

The Patient Experience

Diagnosis

- When symptoms develop, usually once the liver has already been damaged, they can be mistaken for another condition. Flu-like symptoms (high temperature, muscle pain), tiredness, vomiting and stomach pain indicate acute hepatitis C, while tiredness are the main symptoms of chronic hepatitis C and this has a significant impact on quality of life.¹
- Hepatitis C is diagnosed by two standard blood tests. The first one screens for hepatitis C virus antibodies (proteins produced by the immune system as a reaction to the viral infection) in the blood. The second blood test, an RNA test, checks whether or not there is an active hepatitis C infection.^{1,2}

FAQ

- How will hepatitis C impact my liver?
 - How hepatitis C impacts your liver will depend on when the diagnosis is made and whether the infection is acute or chronic. The long-term effect of hepatitis C on your liver can range from slight changes to the liver cells to extensive fibrosis and cirrhosis (scarring) with possible progression to liver cancer.^{2,3}
- Can I die from hepatitis C?
 - If a hepatitis C infection is left untreated this could lead to serious and potentially life-threatening conditions of the liver over many years. You could develop liver failure, cirrhosis, decompensated liver disease, cancer, or other fatal liver complications.³
- Does hepatitis C affect other parts of my body?
 - Clinical trials have shown that hepatitis C infection can affect a person's verbal learning and reasoning as well as their mental flexibility both in patients who are drug users and those who have never experienced drug abuse. Hepatitis C virus could also affect several other organs and promote the occurrence of extra-hepatic diseases such as lymphoma, cutaneous and renal disturbances.^{2,4}
- Can hepatitis C be cured?
 - The main goal when treating hepatitis C is to cure the infection. This means achieving a sustained virological response (SVR), defined as undetectable hepatitis C virus 12 weeks (SVR12) or 24 weeks (SVR24) after completing treatment. When an SVR is achieved there is a 99% chance that the hepatitis C infection is cured.²
 - Hepatitis C can be treated for several months with a combination of medicines that stop the virus multiplying inside the body. Newer hepatitis C medications have proven to be more effective than older drugs. Up to 90% of people with hepatitis C can be cured by the newest treatments.¹
- Do I need to tell people that I have hepatitis C?
 - It is your choice who you decide to tell that you have hepatitis C. The healthcare professionals involved in your tests and treatment will know your status, and they are

bound by confidentiality laws to not reveal this to anyone else apart from other healthcare professionals who are involved in your care.⁵

- You are not obliged to tell your employer about your hepatitis C status, unless you are a healthcare professional. However, you may prefer to inform your manager if you feel that your condition will affect your performance or your attendance at work, and then special allowances can be made for you. You may have to disclose your condition to your insurance provider if you have any insurance.⁵

Other people that you may wish to tell would be those with whom you can share the burden and obtain support – perhaps a close friend or a family member.⁵

- I am pregnant. Will hepatitis C spread to my baby?
 - There is a 1 in 20 chance of hepatitis C being passed to the unborn baby, and the risk is higher with untreated HIV coinfection. To date, there is no way to prevent the spread of hepatitis C to the baby.⁶
 - Standard treatment for hepatitis C would not be safe to use as the medicines could have harmful effects on your baby.¹
 - It is not known for certain whether you can pass hepatitis C to the baby through breast milk. If you are infected, seek advice about breastfeeding from your healthcare professional.⁶
- Will hepatitis C affect my fertility and can I start a family?
 - There is no evidence documenting female fertility during a hepatitis C infection, however, male sperm count may be slightly lower than normal during hepatitis C virus infection.⁷
 - For further advice ask your healthcare professional about the options available. If you become pregnant while you have a hepatitis C infection you should consult your doctor about managing your pregnancy safely.¹

Starting treatment

- If a person has an active hepatitis C viral infection, they will be referred to a specialist for further tests.^{1,2}
- These tests may include:
 - Blood tests – these measure certain enzymes like alanine transaminases (ALT) and proteins like bilirubin or albumin in the bloodstream that indicate whether the liver is inflamed or damaged.
 - Ultrasound scans – where sound waves are used to check for the texture and size of the liver. A specialised test for measuring the stiffness of the liver is the elastography (e.g. Fibroscan) in which an increase in stiffness would suggest that the liver is scarred.
 - Liver biopsy – performed to identify the amount of liver inflammation and liver fibrosis, i.e. scarring, though this is not necessarily a routine procedure in hepatitis C infections, and has been substituted by less invasive methods like elastography.
- These tests will determine which treatment will work best when treating the infection.
- Your healthcare professional will then discuss with you what treatments may be indicated depending on your needs.

FAQ

- Which treatment will I get?

