.

If you are co-infected with hepatitis C, then you're especially encouraged to start HIV treatment when your CD4 cell count is higher than in people without hepatitis. Reducing your HIV viral load appears to reduce the risk of hepatitis C, and of other HIV drugs – such as nevirapine (*Viramune*) – causing liver damage.

Some anti-HIV drugs can cause liver side-effects.

For instance, the older, and now rarely used, drugs ddI (didanosine, *Videx*) and d4T (stavudine, *Zerit*) have been associated with an increased risk of developing hepatic steatosis ('fatty liver'), which is the accumulation of fat in the liver.

You and your doctor should bear these factors in mind when selecting which anti-HIV drugs you are going to take, and careful monitoring of your liver after you start taking HIV treatment is strongly recommended.

Treatment for hepatitis C

Treatments are available for hepatitis C and aim to cure the condition. People with HIV who are newly diagnosed with hepatitis C should consider the pros and cons of starting treatment.

Before treatment is started it is important to have a test to show which strain, or genotype, of hepatitis C you have been infected with, as hepatitis C genotype can predict your response to treatment.

There are at least six types of hepatitis C genotype.

Type 1 is the most common in the UK and Europe. Unfortunately, type 1 responds least well to the currently available treatments for hepatitis C. Genotype 4 is also harder to treat. People with genotypes 2 or 3 respond better to treatment.

Factors such as age, gender, duration of infection, degree of liver damage and whether cirrhosis has developed are also important in predicting if treatment is likely to be effective.

Unlike antiretroviral therapy, treatment for hepatitis C is not indefinite. The length of your course of treatment is dependent upon the genotype you are infected with and how well you respond to treatment. A test after 12 weeks can predict if you are not going to respond to treatment at all. If that is the case, your doctor may suggest you stop treatment.

The current treatments for hepatitis C are ribavirin and pegylated interferon.

Treatment with pegylated interferon and ribavirin is now the standard of care recommended in the UK. Improved response rates are also seen when ribavirin is dosed according to a patient's weight, and avoiding dose reduction. Supporting therapy may be provided, where needed, with a hormone called erythropoietin (EPO).

The best results in people with HIV are seen when treatment is provided soon after a person is infected with hepatitis C. Up to 65% of people who are given treatment at this time, even when infected with the harder-to-treat strains of hepatitis C, clear the virus.

The response rate is much lower – about 30% – when treating hepatitis C that has become chronic in people with the harder-to-treat genotypes 1 and 4, and higher in people with genotypes 2 and 3.

Some people respond to hepatitis C treatment more slowly, and in these cases it may be recommended that they stay on treatment for up to 72 weeks.

If you don't respond to treatment, a second attempt may be possible in some circumstances. This is especially the case if you were not given weight-based ribavirin, or had pegylated interferon or ribavirin dose reductions during treatment, or if you were taking anti-HIV drugs that could interact with your hepatitis C treatment. There may also be new, more effective drugs available in the future.

Your clinic nurse will need to take regular blood specimens while you are on treatment (usually every month) to monitor your health and how you are responding to treatment. They should also be able to provide you with support to increase your chances of taking all the doses of your treatment, and give you tips, support and treatment to reduce any side-effects of the medication.

Aims of hepatitis C treatment

The aim of treatment should be to eradicate hepatitis C virus completely. Doctors often talk about achieving a 'sustained viral response', or SVR, which means that you have no detectable hepatitis C virus in your body six months after your treatment has ended. You will not be considered to have an SVR unless you still have an undetectable hepatitis C viral load at this point.

Side-effects

The side-effects of hepatitis C treatment can be severe, though they can lessen as treatment goes on and, as with the side-effects of any drug, will differ in severity from person to person.

Side-effects may include high temperatures, joint pain, weight loss, skin problems, thinning hair, feeling sick, and depression. Depression is particularly common in people taking interferon and you may be offered antidepressants if you are taking this drug. Some people choose to take an antidepressant to prevent depression occurring. (You can find more information on the links between depression, hepatitis and hepatitis treatment, and on managing depression in NAM's booklet, *HIV, mental health & emotional wellbeing*, in this patient information series.)

Other major side-effects of interferon include blood abnormalities such as low haemoglobin (anaemia), a low white blood cell count (neutropenia), and/or a low platelet count (thrombocytopenia).

Anaemia is a common side-effect and can lead to fatigue and shortness of breath. Doctors may use injections of erythropoietin (EPO) to increase red cells and haemoglobin to counter this. Injections of another drug, G-CSF (filgrastim), can also be used to increase white cell counts.

