

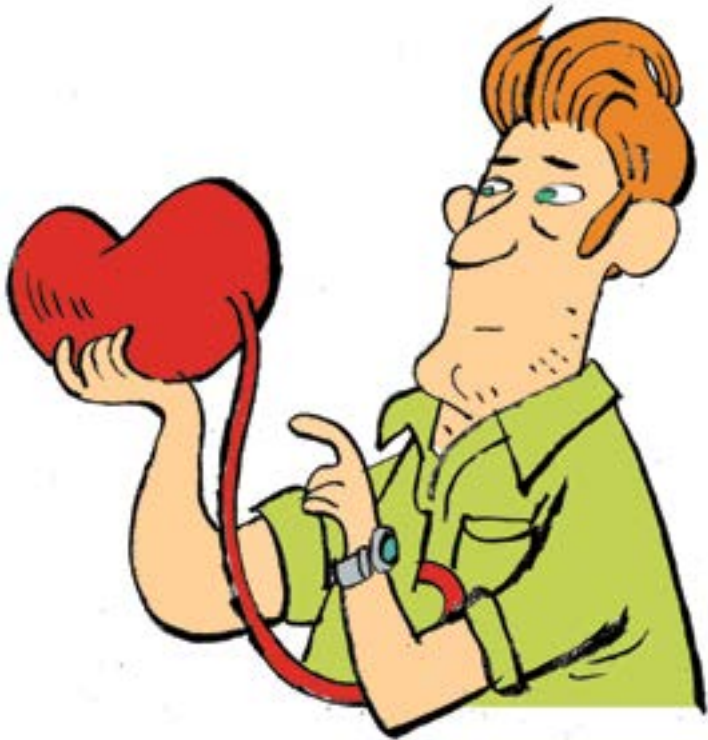
Hep C

**YOU NEED
TO
KNOW**

**New Treatments
Easy to Cure!**

Contents

So what is hep C?.....	1	Testing for hep C.....	28
Are there different types of hep C?.....	2	Window period.....	30
Damage to the liver.....	3	Can I clear hep C naturally?.....	32
OK, so how do I catch hep C?.....	7	Treatment – Can I get rid of hep C?.....	33
Spoons, water and filters.....	8	I’ve just found out I’ve got hep C, what next?.....	36
More ways to catch hep C.....	12	I was tested years ago, what should I do now?..	38
What about sex?.....	17	What about Prison?.....	40
Will I definitely have hep C if I’ve injected?.....	18	Prison Helpline.....	41
How long will hep C take to make me sick?.....	18	Support.....	43
What are the symptoms?.....	20	Hospital Appointments.....	44
Is everyone around me at risk?.....	21	National helpline.....	44
To test or not to test.....	22	Online Information.....	45
Things to consider before being tested.....	25	Support Groups.....	45
Who else could find out if I have hep C?.....	27		



So what is hep C?

Hep C is a short way of saying hepatitis C. The word 'hepatitis' means inflammation of the liver. You may have heard of hepatitis A, hepatitis B, hepatitis C and even alcoholic hepatitis. They are all different but they all cause inflammation of the liver. This booklet will only focus on hep C.

Hep C is a virus. Its main purpose is to reproduce or make copies of itself, and it needs some of the cells in your body to do this.

The cells that hep C likes are found in your liver. This is why hep C causes damage to the liver. Healthy liver cells are used by the hep C virus to reproduce which in turn causes liver damage.

Are there different types of hep C?

Yes, there are different strains of hep C. These are called genotypes. If you have hep C then the hospital will tell you which genotype you have and this will affect your treatment options. You may have heard people say things like:

“I’ve got the good one” or “I’ve got the bad one!”

They are probably talking about genotypes. There is little evidence to show that one genotype will do more damage to you than another. However, when it comes to treating your hep C, some genotypes are easier to clear than others.

In the past your genotype affected the amount of time that you were on treatment and your chances of clearing the virus. Now there are specialist drugs that work better on certain genotypes, and treatment times may be reduced.

The most common genotypes found in the UK are 1, 2 and 3. If you have hep C then you will have the same genotype as the person you caught it from. It is possible to catch more than one genotype. Having two genotypes can be more difficult to treat. So even if you are using with someone and you both know you have hep C – it is still important not to share equipment!

Damage to the liver

The liver is often described as the ‘factory’ of your body. It filters alcohol and other toxins, it helps process fats and proteins from the food you eat and converts that food into energy. It also regulates hormones and performs numerous other vital jobs within your body.

