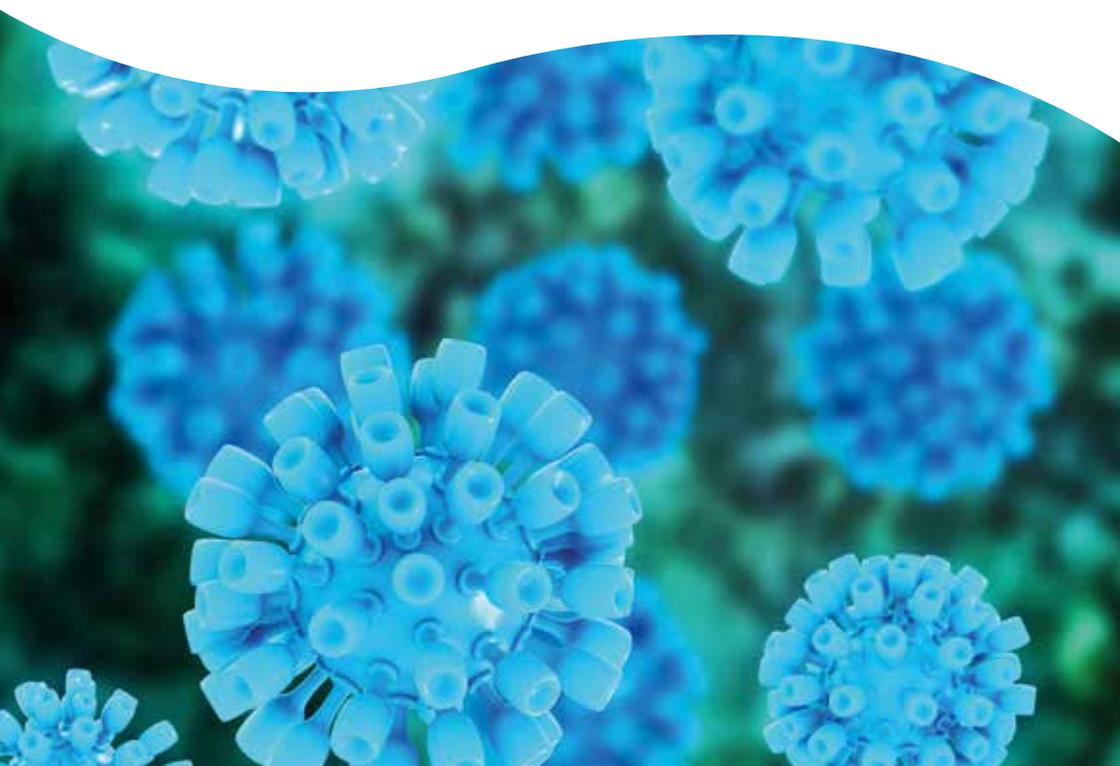


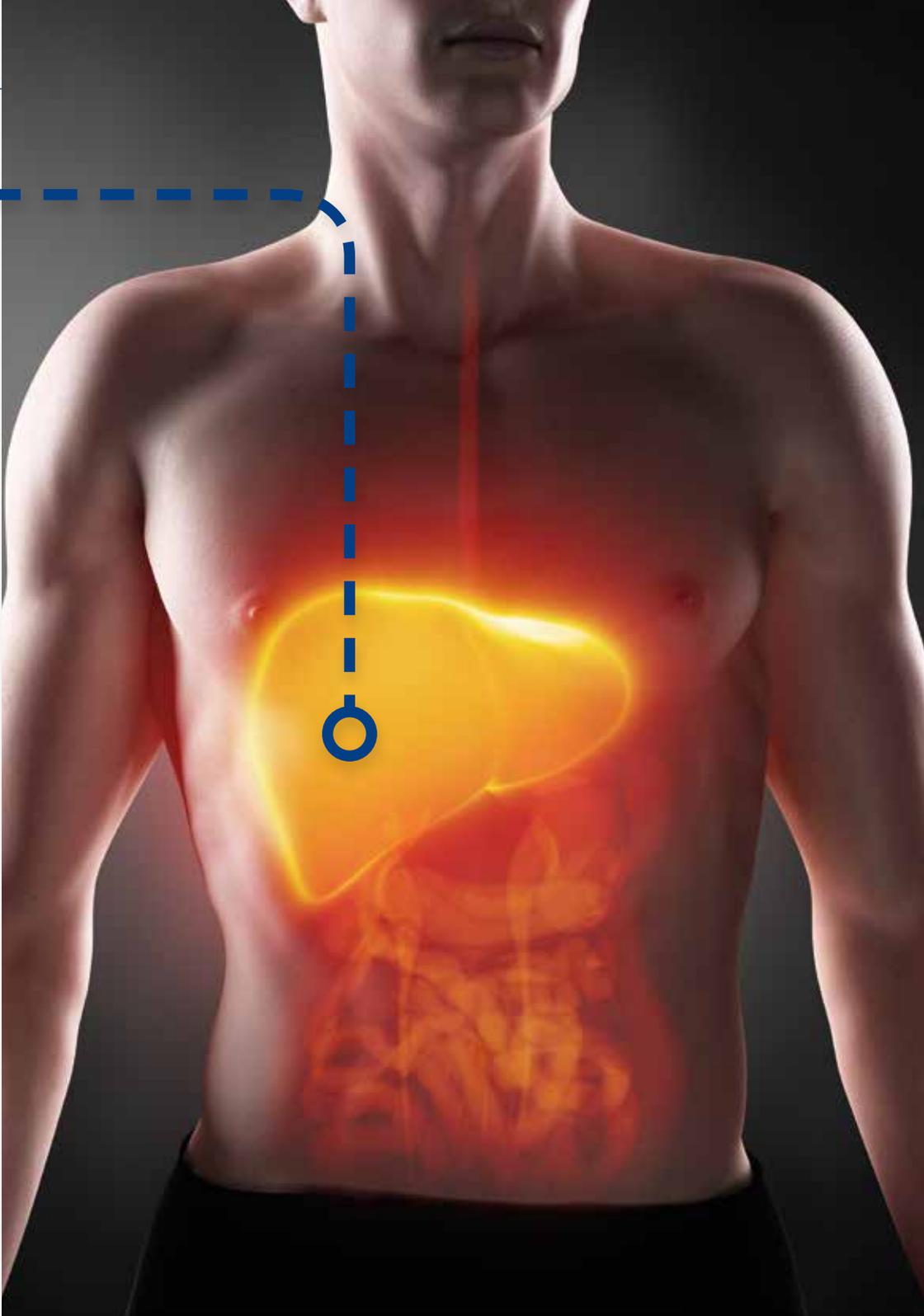
# Hepatitis C treatment and prevention

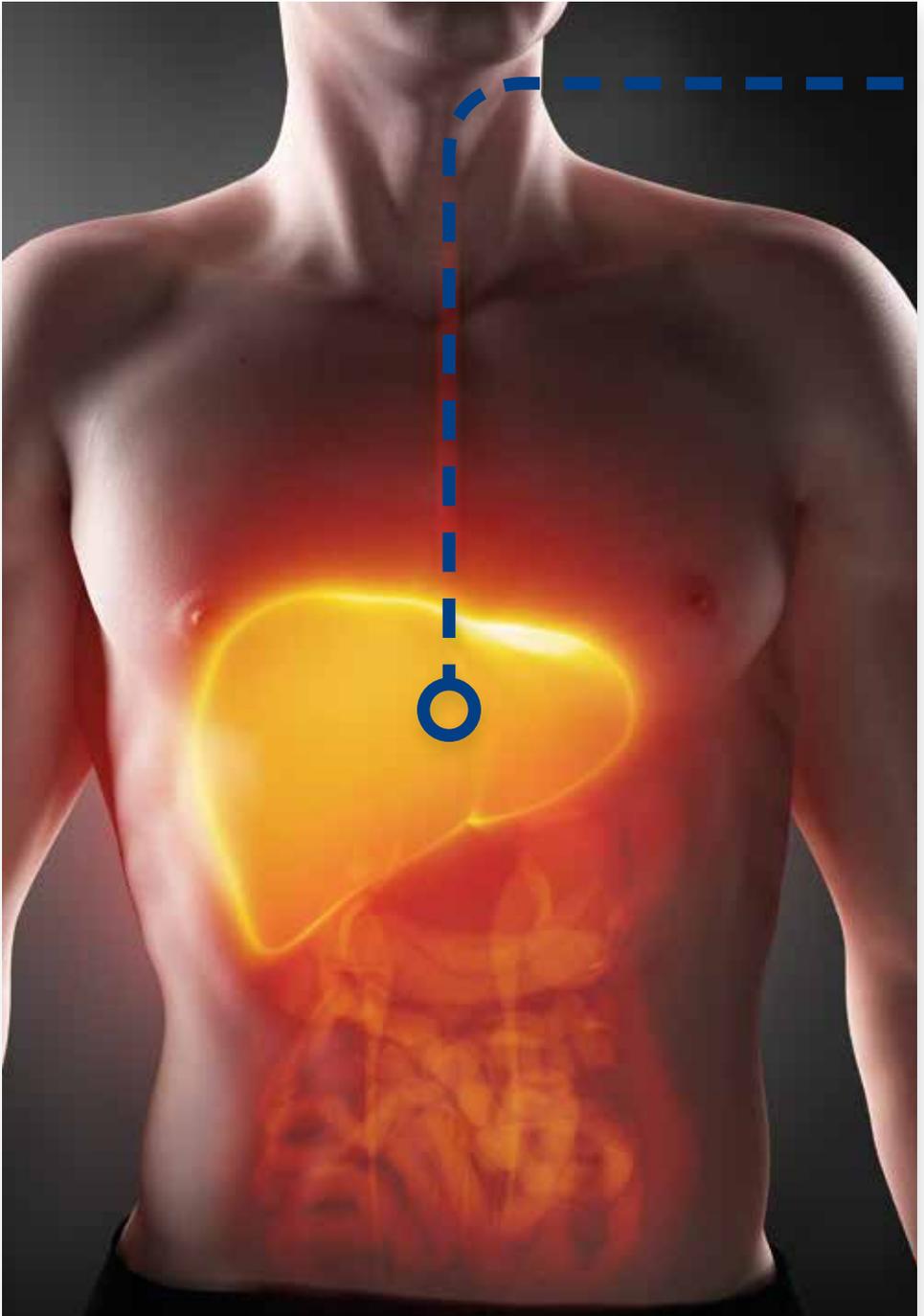
Information for patients



Treatment for hepatitis C can seem complicated so we have put together this leaflet to help you understand more about it.

It gives you information about the treatment pathway, how we monitor treatment, medication and the support you will get during your time in our care. All of our patients receive the latest and most effective medication to treat and cure hepatitis C.





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# What is Hepatitis C?

Hepatitis C is a virus (a type of infection) that targets the liver.

The liver is an important organ because it filters blood from the stomach and intestines so that your body gets the nutrients it needs from food. It breaks down drugs and other chemicals and makes proteins that are important for body functions, such as blood clotting.

If hepatitis C is left undiagnosed or untreated it can damage the liver. This can lead to scarring (fibrosis) or hardening (cirrhosis) of the liver and, in some cases this can eventually lead to liver cancer.

If hepatitis C is treated before significant fibrosis develops then the future risk of liver problems is very low.

'Acute' hepatitis C is the first six months of infection. This can be associated with significant liver inflammation so may require frequent blood tests. About

one in four people clear the virus during this time and the remainder will have an infection that persists beyond six months. If this happens, it is known as 'chronic' hepatitis C.

Hepatitis C often shows no symptoms to suggest a person has been infected. A few people develop jaundice (yellowing of the eyes and skin) during acute infection and chronic infection can be associated with symptoms like fatigue, aches and poor concentration.

There is no vaccine for hepatitis C. If you clear the virus (with or without treatment), you are not immune. You can still be re-infected and get hepatitis C again.

