



Living with hepatitis C

Your treatment and lifestyle decisions

Hepatitis
SCOTLAND

NHS
SCOTLAND

If you have just been diagnosed with hepatitis C, this booklet can help to provide answers to some of the questions you have.

You may also wish to visit www.hepatitisscotland.org.uk for further information.

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What is hepatitis C?

Hepatitis C is an infection caused by the hepatitis C virus (HCV) and is one of the most common causes of liver disease. The virus is passed from one person to another through blood-to-blood contact; this means that the blood of an infected person has to get into the bloodstream of an uninfected person, such as through an open wound, or through items which have come into contact with infected blood.

When the virus first enters a person's body, the person is said to have an "acute hepatitis C infection". Around 1/4 of adults with this early stage of infection fully recover within six months, without the need for medication. The other approximately 3/4 of people who are infected will go on to develop what is called chronic, or long-term, hepatitis C infection and will require treatment.

What does hepatitis C do to my body?

Most people with acute or chronic hepatitis C do not have any noticeable symptoms. Someone may have hepatitis C for years, or even decades, without experiencing symptoms that cause them problems.

Over time, the damage to your liver can get worse. This may lead to scarring and hardening of the liver tissue (liver cirrhosis)

and can eventually cause life-threatening complications such as liver failure and liver cancer.

Approximately two in every ten people who have chronic hepatitis C infection develop cirrhosis after about 20 to 30 years. A further small number of people who get cirrhosis go on to get liver cancer.

A healthy liver stores fuel for the body, helps digest food, and removes harmful waste from the body, such as alcohol. Hepatitis C can interfere with these processes.



How did I get hepatitis C?

Hepatitis C is mainly transmitted through blood-to-blood contact. There are many ways this can happen. You may have been exposed to the hepatitis C virus if you have ever:

- Prepared drugs or injected, inhaled, or snorted drugs using shared equipment, even once, such as needles, syringes, spoons, straws and water, etc.
- Had a blood transfusion in the UK before 1992.
- Received any blood products before 1987 in Scotland (1986 in England).
- Had an organ or tissue transplant in the UK before 1982.
- Had medical or dental treatment abroad in countries where infection control procedures may be poor.
- Worked closely with blood or in a place where you may have come into contact with infected blood, e.g. through a needlestick injury, or in a healthcare institution or correctional facility.
- Had tattoos, piercings, acupuncture or electrolysis where infection control procedures may be poor.
- Engaged in high-risk sexual behaviours. Sexual transmission is very rare, but there is increased risk for men who have sex with men, people who are HIV-positive, and for those who engage in high-risk sexual behaviours such as chemsex or unprotected or rough sex, where cuts and tears can occur.

Treatment for hepatitis C

“ **Hepatitis C is curable in almost everyone. Let’s get on and get rid of it.** ”

Professor John F Dillon
Consultant Hepatologist and Gastroenterologist, NHS Tayside

Hepatitis C affects everyone differently so you should talk to your doctor about your symptoms and options for treatment. The good news is that hepatitis C treatments nowadays work well and give people at least a 90% chance of clearing the virus completely, and with fewer side effects than previous treatments.

Getting treatment is an important decision because you’ll need to commit to a treatment plan and make a number of hospital visits for monitoring. Your doctor or consultant will discuss what’s

best for you and provide more detailed information on treatment and types of tests that will be carried out. You can improve the chances of your treatment being effective, as well as your general well-being, if:

- You take all the treatments you are asked to take, at the right time, and attend all your hospital appointments.
- You consider making lifestyle changes that can prevent further damage to your liver (see pages 10-11).

You will have cleared the hepatitis C virus if tests can’t detect the virus in your blood for **3 to 6 months** after completion of treatment. Your doctor may call this “**sustained virologic response**” or **SVR**.

What are the treatment options?

There are six types, or “strains”, of hepatitis C virus. The different strains are known as **genotypes**, and are simply numbered 1 to 6. In the UK, the most common genotypes are **1 and 3**.

There are many treatment options now available for hepatitis C, with all treatments offering at least 90% chance of clearing the virus completely.