Drinking too much alcohol or having a virus such as hep C will put extra strain on your liver. This can then lead to scarring of the liver and eventually cirrhosis.

Fibrosis of the liver

Your body's own immune system will try to repair any damage done to the liver. It does this by laying down collagen over the affected areas. Unfortunately this process can damage the liver and cause it to harden, this is known as fibrosis. Anyone with a history of drinking lots of alcohol or who has lived with hep C for a number of years could expect to have some damage. This can sometimes be reversed and get better if you clear your hep C or reduce your alcohol intake. This is not generally a problem but if the damage continues then it can lead to scarring.

Cirrhosis of the liver

Cirrhosis occurs when normal liver tissue is replaced by scar tissue. The liver then becomes increasingly hardened, making it difficult for blood to flow through the liver as it should.

Your liver is very resilient and can actually continue doing all the jobs it needs to do in the first stages of cirrhosis. This is called compensated cirrhosis because your liver is able to compensate for the damage and still carry out all of its functions.

If the liver damage continues, the compensated cirrhosis will progress into decompensated cirrhosis.

Decompensated cirrhosis is when your liver is no longer functioning properly and unable to compensate for the damage. All sorts of life threatening complications can occur when the liver stops functioning properly. These complications can lead to liver cancer, internal bleeding and even a coma induced by the liver's inability to process toxins from the blood that supplies the brain. A person with decompensated cirrhosis will probably be admitted to hospital and may need to be put on a waiting list for a liver transplant.



Ok, so how do I catch hep C?

Hep C is a blood borne virus. This means that your blood needs to come into contact with blood from another person who is infected with the virus. You can catch hep C in a number of ways:

Sharing or reusing other people's needles and syringes

The obvious way to catch hep C is sharing syringes to inject drugs. There is always a tiny bit of blood left in the syringe after injecting and if you use that syringe again, you will be injecting that blood into yourself. If the person who used the syringe before you has hep C then it is likely you will get it.

But hep C can be even sneakier than that..

Spoons, water and filters

Sharing equipment used to inject drugs

We know hep C can survive inside a syringe for about a week but it can also survive on other items for a couple of days. This means that if you share the same water, spoon or filter with someone who is not using a clean syringe then you can also become infected with hep C.

If someone has hep C and uses a syringe that's been used before to draw up some water then that water source is also contaminated. Everyone who uses that water is now at risk. This is why it is so important to use a clean syringe to make the hit.

This is also true if someone puts a used syringe into the spoon or onto the filter. The spoon or filter could now be contaminated and anyone drawing up a hit from that filter or spoon is at risk.

Remember that you cannot simply rinse a syringe out to get rid of hep C. Also hep C, and the blood it lives in, is often too small to be seen.



You cannot simply look at water, spoons and filters and decide that they look safe so they are safe!

Use a NEW one!!

Some common complaints we hear from people who inject drugs are:

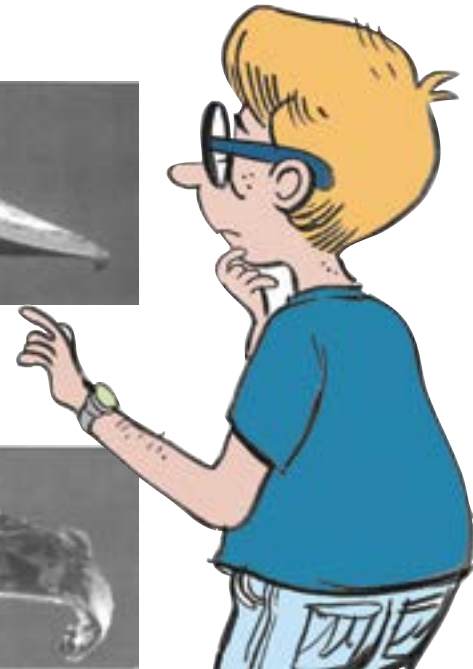
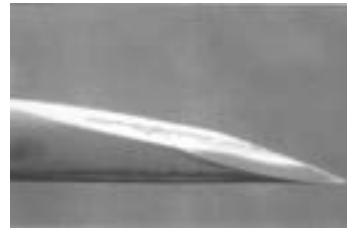
- I can't get a vein
- I'm covered in track marks / bruises
- There's an infection where I inject

Reusing a needle even once will damage the veins much quicker than using a new one EVERY TIME!