# How is hepatitis C transmitted?

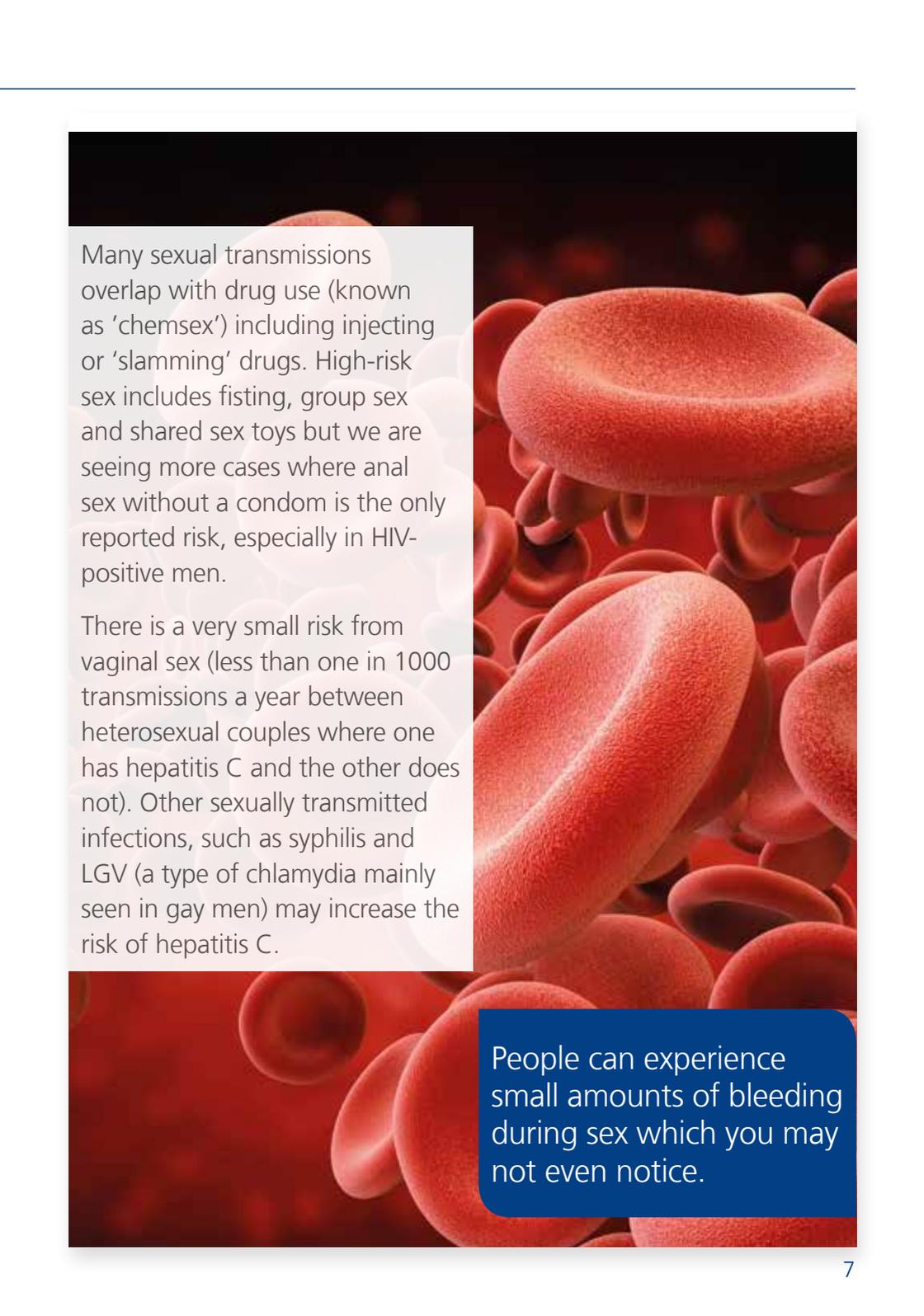
Hepatitis C is mainly spread through blood to blood contact.

