

BOOKLET 2

HEP C CARE

Living with hepatitis C
and treatment options



Living with hepatitis C and treatment options

Writers: Danny Morris and Magdalena Harris

Editor: Magdalena Harris

Design: Mark Bunegar, flukedesign.com

Thanks to all who helped in the development of this resource.

Particularly:

Members of the Hep C Resource focus groups

Participants of the LSHTM Hep C research projects

Martin McCusker and members of the Lambeth Service Users Forum

Andrew Preston, Exchange Supplies

Ashley Brown, Consultant Hepatologist at St. Mary's and Hammersmith Hospitals

Janet Catt, Kath Oakes and Jo Schultz, Viral Hepatitis Clinical Nurse Specialists

Chris Ford, Clinical Director IDHDP

Emma Ward, Jim Conneely and Samantha May, The Hepatitis C Trust

Eliot Albers, INPUD

Emma Burke and Helen Harris, PHE

LJWG, Dovetail, Lumieres and Gilead Sciences

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.

This booklet has been developed through a joint working initiative between The London Joint Working Group on Substance Use and Hepatitis C (LJWG), Gilead Sciences Ltd, Addaction and Imperial College NHS Foundation Trust.

Gilead Sciences had no influence over the content of this resource.

This booklet draws on work by Dr Magdalena Harris at The London School of Hygiene and Tropical Medicine.

Dr Harris is funded by a National Institute for Health Research postdoctoral fellowship [NIHR-PDF-2011-04-0311].

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



NHS
National Institute for
Health Research

Introduction

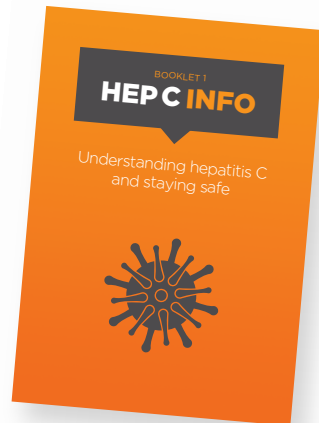
This booklet is about hepatitis C (hep C). It contains information about living with hep C, managing common hep C symptoms, your rights to treatment and treatment choices.

Hep C treatments are improving, with new drugs licenced and in development. As not all of these drugs are widely available your doctor will be able to advise you on your treatment options.

Choosing when to have treatment, or whether to have it at all, is a personal decision. Making this choice can be easier with accurate information. This booklet provides a guide. If there is anything you don't understand or want to discuss, there is space at the back to note questions, and a resources section for information sources.

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

This booklet is the second of two. You can find out more about hep C, testing and prevention in booklet 1: Hep C Info.



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 hepatitis 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 is transmitted through blood. The use of unsterile injecting equipment is the main route of transmission in the UK. It is not considered a sexually transmitted condition (apart from when blood is involved) and cannot be passed on through kissing, hugging, sharing plates or utensils.

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

What are hep C genotypes?

There are six basic types (strains) of the hep C virus.

These are called genotypes 1, 2, 3, 4, 5 or 6. Some genotypes have further variations called subtypes, for example 1a and 1b. Generally, all genotypes can affect the liver the same way. If you have hep C and are thinking about treatment, knowing your genotype is important, as different genotypes respond differently to treatments.

The progression of hep C

Acute stage

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

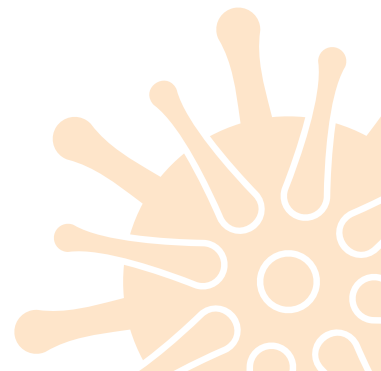
- Most people do not experience symptoms during the acute phase
- Some people may have flu-like symptoms, including fever, tiredness, loss of appetite, stomach pains, nausea and vomiting and, occasionally, jaundice
- Around 20 to 25% of people will clear hep C during the acute stage

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

Chronic stage

- The second stage is chronic (long-lasting) infection, where the virus 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
- Symptoms of chronic hep C include: fatigue and low energy; depression; disrupted sleep; memory loss and difficulty concentrating (brain fog); sweats and chills; appetite loss and nausea; muscular aches and pains; abdominal pain; dry and itchy skin; blurred vision.

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. Liver damage is more likely 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.