The good news is that the treatment available nowadays consists of all-oral medications, and treatments which included PEGylated interferon injections are no longer recommended.

Current treatments usually involve taking a combination of two or three medications to fight the virus. This is called combination therapy.

Treatment can last between 8 to 16 weeks, depending on which treatment you are given.

Before you start treatment, your doctor will assess the health of your liver. This will include blood tests and a fibroscan, a non-invasive scan specifically for your liver.



The decision on which treatment you will be given will depend on what genotype of the virus you have, the level of damage the virus has caused to the liver, whether you have had treatment before, and the treatment most suitable for you.

As there are many individual factors relating to treatment choice you will be given further information about your treatment options after you have attended your initial appointments and your doctor or consultant has all the information needed.

If you are on other medications there are a small number of drug-drug interactions (DDI) that may dictate choice of which medication is used. The University of Liverpool web site www.hep-druginteractions.org should be consulted by your healthcare worker for potential interactions.

Does treatment have any side effects?

Older treatments including PEGylated interferon were known to cause side effects which, in some cases, could be quite severe. However, treatment plans containing interferon are no longer recommended.

With current treatments, some side effects do occur, but these are minimal. Fatigue and headache are the most common side effects.

This means that, for most people, treatment is relatively straightforward and without complications.

If you do experience any side effects, you will be given support by specialist services, although most side effects tend to improve with time as your body gets used to the treatment.

“ The side effects of my new treatment, in comparison to what I had been through before, were really minimal. There are side effects – everyone has their own side effects – but it was, in comparative terms to the older treatments, a relatively easy process. ”

Thomas, patient

If I have cirrhosis can I still get treatment?

If you develop liver cirrhosis this means that your liver is scarred and damaged and can't get rid of harmful waste from your body properly.

However, you still have a good chance of clearing the infection with treatment.

Recent studies have also shown that treatment may be beneficial for people with cirrhosis, and can reduce the level of liver inflammation.

If I have HIV can I still get treatment?

Yes, it is possible to treat both HIV and hepatitis C at the same time and you have an excellent chance of clearing the hepatitis C virus.

Some of the drugs used to treat HIV and hepatitis C can interact so if you decide to start hepatitis C treatment your doctor will discuss with you the best treatment options.

What if treatment doesn't work?

Even if you do not clear the virus, receiving treatment can help slow down the infection and can stop your liver getting swollen and scarred.

A very low percentage of patients will also relapse (this means that the virus becomes detectable again after treatment is completed).

If treatment doesn't work first time or if a relapse occurs, you will be able to talk to your doctor about trying a different course for treatment.

Re-treatment means that the drugs, the dosage and length of treatment are changed to offer an increased chance of success.

If I have been treated, could I get the virus again?

Yes, if you have cleared the hepatitis C virus this doesn't mean that you can't get the virus again.

You can become reinfected with hepatitis C if infected blood enters your bloodstream through blood-to-blood contact. Speak with your worker about ways to avoid this.

After successful treatment, you should also remember to replace or sterilise any personal hygiene items such as toothbrushes, razors, nail scissors, or any other item that can cut or graze the skin, as there is a small chance of becoming reinfected with hepatitis C from your dried blood.

My doctor says I have antibodies, am I still infected?

No. Even when you have been successfully treated for hepatitis C, you will always have hepatitis C antibodies in your blood. Antibodies were created by your immune system to fight the infection, and can't infect anyone with hepatitis C.

It is important to know about antibodies if you get another hepatitis C test. Usually an antibody test is carried out first, which shows if someone has ever been exposed to the hepatitis C virus. However, it doesn't show whether someone is currently infected, because they may have since cleared the virus from their body.

You should tell the person conducting the test you have previously cleared the virus and they will carry out the second test instead, called a PCR test, which shows if you have a current infection.

Living with hepatitis C

There are some lifestyle changes you can make when living with hepatitis C which will help your body and improve your overall well-being. These include:

Reducing or stopping alcohol and drug consumption

Alcohol and drug use can cause further harm to your liver.