Most HIV-positive patients will experience a decrease in their CD4 cell counts whilst on treatment with interferon. This is an interferon effect rather than an HIV effect. Once treatment is complete the CD4 counts should return to the level they were at when hepatitis C treatment was started.

Ribavirin must not be given to pregnant women. It is possible that this could lead to the loss of the baby, or the birth of a baby with deformities or other problems.

Ribavirin can enter the sperm. It is important that sperm that contains ribavirin is not allowed to start a pregnancy and that ribavirin is not allowed to reach an unborn child. Couples who have been treated with ribavirin should avoid pregnancy for at least six months after the completion of treatment.

If either you or your partner has been taking ribavirin and you think there is a chance of

pregnancy, tell your doctor straight away.

Drug interactions

The drugs used to treat HIV and hepatitis C can interact, so also needing hepatitis treatment can affect your choice of HIV treatment.

The anti-HIV drug ddI (didanosine, *Videx*) should never be taken with anti-hepatitis C drugs.

If you have other options available, you should not take AZT (zidovudine, *Retrovir*, also in *Combivir* and *Trizivir*), or d4T (stavudine, *Zerit*), at the same time as treatment for hepatitis C.

Abacavir (*Ziagen*, also in the combination pills *Kivexa* and *Trizivir*) may reduce levels of ribavirin, so its use should be avoided if possible.

Hepatitis C drugs in development

Many doctors are optimistic that much better drugs will be available for hepatitis C in the future. These include hepatitis C protease inhibitors and polymerase inhibitors. However, it could be a few years before these drugs are available. If you have less serious liver damage, you may want to discuss with your doctor whether waiting for new drugs would be appropriate for you.

One option is to consider joining a clinical trial, if there's one available. You should discuss the pros and cons of this with your doctor. This may be an important option for people who have tried hepatitis treatment in the past.

Liver transplant

If your liver becomes damaged to the point where it cannot repair itself, and is likely to fail completely, you may need to consider the possibility of having a liver transplant.

Studies have found that people with HIV can do as well after a liver transplant as those without HIV, although those with hepatitis C do slightly less well.

Organ transplant is a very specialist medical skill, and there's a chance that the hospital where you receive your HIV care may not be a centre with expertise in this area. This could mean that you are referred to another hospital.

If you have a successful liver transplant, you will need to take medication to stop your body rejecting your new liver for the rest of your life. You'll still have to take your HIV medication as well.

A team approach to treatment and care

Your treatments for HIV and for hepatitis B or C should involve a network of specialist doctors.

As well as your HIV consultant, this should include the local hepatology team (doctors who are specialists in treating liver disease), virologists and, if appropriate, the regional transplant centre.

This may mean that you have to see several different doctors and nurses in different hospital departments (or even in different hospitals) for your HIV and hepatitis treatment and care.

There should be good communication between the doctors and departments looking after you, but if you are concerned that important information is not being passed between departments, make sure that you tell a member of your healthcare team.

Remember, if you are not happy with the standard of HIV care you are receiving, you can change and receive your treatment and care from another HIV clinic.

Alternative approaches

Many people with hepatitis use complementary or alternative therapies, either as a treatment for their liver disease, or to help relieve the symptoms or treatment side-effects.

As Chinese medicine has become more popular in the UK, some people with liver disease use herbal treatments such as milk thistle. It's important to be cautious. The use of complementary and alternative medicines can involve risks. Always inform your HIV/hepatitis doctor and pharmacist of any other treatments you are taking, including anything bought over the counter. Some alternative medicines may interact with other drugs you are taking.

There is no evidence from clinical trials to show that complementary and alternative drug treatments work for hepatitis. Some popular herbal treatments, such as the antidepressant St John's wort, can stop some anti-HIV drugs working properly (protease inhibitors and non-nucleoside reverse transcriptase inhibitors, or NNRTIs). Large doses of garlic supplements stop the protease inhibitor saquinavir working properly and large doses of vitamin C have the same effect on the protease inhibitor indinavir (*Crixivan*).