Liver disease can be advanced by the time hep C symptoms occur. For this reason, it is advisable to be tested and treated early, rather than waiting until symptoms develop.

Cirrhosis

Approximately one in five people with chronic hepatitis C will develop cirrhosis 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.



Symptoms of cirrhosis

There are usually few symptoms in the early stages of cirrhosis. However, as your liver becomes more damaged and loses its ability to function properly, you might experience symptoms including:

- Loss of energy, and feeling tired; feeling depressed; loss of appetite; feeling sick; weight loss or sudden weight gain; bruising easily; itchy skin; light coloured or dark, tarry-looking stools;

and if the liver damage becomes very serious it can cause:

- Jaundice (yellowing of skin or whites of the eyes)
- Build-up of fluid (oedema) leading to swelling of the abdomen, legs and ankles.
- Abdominal pain, especially in the liver area and bloating (ascites)
- Vomiting blood
- Confusion, disorientation, and personality changes (encephalopathy)

If the damage continues, eventually the working parts of the liver can no longer support, or compensate for, the damaged parts. This is known as decompensated cirrhosis and can lead to serious and life-threatening complications.

Max



In the intensive care, I was laying there and I thought physically this body can't take much more, because everything was happening. I was vomiting blood and I was shitting through the eye of a needle. I was so weak, my legs weren't working, and I thought, physically I can't take any more, and I just looked up into a dark space and I smiled and I thought, well, here I am.

(just before his liver transplant)

Living well with hep C

Hep C is sometimes known as ‘the silent disease’ because its symptoms aren’t always obvious. Common symptoms, such as fatigue, nausea, brain fog and depression, can be easy to overlook or attribute to something else. Symptoms may begin months or years after getting hep C and can come and go.

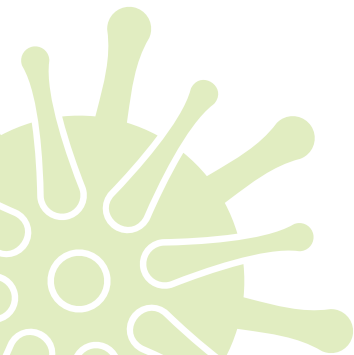
Making lifestyle changes can reduce symptoms and slow down the development of liver disease. These changes may include reducing alcohol consumption, eating a healthy diet, drinking plenty of water, exercising, managing stress and getting enough rest.

It’s worth talking to your doctor and other people involved in your care to get advice about the things that can help you stay as healthy as possible and cope better with hep C.

Hannah



I found out I had hep C last year and I've made some changes since then. I haven't had a drink since that day, I've lost two and a half stone. I had ten weeks of thinking "oh my god, I'm going to drop down dead". Then I took charge of it rather than it taking charge of me. I thought "this isn't going to kill me, I'm going to be well"



Managing common hep C symptoms

Fatigue and sleep problems

Fatigue, an intense tiredness or lack of energy, is the most common hep C symptom.

Allow yourself to rest when you are able to. Eating small meals throughout the day, gentle exercise and drinking plenty of water can help maintain energy.

Hep C fatigue is not necessarily related to sleep problems, although people with hep C can also have trouble sleeping.

Sleep problems can be helped by:

- Introducing some exercise into your day
- Avoiding heavy exercise, meals, caffeine, alcohol or computer use close to bed time
- Relaxation tapes, meditation or deep muscle relaxation
- Talking to someone about, or writing down, any recurring thoughts or anxieties that might be disturbing your sleep

Fatigue and sleep problems can also be caused by **stress, depression and a variety of health problems**. If you are affected by lack of sleep for any length of time, **tell your doctor**.



Depression, irritability and anxiety

Hep C can cause or increase low mood, depression, irritability and anxiety. Understanding the connection between these feelings and your hep C can help, especially if you are able to get support from those close to you.

Consider talking to your doctor.

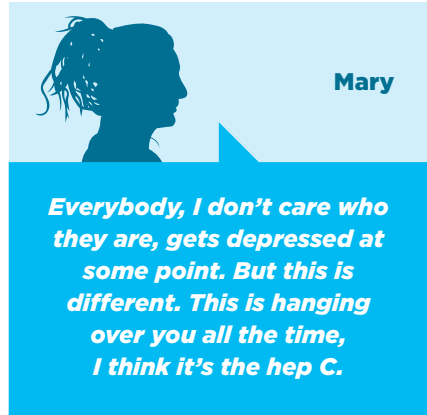
They might advise a course of anti-depressants, talking therapy (such as CBT) or lifestyle changes, such as taking up exercise or relaxation techniques. Connecting with friends and/or support groups can also help.

