

# HIV HEALTH SERIES

## Living with HIV and hep C

**We know a lot about HIV, but some of us may not know as much about hep C. An estimated 13% of people with HIV in Australia also have hep C.**

Some people could underestimate the impact of hep C because they still see HIV as being more serious.

The most important aspect of dealing with hep C and treatment is to become better informed about choices that affect your health.

Being prepared means you can better look after yourself. This can include everything from finding support (e.g. financial and emotional) to preparing for hep C treatment.

This factsheet is based on personal experiences and clinical expertise. It shares some strategies on living with HIV and hep C, and enhancing 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 with the liver (inflammation and swelling). There are six different main strains of hep C called genotypes. The most common genotypes in Australia are one, two and three.

### **Who is at risk?**

In Australia, hep C is usually transmitted by sharing injecting equipment (including needles, spoons, tourniquets and filters) and in a small number of cases by tattooing or body piercing with contaminated equipment. However, sexual transmission is also possible in certain situations.

Sex that increases the risk of injury to the lining of the anus (e.g. fisting, longer sex sessions, unprotected anal sex) or vagina may increase the risk of passing on or getting hep C. Exposure to tiny particles of infected blood on razors, toothbrushes and nail scissors, can also be a risk for hep C.

Hep C can be passed on from mother to infant during pregnancy, or during labour and delivery. The risk is higher if the mother has HIV.

**All these can involve exposure to blood, bleeding or broken skin, and therefore exposure to the hep C virus.**

## How do you know if you have hep C?

You don't know for sure unless you have a blood test. You can have hep C for many years and not know it.

Hep C symptoms can take years to develop. Signs or symptoms can include fatigue, nausea, muscle aches or abdominal pain.

It is estimated that around 25%<sup>1</sup> of people who have hep C will clear the infection without treatment, but this is estimated to be lower in people with HIV.

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

## How can you prevent it?

The best way to prevent passing on or getting hep C is to avoid exposure to infected blood. You can minimise contact with blood and reduce the risk of getting or passing on hep C by:

- Using your own injecting equipment (including fits, spoons, swabs, cotton wool and tourniquets)
- Using condoms and lube, and latex gloves if you are into group sex, fisting or longer, harder sex sessions, and changing them between each partner; or using condoms if you have sex during menstruation
- Avoiding sharing items that may contain blood, such as razors, toothbrushes or nail scissors.

## What are the effects of hep C if you're already HIV-positive?

For people with HIV, co-infection<sup>2</sup> can affect both health and treatment options. If left undiagnosed and untreated, hep C can seriously damage your liver, which can make it harder to take HIV medication. This is because medications are processed by the body through the liver.

"I NEEDED TO BECOME KNOWLEDGEABLE ABOUT WHAT WAS GOING TO HAPPEN WITH REGARD TO MY HEALTH AND WELLBEING."  
— BEN

"I HAD PROFESSIONAL SUPPORT AND ADVICE ... I WAS ABLE TO MAKE WELL-INFORMED DECISIONS ABOUT MY TREATMENT AND ITS SIDE EFFECTS."  
— JOHN

Ageing, contracting hep C after the age of 40, being male, having hep C for a long time, low CD4 count, heavy alcohol intake (more than 40 grams per day) or a hep B diagnosis can all worsen the progression of hep C.

**Hep C can be more serious and progress faster in people with HIV, so testing and regular monitoring (if you have it) are even more important.**

## Where can I go for testing and treatment?

You can ask your GP or HIV doctor for a test when you have regular blood tests done. You can also go to a Sexual Health Clinic. These are free and you don't have to use your real name.

**If the results show you are co-infected with hep C and HIV, it's important to find a doctor with experience in co-infection.**

**If you have hep C, the earlier you find out, the more likely your treatment will be successful.**

## How is it treated?

Hep C treatment has significantly improved in recent years. Treatment for hep C is a combination of two drugs: pegylated interferon (injected weekly) and ribavirin (a tablet taken twice daily). This treatment is taken for six to twelve months. The drugs can have significant side effects, which may vary in severity as treatment progresses.

The success of treatment depends upon the genotype. Genotypes two and three respond better to treatment (80% cure rate) than genotypes one and four (50% cure rate).