We decided to get a microscope out to see what happens to a syringe that gets reused. As you can see on the page opposite, the needle actually becomes 'barbed' after the first use. This means you're sticking a tiny barb in and out of your veins each time you reuse a needle and that means veins will be harder to find and hits will take longer and be messier.

So, if you want to prolong the life of your veins –
Use a NEW one!!

Using new kit each time you inject will also reduce getting bacterial infections, including abscesses, which cause damage to your veins, making it harder to inject well.



More ways to catch hep C

Sharing of drug snorting equipment

The hep C virus is so small that it can also be transmitted by sharing notes or straws to snort drugs with. This is because the lining inside the nose is very sensitive. The drugs that people snort often act as an anaesthetic and are often cut with quite abrasive powders. This combination means that you may not feel a cut inside your nose that could be bleeding. You could get blood on the note or straw and probably wouldn't see it. If the straw is passed to another person, this blood could then get into that person's bloodstream.

Sharing pipes to smoke crack

Smoking crack can often cause the lips of regular smokers to become cut and chapped. This is where a blood to blood transmission of hep C could occur. If you smoke crack then you may well be smoking with someone who has also injected drugs and could be hep C positive.

The important message for all these types of using is to always use your own equipment - all of it, including water, filters, spoons, pipes, notes and straws!



Tattooing and body piercing

Tattooing and body piercing both involve equipment that comes into contact with your blood. If this equipment is not new or has not been properly sterilised then there is a chance that it could transmit the virus from one person to another.

You're pretty safe if your tattoo or piercing was done in a UK high street parlour as they are all regulated. However, if you had a tattoo done in prison, at home or in a parlour that wasn't regulated then you may want to consider getting a test for hep C.

Mother to baby

Approximately 1 in 20 mothers who have hep C will pass it on to their baby while giving birth. At present a mother is not routinely tested for hep C when she is pregnant. She may well be tested for other infectious diseases but not necessarily hep C.

The mother will not pass hep C onto her baby during the pregnancy. The risk occurs at the actual birth where the contamination of blood from mother to child can occur. Some procedures can be put in place at the birth to try and reduce the risk but there is no evidence that they work.

However, if a mother gets a test and discovers that she has hep C then her child can be tested. If the child is positive then they may be treated in childhood, where the side effects are generally better tolerated. Otherwise a child's hep C status may go undiscovered until they possibly develop advanced liver disease.

If you are a mother or a mother-to-be and have ever engaged in risky drug taking behaviour then it is strongly recommended that you take a test for hep C.

Blood transfusions prior to 1992

Before 1992 the risk of catching hep C from blood given to you at a hospital was quite high; this is because hep C was only identified in 1989 and UK blood banks did not screen blood or blood products for the virus at that time. Since 1992, the NHS screens all blood for hep C and it is therefore safe. However, not all countries adopt the same standards of screening blood supplies as the UK and this is worth considering if you have ever received medical treatment abroad.



What about 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 and the risk of passing on hep C when having sex is when's there's blood to blood contact.

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 a sexually transmitted infection 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.

Will I definitely have hep C if I've injected?

Many people with a drug history often resign themselves to having hep C without even being tested. In reality there are many people who 'think' they have hep C and discover that they don't have it when they get tested. You may have been less careful about sharing drug equipment if you already thought you had hep C.

If you **don't have** hep C now then you **don't have to have** hep C in the future.

If you have a drug-using history and haven't caught the virus, then you can take simple steps now to ensure that you don't catch hep C if your drug use continues.

How long will hep C take to make me sick?

Hep C is sometimes thought of as a disease that can take 20 to 30 years to do any damage and most people can feel no symptoms for many years.

You often hear people say:

“Why should I worry about something that won't affect me today or even next year?”

Actually, the time that the disease can take to do its damage is very hard to predict. Some people will remain unaffected for 20 years or more, while others will develop liver damage within this time.

It's important to remember that the amount of liver damage is not always connected to your symptoms. You can feel fine and have dangerous liver damage or feel lousy but have no significant damage.

The amount of liver damage that occurs varies from person to person. There are also certain factors that may speed up or slow down the rate of damage. Your age can play a part in this but the most obvious factor will be your alcohol intake!

Think of hep C as a virus that is attacking your liver. If you choose to 'attack' your liver further with alcohol then you will speed up the rate of liver damage.

Remember that the hep C virus will start doing damage immediately, even though some people can take years to develop actual symptoms.

What are the symptoms?