Nausea and poor appetite

Hep C can cause episodes of nausea and indigestion which can affect your appetite. Try eating small meals often and avoiding fatty and highly processed foods. Ginger, peppermint, spearmint, fennel seed and aniseed teas can reduce nausea, bloating and abdominal cramps. Bitter foods (lemon and water, olives, rocket) taken before meals can aid digestion.

Brain fog and forgetfulness

Many people with hep C experience 'brain fog' where thinking clearly or concentrating can be difficult. Like other symptoms of hep C, brain fog can come and go. The exact cause of brain fog in people with hep C is poorly understood but complementary therapies like meditation, deep breathing exercises, and yoga can help ease symptoms. Practical tips include making lists of things you need to do and talking through important decisions with someone you trust. Many people find they are able to think more clearly after successful hep C treatment.



Mary

Everybody, I don't care who they are, gets depressed at some point. But this is different. This is hanging over you all the time, I think it's the hep C.

Abdominal pain

Hep C can cause liver discomfort. Soreness may be felt just below the ribs on the right hand side. Some people find heat packs helpful, especially at night. Over the counter pain relief (e.g. paracetamol) can help, but get medical advice from your doctor first.

Dry skin, rashes and itching

Skin rashes and complaints are fairly common and may come and go. Un-perfumed soap and moisturisers can help to reduce skin dryness and soothe irritations, minor rashes and itching. Your pharmacist or doctor can provide advice on over-the-counter or prescription medicines (such as steroid creams) to manage skin complaints.

Some hep C symptoms (such as dry skin and nausea) are similar to hep C treatment side effects. See page 22 for additional self management tips.

Mary



I thought there's something wrong with me but I put it down to being menopausal, too stressed, I thought this is getting older; this is the start of memory loss. But afterwards when I started to put it together and learn more about hepatitis C I thought, yes, that's exactly what I had.



How will hep C impact my lifestyle?

Alcohol

Your chances of developing liver damage are higher if you have hep C and drink alcohol. Stopping drinking or drinking less can be the first step towards reducing your risk, although this isn't easy for everyone.

If you have difficulty cutting down how much you drink, there are a variety of organisations that can help – see page 37 or ask your doctor for support.



Diet

Most people with hep C don't need a special diet. Eating a wide variety of food and having a balanced diet can help keep your liver healthy. Some people with hep C find they can't eat fatty foods. It can also help to cut down on sugar, salt, fried and processed foods.

Avoid putting on too much weight. Being overweight is linked to type 2 diabetes, which is more common among people with hep C than the general population. Having both hep C and diabetes can increase the risk of serious liver disease.



Drugs

The liver breaks down the drugs we take. The amount of liver damage you have will effect how well your liver can process over-the-counter, prescribed and illicit drugs. Alcohol is the primary drug to avoid for anyone with liver disease. Tobacco smoking is associated with increased fibrosis and gum disease. Paracetamol is a recommended pain killer for people with hep C, but it is important not to take more than eight 500mg tablets a day.

There is not a lot of information about how street drugs (such as heroin, crack, ecstasy or speed) affect the liver. Heroin is not liver toxic, but the substances it is cut with might be. Generally stimulants are more likely to stress your immune system and impact your overall health.

Studies suggest that daily cannabis use increases liver damage. However, some people find that cannabis can be an alternative to alcohol and can help relieve some hep C symptoms and treatment side effects.

If you inject drugs take special care with your equipment. Hep C is easily spread by sharing works, filters and cookers. Booklet 1 has more information on staying safe when injecting and preventing transmission of hep C, other blood borne viruses and infections.

Complementary and alternative medicines

Some people find that complementary or alternative medicines (CAM), such as herbs, massage, aromatherapy, reflexology, t'ai chi, meditation and acupuncture, can help relieve stress and some hep C symptoms. They cannot clear the virus.

Some alternative medications (such as herbal preparations) can be liver toxic or react with prescribed medicines – ask your doctor for advice, especially if you are considering hep C treatment.



Stress and exercise

The stress of living with a chronic illness like hep C can affect your overall health. Techniques to reduce stress include: having a bath, massage, yoga or meditating. Taking up new interests or challenges, exercise and meeting with friends can also help.



Being active can improve overall health and has both physical and mental benefits. There are many ways to increase activity. Your choice will depend on what you enjoy, how fit you are and how your body reacts to exercise.

As well as helping you feel better, being active can keep your weight in check and help with other hep C symptoms, including sleep problems, joint pain and fatigue.