Globally, sharing needles or other equipment for injecting drugs is the main cause of transmission. In some countries, transmission still occurs through blood transfusions or unsafe medical practices. Other routes of transmission include tattoos or piercings with unsterile ink or equipment and unprotected sex.

In Europe, including the UK, there has been a marked rise in hepatitis C in men who have sex with men. At first, this rise was seen in HIV positive men but, increasingly, more cases are being seen in HIV negative men too.

We get a lot of questions about the actual risk of getting hepatitis C through sex. Previously it was thought that transmission through sex was related to blood.

People can experience small amounts of bleeding during sex which you may not even notice. This can happen particularly with anal sex as the anus is tighter and drier than vaginas or mouths. However, research now shows that hepatitis C can be found in semen and in rectal fluids, even without blood present. The amount of the virus found in rectal fluids can be enough to lead to transmission of hepatitis C through anal sex.

A detailed 3D rendering of numerous red blood cells, also known as erythrocytes, in a dark red, almost black, background. The cells are shown in various orientations and depths, creating a sense of a dense population of cells. Each cell has a characteristic biconcave disc shape with a lighter red center and a darker red outer rim. The lighting highlights the texture and three-dimensional form of the cells.

Many sexual transmissions overlap with drug use (known as 'chemsex') including injecting or 'slamming' drugs. High-risk sex includes fisting, group sex and shared sex toys but we are seeing more cases where anal sex without a condom is the only reported risk, especially in HIV-positive men.

There is a very small risk from vaginal sex (less than one in 1000 transmissions a year between heterosexual couples where one has hepatitis C and the other does not). Other sexually transmitted infections, such as syphilis and LGV (a type of chlamydia mainly seen in gay men) may increase the risk of hepatitis C.

People can experience small amounts of bleeding during sex which you may not even notice.

# Can hepatitis c be cured?

Hepatitis C infection is curable with a short course of highly-effective treatment varying between eight and 16 weeks.

The treatment options are complex and regulated by centralised treatment networks which approve the appropriate treatment options for individual patients.

## Our hepatitis C clinic

Patients with a hepatitis C infection will be seen by our specialist Hepatitis Team at the Bloomsbury Clinic based at Mortimer Market Centre or in outreach clinics.

## Your first appointment

You will usually be asked to have a blood test before your first appointment but if you are unable to do so, this can be done on the day of your appointment instead.

At your first appointment, you will be seen by one of our doctors who will ask you a range of standard questions and review your blood results. They may request more if needed.

They may also arrange other investigations to assess your liver health, including a FibroScan and an ultrasound scan. You can find out more information about these scans below. Your doctor will also examine you to assess your general health.

You will be given information about medication options for your specific hepatitis C genotype (the type of hepatitis C that you have) and we will tell you about transmission risks. There can be a wait of a few weeks for treatment. This will depend on your liver health and will be discussed with you in more detail at your appointment.

It's a good idea to think about any questions you would like to ask the team before your appointment.



# More information about the tests we may need to do

## Blood tests

**Hepatitis C antigen test:** This is a test we use to screen for hepatitis C. It has a window period of four weeks which means it can take up to four weeks after you've been infected for hepatitis C to show up on a test. If your last risk was more than four weeks before the test then a negative test means you do not have hepatitis C.

Sometimes we see false positive results with this test which is why we confirm them with an RNA test (see below for information). When your hepatitis C infection has cleared, this test will show as negative.

**Hepatitis C RNA test:** This measures the amount of hepatitis C virus in the blood. We use it to confirm a positive hepatitis C antigen test, to monitor early hepatitis C (about one in four

people with early infection clear it themselves) and to monitor response to treatment. When your hepatitis C infection has cleared, this test will show as negative.

**Hepatitis C antibody test:** This test tells us if someone has ever been exposed to hepatitis C. The test remains positive even after the infection has cleared. It can also help us estimate how long someone has been infected as this test takes longer to become positive than the other tests (up to three months or more).

**Hepatitis C genotype:** Currently we know about seven genotypes or subtypes of hepatitis C. The genotypes most common in the UK are 1 and 3. Treatment options vary by genotype.

