

HIV & HEP C

We know a lot about HIV, but some of us may not know as much about hepatitis C (hep C). An estimated 13.1%¹ of people with HIV in Australia also have hep C, which is commonly referred to as co-infection. Some people living with HIV (PLHIV) may underestimate the impact of hep C because they identify HIV as being more serious.

This factsheet is based on personal experiences and clinical expertise. It shares some strategies on living with a co-infection and enhancing your quality of life.

WHAT IS HEP C?

Hep C is caused by the hepatitis C virus (HCV). It is passed on through blood-to-blood contact and causes problems such as inflammation and scarring (cirrhosis) of the liver. The function of the liver is to clear toxins from the body, processes food nutrients and is involved in regulating the body's metabolism. The inflammation and scarring of this vital organ caused by hep C can damage the liver. The amount of damage varies from person to person; it may be slight (mild inflammation) or serious (liver disease).

There is a treatment for hep C which can clear (cure) the virus in around 60% of cases. The chance of successful treatment depends on an individual's genotype. There are six different genotypes (or strains) of hep C and some respond better to treatment than others. The most common genotypes in Australia are 1, 2 and 3. If diagnosed with hep C it is important to remember that with the advancements in medical research, treatments for hep C are changing and improving all the time.

HOW IS HEP C TRANSMITTED?

Unsterile drug injecting equipment is the most common way of contracting hep C in Australia, as well as tattooing or body piercing with unsterile equipment. However people have also contracted the hep C virus through:

- sex with blood present, including sexual activities that increase the risk of injury to the lining of the anus or vagina (e.g. fisting, longer sex sessions, unprotected anal sex)
- childbirth, from a mother to her baby (risk is about 5%, but this significantly increases with co-infection)
- sharing razors, toothbrushes or other things that may have tiny traces of blood on them, and sharing nasal straws (e.g. as used with cocaine and other drugs).

HOW DO YOU KNOW IF YOU HAVE HEP C?

There is no way of knowing whether you have hep C unless you have a blood test. You can have hep C for many years and not know it as hep C symptoms can take years to develop in the body. Signs or symptoms can include fatigue, nausea, muscle aches or abdominal pain.

We know that around 25%² of people who have hep C will clear the infection without treatment, within the first six months. This clearance rate is estimated to be lower in PLHIV.

Most people with HIV have regular blood tests, but these don't routinely include testing for hep C. You need to specifically ask for a hep C test.

HOW CAN YOU PREVENT HEP C?

The best way to prevent passing on or getting hep C is to avoid exposure to infected blood.

Unsterile injecting, tattooing and piercing are the main transmission risks.

You can reduce the risk of transmission by:

- never sharing injecting equipment, including fits (needles and syringe), spoons, swabs, cotton wool and tourniquets.
- always using registered tattooing and body piercing premises, and discussing sterile practices with the individual artist doing the tattoo or piercing
- avoid sharing items that may contain blood, such as razors, toothbrushes or nail scissors
- remembering that sexual transmission is possible during sex if blood is present; risk increases during anal sex and sex during menstruation
- using condoms and water based lube during sex, especially anal sex (including sex toys)
- using gloves and lube for fisting.

Decisions about safe sex with your partners are likely to be very individual but should be based on reliable information. Using condoms may be your preferred option however some PLHIV with HIV positive partners choose not to use condoms. If you are having sex with someone who is also HIV positive, but not hep C positive, you should both talk to your doctor about some of the potential risks for the sexual transmission of hep C.

WHAT ARE THE EFFECTS OF HEP C IF YOU'RE HIV POSITIVE?

For PLHIV, co-infection with hep C can affect both your health and treatment options. Hep C can be more serious and progress faster in PLHIV, so testing and regular monitoring (of HIV and hep C) is extremely important.

If left undiagnosed and untreated, hep C can seriously damage your liver, which can make it harder to process your HIV medication. This is because medications are processed by the body through the liver.

Ageing, being male, contracting hep C after the age of 40, having hep C for a long time, a low CD4 count, heavy alcohol intake (more than 40ml per day) or a hep B diagnosis can all speed up the progression of hep C and/or impact on the success of treatment.

WHERE CAN I GO FOR TESTING AND TREATMENT?

You can ask your GP or HIV doctor for a HCV antibody test when you have regular blood tests done. You can also go to a sexual health clinic such as Melbourne Sexual Health Centre and receive free testing. Please note that a person must give their consent to be tested for hep C.

