

BOOKLET 1

HEP C INFO

Understanding hepatitis C
and staying safe



Understanding hepatitis C and staying safe

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All quotes are genuine (all names have been changed) and are the result of Dr Harris' interviews with service users and people living with hepatitis C.

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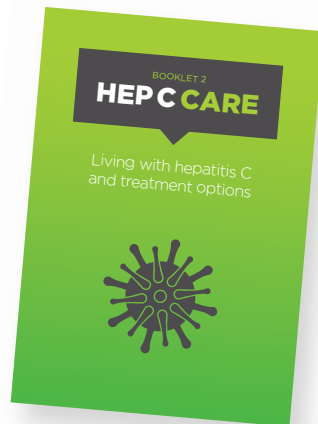
Introduction

This booklet is about hepatitis C (hep C). It explains what hep C is, how people catch it, and how to avoid it. If you think you might have hep C, there are sections on testing and disclosure decisions.

Making choices about your health is easier when you have the information you need. If there is anything you would like to discuss or don't understand, it can be helpful to go through this booklet with a healthcare worker or someone from a hep C organisation (see page 32).

Although the booklet has been produced for people who have, or may be at risk of, hep C, it can also be useful for partners, friends, family members and anyone else who wants to know more.

This booklet is the first of two. You can find out more about living with hep C and treatment options in booklet 2: Hep C Care.



What is hep C?

Hepatitis means swelling (inflammation) of the liver, and it has many different causes.

Hepatitis can be caused by liver toxic chemicals, heavy drinking (alcoholic hepatitis), some immune conditions or by one of a group of viruses, known as the hepatitis viruses, including hep A, B, and C.

The hepatitis C virus (hep C) is carried in the blood, and affects the liver by preventing it from working properly, and causing the liver cells to die. Over time, the virus can cause inflammation, scarring (fibrosis) and, sometimes, significant damage to the liver (cirrhosis).

Cirrhosis increases the risk of developing liver cancer, which can be fatal.

Hep C can be treated and, in most cases, it can be cured.



What is the liver?

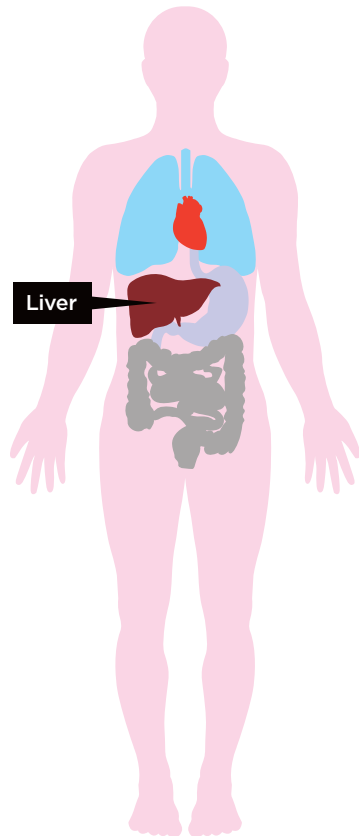
The liver is one of the largest and hardest working organs in the body, with about 500 different functions. It is located behind the ribcage on the right side of the body.

The liver is wedge-shaped, divided into left and right lobes, weighs around 1.5kg and measures approximately 13cm by 18cm

Why is it so important?

The liver has many functions relating to digestion, metabolism, filtering the blood, fighting infection and the storage of nutrients in the body. It has a vital role in supporting almost every other organ of the body and is essential for maintaining good health.

The liver has an incredible capacity for regeneration, but permanent scarring and/or damage to the liver tissue can limit its function, cause poor health, and potentially lead to liver cancer.



How is hep C different from hep A and hep B?

Hep A and hep B are caused by other viruses that also affect the liver. These viruses can cause similar problems but they are passed on in different ways.

Hep C is blood-borne, which means it is transmitted through blood.

Hep A can be transmitted through contaminated water or food. It is also found in the faeces of people who have the virus.

Hep B is spread through contact with the blood or other body fluids (such as vaginal fluids, semen) of a person who has the virus.

Anna



I thought hepatitis was a generic illness. I said to my GP, "But I can't have hep C I've been vaccinated against it." From having travelled, I assumed I'd had a hep C vaccine.