Hep C affects the liver. The liver plays so many important roles within our bodies that the symptoms can vary from person to person. The most common symptoms are:

- **Extreme tiredness**
- **Difficulty in concentrating, or 'brain fog'**
- **Depression**
- **Aches, pains or sensations in the liver**
- **Aches or pains of the abdomen and joints (most commonly the hands and wrists)**
- **Digestive problems**

It is not wise to assume that all of your aches and pains are related to hep C. People with hep C often have other things wrong with them as well. If you feel that you have symptoms that are associated with hep C and you have not been tested, then you should see a doctor and get tested.

Is everyone around me at risk?

The simple answer is no. People around you are only at risk if their blood comes into contact with your blood. This is not as easy as it may sound. As long as you are not sharing drug, piercing or tattooing equipment the risk to others is extremely low. Many people who have hep C lead healthy lives amongst family and friends. Some of the precautions they might take are keeping their toothbrushes and razors separate from family or friends, and being careful to mop up blood spills.

Everyday activities including hugging, kissing, shaking hands and sharing cutlery will not transmit the virus. In the UK you are allowed to carry out most jobs, including childcare and food preparation, if you have hep C.

To test or not to test

Taking a test for hep C is entirely your choice. No one can force you to take the test. But if you feel that you may have been at risk then it is sensible to take the test.

Some of the reasons that you may want to get tested are:

- **Peace of mind ...**

“I’m worried that I may have taken risks”

- **Pregnant or thinking of starting a family ...**

“I didn’t realise the risk of passing hep C to my baby.”

- **Knowing that an effective treatment exists ...**

“I didn’t want a test before, but now that I know it could be cured...”

- **Protect others ...**

“I’ve just starting living with my partner and want to know if I should pay special attention to keeping toothbrushes / razors separate”

- **Taking responsibility for your own health ...**

“I want to start getting checked out, I often feel tired and want to rule out all of the possibilities”

There are many good reasons to get tested!



“What happens if I’ve got it?”

“Who will find out if I take the test?”

“Who will find out if I’ve got it?”

Things to consider before being tested...

You may want to prepare yourself for the impact of a positive diagnosis. The result may cause very strong emotions that can be difficult to handle on your own. You may, for example, experience a lot of anger about how you caught hep C. Different people react in different ways. You may wish to have someone you can talk to nearby when you get the result.

There should be someone present when you get the result that will be able to answer some of your questions. Try not to get the result on a Friday as some support services may not be available over the weekend, should you need them.

There are a few things that you will be told about before taking a test for hep C. If you take a test and you do not have hep C then no one needs to know that you took the test. If you are found to be positive and do have hep C then the next page will explain some things that you may wish to consider.

GPs

In most cases, it will not be necessary for your GP to know your test results. A referral to specialist care can often be made without a GP. However, if you decide you want to get treated for your hep C then your GP is likely to be informed. On the day of your test you will be asked to give your permission for your GP to be informed. The decision is yours but it is worth considering that if you test positive then your care and associated needs may stretch over a period of time and a good relationship with your GP could prove invaluable.

Insurance & Mortgages

If you test positive you can still receive mortgages and insurances. Having hep C is unlikely to affect your ability to get a mortgage. However, life insurance policies will often require that you inform them if you have hep C. The price of the policy may be higher, or they may refuse to cover any claim that comes about from an existing condition such as hep C.

If you apply for a mortgage or insurance, you may well be asked about your health. You are required by law to give an honest answer. If you have hep C, your insurance may be invalidated and any claims refused if you do not disclose your hep C status.

Who else could find out if I have hep C?

Some diseases need to be reported by law in our country. This means that the Health Protection Agency may get notified of positive results. This is so that outbreaks of particular diseases can be discovered and traced back to the source so that prevention measures can be put in place.

Hepatitis C is a notifiable disease if you test positive, but your details will only ever be used if it is felt that an outbreak has occurred and further action needs to be taken to protect others.

However, due to the nature of hep C, this does not happen very often.

Testing for hep C

Two tests are required for hepatitis C, these can often be done from ONE blood sample from you. The laboratory can then perform two tests on your sample. The tests are:

- **Antibody test**

If you have ever come into contact with the virus, your body will try to fight the infection by producing antibodies. If antibodies are detected in this test then a second, more advanced test will be performed.

- **PCR (RNA) test**

This will test for the presence of ACTUAL virus in you. It is important to remember that approximately 20% of people who come into contact with hepatitis C will clear it naturally within the first six months. This means they will always test positive for antibodies but will not test positive in the PCR (RNA) test.