With alcohol, it is essential to minimise alcohol intake or cut out alcohol completely in order to keep any damage to your liver to an absolute minimum. Research has shown that even moderate drinking can accelerate the progress of liver disease in people with hepatitis C.

Drug use can quicken the speed that damage is being done to your liver. If you have hepatitis C and are sharing equipment to prepare or inject, inhale or snort drugs, it

can also put other people at risk of getting the virus. To protect your liver and to reduce the risk of passing on the virus, consider stopping drug use, or use new equipment every time and never share.

If you have successfully been treated for hepatitis C, you must also be aware that you are at risk of reinfection if you are using drugs and sharing equipment.

Support is available if you need help to change your drinking or drug use habits (see page 21).

“ I was a heavy drinker, and had drunk every day for at least 10 years, but I was determined to give this treatment the best chance to work. I found the strength to stay on the wagon. ”

Phil, patient

Eating a healthy, balanced diet

It is important to maintain a healthy weight for your gender, age and height, and also to ensure that you eat a healthy, balanced diet. A healthy, balanced diet can help improve liver health and lower your risk of developing liver cirrhosis.

This includes:

- Drinking plenty of water to help the liver flush out toxins.
- Eating plenty of fruit and vegetables, good carbohydrates and proteins, foods which are high in fibre (e.g. wholegrain breads and cereals), and foods which are low in saturated fat (e.g. rice and pasta). These foods are much easier for the liver to process than fried, salty, and sugary foods.

You can arrange an appointment with a dietician to support you to make positive changes to your diet.

Staying active

There are many benefits to taking regular exercise including energy gain, weight loss, and mental well-being. All of these make a big difference to living with hepatitis C. People with hepatitis C are encouraged to take mild to moderate exercise, which can even include taking a brisk walk. Keep in mind, however, that if you are receiving treatment for hepatitis C, you may find your

capacity for exercise to be less.

Being active can:

- Improve your mood if you are feeling down
- Help relieve stress
- Help you sleep better
- Help you maintain a healthy weight
- Improve your body's ability to fight infections.

How can I prevent giving hepatitis C to other people?

It is important to understand that hepatitis C is spread through blood-to-blood contact (when blood of an infected person enters the bloodstream of an uninfected person) and to be fully aware of day-to-day and other situations where this might occur. If you take part in sports, for example, you must be aware that contact and team sports can often lead to injuries that may result in bleeding. If you use drugs, you

must make sure not to share any equipment used to inject, snort, inhale or prepare drugs and use a new set of equipment each time.

For some more situations on where blood-to-blood contact may occur, you may want to visit **www.hepatitisscotland.org.uk**. Always contact your GP, nurse, or other health care professional if you have any queries or concerns.

How can I protect my friends and family?

Firstly, it is important to know that hepatitis C can't be spread through kissing or cuddling, or from sharing cutlery or cups.

You can take simple precautions at home to prevent passing on the infection to others. You should avoid:

- Sharing personal hygiene items such as razors, toothbrushes, nail scissors, or any other item that can cut or graze the skin
- Lending or sharing jewellery that pierces the skin such as earrings or nose rings
- Sharing bath or hand towels that may have fresh or dried blood on them.

You might want to consider storing all your own items that can cut or graze the skin in a separate container. Label the box and the items, and let others know not to borrow them as a simple precaution for family and friends.

What do I do if I injure myself?

If you are bleeding, or come into contact with another person who is bleeding, you must make sure you know how to protect cuts and clear up blood spills properly with a **bleach-based product** to stop passing on your infection to someone else.

The hepatitis C virus can survive in both fresh and dried blood and is passed through blood-to-blood contact, but it is much harder for the infection to be passed on in dried blood.

If you cut yourself, wash your hands with soap under warm running water. Hold the cut under running water and clean the wound with soap, and cover the cut immediately with a waterproof dressing.

For a more detailed explanation on how to clean up blood spills please visit:

www.hepatitisscotland.org.uk

How do I protect my sexual partner?