**You can be vaccinated against hep A and hep B
- there is no vaccination for hep C.**

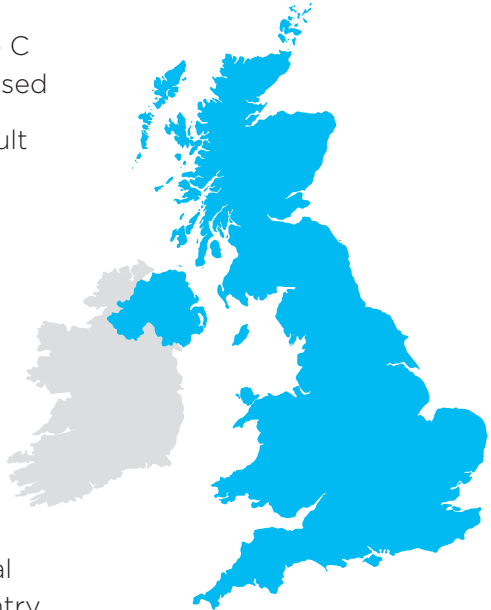


How common is hep C?

Hep C is a global health issue: It is estimated that around 180 million people worldwide (approx. 3%) have hep C.

In the UK:

- Approximately 216,000 people have chronic hep C
- Only 50% of people with hep C have been tested and diagnosed
- Most new cases of hep C result from using contaminated injecting equipment
- Around 50% of people who have ever injected drugs have hep C
- People who received blood products before 1987 or a blood transfusion prior to 1991 are at risk.
- People who have had medical or dental treatment in a country where hep C is common and infection control is inadequate may have been at risk.



The progression of hep C

Acute stage

Acute hep C occurs after infection, and lasts for about six months.

- Most people do not experience symptoms during the acute phase
- Some people may have flu-like symptoms, including fever, tiredness, loss of appetite, stomach pains, nausea and vomiting and, occasionally, jaundice.
- Around 20 to 25% of people will clear hep C during the acute stage

Clearing the virus will not protect you against getting hep C again.

Chronic stage

- The second stage is chronic (long-lasting) infection, where hep C remains in the body
- The 75 to 80% of people who don't clear the virus in the acute phase will develop chronic hep C

Having hep C doesn't automatically mean you'll experience symptoms or develop serious liver disease.



Hep C and liver damage

The longer you have lived with hep C, the more likely it is that you have some sort of liver damage.

There is a higher risk of liver damage if you are: male; over 40 when you contracted hep C; overweight; also living with HIV, hep B or diabetes; a regular or heavy alcohol user

Approximately one in five people with chronic hep C will develop cirrhosis (severe liver scarring) within 20 years. Liver cirrhosis is a slowly progressing condition in which the healthy liver tissue is replaced with scar tissue,

eventually preventing the liver from functioning properly. The scar tissue blocks the flow of blood through the liver and slows the processing of nutrients, hormones, drugs and toxins. Untreated, cirrhosis can lead to end stage liver disease, liver failure and liver cancer.

Kai



It [cirrhosis] means I've got a scarred liver so it's not processing any blood like it should be. Smaller, all shrivelled and bumpy, hasn't got the smooth, glossy surface like it should have.



Healthy liver



Cirrhotic liver

What happens if I get hep C?

Everyone's experience will be different, but for most people hep C develops slowly. Hep C is known as a silent disease because the symptoms aren't always obvious.


Symptoms may begin months or even years after getting hep C, and can come and go.

What are the symptoms of chronic hep C?

If they do happen, symptoms can be mild or severe and can include:

- Loss of energy and fatigue, much more than usual tiredness
- Low mood, depression and irritability
- Headaches
- Disrupted sleep
- Memory loss and difficulty concentrating - 'brain fog'
- Night sweats and chills
- Loss of appetite, nausea and weight loss
- Muscular pain and achy joints
- Pain in the abdominal and liver area
- Dry and itchy skin

Sam



I reckon I've had hep C for over 30 years. I was essentially symptom free until 2012 when I started to feel weak and it just went on and on. Eventually I had a battery of tests and hep C came up.

Some hep C symptoms, particularly poor sleep, difficulty concentrating or 'brain fog' and general aches and pains are easily overlooked. These symptoms can be dismissed as of drug and alcohol use, age or overwork, rather than hep C itself.

Many people who have cleared hep C only realise that they were experiencing symptoms once they begin to feel better.

Making lifestyle changes can reduce symptoms and slow down the development of liver disease. These changes may include reducing the amount of alcohol you drink, eating a healthy diet, drinking plenty of water, exercising, managing stress and getting enough rest.