- The treatment you receive will depend on whether the hepatitis C infection is acute or chronic, the subtype or strain of the virus, and the degree of liver disease. If the infection is diagnosed at an early stage, during an acute infection you may not start treatment immediately. Your body will be given the chance to fight off the virus first, and you will have a blood test a few months later to confirm whether or not the virus is present. If the infection has not gone then your doctor will prescribe treatment to deal with the chronic infection.¹
 - Once you are diagnosed with hepatitis C a liver specialist can give you information about the risks and benefits of the different treatments. As treatment lasts for up to 24 weeks, with interferon-based treatments lasting up to 48 weeks and producing side effects, it is important to select the right combination of medications for you. Newer drugs have a more favourable tolerability profile than interferon-based treatments.^{1,2}
 - Furthermore, different treatments are not advised in certain patients, so your healthcare professional will need to check your medical history in order to establish the best treatment plan.²
 - During your treatment you will take blood tests in order to check that your medication is working. If the treatment is not working your healthcare professional will switch you to a different one.¹
 - Your healthcare professional will also encourage you to make lifestyle changes to help prevent further damage to your liver and reduce the risk of spreading the infection.¹
- Why is it important to be treated early?
 - The goal of therapy is to cure the hepatitis C infection in order to prevent liver complications, including cirrhosis and cancer.²
 - It is important to treat hepatitis C early in order to limit the progression of liver disease and help prevent the spread of the infection to others.¹
 - What are the side-effects and how do I handle them?
 - Side effects vary depending on the treatment regimen chosen. Newer medications have a more favourable tolerability profile than interferon-based treatments. However, reported side effects with newer medications and their combination treatments include fatigue, headache, nausea, rash and insomnia.²
 - In the case of interferon-based treatments reported side effects are more frequent than newer drugs and included headache, tiredness, fever, anaemia, constipation, diarrhoea, and loss of appetite.^{1,2}
 - These treatments can also interact with other medications you are taking, and lead to side effects. Let your healthcare professional know what other medicines you are taking before you start your treatment.¹
 - Usually, side effects lessen over time as your body becomes used to the medication. However, if these persist and if they are affecting you significantly then tell your healthcare professional.¹
 - You should continue to take your medicine as directed, and do not stop taking your treatment without checking with your healthcare professional. Missing doses will

reduce the effectiveness of your treatment and will affect the chances of your infection being cured.¹

- How long will it be before I am treated?
 - When you receive treatment depends on the severity of the infection and the healthcare policy in your country. Patients are given priority if they have significant fibrosis or cirrhosis. In addition, patients with HIV or hepatitis B co-infection are also treated as soon as possible, as well as those who have had liver transplants, debilitating fatigue and those at risk of transmitting the hepatitis C virus.¹
 - Patients with no liver disease or mild disease can have their treatment deferred for a few months.¹

During treatment

- During treatment, blood tests will be carried out to determine viral load (whether there is still an active infection) and monitor the secondary effects.¹
- This will indicate if, and how well the treatment is working.¹
- Current treatments range from 8 to 24 weeks and up to 48 weeks with interferon-based treatments depending on the type of hepatitis C, the extent of the liver damage (whether or not cirrhosis is present) and the pre-treatment status.^{1,2}

FAQ

- How long does treatment take?
 - The goal of treatment for hepatitis C is to cure the infection through a sustained virological response. To achieve this you would need to receive your treatment for 8 to 24 weeks, or 48 weeks if on interferon-based treatment. The length of treatment will depend on the type of medication you are on, the type of hepatitis C virus that you have, the stage of liver disease, and your body's response to the treatment. Your healthcare professional will keep you informed of your progress while you are receiving treatment.^{1,2}
- What happens if I forget to take my pills?
 - Ideally, you should follow your treatment plan and avoid missing doses as this will reduce the chances of the hepatitis C infection being cured.⁸
 - Here are a few tips to help you stick to your treatment plan:⁸
 - Use a 7-day pill box to organise your pills for the week.
 - Set alarms (E.g. vibrate alerts on your mobile phone or watch) to remind you to take your medicine.
 - Keep a regular daily routine.
 - Plan ahead for unexpected situations that may arise such as travelling, or being held up in a meeting.
 - The treatment that you are taking gives information on what to do if you miss a dose.⁸
 - If you miss a dose you can refer to this information or contact your healthcare professional.⁸

- Will treatment reverse the scarring and regenerate my liver?
 - Scarring is caused by continuous damage to the liver due to different causes. Irregular bumps (nodules) appear on the liver and make the tissue rough and hard. This scarring and the nodules lead to fibrosis and cirrhosis.⁹
 - Treatment aims to stop the cirrhosis from getting worse, reverse some damage, and treat any disabling or life-threatening complications. However, reversal of scarring depends on the cause and the stage of the cirrhosis. Lifestyle changes such as stopping drinking alcohol and weight control may help delay progression.⁹
 - The liver is able to regenerate after loss of tissue or surgery, however it is less able to do so if it is damaged as a result of cirrhosis.¹⁰
 - Recent research has shown that it may be possible to heal scarring and even cirrhosis where the liver disease causing this damage is able to be successfully treated.⁹

- Can I go on holiday while on treatment?
 - You can travel while on treatment as long as you can transport and store your medication safely. If you are going abroad speak to your healthcare professional beforehand to check if you need any vaccinations or should take special precautions. You may wish to consider taking details of medical tests with you in case you need medical treatment while abroad.¹

 - Certain drugs used to treat hepatitis C are photosensitive.¹¹ Please speak to your healthcare professional for guidance before travelling.