It may take up to three months for the antibodies to appear in your blood following hep C infection (although it is usually positive by six weeks). This is known as the 'window period'. It is important to be aware that anyone who has ever had hep C will test positive for hep C antibodies. Even the 25% of people who naturally cleared hep C and those who were successfully treated will test hep C antibody positive. Because of this, all positive hep C antibody tests should be followed up by a Polymerase Chain Reaction (PCR) test which will show whether or not a person currently has the virus in their bloodstream³.

If the results show you are co-infected with hep C and HIV, it's important to find a doctor with experience in HIV and hep C co-infection. If you have hep C the earlier you find out the more likely it is that your treatment will be successful.

HOW IS HEP C TREATED?

Co-infection of hep C and HIV may impact on how long treatment for hep C will take and the expected success rate, however in general terms;

Current treatment for hep C is a combination of two drugs: pegylated interferon (injected weekly) and ribavirin (tablets taken orally twice daily). This treatment is taken for 6 or 12 months, depending on a person's hepatitis C genotype. The drugs can have significant side effects, which may vary in severity as treatment progresses and these must be factored into the decision to commence treatment. The primary goal of treatment is to clear hep C. A secondary goal is to improve liver health by reducing inflammation.

The success of treatment depends upon a number of factors which include, viral load, age, gender, stage of liver disease, other illnesses such as diabetes, lifestyle factors and the genotype. Genotypes 2 and 3 respond better to treatment and usually require 24 weeks of treatment with approximately 80% chance of clearing the virus. Genotypes 1 and 4 usually require 48 weeks of treatment with approximately 50% chance of clearing the virus.

It is important to note that you may not feel 100% when you first finish treatment and you may not feel well again for several months. Pegylated interferon

takes approximately 8 weeks to clear from the blood system and Ribavirin can take up 6 months.

When considering treatment, one of the biggest questions is 'when should I start?' The best time to treat hep C is different for many people and this makes getting the right balance between delaying treatment and not waiting too long important. Treatment is less effective if the liver becomes seriously scarred (cirrhosis).

Treatment may also lower the risk of long-term complications including liver cancer, even in people who do not clear hep C. Treating hep C before starting HIV treatment may reduce the risk of liver-related side effects from HIV drugs later on. Clearing the virus also removes the risk of mother to baby transmission during childbirth.

HOW CAN I LIVE WELL WITH HEP C?

Lifestyle changes like reducing or avoiding alcohol intake, reducing or avoiding smoking, eating and resting properly, exercising and reducing your stress levels are important. Some of these can reduce the risk of hep C progression, especially reducing or avoiding alcohol. If you are using recreational drugs you may want to consider reducing or stopping altogether.

Vaccinations for hep A and hep B are recommended if testing shows no evidence of previous infection and/or protection. This

“I was able to make well-informed decisions about my treatment and its side effects.” – John

may help protect your liver from further damage. In August 2010 the Victorian Department of Health announced free hep B vaccinations for PLHIV. See your HIV doctor or local sexual health clinic to discuss hep A and hep B testing and to arrange vaccinations.

WHAT TO TREAT FIRST – HIV OR HEP C?

The infection which poses the greatest concern to your health should be treated first.

There is some evidence that starting HIV treatment early is especially important for people with both HIV and hep C⁴.

HIV treatment can boost the immune system and this may mean that the rate of liver scarring (cirrhosis) is significantly slowed.

HOW IS LIVER DAMAGE ASSESSED?

A liver biopsy can help you make a treatment decision. A liver biopsy can give you valuable information about the amount of liver damage. However, a liver biopsy can be an uncomfortable experience. Some hospitals are now able to test for liver damage using a ‘Fibroscan’ – a non-invasive ultrasound-based test.

HOW DO I PREPARE FOR HEP C TREATMENT?

For some people, deciding whether to start treatment is an easy decision. For most people, there are many factors to consider.

One approach to managing hep C is to decide first what your priorities are:

Clearing hep C is the most important goal for many people, but not for everyone. In some cases, treatment may be more likely to improve the condition of your liver than to clear hep C. In other cases, treatment may not be necessary right away. You need to consider both HIV and hep C and carefully plan your treatment in conjunction with your doctor.

For John, it was important that his HIV specialist and his Hepatologist collaborated with each other to work out what was best for him:

John: I had the professional support and advice of my Hepatologist. I was able to make well-informed decisions about my treatment and its side effects. He was always ready to discuss even the most ordinary things about my routine. Better still, he collaborated with my HIV specialist on the drug interactions.

Careful planning and support can reduce the impact of side effects:

Many people find that being informed about the side effects is crucial to their success in managing them. Talking to your hep C nurse or doctor about how to prepare for side effects can also be very helpful. Side effects can include flu-like symptoms, tiredness, irritability, depression and anxiety. These can interfere with your work commitments and general quality of life.