More information about living with hep C and managing common symptoms can be found in booklet 2: Hep C Care.

Adam



Brain fog stuff, I can deal with it. But the fatigue is really, really draining. I give myself a hard time because I think am I being lazy or am I genuinely tired?

Alex



The hep C is clear. I didn't realise how ill I was. It affected my brain, it affected my sex drive, it affected all parts of my body.



Have I been at risk?

Hep C is a blood borne virus: it is only spread when blood from someone with hep C gets into someone else's bloodstream. Only tiny amounts of blood are needed to transmit the virus.

Highest risk: Using a needle or syringe that has been used by someone else with hep C

Sharing other injecting equipment including cookers, filters and water is also high risk.

Other causes of hepatitis C transmission:

- Having medical or dental procedures in countries where hep C is common and infection control is inadequate
- Receiving blood products in the UK before 1987 or a blood transfusion prior to 1991
- Acupuncture, tattooing, piercing or cosmetic injection procedures if any equipment is reused or inadequately sterilized
- Occupational exposure for healthcare workers, for example through a needlestick injury



- Sharing crack pipes or straws to snort drugs
- Transmission from mother to baby during birth
- Sexual activity where there is a risk of blood to blood contact
- Sharing items such as razors or toothbrushes.

Hep C cannot be spread by social contact like:

- Sharing cups, cutlery or dishes
- Kissing or hugging
- Holding hands
- Sneezing or coughing

Taj

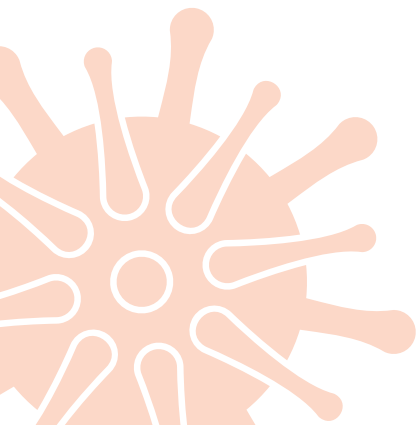


My sister-in-law advised me: your shaver and blades, keep them away from everyone, till you get cleared.

Hep C is **not** transmitted through semen or vaginal fluids

It is **not** transmitted in food or water.

It is **not** transmitted by blood sucking insects such as mosquitos.



Testing for hep C

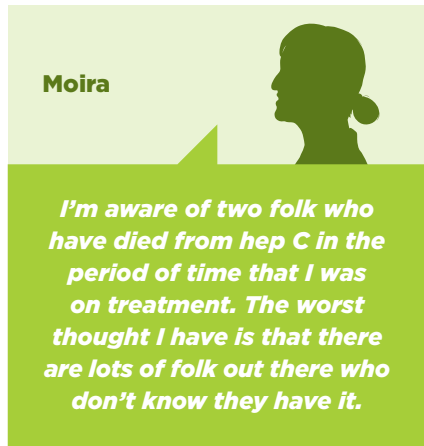
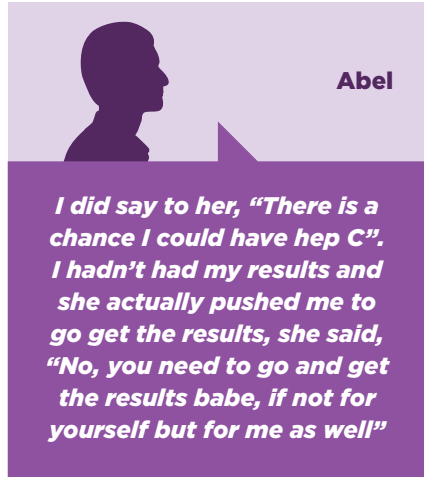
What do I do if I think I may be at risk?

Hep C can be cured.

If you think you might be at risk, then the only way to tell is to get tested. You cannot rely on symptoms or how you are feeling.