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**Liver profile:** *Alanine*

*Transaminase (ALT), Bilirubin, Albumin* are all indicators of liver inflammation or injury. If ALT levels are very high (meaning the liver is very inflamed) you might need to have more frequent tests and stop using anything that might further irritate your liver, such as alcohol, some medications, herbal remedies and gym supplements.

Other tests may be required which you can discuss with one of our team in more detail.

**Imaging****Liver elastography (Fibroscan):**

This test is done at Mortimer Market Centre with an instant result. You will be asked to not eat anything for two hours before the test. The test uses a hand-held probe (with a small amount of gel) to send a sound wave through the liver to measure liver fibrosis or scarring.

During the test you will lie flat and the doctor or nurse doing the test will position the probe between your ribs on the right side. It might take a few attempts to get the right position and then 10 readings will be taken and a result provided immediately.

It is not painful – you will feel a gentle push from the sound wave but no pain. Your Fibroscan score is one of the factors that we use to decide your priority score for treatment.

**Abdominal ultrasound:** this scan also uses a hand-held probe and gel to check size and texture of your liver and other organs. Unlike Fibroscan, where the probe is held in the same place once the right position is found, an ultrasound scan involves the probe being moved around your abdomen to view the liver from different angles.

This test is done at University College Hospital's (UCH) imaging department. The doctor or nurse you see at Bloomsbury Clinic will request the test and you will usually receive an appointment through the post from UCH. We can arrange for appointments to be made over the phone or by text if you do not have a fixed address or, if it is more convenient, we can ask your GP to arrange the scan.

**Occasionally other investigations might be needed. These might include:**

**Ultrasound guided liver**

**biopsy:** We can usually assess the liver with the blood tests and the scans described above but sometimes a biopsy liver biopsy is recommended. This is very rare. For example, this is recommended if the other tests suggest you may have liver disease not related to hepatitis C. This will involve attending the clinic for blood tests and, usually within four weeks, you will receive an appointment for the biopsy at UCH.

Using an ultrasound probe to find the best position, a needle is used to collect a tiny amount of the liver. It is best described as having a blood test taken from between your ribs. It can be uncomfortable but there is a very low risk of any complications (like bleeding).

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You will be given more information if the team think you need this test.

### **Before starting treatment**

The type and timing of treatment for hepatitis C varies depending on your genotype, your liver health and other conditions you might have.

All of the new treatments are interferon-free which means there are no injections and fewer side effects. The new drugs are called direct acting agents or DAAs. These are used in various combinations and the number of pills varies from one to 10 pills a day. More than 90 per cent of patients are cured by taking a course of this medication and there are very few side effects.

As costs for the new medications are high, NHS England has regulated access to treatment. To access treatment each patient

has to be referred for discussion at a weekly meeting based at the Royal Free Hospital with doctors, nurses and pharmacists in attendance. Each referral will be discussed according to a priority score and patients with more advanced liver disease (for example, those who have a high fibroscan score) will get treated more quickly than patients with no major liver disease.

Since October 2018 approval for treatment will be usually given within a couple of weeks.

Once treatment has been approved, our team will contact you to set up a date for you to start your treatment. This could be at short notice as sometimes we need to fill places which are allocated on a monthly basis. Alternatively, you might need to wait for the next month if the monthly capacity has been already reached.

Before starting treatment, we will carefully review your current medication to avoid any potential drug interactions.

Drug interactions can lead to increased blood levels of one or more drugs. This can lead to side effects or the medication becoming less effective.

The other medications you are taking may need to be changed or stopped during hepatitis C treatment. You will be able to restart or switch back to your medication once the course of hepatitis C treatment is completed.

It is very important to tell the Hepatitis Team if you start to take any new medications (including things purchased in a pharmacy or online) before or during your treatment. Some hepatitis C drugs may interact with recreational drugs. Speak to the team if this might affect you.