There may be a very small risk of passing on hepatitis C while having sex. For people who are co-infected with HIV and hepatitis C, particularly gay or bi-sexual men, the risk of passing on hepatitis C through sex is increased.

The best way to prevent passing on the virus is by using a condom. Some kinds of sex are more risky than others, such as sex during a woman's period, anal sex, and sex where one of you has broken skin due to a sexually

transmitted infection. You should also avoid activities that nick or cut the skin to expose blood, such as biting or scratching.

Telling your sexual partner may or may not be easy but, however they react, it is important for them to have accurate information about hepatitis C and to know that simple precautions, like using a condom, can protect against passing on the infection.

I'm planning on having a baby – what should I know?

If you are on treatment or considering starting treatment, you need to tell your doctor or nurse if you are pregnant or planning to have a baby. As one of the treatments for hepatitis C can harm unborn babies, your doctor or nurse will advise what the best treatment option is for you.

You should also use two forms of contraception while on treatment, and for six months after treatment

has ended, if you are being treated for hepatitis C and if you:

- Are a woman of child-bearing age.
- Have a female partner who is of child-bearing age.

The doctor involved in your care can advise which forms of contraception may be most suitable for you.



If you are planning on having a baby then you may decide to delay having treatment for hepatitis C.

Many women who have hepatitis C have normal pregnancies and don't pass the infection on to their babies.

A small minority – about five in every 100 babies born to mothers who have hepatitis C – will get the infection.

What impact can hepatitis C have on my family and friends?

If you feel tired and unable to function normally, the people you are close to will naturally want to give you help and support.

They should know that the infection may not only make you feel physically unwell, but that it may also affect your mental well-being, and that any treatment side effects may mean you have to take time off work.

It is important that the people you decide to tell have good information about the symptoms and how the infection is treated. Understanding how to protect against infection will help to reassure the people in your life that they won't get infected. The people close to you may also need support and advice.

Who should I tell?

While you may hope that friends and family will be positive and supportive, you may be worried that telling others could harm your relationship with them.

When you are deciding who to tell, be sure you understand how to prevent infecting others and how easy it is for them to protect themselves. You may find it helpful to think about:

- The person's likely reaction
- Whether it will help you to cope if you tell someone
- The people you would really like support from
- The people who are likely to be affected by your hepatitis C, for example, the people you live with
- If anyone is, or has been, at risk of getting the infection from you.

You may feel it is responsible to tell people who could be exposed to your blood, for example, dental surgeons or healthcare workers.

Do I need to tell my employer?

You do not need to tell your employer unless you work in a job that could increase your chance of infecting others. This could be if you work closely with blood, e.g. if you are a healthcare worker, or if you work in a place where you may come into contact with blood, e.g. in a prison.

Once you know your treatment plan you may need to make some practical changes to your working arrangements.

You may get more support and help from your employer if you tell

them you need to be treated for a serious illness. Your employer may be able to change your hours or arrange for someone to cover your time off.

If you think it will help, you can ask your GP or specialist for a letter describing what is necessary. This doesn't need to reveal your hepatitis C diagnosis.

Many people with hepatitis C continue to work and find they don't need to tell their employer about their infection.



Some common concerns

What are my rights?

If you need time off work, you do have some legal protection. Discrimination against anyone with hepatitis C is unlawful under the Equality Act 2010.

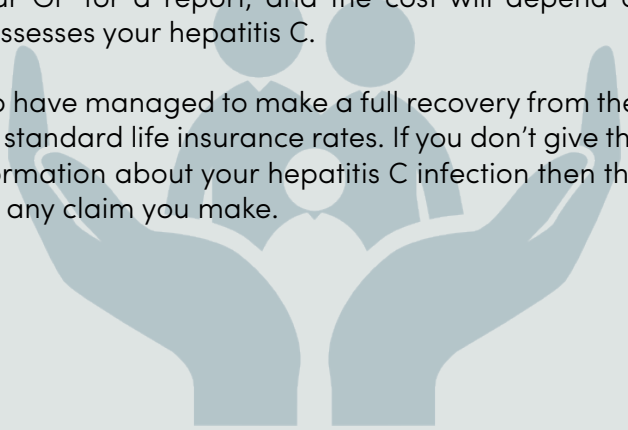
Money

If you have hepatitis C, you can still shop around to find financial products that will suit your circumstances.