Getting a test can help you to:

- Understand symptoms you might have been feeling for some time, such as fatigue
- Make lifestyle changes (such as reducing alcohol consumption) to reduce your chance of developing advanced liver disease
- Get support from your GP and referral to a specialist to monitor your liver health
- Get expert advice around your treatment options.
- Reduce transmission risk to others.
- Get support from loved ones

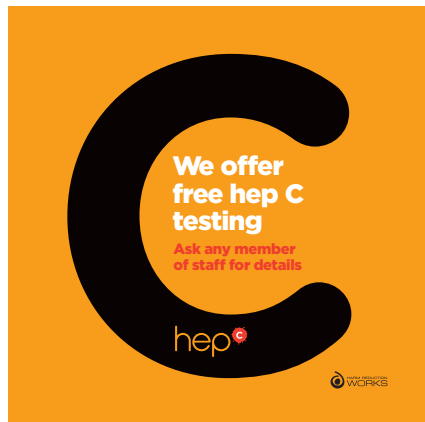


The tests

Hepatitis C testing is a two-stage process requiring a blood sample. Often the same blood sample can be used for both the antibody and PCR test. Traditionally collected by needle and syringe, some areas can offer dried blood spot (finger-prick) testing or oral swab testing.

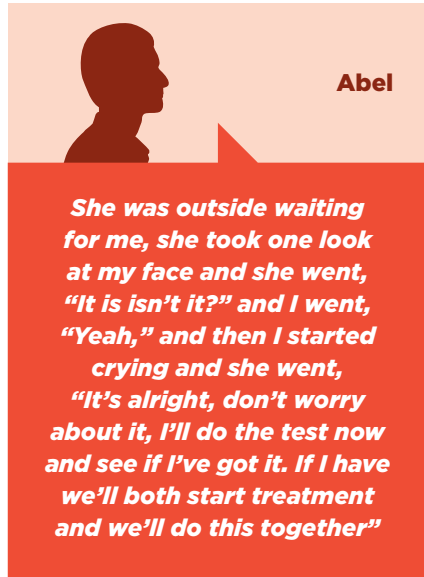
1. The antibody test

- This will show if you've ever been exposed to hep C.
- If you've been exposed to hep C, your immune system will have produced antibodies to try and fight it off. These antibodies remain even if the virus is no longer active.
- If you have recently been at risk but the antibody test is negative you will need another test in a few months. Hep C can take 6 to 12 weeks to show up in the blood after infection (this is known as the window period).
- A positive antibody test does not mean you have ongoing (chronic) hep C.
- You will need a second (PCR) test to confirm if you've developed chronic hep C.



2. The PCR test

- The PCR (also known as HCV RNA) test will show if you have active (chronic) hep C.
- If you have a positive PCR test, you can ask for a referral to a specialist service to check your liver health and discuss your treatment options.



Your rights to hep C testing and GP care

If you've been at risk, you have the right to have a hep C test at a location that suits you. Free and confidential tests are available at most GP services, sexual health clinics, drug treatment services and some pharmacies.

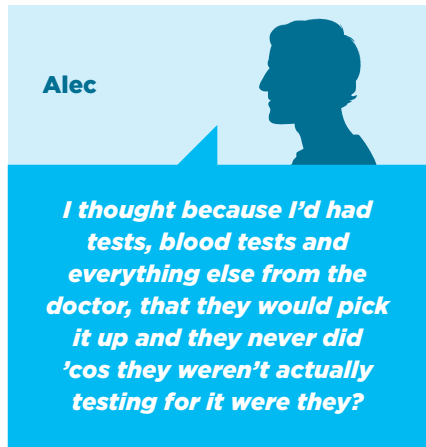
You may need to specifically ask for a hep C test, as this is not usually tested for in routine blood screens.

Everyone has a right to see a specialist to discuss hep C treatment options. If you have been diagnosed with hep C and would like a referral, ask your GP.

What if I don't have a GP, or want to change the one I have?

You don't need to be registered with a GP to get a hep C test or treatment, but they can be a good source of support and help manage any hep C health concerns.

If you live in the UK, you have the right to be registered with a GP practice close to where you live and to receive free NHS treatment when you need it.

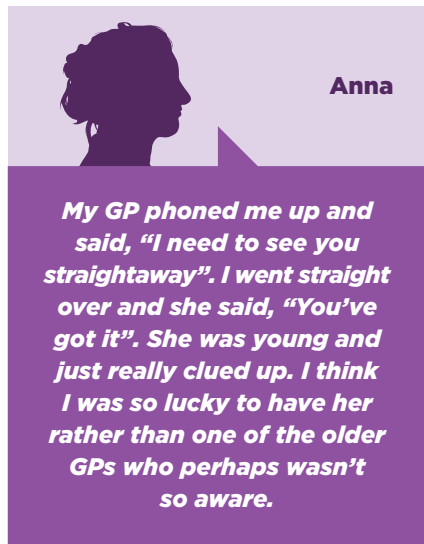


If you're not registered with a GP or you want to change the one you have, visit the GP surgery you want to join and ask them to register you as a patient. They'll ask you to complete a short form and to provide documents showing your name and address, proving who you are and where you live.