Sex

People with hep C can be unnecessarily afraid of passing it on to their lovers. Some describe feeling isolated because of this fear.

The risk of catching hep C through sex is generally very 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.

Some people find that hep C reduces their sex drive. It can help to talk about this with partners, to reduce any potential strain on a relationship.

Jerry



She told me when we started going out. Look, she said, I've got hepatitis C. I talked to me doctor about it, he says, it doesn't matter. You can use a condom or not use a condom but the chances of you catching hepatitis C through sex is about one percent. He said it's very low indeed.

Theo



My sex drive is zero. When my liver was bad it was getting lower and lower. I've always been pretty active in that department, so it's a bit of a disappointment. My partner is very understanding, so I'm lucky in that respect.



Treating hep C

Hep C is treatable and curable.

Choosing whether or not to start treatment is not always an easy decision. There are many factors to consider, including how you're feeling right now, the treatments available and how any side effects might affect day-to-day living, relationships or work.

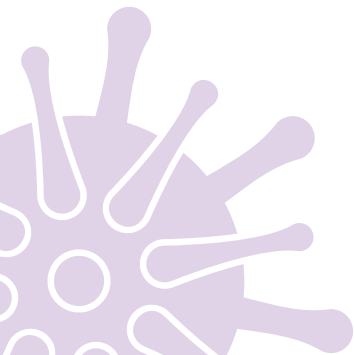
Recent drug developments have resulted in shorter, more tolerable and effective treatment regimes, although these are not widely available for all. Generally speaking, if your liver is in good health you can afford to wait, but if you have advanced fibrosis having treatment sooner will be the better option.

Your doctor or nurse can guide you about your 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 helplines (see page 37).



Jake

Believe it or not I'm kind of looking forward to it. Facing up to this thing that I've been running away from for so many years.



Your rights to treatment and care

Everyone has a right to see a specialist to discuss hep C treatment options. If you would like a referral, but have not been offered one, ask your GP.

If you do not have a GP or still have problems obtaining a referral or assessment, organisations such as the Hepatitis C Trust (see page 37) can provide names of suitable GPs and hospitals for your care.

GP Care

You don't need to be registered with a GP to get treatment, but they can be a good source of support. Under the NHS Constitution (see page 38) you have the right to register with a GP practice near where you live, even if you originally come from abroad.

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.

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. You will need to fill in a form and provide proof of who you are and where you live. GPs who work in partnership with drug treatment services often have more knowledge about hep C and can be a good choice if you want a new doctor.



What if I'm using drugs?

Everyone with hep C is entitled to hep C treatment assessment, including people who are currently using illicit drugs.

National (NICE) and European (EASL) hep C treatment guidelines make it clear that people who inject drugs are eligible for hep C treatment:

[Hep C] treatment must be considered for people who inject drugs, provided they wish to receive treatment and are able and willing to maintain regular appointments.

(EASL hepatitis C treatment guidelines 2014)

If you are refused treatment on the grounds of illicit drug use alone, you have the right to be referred to another hospital for your care.

Hep C treatment is generally provided in specialist hospital settings. In some areas, hep C treatment can also be accessed at drug treatment services, or through shared care with your GP.

Some services offer multi-disciplinary support throughout hep C treatment. This care is usually coordinated by a dedicated nurse and can include input from drug and alcohol services, psychiatric services, social work and other social care services, including peer support.

Davey

My hep C nurse sent a message to my key worker and got in touch with my doctor. They know what's happening and what to expect. I just feel like everything's a bit more secure with it all, rather than going to the hospital and no-one knows.

Methadone and buprenorphine

Hep C is very common among people on opioid substitution treatment (OST), such as methadone or buprenorphine. OST should not be a barrier to hep C treatment, and some people find that increasing doses of methadone or buprenorphine can help them manage side effects.

It is generally not recommended to reduce OST while on hep C treatment.

Co-infection

If you have hep C and another infection such as HIV or hep B, your liver disease is likely to progress faster. However, if you do have HIV or hep B your hep C can still be effectively treated.

Having hep C can impact on your HIV treatment choices, as some HIV treatments are more toxic to the liver than others. In this case your specialist HIV doctor can advise you on the best treatment options.

A hep B vaccination is recommended for anyone living with hep C.