You will be told at the time of your test when to come back for the results of your test. This should not be much longer than 3 weeks.

Window period

Your body can take up to 3 months before antibodies are detectable!

This is very important because although it is a good idea to get tested as soon as possible, you will also need to take another test later if you had, for example, engaged in risky behaviour yesterday.

This is because the test may not be accurate if you 'caught' the virus within the last 3 months.



Can I clear hep C naturally?

Approximately 20% of people who catch hep C will clear it naturally. These people will always show up as having the antibodies to hep C but will test negative in the actual PCR test for the virus. It is not known why this 20% of people manage to fight it off naturally. If you have hep C and have not cleared it naturally within six months then you will have hep C for the rest of your life or until it is treated.

If you have cleared the virus naturally and you catch hep C again you may not clear it naturally the second time round!

There is no vaccine against hep C.

Everybody has the potential to have hep C for life!



Treatment – Can I get rid of hep C?

Yes you can! The new treatments that are available on the NHS cure hep C in almost everyone who takes them and they are very easy to take! Exactly which treatment you are offered may depend on your genotype, how much liver damage you have or other medications you be taking but all the new treatments get rid of the virus more than 90% of the time.

It is important to remember that if your liver has already developed severe damage then this may not be reversible after treatment and could still lead to life threatening health complications. This is why it is important to engage with specialist care as soon as possible and access treatment before the severe damage can occur.

Isn't treatment horrible to take?

No. Not any more! The new treatments do not contain interferon. Interferon used to be the main drug used to treat hep C but is has been replaced by drugs that have very few side effects and even they are mild.

Not only that, the new treatment just consists of pills (no injections!) and is now much shorter, only lasting 8-12 weeks.

If you have cirrhosis, you might have to take ribavirin as well. That's another good reason to get treated soon before your liver disease progresses. Ribavirin does have some side effects, although nothing like interferon. Ribavirin is being phased out as yet newer drugs are more widely used.

But will the NHS treat me?

Yes. The NHS wants to cure as many people as possible because the government has agreed to eliminate hep C in the UK by 2030 at the latest. Treatment should be available wherever you are, even if you're in prison. However, not all treatment services run perfectly so if you are having trouble getting treatment please call The Hepatitis C Trust's national helpline - details at the back of this booklet.

What does it mean to be cured?

Lots of people with hep C don't notice that it's making them feel unwell – until after they've been

cured. Often when they have been cured they feel they have much more energy and can think more clearly. Maybe their depression lifts and they have fewer digestive problems. In other words they just generally feel better.

The drugs cure hep C but they don't repair any liver damage you've already got. Repairing liver damage means looking after your liver even after you've been cured. If you do look after it, your liver may become perfectly healthy again. If you don't or if you start drinking a lot, your liver damage may get worse even though you don't have hep C any more. And if you already have cirrhosis, you need to be regularly monitored to make sure you don't develop complications even after treatment has finished.

Once you've been cured of hep C you can't give it to anyone else, which can be a relief. You sometimes hear people say:

'Having hep C makes me feel dirty'

Getting rid of hep C stops that! But it doesn't stop you catching it again if you put yourself at risk. Unlike hep B where if you catch it and get rid of it you are immune and can't get it again, getting rid of hep C does not make you immune.

I've just found out I've got hep C, what next?

Referrals

If you have tested positive for hep C then a referral will be made for you to see a specialist, probably at your local hospital. The nurse will probably take another blood sample to confirm you are (PCR) positive for hep C and to determine your genotype and the amount of virus in your blood. You may then be asked to do a simple scan which will help determine the condition of your liver.

Attending specialist care

In the past many people have associated the liver unit at the hospital with interferon treatment. They may have thought...

“I don't want interferon treatment so what is the point of going to the hospital appointment”

Interferon is no longer used by the NHS to treat hepatitis C!

The hospital or specialist clinic is the only place where you can determine the true condition of your liver. A doctor at a GP surgery is not able to tell you the real condition of your liver and finding out is very important if you have a history of excessive drug or alcohol use and are living with hep C. The specialist will then be able to offer you the new treatment for hep C.

Some people decide to ignore their hep C status as they feel it does not really bother them. However it will become a problem for the majority of these people eventually. You cannot hide from the fact that you are living with a potentially life threatening virus.

The hospital or specialist clinic can shine a light on many of these fears and concerns. A simple scan will provide a good insight into the condition of your liver.