You are entitled to register with a doctor if you are homeless. You can use a temporary address, such as a friend's place or a day centre.

- It can be worth asking friends, drug treatment workers or hep C organisations if they can recommend a GP who has an interest in hep C.
- GPs who care for people who use drugs or work in partnership with drug treatment services, often know more about hep C and can be a good choice if you want a new doctor.

The NHS Constitution sets out your rights as an NHS patient. These rights cover how you access health services, the quality of care you should receive, the treatments and programmes available to you, confidentiality, information and your right to complain if things go wrong (see page 32).



If I test positive for hep C, who should I tell?

You are generally under no obligation to disclose that you have hep C (except in specific situations, below) but telling people close to you can provide a valuable source of support. There is no guarantee they will respond as positively as you like, which can make disclosure decisions difficult.

Some healthcare professionals can provide good guidance, but you may want to also talk to people you know who have hep C about their experiences. Hep C organisations can provide a helpful link to support groups as well as confidential information and advice (see page 32).

Sam



I still feel stigmatised by it. I don't know why. I shouldn't but I do, I don't feel that I can tell people just off the cuff.



Family and friends

Practical and emotional support from your family and friends can be important.

You cannot pass on hep C to your family and friends through everyday activities, such as sharing utensils, hugging or kissing although they may not understand this at first.

Providing your loved ones with this booklet or putting them in touch with hep C organisations (see page 32) can help reduce any fears or concerns.

Work

You are under no obligation to tell your employer you have hep C (unless you are a health care worker who conducts exposure-prone procedures). Some people find it easiest to say they have a 'liver condition' or other non-specific illness if they need to take time off work due to hep C symptoms, hospital appointments or treatment. You can ask your doctor to write this on any required medical certificates rather than hep C.



Taj

I think it does make a difference if you have a good family, friends, a good environment. It won't bring you down and I'm lucky to have that.



Taj

I don't really have an issue telling anybody. Only I don't really want to discuss it with anybody at work...

Finance

When applying for life insurance you are required to give consent for the release of your medical information from your GP. If you already have life insurance you are generally required to tell the insurance providers if you have hep C – if you don't, it may invalidate your insurance.

Health care providers

There is no legal obligation to disclose your hep C to health care providers, including dentists. This is because all NHS health care workers are required to comply with universal infection control precautions, designed to prevent cross-contamination from recognized and unrecognized sources of infection. It can be beneficial to tell health care workers so they can provide care that takes into account any liver disease.

Disclosure requirements

There are only a few situations when you are required by law to disclose if you have hep C. These include: when applying for life insurance, blood-bank questionnaires (you cannot donate blood if you have hep C), if donating sperm, and if you are a health-care worker that conducts exposure-prone procedures (e.g. surgery or dentistry). If you are unsure about any disclosure decisions or requirements, organisations such as the Hep C Trust can provide confidential advice.



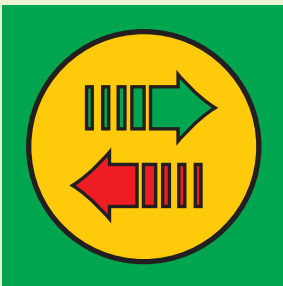
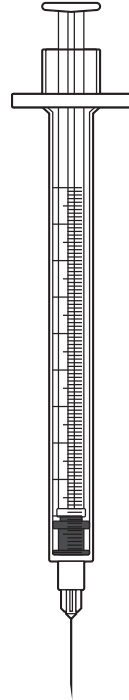
Staying safe

Injecting drugs

Hep C is only spread when blood from someone with the virus gets into someone else's bloodstream. Most new cases of hep C in the UK result from the use of contaminated drug injecting equipment.

When injecting drugs (including heroin, crack or cocaine, speed, mephedrone, crystal meth and steroids) the best practice is to use new equipment and dispose of it safely to avoid catching hep C or passing it on.

Your local drug service should be able to provide you with sterile injecting equipment and disposal bins. Many areas also have pharmacy based needle exchanges, which supply injecting equipment.



The National Needle Exchange sign has been used to discreetly signpost free and confidential needle exchange services in the UK for over 20 years.