Pregnancy and contraception

Ribavirin can cause birth abnormalities and it is important to avoid pregnancy and breastfeeding while on hep C treatment and for 4 to 6 months after treatment ends. Women of childbearing age and also their partners will be advised to use effective contraception when either partner is on treatment. If you are considering starting a family, discuss this with your nurse or doctor when considering your treatment options. You may decide to have treatment before getting pregnant to avoid the small chance of passing hep C on to your baby (around 5%).

What is hepatitis C treatment?

Hep C treatment is a rapidly evolving field. Speak to your treatment doctor or nurse to find out what treatments are available and advised for you.

Until recently, standard treatment has consisted of two antiviral drugs: a weekly injection of pegylated interferon plus ribavirin tablets twice daily for 24 to 48 weeks. Both drugs commonly cause side effects. Treatment success rates vary depending on the genotype of the virus (around 50% cure for people with genotype 1 and 70 to 80% for people with genotypes 2 and 3).

A growing understanding on how the hep C virus works has led to the development of a new class of drugs for treating hep C.

These first generation direct acting antiviral (DAA) drugs became available in 2011. When used with ribavirin and interferon as triple therapy, this combination has improved cure rates for people with genotype 1. However, these drugs are also associated with side effects, including rash and anaemia.

More recently a range of second generation direct acting antivirals have been developed. Where available, these new therapies offer shorter treatments with fewer side effects and higher cure rates (around 90%). These newer DAAs do not have to be used with interferon and are more suitable and safer for people with cirrhosis or advanced liver disease than earlier treatment options.

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

What are the side effects of treatment?

Interferon and ribavirin treatment, with or without a DAA, often involves side effects. The most common are flu-like symptoms such as: chills, fever, headaches, fatigue, muscle pains and loss of appetite. Other common side effects include: anaemia, depression, mood swings, sleep-disturbance, skin irritation/rash, dry/sensitive eyes and brain fog.

Management of side effects has improved over the years and with the right help most people who start treatment now complete it.

When side effects occur, tell your treating doctor or nurse. They can help you manage and reduce side effects. This might involve an adjustment of the combination medication dosage or taking additional medications.

Matt

It [treatment] really did knock me sideways, and there was one point I just wanted to jack it in. That would be stupid because I'd regret it afterwards, but that's how I was feeling at the time.



Managing common side effects

Below are some tips to help manage common side effects of treatment containing interferon and ribavirin. If you do experience any side effects or distressing symptoms on treatment, let your doctor know.

Side effect	Things that can help
Anaemia (tiredness, shortness of breath, faintness, increased heart rate, lower leg cramps)	<p>Tell your doctor or nurse specialist if you experience any of these symptoms as you may need to reduce some of your medication.</p> <p>Take it easy, rest when you are able to. If possible delegate tasks and don't take on extra obligations.</p>
Dry skin and rash	<p>Tell your doctor about any rash that occurs during treatment, especially if it is spreading fast.</p> <p>Try non-perfumed skin products, laundry detergents and soap.</p> <p>Use sunscreen when in the sun.</p> <p>Try moisturising creams and warm (not hot) oil baths.</p> <p>Tell your doctor or pharmacist if skin problems persist. Some over the counter and prescription creams can help.</p>
Dry or sensitive eyes	<p>Try eye ointments or drops</p> <p>Consider wearing glasses rather than contact lens</p> <p>Avoid smoke and air conditioning</p>
Hair loss	<p>Hair loss isn't medically serious but it can be upsetting.</p> <p>Hair usually grows back to normal after treatment.</p> <p>Keeping your hair short can help disguise any loss.</p> <p>Avoid harsh chemicals and hair dyes</p>

Side effect	Things that can help
<p>Headache, joint or muscle pain and flu-like symptoms</p>	<p>Paracetamol is recommended for headaches, joint and muscle pain. If this has no effect speak to your doctor and don't take more than the advised dose.</p> <p>Drink water throughout the day</p> <p>If taking interferon, try having your injection before going to bed. This, and taking paracetamol an hour before the injection, can help reduce flu-like symptoms.</p> <p>These symptoms are more likely the first or second day after interferon injections. Avoid planning major events for these days.</p> <p>Some people find massage, aromatherapy, acupuncture, reflexology or osteopathy helpful.</p>
<p>Abdominal pains</p>	<p>Liver pains are common. It's not clear why they occur, but speak to your doctor if they persist.</p> <p>If you drink alcohol, drinking less may help.</p>
<p>Appetite loss or nausea</p>	<p>Try eating small, frequent meals and snacks with protein (e.g. cheese, eggs, nuts).</p> <p>Ginger (tea, lozenges etc) can help with nausea</p> <p>Eating bitter foods (olives, rocket etc) or drinking lemon juice and water before meals can improve digestion.</p> <p>Speak to your doctor if you think you might need protein-supplement drinks or vitamins.</p>
<p>Coughs</p>	<p>Sip water regularly, suck sugar-free lozenges or use cough medicines.</p> <p>Warm water with honey and lemon can also be soothing.</p>
<p>Depression and mood changes</p>	<p>Depression can be accompanied by feelings of irritability, anger, restlessness and worrying thoughts.</p> <p>These are related to the treatment and are temporary.</p> <p>If possible, explain to family and friends that hep C treatment can affect the mood so they can be supportive.</p> <p>Moderate exercise can help.</p> <p>Talk to your doctor or nurse specialist. Anti-depressant drugs might be an option. It can help to start these before commencing treatment as they take a couple of weeks to work.</p>