There are many forms of complementary therapy, such as massage, reflexology, t'ai chi and meditation, that may be able to help with some symptoms of hepatitis, or side-effects of treatment, such as tiredness and aching muscles. Many people find that these therapies can be very beneficial in reducing physical discomfort or stress. Always search for a practitioner via a reputable agency such as the Complementary Therapists Association (CThA), which is recognised by the Department of Health: **www.complementary.assoc.org.uk**

Further information

Your HIV clinic should be able to offer you information and support about hepatitis. You may also find the following organisations useful:

The British Liver Trust
2 Southampton Road, Ringwood BH24 1HY
0800 652 7330
www.britishlivertrust.org.uk

The Hepatitis C Trust
27 Crosby Row, London, SE1 3YD
The Trust runs support groups, including a co-infected gay men's group.
0845 223 4424 (10.30 to 4.30, Mon-Fri)
Hepatitis C helpline for information and support.
www.hepctrust.org.uk

UK Hepatitis C Resource Centre
15 Mansfield Place, Edinburgh EH3 6BB
0870 242 246
http://hepccentre.org.uk

Terrence Higgins Trust
THT runs a free six-week course for gay men in London on HIV and hepatitis co-infection.
0845 12 21 200 (THT Direct)
Contact helpline for more information on this and other services.
www.tht.org.uk

Haemophilia Society
First floor, Petersham House,
57a Hatton Garden, London EC1N 8JG
Freephone helpline 0800 018 6068
www.haemophilia.org.uk

Summary

- The liver is an organ that plays an important part in processing drugs.
- Hepatitis B and hepatitis C are serious viral infections that affect the liver.
- You should be tested for hepatitis B and hepatitis C.
- Co-infection with HIV and hepatitis B or hepatitis C (or both) is quite common.
- HIV treatment can be safe and effective in people who also have HIV.
- Hepatitis B can make you ill in both the short and long term.
- Treatments are available for hepatitis B, some of which also work against HIV.
- Hepatitis C can cause serious long-term health problems and is a major cause of illness and death in people with HIV.
- Treatments are available for hepatitis C, and treatment decisions should be made on an individual basis.

- Vaccinations are available for hepatitis A and B and anybody who is HIV-positive and not already immune should receive them.

- Your HIV and hepatitis healthcare teams should work closely together to ensure you get the best possible care.

Glossary

acute A recently developed condition.

anaemia A shortage or change in the function of red blood cells. These carry oxygen to the cells of the body.

antibody Protein substance produced by the immune system in response to a foreign organism or protein.

antigen Something the immune system can recognise as foreign and attack.

antiretroviral A substance that acts against retroviruses such as HIV.

antiviral A drug that acts against viruses.

biopsy A small sample of tissue that can be examined for signs of disease.

CD4 A molecule on the surface of some cells on to which HIV can bind. The CD4 cell count roughly reflects the state of the immune system.

cholesterol A waxy substance, mostly made by the body and used to produce steroid hormones.

chronic A long-term condition.

clinical trial A research study involving participants, usually to find out how well a new drug or treatment works in people and how safe it is.

diabetes A condition characterised by raised concentrations of sugar in the blood, due to problems with the production or action of insulin.

genotype The genetic make-up of an organism.

haemophilia An inherited condition, characterised by an inability of the blood to clot and causing serious bleeding and bruising from even minor cuts and injuries.

hepatitis Inflammation of the liver.

insulin A hormone produced by the pancreas that tends to lower blood sugar levels.

jaundice A yellowing of the skin and whites of the eyes associated with liver and gall bladder problems.

liver The organ involved in the digestion of food and excretion of waste products from the body.

metabolism The mechanisms which sustain life, turning sugar and fat into energy.

nausea Feeling sick.

neutropenia A shortage of neutrophils, immune cells in the blood that can attack bacteria and fungal infections.

NRTI Nucleoside reverse transcriptase inhibitor, the family of antiretroviral drugs that includes AZT, ddI, 3TC, d4T, abacavir and FTC.

pancreas A glandular organ situated behind the stomach that secretes insulin and digestive enzymes.

pancreatitis An inflammatory condition of the pancreas, causing severe abdominal pain, shock and collapse, which can be fatal.

protease inhibitor Family of antiretrovirals that targets the HIV protease enzyme.

seroconversion The time when someone's antibody status changes from negative to positive.

strain A variant characterised by a specific genotype.

toxicity The extent of ways in which a drug causes damage in the body.

tumour Uncontrolled new tissue growth, in which cells multiply rapidly.

undetectable viral load A level of viral load that is too low to be picked up by the particular viral load testing being used.

vaccine A substance that contains components from an infectious organism. By stimulating an immune response (but not disease), it protects from subsequent infection by that organism.

viral load Measurement of the amount of virus in the sample.

virus A microscopic germ that reproduces within the living cells of an organism it infects.

Keep yourself up to date – get more from NAM

HIV Treatment Update

NAM's regular newsletter keeps you up to date with the latest news and developments about HIV, to help you talk to your doctor, and make decisions about your health and treatment.

HIV Weekly

NAM's weekly email round-up of the latest HIV news. Sign up today for straightforward news reporting and easy-to-read summaries of the latest HIV research.