Good injecting technique and using clean works can protect not only from hep C, hep B, HIV and bacterial infections, but also can help to reduce vein damage and injecting discomfort. If you have damaged veins or difficulties injecting, using new sharp works can make the process easier and less stressful.

Harm reduction tips

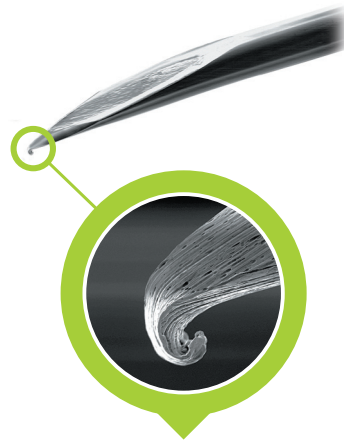
If you're homeless and have to inject in public places adopting best practices can be more difficult. Below are harm reduction tips that provide a number of options for different situations:

- If possible, be prepared. Get more injecting equipment than you think you might need. Consider stashing unwrapped equipment if there are safe places to do so.
- Ideally use a sterile needle and syringe for every injection. If that's not possible, thoroughly clean your works before using them. See page 27.

Ford



Even if I was having one hit and I didn't get it in the first time, I'd throw that syringe away and use another one. As soon as it penetrated my skin, it's blunt, it's useless.



This needle has been through the skin a few times in the search for a vein.

Images taken using a scanning electron microscope at the Department of Medical Microscopy Sciences, University of Wales College of Medicine, Cardiff.
With thanks to Dr Jan Hobot.

- Don't share any equipment (e.g. spoons, water containers, water, swabs, tourniquet) when preparing and injecting drugs. If you have to reuse cookers clean with soap and water or bleach solution first.
- Use sterile or freshly boiled water to prepare your drugs.

If you don't have access to sterile water amps or boiled water, tap water is probably the next best thing. Bottled water should be avoided unless it's freshly opened and not been drunk from. Never use water – wherever it comes from – if it's previously been used to flush out works.

- If possible, wipe down surfaces where your injection is being prepared: keep things as clean as possible.

If you can't clean a surface for preparing your hit or if you're injecting outside, use a layer of tissue, toilet paper, or newspaper to lay your injecting equipment on.

- Try not to rush your drug preparation or injecting, as this can lead to more risks and a greater chance of discomfort, pain and injecting damage.

Jeff



That's why I always inject in a calm environment, because it f*ing hurts if you get it wrong.***

- If withdrawing ('clucking') try smoking or snorting a little heroin to settle you before having a hit. It's easy to rush your preparation and injecting when withdrawing. If you don't have any clean equipment, smoking some heroin can hold you until you get new works.
- If possible, find a safe and warm place to prepare and inject your drugs. It's harder to find a vein if you're cold. If you are cold allow yourself a few minutes to warm up – jumping up and down can help!
- Wash your hands before and after injecting, preferably using soap and water or if running water isn't available, try baby wipes or alcohol gel.
- If you need to use an acid (like citric) to prepare your drugs, use as little as possible. Using too much acid increases discomfort and damage to your veins.



Alice

Even if I'm withdrawing really badly I would never share works, I'd put it on a bit of foil instead.



Jeff

I'd sooner sit there stirring for hours trying to get it down because citric burn is awful. I always use as little citric as possible even if it involves putting a few sprinkles at a time and a little bit more and a little bit more. Those sachets that they hand out, I get about three or four uses out of one of these.

- After injecting, firmly apply a clean, dry swab or tissue to the injecting site for a few moments to stop bleeding and bruising. Don't use alcohol swabs as this prevents blood clotting and encourages bleeding.
- Immediately after use, dispose of needles and syringes in a Sharps Bin.

If you don't have a Sharps Bin, hold on to your works until you can dispose of them safely. Or put the used works in an empty drinks can. Crush the can to prevent them being removed and put in a rubbish bin. This is a safer way of disposing works than throwing them in the rubbish unprotected.

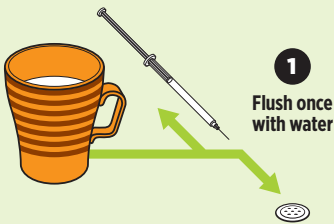


- If you've got a heroin habit consider getting a methadone or buprenorphine script from your doctor or drug service. This can help you manage your drug use, prevent withdrawal and help reduce any urgency around injecting.