Side effect	Things that can help
Insomnia	<p>Some people find it helpful to:</p> <ul style="list-style-type: none"> ■ Establish regular sleep time, aiming for 8 hours a night ■ Keep naps short and early in the day ■ Have a warm (not hot) bath before bed ■ Try relaxation techniques to reduce stress ■ Avoid heavy meals before bed ■ Avoid tea, coffee or other drinks that contain stimulants, including some herbal teas. Warm milk at bedtime can help. ■ Prescription and over-the-counter drugs can be effective, although these can be habit forming and tend to only work in the short term.
Mouth ulcers	<p>Use a soft toothbrush and be gentle when brushing your teeth</p> <p>Avoid spicy foods</p> <p>Avoid mouthwash containing alcohol. Try a mouthwash made with warm water and a teaspoon of salt and baking soda</p> <p>Sugar-free lozenges or chewing gum can help</p> <p>Talk to your doctor or nurse about any medications that may help soothe your mouth.</p>
Dry mouth	<p>Drink lots of water.</p> <p>Keep a glass of water by the bed at night and take a bottle of water with you when you go out.</p> <p>Pharmacists can advise on products that can help reduce the discomfort of dry mouth including mouthwash, mouth gels and chewing gum.</p>
Brain fog	<p>List things you need to do, note down questions to ask your doctor</p> <p>Give yourself time to complete tasks.</p> <p>Talk to someone you trust before making major decisions.</p>

Pros and cons of treatment

The main benefit of treatment is that it's the only proven way of clearing chronic hep C.

Many people who clear hep C notice their energy return and their quality of life improve significantly.

Even if treatment is not successful, it can improve liver health by reducing inflammation.

Knowing that you've given it a go can boost self confidence and put you in touch with professionals for ongoing liver monitoring and updates on treatment options.



Matt



I realised how much better I was feeling, once it was out of my system, I definitely had more get up and go.

Ivan



Getting shot of hep C, it's making me more confident, free ... I just feel so much more lifted, I really do and if it didn't work, let's have it right, at least I was given the option, at least people are trying for me, they've not given up on Ivan, he's not worthless, he's worth it, let's give him an hand.

There may be good reasons for putting off treatment, such as if you are pregnant or trying for a family, have severe depression, or simply that it is not the right time for you.

Interferon and ribavirin based treatment is associated with side effects. Not everyone has them, they are temporary and manageable, but it is possible that you will feel unwell some of the time. It can take a few months after the treatment ends before the drugs are cleared from your system. Some people experience ongoing side effects after treatment.

Treatment and side effects can temporarily impact your relationships, work and social life, but this impact will become less in the future, as new drugs with fewer side effects become available.



Shane



They [nurses] said that one of the side effects of Interferon is depression and they wanted to talk to my GP to make sure I'd be stable enough to have the treatment.

Abel



I think it took about a month and then slowly I started realising I'm feeling better. Then before you know it like that cloud is going, it's drifting away and realising I can walk upstairs without getting out of breath and that's when you think yeah, wow, I am getting better man, yeah.

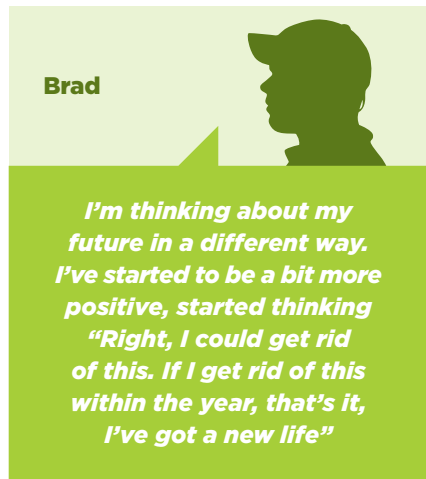
Is it the right time for me to have hep C treatment?