You cannot have hepatitis C treatment if you are pregnant because some drugs are harmful if taken when pregnant. Women may need a pregnancy test before starting medication and will need to use reliable contraception during and up to six months after treatment

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# Treatment

During treatment and after your treatment, we need to keep to a very tight schedule. We try to accommodate time restraints and travel plans as much as possible but when you start your treatment we require 100 per cent commitment from you. If you have plans that will interfere with your ability to attend for tests or appointments it may be better for you to defer your treatment. We will talk to you about this before we start any treatment.

Following the schedule is important as it helps us to monitor drug safety, side effects and how well the treatment is working. If the level of hepatitis C virus remains high or bounces back up after becoming undetectable then we will need to check for resistance. NHS England may refuse to reimburse the costs of the drugs if we don't perform the required monitoring. This is not something our service can afford and we will contact you if you miss an appointment or test.

## Re-infection

Hepatitis C medication does not give you immunity. You can still get re-infected after you have been cured and there is no vaccine to prevent re-infection. As part of your treatment pathway we offer a unique module to help you to avoid re-infection.

All of our patients are required to attend a Hepatitis re-infection prevention workshop.

This will help you to challenge the stigma attached to Hepatitis C. Our workshops provide a safe space for you to share your concerns and fears., You will learn the facts about transmission and we will dispel the myths so you can avoid getting re-infected and keep your life hepatitis free.

We will give you tips on how to improve your health and psychological wellbeing and we also offer further emotional and practical support.

Currently there is only one chance for hepatitis C treatment. NHS England does not approve a second course of hepatitis C treatment if you get re-infected. The only option if you need treatment again, is to sign up to a trial (places are very limited and get filled quickly) or to buy your own treatment online. This is entirely legal in England and we are happy to provide the necessary tests if you go down this route. Please chat to the team for more advice.

Hepatitis C medication does not give you immunity. You can still get re-infected after you have been cured and there is no vaccine to prevent re-infection.

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# Treatment schedule

Your personal schedule will be given to you once you start treatment but it will include the following key dates:

## **During treatment:**

- We will call you after one week to see how you are managing
- You will be asked to come in for tests and appointments at specific times during treatment.

## **End of treatment:**

This will be eight to 16 weeks after you started treatment depending on your type of infection, level of liver disease and medication

## **After treatment:**

- Typically we will ask you to attend for tests and appointments four, 12 and 48 weeks after your treatment is complete. This is to check the impact of treatment on your liver tests and to make sure the virus has not rebounded

- If the virus was undetectable at the end of treatment and remains undetectable 12 weeks after treatment is complete then the virus is considered cured. If the virus rebounds during treatment or within 12 weeks of completing treatment, it is likely due to the same virus. If the virus rebounds more than 12 weeks after completing treatment it is most likely a re-infection.

Once you have completed all the post-treatment monitoring we will discharge you from our care back to your regular HIV doctor or to your GP. If the treatment did not work or you are re-infected, we will continue to monitor you. Screening for hepatitis C should remain part of your routine monitoring as long as you are at risk. This can be done by your GP or at a sexual health clinic or your HIV clinic if you attend one.



## Tell us we're listening

We want to hear your feedback so we can make improvements.

You can speak to our team directly if you have any feedback or concerns.

You can visit: [www.cnwl.nhs.uk/have-your-say/feedback-compliments-complaints/](http://www.cnwl.nhs.uk/have-your-say/feedback-compliments-complaints/) to complete a Friends and Family Test online.

## Contact us

Hepatitis Team  
Bloomsbury Clinic  
Mortimer Market Centre  
Capper Street  
London WC1E 6JB

**Tel:** 020 3317 5100

[www.sexualhealth.cnwl.nhs.uk/clinics/bloomsbury-clinic/](http://www.sexualhealth.cnwl.nhs.uk/clinics/bloomsbury-clinic/)

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# Frequently asked questions about lifestyle

## **What do I need to know about Hepatitis C transmission in pregnancy and breastfeeding?**

If you are pregnant, breast feeding or trying to conceive, we will talk to you about this in more detail at your first appointment.