Cleaning syringes

The best advice is to use a sterile needle and syringe for every injection. However, if you find yourself without clean injecting equipment, cleaning a used needle and syringe with bleach and water can reduce the risk of spreading hep C and other blood borne viruses.

Get two clean cups. Fill them with clean water (do not use boiling water – it can make the blood clot). **Pour out a capful of thin bleach.**



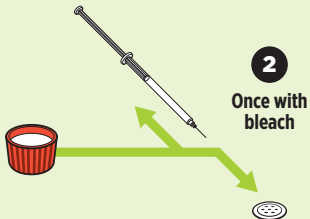
1

**Flush once
with water**

Draw up water from the first cup

(Fill the syringe completely to rinse and clean it)

Empty the syringe into the sink



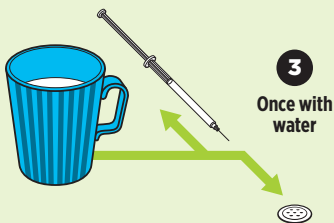
2

**Once with
bleach**

Draw up the thin bleach

(Make sure the outside of the needle gets dipped in bleach to kill any virus that is on the outside)

Empty the syringe into the sink



3

**Once with
water**

Draw up water from the second cup

Empty the syringe into the sink

Carefully put the cap back on the syringe

Pour the contaminated water and bleach down the sink

Tattoos and body piercing

If you get a tattoo or body piercing, you could be at risk of contracting hep C and other blood-borne viruses unless clean, sterile equipment is used every time.

To reduce this risk, don't get tattoos or piercings in unlicensed premises (especially in private homes or prisons).

When choosing a tattoo or body-piercing studio, look for clean, hygienic, well-lit premises and where they use new needles and inks each time. If they re-use needles, check that they are properly sterilised.



Birth and breastfeeding

There is a small chance (around 5%) that hep C can be passed from mother to baby at birth (vertical transmission). Babies are often born with their mothers hep C antibodies, but this does not mean they have active hep C. It is not until a baby is around 6 months old that a test will tell if they have hep C or not.

Breastfeeding is considered safe for women with hep C. However, if your nipples are cracked or bleeding you should stop breastfeeding temporarily (express and discard your milk during this time).

Sex

The risk of catching hep C through sex is low. Unlike HIV, hep C is not classed as a sexually transmitted infection.

Hep C is not transmitted in semen or vaginal fluids, only through blood. When there is little risk of blood-to-blood contact during sex, there is usually no need to adopt safer sex practices.



Blood to blood contact during sex is more likely to happen if you are having rough sex, having sex for a long time, if you are living with HIV or have an STI such as herpes, genital warts or syphilis. In these circumstances using condoms and dental dams can reduce risk.

Men who have sex with men do seem to be at more risk of catching hep C through sex. Adopting safer sex practices is recommended, especially if one of the partners is HIV positive.

Preventing transmission around the home

The hep C virus is transmitted in blood. While there is a very low risk of transmission, care should be taken not to share your razors or toothbrushes as they could carry small amounts of blood.

First aid precautions

The risk of getting hep C from cleaning up spilt blood is low. Health care professionals will use universal infection control procedures for all blood spills. To reduce any risk when cleaning up blood:

- Wear disposable rubber gloves and cover any cuts, abrasions or skin rashes
- Clean surfaces with detergent and water or mild bleach
- Use disposable materials such as paper towels. Place them in a plastic bag and dispose in the rubbish after use.

Hep C is not passed on through social contact such as:

- kissing
- hugging
- sneezing/coughing
- sharing utensils

Because of this there is no need for separate crockery, cutlery, towels or other household items or to wash your clothes separately.



Treating hep C

Hep C is treatable and curable.

Recent advances in hep C drug therapy have resulted in much better cure rates for most people. Treatment durations are becoming shorter with fewer side effects. Many people will be able to benefit from these new drugs in the future, but at the moment they are not widely available for all.

Choosing whether or not to start treatment is not always an easy decision. Factors to consider include: the treatments available; the health of your liver; how hep C currently affects your life; if you are pregnant or trying for a baby; how much support you have; and how any treatment side effects might impact your mood, work and relationships.