This simple exercise can help you decide if it is the right time to start hep C treatment. List the reasons why you want to get treated (pros) and the reasons why you're uncertain (cons).

Then look at how important each one is to you. Comparing the pros and cons can help you decide on your next steps. You might find that your motivations change over time as your situation changes or as new treatments become available.

Example pros or motivations for treatment:

- I might get rid of the hep C
- It is a chance of feeling better for the long term
- I might stop feeling so exhausted and irritable
- I can get rid of this brain fog
- I can improve my liver health
- I can drink alcohol again
- I won't need to worry about passing on hep C to someone else
- I want to get rid of hep C so I can get pregnant
- I won't have to worry about whether to tell people I have hep C any more
- I can live free from fear of serious liver disease or liver cancer.



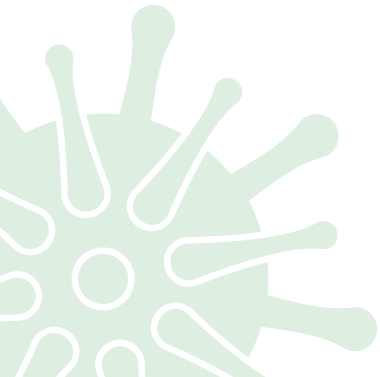
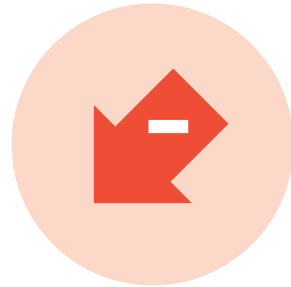
Examples of treatment concerns:

- The treatment might not work
- I might have to take time off work
- I don't want to tell my partner/friends/children
- I might not cope well with the side effects
- There is too much going on in my life at the moment
- I might not be able to care for my kids
- I don't want anyone to know I have hep C or am going through treatment
- I don't have enough support
- I don't have a stable place to live
- I hate hospitals!

Alec



[I was frightened] because of all the stories I was hearing, the medication, what it does to you, this and that. But now I understand it more, maybe because I'm in a better place. So I'm ready to deal with it.



Tests before and during treatment

Before starting treatment, you will usually need more tests to help you and your doctor decide the best treatment option for you.

As well as discussions about your lifestyle, other medical conditions and medicines you might be taking, your assessment can include tests for liver damage. Knowing how much scarring or cirrhosis you have can determine the type and length of your treatment.

Tests include:

- Blood tests such as liver function tests (LFT)
- A genotype and viral load test
- Ultrasound scan, or fibroscan
- Liver biopsy is no longer necessary for everyone. It is often reserved for cases where the results from the ultrasound or fibroscan are not clear.



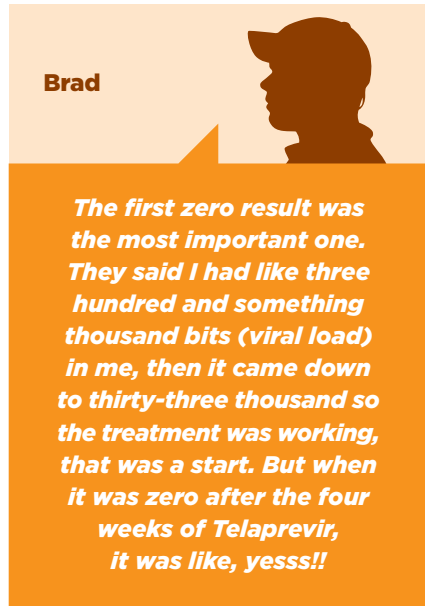
Sammy

I said to a friend "I've got to go for this liver scan and I'm shitting myself because I'm thinking they might find something else wrong with me". They went "just go because it don't make no difference, you never know until you go"



Once you start treatment the levels of the hep C virus in your blood (viral load) will be monitored. The results of these tests include:

- **Rapid Viral Response:**
viral clearance at week 4 of treatment. This means your chances of treatment success are very high.
- **Early Viral Response:**
viral clearance or significant drop at week 12 of treatment
- **Non-Response:**
no significant drop in viral load at 12 weeks of treatment. This means the treatment is unlikely to work.
- **Sustained Viral Response:**
viral clearance (a negative PCR result) 24 weeks after treatment finishes.



This means the hep C is cured and is very unlikely to return. In newer treatment regimens the SVR can be determined at 12 weeks post treatment.