What about my life insurance?

People with hepatitis C can get new life insurance cover but it is likely to be expensive, so you'll need to shop around to find providers and get the best deal on the products that suit you. The company will then contact your GP for a report, and the cost will depend on how the company assesses your hepatitis C.

People who have managed to make a full recovery from the virus have been given standard life insurance rates. If you don't give the company correct information about your hepatitis C infection then the company may refuse any claim you make.



Can I get a mortgage?

Yes. Mortgage lenders differ hugely in their criteria for sanctioning a mortgage these days and, in particular, the amounts they will advance to applicants.

You'll need to get good advice about the best option for you.

Visit www.unusualrisks.co.uk for information on financial products for people living with hepatitis C.

Can I get benefits?

If you are finding it difficult or impossible to stay in work due to having hepatitis C, then you may be eligible to claim benefits.

The Employment and Support Allowance (ESA) offers financial support and/or personalised help so that you can work if you are able to. If you are making a claim for this benefit, you may need to have a Work Capability Assessment to find out what work you will be able to do.

If you intend to make a new claim, you will be asked to complete the Work Capability Assessment to check if you can claim the Employment and Support Allowance. This assessment will work out what work you'll be able to do. You'll then be given support and advice to help you get back to work if you are able.

Services are available to assist people to make a claim. Ask your nursing team for information on local benefits support for people with hepatitis C.

For more information on Employment and Support Allowance, visit www.gov.uk/employment-support-allowance.

Where can I get more help?

Hepatitis C

Hepatitis Scotland

Provides education, information and support on viral hepatitis.

T: 0141 225 0419

W: www.hepatitisscotland.org.uk

NHS Inform Hepatitis Helpline

A free and confidential helpline providing information about viral hepatitis.

T: 0800 22 44 88 (Mon-Fri 8am-10pm, Sat-Sun 9am-5pm)

Waverley Care

Provides care and support to people living with hepatitis C or HIV.

T: 0131 558 1425

W: www.waverleycare.org

Hepatitis C Trust

Provides information and support to those affected by hepatitis C, including to family and friends.

T (confidential helpline): 020 7089 6221 (Mon-Fri, 10.30am-4.30pm)

E: helpline@hepctrust.org.uk

W: www.hepctrust.org.uk

Hep C Scot

Information provided by third sector organisations working in partnership with NHS Boards.

W: www.hepcscot.org

Healthy living

Active Scotland

Provides information on local opportunities to be active.

W: www.activescotland.org.uk

Take life on, one step at a time

Tips on healthy living from Scottish Government.

W: www.takelifeon.co.uk

Mental health and well-being

Samaritans

A free and confidential 24-hour listening service for anyone who is struggling to cope or experiencing feelings of distress.

T: 116 123

W: www.samaritans.org

Breathing Space

A free, confidential phone service for anyone experiencing low mood, depression, or who is unusually worried and in need of someone to talk to.

T: 0800 83 85 87 (Mon-Thur 6pm-2am, Fri-Mon 6pm-6am)

W: www.breathingspace.scot

NHS 24

NHS 24 provides comprehensive up-to-date health information and self care advice for people in Scotland.

T: 111

Living Life to the Full

Free online courses covering low mood and stress and all of the common linked problems this causes.

W: www.lltff.com

Alcohol and other drugs

Scottish Drugs Forum

A drugs policy and information organisation which offers a national resource of expertise on drug issues.

T: 0141 221 1175

W: www.sdf.org.uk

Drinkline Scotland

A free and confidential helpline providing support and advice on any alcohol-related concerns.

T: 0800 7 314 314 (8am–11pm, 7 days a week)

Know the Score

A free and confidential helpline providing information, advice and support on drugs and drugs-related issues.