- Will I pass on the hepatitis C infection to my loved ones if I hug or hold them?
 - Hepatitis C is spread through exposure to an infected person's blood i.e. blood to blood contact. It is not contagious and you cannot get or pass on hepatitis C through every day contact such as:⁸
 - Kissing
 - Hugging
 - Holding hands
 - Casual contact
 - Sneezing
 - Coughing
 - Sharing eating utensils
 - Sharing food or drink

 - As hepatitis C can be spread through blood to blood contact you should not share toothbrushes, razors or syringes with others if you have hepatitis C.¹
 - There is a low risk of spreading hepatitis C through sexual contact, however the risk is increased if there is blood present.¹
 - Using barrier protection (condoms) during sex is recommended if it is with a new partner or if you are having anal sex. In stable monogamous relationships there is no recommendation to use condoms as the risk of transmission of the hepatitis C virus is very

low (0.07% per year). The couple should therefore decide the best option between them.^{1,12}

- If you have any doubts about having passed hepatitis C infection to your loved ones consult your healthcare professional to see if they should be tested for the hepatitis C virus.

Cure

- After completing treatment, there is a period when the hepatitis C viral load in the blood is undetectable. If this period lasts for 12 consecutive weeks after treatment has been stopped, it is called a sustained virological response (SVR12).²
- Many doctors who have had experience with testing the new all-oral treatments in clinical trials generally consider their patients cured if they have achieved SVR12.²

FAQ

- Now I am cured, what are the chances of a reinfection?
 - When treated with the newer medicines, up to 90% or more of people with hepatitis C may be cured. However, you won't be completely immune from getting another infection. You should therefore make lifestyle measures to reduce your risk of having another infection.¹
- My treatment was unsuccessful, what other treatments am I eligible for?
 - If treatment does not work, it may be repeated, extended or a different combination of medicines may be prescribed.¹
 - The alternative treatment would depend on the strain of the hepatitis C that you have, as well as whether or not you have a coinfection with HIV, and whether or not cirrhosis or fibrosis of the liver is present.¹
- What is the likelihood of success, following additional treatment?
 - The effectiveness of treatment for hepatitis C can depend on the strain of the virus you have. Certain strains of hepatitis C are more difficult to treat than others, and until recently less than half of those treated would be cured.³
 - However, with the newer medications, the chances of a cure can be much higher. Combinations of tablets can now have a cure rate of more than 90%.^{1,13}
 - If the virus is successfully cleared with treatment, it is important to know that you are not immune to getting another hepatitis C infection.¹

Life after cure

- Achieving a cure removes the feeling of being limited by the disease.
- There is also the sense that being free from hepatitis C virus means being able to go back to life before contracting hepatitis C such as:
 - Participating in activities (physical, mental, or social) which were not possible when you had the infection¹
 - Having intimate relationships again without risk of infecting loved ones

- Feeling emotional relief from the stigma around the condition

FAQ

- What lifestyle/diet modifications should I make to take care of my liver?
 - In general, it is best to aim for as near to your usual lifestyle as possible. However, there are some things you can do to maintain a healthy lifestyle to slow down the progression of any scarring or reduce the chance of the infection coming back:⁹
 - Take exercise and get enough rest
 - Maintain a high level of hygiene
 - Avoid alcohol intake
 - Before taking over-the-counter medications check with your healthcare professional that these are safe to use and will not interact with your treatment or make your cirrhosis worse.⁹
 - Take precautions against catching colds and other infectious diseases.⁹
 - Talk to healthcare professional about having a flu vaccination during the winter months.⁹
 - Eat a balanced diet that provides a good source of vitamins and minerals, though avoid salty foods or adding salt to your food to control fluid retention.⁹
 - Cirrhosis can affect your ability to store glycogen (excess energy from glucose intake) in the liver. This means that your body has to use its own muscle tissue and this can lead to muscle wasting and weakness.⁹
 - You can reduce this effect by eating snacks between meals to top up calories and protein. You can also eat three or four small meals in a day instead of one large protein or carbohydrate meal. It is best to obtain further advice from your healthcare professional.⁹
- Do I need to disclose that I have had hepatitis C?
 - Your doctor cannot disclose your condition to anyone as they are bound by confidentiality laws. The only people they can notify about your status without your permission are other healthcare workers who may be involved in your follow-up.⁵
 - If you have any insurance that is renewed on an annual basis, such as private medical insurance, then you may need to tell the insurer.⁵
- Can I give blood after I have been cured?
 - If you have ever had the hepatitis C virus, experts recommend that you never donate blood.¹

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