Depending on your treatment regimen you will also be monitored for changes in your haemoglobin (red blood cells, affecting anaemia), neutrophils (white blood cells, affecting immunity) and other blood markers throughout treatment.

After successful treatment you will continue to have antibodies in your blood, showing that you have been exposed to the virus in the past. This does not mean you have active hep C, but also does not mean you are immune from catching it again.

Managing appointments and medication

You have the right to take someone with you to any hospital appointment or hep C assessment. Many people find it helpful to have a friend or family member there for support and to talk through the options, especially in the early days when there is a lot to take in.


Hep C might affect your memory. Having ‘brain fog’ can make remembering appointment and medication schedules difficult.



Taj

I was scared in the beginning, seriously scared ... my brother came with me to my first and second appointment. I'm saying "No, stay away, I'm okay", he was like "No, I'm coming with you". It felt like an extra hand, you feel you've got a right hand with you.

Marta



She [the nurse] did everything for me. She booked everything and wrote it down, she sent the letters and all the tests. She would call me, send a text to remind about the appointment. She was really good. If it wasn't for her, I wouldn't be doing it.

It is important to take hep C medication as prescribed. If you skip doses or stop treatment, you run the risk of not clearing the virus.

Tips for helping to remember medication and appointment times include:

- Daily pill containers
- A calendar or electronic organiser to note appointments and medication times
- Medication reminder apps – there are many available to download
- Phone or clock alarms
- Organise text or phone appointment alerts through your doctor.
- Post-it notes to remind yourself of appointments and medication schedules
- Create habits and daily routines
- Ask house mates, friends or family to remind you

Taj

One morning I had a tablet and a few minutes later, "I can't remember, did I have my tablet or not?". Now my wife or my mum or someone brings them to me on the table, I will not forget, it's in front of my eyes.



Treatment support

Before you start treatment it is advisable to have a discussion with your doctor or nurse to plan the support you need, based on your individual circumstances and needs. Ideally you should be given advice on managing side effects, and on alcohol and drug use (prescribed and illicit) during treatment.

If this doesn't happen or you feel you need more information, see resources page for more support options. Writing down questions to ask your doctor or nurse at your next appointment is also a good strategy (spaces on next pages).

As well as healthcare professionals, partners, family and friends all play an important role in providing emotional and practical support when you are on treatment.

If you're feeling unwell, or need to get to a hospital appointment, practical help with household tasks or childcare can make a big difference.

Peer support, local groups and online forums are a useful resource if you are finding it hard to manage or want to talk about your treatment options. (You can find information on hep C support groups and on-line forums on page 37)



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, including accessing treatment. 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.

European Association for The Study of the Liver (EASL)

www.easl.eu/_clinical-practice-guideline

Clinical Practice Guidelines: Recommendations on Treatment of Hepatitis C 2014 define the current best practice for the diagnosis, treatment, management and prevention of hep C.

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.

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.

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.

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

NHS Choices

www.nhs.uk

A comprehensive health information service with resources written by patients, carers and clinicians.

NHS Constitution

www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Pages/Overview.aspx

The NHS Constitution sets out your rights as a patient, including 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.

Citizens Advice Bureau: Advice Guide

www.adviceguide.org.uk

The main public information service of Citizens Advice, providing information on your rights, including benefits, housing and employment, and on debt, consumer and legal issues.

Living with hepatitis C and treatment options

A booklet about hepatitis C (hep C) with information about living with hep C, managing common hep C symptoms, your rights to treatment and treatment choices.

**This booklet draws on work by
Dr Magdalena Harris at The London
School of Hygiene and Tropical Medicine.**

Dr Harris is funded by a National Institute for Health Research postdoctoral fellowship [NIHR-PDF-2011-04-0311].

LONDON
SCHOOL *of*
HYGIENE
& TROPICAL
MEDICINE




**LONDON JOINT
WORKING GROUP**
ON SUBSTANCE USE
+ HEPATITIS C

 **GILEAD**

addaction

THE HEPATITIS  TRUST

REACH
RE-ENGAGE AND COMBAT HEPATITIS C

Imperial College Healthcare 
NHS Trust

This booklet has been developed through a joint working initiative between The London Joint Working Group on Substance Use and Hepatitis C (LJWG), Gilead Sciences Ltd, Addaction and Imperial College NHS Foundation Trust.

Gilead Sciences had no influence over the content of this resource.

January 2015

HCV/UK/15-01/MM/1028a