To subscribe to either of these publications, please use the form on the reverse

Order form

Please set up my free subscription to the following publications

☐ **HIV Treatment Update** – NAM's regular newsletter
Please tick which format you require ☐ Paper ☐ Email (PDF) ☐ Audio CD

☐ **HIV Weekly** – NAM's weekly HIV news round-up by email

Name .....

Address.....

.....

Postcode..... Email.....

Signature .....

☐ Please do not send me information about NAM's full range of publications on HIV
☐ Please tick this box if you would not like to receive information about NAM's fundraising campaigns

NAM is unable to provide free subscriptions to *HTU* to professionals or organisations – please contact us for prices

Please complete this form and send to NAM, FREEPOST LON17995 London, SW9 6BR

Under the terms of the Data Protection Act you may advise us at any time if you do not wish to receive further mailings from NAM

What did you think of this booklet?

NAM wants to make sure this booklet is useful to you. We would be grateful if you could take a minute to provide us with some valuable feedback. The questionnaire is anonymous and confidential.

As a result of reading this resource have you learnt anything about HIV, your health and treatment?

☐ I have learnt nothing new

☐ I have learnt something but it's not particularly useful to me

☐ I have learnt something that is useful to me

☐ I have learnt something that seems vitally important to me

Please tell us in your own words what you have learnt:

.....

.....

.....

.....

As a result of reading this resource I am more likely to: (tick all that apply)

☐ Discuss my treatment and care with my healthcare team

☐ Feel more confident talking to my healthcare team

☐ Feel better equipped to take decisions regarding my treatment and care

☐ Feel more informed about HIV treatment and living well with HIV

☐ Find other information and support, if I need it

☐ None of the above

Please tell us if there is anything else you are more likely to do or feel as a result of reading this booklet:

.....

.....

Please tear off this page and post it to: NAM, FREEPOST LON17995 London, SW9 6BR.

We would like to ask you a few more questions. You don't have to answer these, but if you do, it will help us make sure our information is relevant and useful to our readers.

Please circle the description that best describes you

I am: male / female / transgender

I live: in London / in the UK but outside London / outside the UK (please specify).....

My ethnic background is: White / Black – Caribbean / Black – African / Black – other / Indian or Pakistani or Bangladeshi / other Asian or oriental / other or mixed

My HIV status is: unknown / negative / positive

(If positive) I think I got HIV as a result of: sex between men and women / sex between men / injecting drugs / from blood or blood products / mother-to-child transmission / other / don't know / rather not say

I work: in the HIV field / not in the HIV field / I do not work at the moment

I got this booklet from: nurse / doctor / clinic / THT's HIV Health Support Service / support group / friend / family member / NAM / other (please specify) .....

Thank you very much for taking the time to fill in this questionnaire.
NAM really values your feedback. It helps make the information we provide better.
If you have any other comments on the content of this booklet please email info@nam.org.uk

HIV helplines

THT Direct
From the Terrence Higgins Trust
Telephone 0845 1221 200
Opening hours Monday-Friday, 10am-10pm
Saturday & Sunday, 12pm-6pm

African AIDS Helpline
Telephone 0800 0967 500
Opening hours Monday-Friday, 10am-6pm

HIV i-Base Treatment Phoneline
Telephone 0808 800 6013
Opening hours Monday-Wednesday, 12pm-4pm

More from NAM

NAM Information Forums
Free meetings offering an opportunity to hear the latest news, views and research around HIV treatments. Held in the evening at a central London location. **Call NAM for details.**

HIV Health Support Service
NAM supports THT in providing one-to-one and group skills sessions on health and treatments to people living with HIV.
Call THT Direct for details.

NAM information series for HIV-positive people
The booklet series includes: • Adherence & resistance • Anti-HIV drugs • CD4, viral load & other tests • Clinical trials • HIV & children • HIV, mental health & emotional wellbeing • HIV & sex • HIV & stigma • HIV & TB • HIV therapy • HIV & women • Nutrition • Side-effects

NAM
Lincoln House
1 Brixton Road
London SW9 6DE
UK

tel: +44 (0) 20 7840 0050
fax: +44 (0) 20 7735 5351
website: www.aidsmap.com
email: info@nam.org.uk
Registered charity no. 1011220

Sixth edition 2010

This booklet can be viewed in large print as a pdf file using Acrobat Reader.

Call NAM on 020 7840 0050.

About NAM

NAM works to change lives by sharing information about HIV and AIDS. We believe independent, clear and accurate information is vital in the fight against HIV. We produce useful information that you can trust.

Please make a donation by visiting **www.aidsmap.com/donate** or by ringing us on 020 7840 0050.