- A woman infected with hepatitis C can become pregnant
- The risk of mother-to-child transmission during pregnancy is approximately five per cent (one in 20 pregnancies). This may be lower if you have a low level of virus
- Transmission during pregnancy (before delivery) is low. During birth transmission is associated with exposure to the mother's blood
- Having a caesarean is not thought to change the risk of transmission
- There is no evidence of hepatitis C in breast milk therefore an infected mother cannot pass the virus to her child through breast feeding. However, if a woman has cracked or bleeding nipples, breast feeding should be avoided
- Treatment for hepatitis C should not be taken during pregnancy
- If you have received ribavirin you should not conceive for six months after you have completed the treatment. This applies to men and women, and includes sperm donation
- If you are a woman wanting to conceive, please talk to us about getting your hepatitis C treated first to eliminate any risk of transmission.

### Can hepatitis C be transmitted through saliva and bites?

- Case reports have shown that Hepatitis C can be transmitted through bites but it's uncertain how reliable these reports are and the risk is likely very small
- Hepatitis C can be detected in saliva but there is no evidence of transmission through saliva or kissing. If the person with hepatitis C has bleeding in their mouth and the person without hepatitis C has gum disease or a cut or sore then there is a theoretical risk of transmission but there have been no reports to date
- Transmission has been reported from rimming (licking, kissing or tonguing the anus) as the hepatitis C virus can be found in rectal fluids. The risk is higher if there is bleeding or open wounds or ulcers.

### How should blood and bodily fluid spills be cleaned from surfaces?

- Blood should be cleaned with bleach diluted in water (one part bleach to nine parts water) or Milton's fluid (diluted according to instructions). Make sure gloves are worn
- Bleach can damage materials so alternatives include hydrogen peroxide, alcohol (70per cent isopropanol – not the alcohol that you drink!) or soap and waters though these are all less effective. Remember, if you spill blood, it has to then get into another person's blood stream to transmit hepatitis C so blood spilt on floors, clothes or sheets is very unlikely to lead to a transmission anyway.

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## **What should I do about personal hygiene items?**

- Hepatitis C can survive outside the body on surfaces for up to three weeks
- We advise patients not to share razor blades, tooth brushes, scissors, hair clippers or nail clippers. If these have any blood on them then it may be possible to transmit hepatitis C to someone else if they cut themselves. The risk very low though
- As soon as you have cleared hepatitis C (either spontaneously or through treatment), we recommend you change or sterilise the items listed above.

## **What should I do about sex toys, lube and fisting?**

- Using condoms on sex toys will reduce the risk of transmitting infection. You should change them with each use and each partner
- You should clean sex toys after each use. How you clean them depends on what they are made of and whether they have batteries. Sex toys from reputable suppliers will include cleaning instructions
- Plastic sex toys should be washed with antibacterial soap and warm water and then soaked in a solution of one part household bleach to nine parts water. They should then be rinsed thoroughly and allowed to dry

- Latex, rubber or jelly toys are harder to clean and new condoms should be used each time if you share them
- Since hepatitis C can survive for up to 60 days in water, it is safest to assume the same applies to lube as well – use separate lube sachets to avoid transmitting infections.

### Safe drug use

- When injecting or slamming drugs, the risk of transmission of hepatitis C is not just through sharing needles – any of the injecting equipment (or ‘works’) should not be shared including, syringes, the fluid used to mix the drugs, tourniquets, spoons or swabs. These should not be shared even with someone you know well. You can find local needle exchanges online and some sexual health clinics provide ‘slamming packs’

- Steroids: the same advice applies to injecting steroids or other body enhancing drugs – do not share any equipment including vials of drug or hormones
- Snorting: the lining of the nose bleeds easily so if you share snorting equipment (straws, bank notes etc.) this could lead to transmission of hepatitis C. Do not share snorting equipment.

### Other routes of transmission

- There have been two published cases of hepatitis C transmission through fighting
- Boxing in a controlled environment will be safe if you use gloves and any cuts or bleeds are cleaned up and dressed.



Using condoms on sex toys will reduce the risk of transmitting infection. You should change them with each use and each partner

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