T: 0800 587 587 9 (8am–11pm, 7 days a week)

W: www.knowthescore.info

Addaction

A UK-wide treatment agency that helps individuals, families and communities manage the effects of drug and alcohol misuse. To find the nearest Addaction service, use the service finder on their website.

T: 020 7251 5860 (general enquiries and information)

W: www.addaction.org.uk

NHS Inform - Stopping Smoking

A NHS resource providing information and support on stopping smoking as well as Smokeline, a free and confidential advice and support line for anyone trying to stop smoking in Scotland.

T: 0800 84 84 84 (Mon–Fri 8am–10pm, Sat–Sun 9am–5pm)

W: www.nhsinform.scot/healthy-living/stopping-smoking

Equality and human rights

Equality Advisory and Support Service Helpline

A free to call helpline which advises and assists individuals on issues relating to equality and human rights.

T: 0808 800 0082 (Mon–Fri 9am–7pm, Sat 10am–2pm)

W: www.equalityadvisoryservice.com

Employment and welfare rights

Acas Helpline

The Acas Helpline provides free, confidential and impartial advice about any kind of employment dispute, as well as employment rights and rules.

T: 0300 123 1100 (Mon–Fri, 8am–6pm)

W: www.acas.org.uk

Citizens Advice Direct

Citizens Advice Direct provides advice on any issue including, but not limited to, benefits, employment, housing, relationships and debt.

T: 0808 800 9060 (Mon–Fri, 9am–6pm)

W: www.advice.scot

GOV.UK

Provides information on government services and information for citizens and businesses, including guidance regarding benefits and employment.

W: www.gov.uk

Glossary

acute A recently developed condition. For viral hepatitis, the first six months of infection.

antibody Antibodies are proteins produced by the immune system to help fight against infections. You will always have antibodies in your blood, even when you have been successfully treated for hepatitis C.

blood-to-blood contact When someone's blood gets into the bloodstream of another person, such as through an open wound, or through items which have come into contact with infected blood.

chronic A condition which persists for a long time. For hepatitis, when the infection lasts longer than six months.

cirrhosis Advanced liver fibrosis, or advanced scarring of the liver caused by long-term liver damage. Healthy liver tissue is replaced by scar tissue and prevents the liver functioning properly.

combination therapy When more than one medication or therapy is used to fight the same condition. This often means that a combination of two or more drugs are used.

compensated cirrhosis When the liver is heavily scarred but can still perform many important bodily functions. Many people with compensated cirrhosis experience few or no symptoms and can live with the condition for many years without serious complications. Compensated cirrhosis eventually progresses to decompensated cirrhosis.

decompensated cirrhosis When the liver is extensively scarred and can't function properly. People with decompensated cirrhosis eventually develop many symptoms and complications that can be life-threatening.

detectable This means that the virus is at a level in your blood which can be measured by tests.

drug-drug interactions (DDI) These occur when two or more drugs react with each other. They may make your drug less effective or cause you to have an unexpected side effect.

fibroscan A non-invasive device, which is similar to an ultrasound but specifically for the liver, and which determines if liver damage (fibrosis or cirrhosis) is present.

fibrosis Damage to the liver which occurs when healthy liver tissue is replaced by scar tissue and prevents the liver functioning properly.

genotype For viral hepatitis, the genetic make-up of the virus. There are six major genotypes, or strains, of hepatitis C virus and these may influence treatment options.

jaundice The term used to describe the yellowing of the skin and whites of the eyes. It is associated with liver and gall bladder problems.

liver An organ involved in the digestion of food, storage of nutrients, and removal of toxins, as well as many other important bodily functions.

reinfection The term used when someone who has previously been infected with hepatitis C, and then cleared the virus, is re-exposed to the virus and becomes infected again.

relapse The term used if the virus becomes detectable in the blood again after treatment is completed.

sustained virologic response (SVR) The term used when tests can't detect the virus (undetectable) in the blood for three to six months after treatment is completed.

undetectable This means that the virus is at a level in your blood which is too low to be measured by tests.

Notes and questions

Use this page to write down any notes or questions you may have for your doctor or nurse about hepatitis C treatment or living with hepatitis C.

Hepatitis

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