Most people will discover that they have a mid level of damage and treating it now will prevent further damage occurring from hep C. A smaller amount of people may discover that their liver is very damaged in which case their life may have been saved by attending the liver unit in the first place. For example, you may discover that you have advancing liver disease and treating it now can prevent you from having cirrhosis of the liver!

Attending specialist care really is a 'Win Win' situation.

There are many people who have chosen not to do treatment in the past. However, we now have incredible new treatments that are very effective and easy to take. And, as a bonus, you feel healthier once you have cleared the virus!

Get treated and feel better!

I was tested years ago, what should I do now?

Testing for hep C, and the care given after the test, has improved a lot over the years. In the past people have fallen out of the care pathway and we often hear people say things like:

“I was tested for hep C before but was not referred to see a specialist”

“I’m pretty sure they told me I had it but I’m not certain”

“I moved location or lost track of my appointments with the local hospital”

If any of these statements apply to you, then it is definitely worth getting another test. Another test could put aside any doubts that you may have about your last results. It is also often the best way to get back into the care pathway. This is because if you have another test and are positive for hep C, a referral will be made to see a specialist that is local to where you live now. Being in a care pathway for your hep C could be your first step in taking control of your health. Please read the previous section about attending specialist care.

What about Prisons

Everyone entering prison should be offered a BBV test, this is to test you for hepatitis C, hepatitis B and HIV.

If you were offered the test and declined it, or if you were not offered the test on reception, you can request a test at any time from the healthcare staff. The test results are confidential between you and those involved in your healthcare.

If you find out that you are positive for hepatitis C, don't panic. You will be referred to healthcare who will complete further tests to assess the damage to your liver and link your case into the local hospital or specialist liver clinic.

Depending on the amount of time you have left to serve you may be able to access treatment while you are in prison. If you don't have long to go before release, don't worry, your details will be forwarded from the prison healthcare team to your local hospital, liver clinic and you will be able to access treatment in the community.

Prison Helpline

If you have any questions or worries you can call our dedicated Prison Helpline, this is a free number which you should already have on your pin. **0800 999 2052**

This service is staffed by people who have, or have had hepatitis C and they can provide support and information on any issues relating to hepatitis C.

The Helpline is open from **10.30am to 4.30pm**
Monday to Friday

If you are not able to call between these times then please leave a message with your name, prison number, prison name and the main reason for your call and they will write back to you straight away with further information.





Support

Being diagnosed and living with hep C can be a major life change. You will probably want to learn and understand new information about the illness and how it affects your health. This can seem very daunting, and you may not be able to understand everything at first but don't worry, you can do this in your own time.

There should always be someone available for you to talk to after you receive the result of a hep C test. This person will often be able to point you in the direction of local support services such as specific hep C groups or peer support services. You may be introduced to someone else who is living with the virus and this can go a long way to set many fears at ease.

Many services now offer peer support. A peer will share their experience of hep C with you and can help you gain the confidence and support that you may need to attend a local clinic. Please call The Hepatitis C Trust helpline if you want to find out about peer support in your area.

Hospital Appointments

Being referred to see a specialist in a liver unit at your local hospital is probably one of the most important forms of support you can seek. There will be specialist nurses at the hospital who can answer all of your questions and discuss treatment with you. The nurses can often point you in the direction of other forms of support in your area.

National helpline

The Hepatitis C Trust is a national charity that supports people who have hep C. They have a helpline that is manned by people who have experience of living with hep C and doing treatment. The helpline is open Monday to Friday from 10.30am to 4.30pm

Call 020 7089 6221 or email

helpline@hepctrust.org.uk

Online Information

The Hepatitis C Trust website is:
www.hepctrust.org.uk

Support Groups

Support groups and peers are another very useful source of information. You will be able to share experiences, tips, feelings and thoughts with others who know what you're going through. Peers may even be able to help you attend clinic appointments. The Hepatitis C Trust helpline can help you find some of these support services in your area.

Use this space for support services that may be local to you

Use this space if you wish to keep a record of when your next appointment is

Where.....

When....



National Helpline

0845 223 4424 or

020 7089 6221

www.hepctrust.org.uk

The Hepatitis C Trust is a registered charity. We have adopted the Information Standard which means we are committed to providing reliable and evidence-based information.

Charity Registration numbers: Scotland SC039914, England and Wales 1104279, Company Number: 05069924

Registered Office: 27 Crosby Row, London SE1 3YD.