For many, work, its achievements and routines, can help deal with the challenges of treatment. John found that structured planning of his everyday life, plus regular but light exercise helped him to manage treatment side effects:

John: My low energy levels were a problem but I found that I could function better in the mornings than later in the day, so I adjusted my lifestyle to that. You need to structure every day. Every second morning I swam. Doing some exercise and achieving something on a regular basis was integral to managing the side effects. Work was important because that kept me in touch and gave me an added sense of achievement.

“My low energy levels were a problem but I found that I could function better in the mornings than later in the day, so I adjusted my lifestyle to that.” – John

“I had no idea about counselling and government support options. I thought I had no other option but to continue working while on treatment.” - Ben

Consider what else is going on in your life:

When making a decision to take treatments, consider what else is going on in your life (e.g. work or study commitments, whether you are emotionally and physically ready and the access you have to support or services in your area).

While many continue to work while on treatments, others may feel they need to take a break during this time. By identifying his needs, Ben was able to reassess his situation and find the support he needed:

Ben: I was working nine to five, five days a week in a corporate job. I didn't have time to prepare for treatment at all and jumped straight in. I had no idea about counselling and government support options. I thought I had no other option but to continue working while on treatment. I could have stepped out of that difficult situation a bit earlier if I had have known about Newstart, which I could get. It was about finding the right thing to do in my life. It was a really positive time to reassess my whole life and my attitude on everything.

“You need support. I have close friends and a good counsellor.”
- Samantha

ARE YOU READY TO MAKE LIFESTYLE CHANGES?

Samantha explains planning for treatment also meant changing her lifestyle, which included giving up drugs. She outlines the importance of being ready to make lifestyle changes:

Samantha: Everybody is different. A change of lifestyle; a new diet and getting off the alcohol and drugs were important for me. Mindset is important - being strong and keeping healthy. The biggest thing I had to do was to move away from my social circle, I had to change my scene and get away from the influences. For this to work, I had to be ready.

Identify your support networks:

As with HIV, knowing other people in the same situation can give you ideas about how to deal with the challenges and issues you may encounter.

Samantha and Nigel found support from a counsellor, as well as from other people with hep C before and during treatment helps to play a key role in coping with side effects:

Samantha: You need support. I have close friends and a good counsellor. I recommend Hep C Infoline for telephone information and support. You can talk to other people who have been through similar experiences, especially with treatments.

Nigel: Going to a support group for people on hep C treatments helped me. There were people who were going through treatment at different stages, so I was interested to hear their stories. Other people's stories give you an understanding of what you're going through.

Because depression and anxiety are common treatment side effects, it is important to organise access to mental health care during (and sometimes after) hep C treatment. Mood changes, including depression are the main reasons that people stop treatment.

Because he didn't understand what was going on Ben got even more depressed and found talking to a social worker helped:

Ben: We got to the root of the problem. I wasn't giving enough thought to the fact the side effects were causing my personality to change. Counselling is important and talking helps when you're overwhelmed with everything that's going on and you can't see a way out.

“Food made me nauseous, so I developed a litany of ‘every bite is good for me.’” – Nigel

A nutritionist and your doctor can help you plan a healthy diet:

Weight loss often happens during hep C treatment, because people lose their appetite and/or feel nauseated. For Nigel, eating lots of small, light meals helped to keep his energy up:

Nigel: Food made me nauseous, so I developed a litany of ‘every bite is good for me’. I had smaller more regular meals and dietary supplements.

Drinking plenty of water and juice helps to lessen flu-like symptoms and keeps you hydrated. It also helps your liver filter waste and toxins. A healthy diet means eating less fatty, salty and high sugar foods. It also means eating more fresh fruit and vegetables, complex carbohydrates (whole grains, breads, rice, pasta, cereals, vegetables, fruits, beans, nuts and seeds), low-fat foods, high-fibre foods and an adequate amount of protein.

DO COMPLEMENTARY THERAPIES OR SUPPLEMENTS WORK?

There has been only limited research into the effectiveness of complementary therapies for hep C. Some people with hep C have reported good results while using complementary therapies, others notice few benefits. As a general rule most complementary therapies for hep C focus on managing symptoms, improving liver function and/or overall health, not on clearing hep C.

It is important that before you start any complementary therapies or supplements that you discuss your options with your doctor.

IF YOU’VE CLEARED HEP C, CAN YOU GET IT AGAIN?

Yes. You can be re-infected with hep C, even after you’ve been treated or have cleared the virus naturally.