Brad



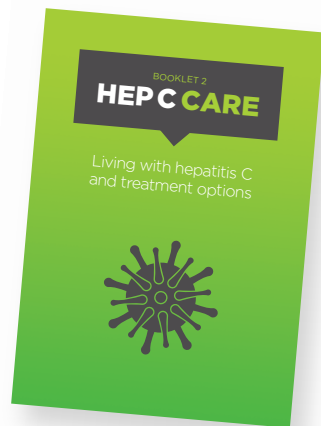
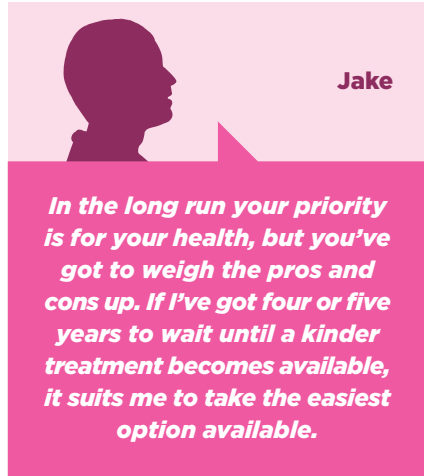
As I soon as found out about it, that's when I started looking, what is it, what does it do, how do you catch it, how do you get rid of it? I wanted to get rid of it straightaway. I'd read about the side-effects and I thought, I don't care. I just said [to the nurse] get me on treatment. Now!



Hep C treatment is changing fast and even if you decide treatment isn't right for you now, keep in contact with your doctor or nurse. This way they can monitor your health and liver function and let you know as new treatments become available.

To find out more talk to a doctor or nurse about treatment options, and whether it's better for you to be treated now or to wait until newer drugs are available. People who have been through treatment themselves can provide support and guidance, as can support groups and hep C organisations (see page 32).

You can find out more about living with hepatitis C and treatment options in the second booklet in this series: Hep C Care.



Support and resources

The Hepatitis C Trust

www.hepctrust.org.uk

Helpline: 0845 223 4424

Run by people with personal experience of hepatitis C, the Hepatitis C Trust runs a confidential helpline and provides information, support and representation for people with hep C. They also provide a directory of local hep C support groups and help for people wishing to start their own support group.

The British Liver Trust

www.britishlivertrust.org.uk

Working to reduce the impact of liver disease through awareness, care and research, the British Liver Trust has an extensive range of factsheets and information leaflets on a range of liver conditions including hep C and cirrhosis.

The NHS Constitution

www.nhs.uk

The NHS Constitution sets out your rights as a patient. It covers how patients access health services, the quality of care you'll receive, the treatments and programmes available to you, confidentiality, information and your right to complain if things go wrong.

Harm Reduction Works

www.harmreductionworks.org.uk

A range of harm reduction materials and resources including information on HIV, hepatitis B & C, overdose prevention and safer injecting practice, aimed at drug users and drug service providers.

Injecting Advice

www.injectingadvice.com

Support and advice for people working in harm reduction services and for injecting drug users.

The International Network of People who Use Drugs (INPUD)

www.inpud.net

People who use drugs (current and former) working together to ensure that the human rights of people who use drugs are respected, and for the implementation of effective harm reduction measures.

Release

www.release.org.uk

Help and advice line: 020 7324 2989

Release provides a free confidential and non-judgmental national information and advice service in relation to drug use, drug laws and human rights. The telephone help and advice line is open from 11am to 1pm and 2pm to 4pm Monday to Friday. A message service is available 24 hours and you can also contact by email: ask@release.org.uk

Safer heroin injecting (YouTube)

www.youtube.com/watch?v=Miv8i-sIK2w

A film designed to help people to identify ways to reduce potential injecting-related harms. The film is aimed at people who inject heroin, but many of the steps shown can be applied to the injection of other drugs.

FRANK

www.talktofrank.com

FRANK is a website and a confidential telephone helpline service offering drug related advice, information and support to users, their families, friends and carers. FRANK's support section provides details of local and national drug and alcohol treatment services.

infohep

www.infohep.org

infohep is an online resource providing up to date hepatitis treatment news. Its aim is to increase awareness of viral hepatitis, its treatment, and the needs of people living with viral hepatitis in Europe.

Understanding hepatitis C and staying safe

A booklet about hepatitis C (hep C) that explains what hep C is, how people catch it, and how to avoid it. If you think you might have hep C, there are sections on testing and disclosure decisions.

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**LONDON JOINT
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ON SUBSTANCE USE
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THE HEPATITIS  TRUST

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RE-ENGAGE AND COMBAT HEPATITIS C

Imperial College Healthcare 
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