WHO SHOULD I TELL?

Generally, who, when and how to tell is up to you, but there are some situations where you are obliged to disclose your hep C status. These include on blood donation questionnaires and life insurance applications. You also need to disclose your status, if you are a health care worker who performs exposure-prone procedures or if you are a member of the Australian Defence Forces. One major reason you may have for disclosing your status is to get support. It is also a good idea to tell your doctor as this is necessary for good health care. You can take time in deciding who else you want to tell.

SUMMARY

- hep C and HIV is called a co-infection
- hep C is a virus that causes liver inflammation and liver disease
- hep C is spread through blood-to-blood contact
- there is no vaccination currently available for hep C
- there is a treatment for hep C called pegylated interferon and ribavirin
- hep C can be more serious and progress faster in PLHIV so regular monitoring is extremely important
- consider both HIV and hep C and carefully plan your treatment with your doctors (find a doctor who is knowledgeable about both hep C and HIV)
- regular exercise, a healthy diet and reducing alcohol intake can improve your ability to cope with treatment side effects
- it is a good idea to get vaccinated for hep A and hep B this will protect your liver from further damage
- seek peer support and counselling to offer support through the difficult times (treatment).

REFERENCES

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WHERE CAN I GET INFORMATION AND SUPPORT?

Hep C Infoline 1800 703 003

provides assistance and support for people affected by or concerned about hep C as well as their family and friends.

The infoline is open from 9.30am - 6.00pm Monday to Friday and it is a free call number.

Hepatitis C Victoria provides information, support and referral services including a support group for people living with hep C. Ph: 03 9380 4644, email: info@hepcvic.org.au or visit www.hepcvic.org.au

People Living with HIV/AIDS

Victoria is the peak body for PLHIV, providing education, information and representation for all PLHIV in Victoria. Ph: 03 9863 8733 email: info@plwhavictoria.org.au or visit www.plwhavictoria.org.au

Country Awareness Network

Victoria (CAN) is the peak rural body providing information, education, support and advocacy around HIV, hep C and sexual health. Ph: 03 5443 8355 email: can@can.org.au or visit www.can.org.au

Multicultural Health and Support

Service offers services to migrants and refugee communities including information and support on sexual health, HIV and blood-borne viruses. Ph: 03 9342 9700 or visit www.ceh.org.au/mhss

Education and Resource Centre

at the Alfred statewide resource centre for HIV, Hepatitis and STIs. Ph: 03 9276 6993 email: erc@alfred.org.au or visit www.hivhepsti.info

Straight Arrows offers peer support, information, advocacy, health promotion and a referral service for heterosexual PLHIV, their partners and families. Ph: 03 9863 9414, email: information@straightarrows.org.au or visit www.straightarrows.org.au

Positive Women a support and advocacy organisation for women with HIV, providing peer support, referrals and information. Ph: 03 9221 0860 email: info@positivewomen.org.au or visit www.positivewomen.org.au

Liver Clinics and Monitoring Services

Gastroenterology Departments are available in most public hospitals throughout Victoria. Many of these have liver clinics or infectious diseases clinics which offer hep C services including treatment. Some private specialist also offers treatment for hep C. You will need a referral from your doctor or general practitioner (GP) to see a liver specialist. To find out more call Hep C Infoline on 1800 703 003.

Melbourne Sexual Health Centre is a specialist clinic for testing and treatment of sexually transmissible infections. Hep A and B vaccinations are available. No Medicare card required.
Ph: 03 9341 6200
Free call: 1800 032 017
TTY: 03 9347 8619
(for the hearing impaired)
HIV Clinic (The Green Room)
Ph: 03 9341 6214
or visit www.mshc.org.au

Drug and Alcohol Information Services

DirectLine 1800 888 236 is a free, anonymous and confidential alcohol and drug phone service. DirectLine provides 24-hour, 7 day counselling, information and referral service.

Turning Point provides a wide range of specialist treatment and support services to people affected by alcohol and drug use.
Ph: 03 8413 8413
email: info@turningpoint.org.au
or visit www.turningpoint.org.au

Financial and Legal Assistance

Centrelink advises on government disability, sickness and carers payments. Ph: 13 27 17
or visit www.centrelink.gov.au

Victorian Equal Opportunity and Human Rights Commission provides information and help on issues of discrimination and human rights. Ph: 1300 891 848, TTY: 1300 289 621. Email: information@veohrc.vic.gov.au or complaints@veohrc.vic.gov.au
www.humanrightscommission.vic.gov.au

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Disclaimer: This information is intended as a guide only. It is not intended to replace expert or medical advice.

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