New drugs are being developed that may be more effective and easier to tolerate. However, it will take a few years for them to be tested and approved. Waiting for better treatments may be a good option if your liver is okay and if your hep C is not progressing.

## When to treat hep C is different for many people

Getting the right balance between delaying treatment and not waiting too long is important because treatment is less effective if the liver becomes seriously scarred (cirrhosis).

## The primary goal of treatment is to clear hep C

A secondary goal is to improve liver health by reducing inflammation. **Treatment may also lower the risk of long-term complications including reducing liver cancer, even in people who do not clear hep C.**

And, treating hep C before starting HIV treatment may reduce the risk of liver-related side effects from HIV drugs later. Clearing the virus also removes the risk of mother to infant transmission.

## Look at other parts of your life in order to reduce stress and improve both quality of life and general health

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

## There is no vaccination for hep C. If you are co-infected with both HIV and hep C get vaccinated for hep A and B. This will protect your liver from further damage

Vaccination for hep A and hep B is recommended if testing shows no evidence of previous infection and/or protection. See your doctor or Sexual Health Clinic to discuss hep A and hep B testing.

## Whether you are considering treatment or not, it is important that your doctor regularly monitors not only HIV, but also hep C.

“GOING TO A SUPPORT GROUP FOR PEOPLE ON HEP C TREATMENTS HELPED ME ... OTHER PEOPLE’S STORIES GIVE YOU AN UNDERSTANDING OF WHAT YOU’RE GOING THROUGH.” — NIGEL

## 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 C.<sup>3</sup> 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. Biopsies give you valuable information on the level of liver damage. However, a liver biopsy can be an uncomfortable experience. Some hospitals are now able to test for liver damage using ‘fibrosan’ – an ultrasound-based test. For more information talk to your doctor.

## How do I prepare for hep C treatment?

For some people, deciding whether to start treatment is an easy decision. For most, 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.

“EVERYBODY IS DIFFERENT. A CHANGE OF LIFESTYLE – NEW DIET, AND GETTING OFF THE ALCOHOL AND DRUGS WERE IMPORTANT FOR ME. MINDSET IS IMPORTANT – BEING STRONG AND KEEPING HEALTHY.” — SAMANTHA

## You need to consider both HIV and hep C, and carefully plan your treatment with your doctors

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.

## With planning and support, the impact of side effects can be reduced

Many people found that being informed about side effects is crucial to their success in managing them. Talking to the hep C nurse or your doctor about how to prepare for side effects can also be very helpful.

Side effects can make you feel more tired, irritable and unwell. These can interfere with work commitments and general quality of life.

For many, work and its achievements and routines can help deal with the challenges of treatment. John found planning ahead and structure in his everyday life, and regular but light exercise, when possible, 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 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 continuing to survive the side effects. Work was important because that kept me in touch and gave me an added sense of achievement.

## 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 you have access 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 doesn't cover everything, so I had to work out a way to get out of the arrangement I was in. It was about finding the right thing to do in my life. It was a really positive time to reformat my whole life and my outlook on everything.

## Are you ready to make lifestyle changes?

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

**Samantha:** Everybody is different. A change of lifestyle – 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.

“COUNSELLING IS IMPORTANT AND TALKING HELPS WHEN YOU’RE OVERWHELMED WITH EVERYTHING THAT’S GOING ON AND YOU CAN’T SEE A WAY OUT.” — BEN

## 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 other people with hep C or their counsellor before and during treatment played a key role in coping with side effects:

**Samantha:** You need support. I have close friends and a good counsellor. I recommend Kirketon Road Centre if you want face-to-face counselling and Hep Connect for telephone counselling. It helps with isolation and questions around treatment. 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, so they can be treated.

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.

## 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 also the 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. Eat 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.

## Discuss the use of complementary therapies or supplements with your doctor

Some people use complementary therapies because conventional hep C treatment has not worked for them, or because of concerns about side effects. There are many different paths to take with complementary therapies and some trials have shown that some people feel better and have improved liver functions.

## If you've had it once can you get it again?

Yes. You can be re-infected with hep C, even after you've been treated.

## 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 bank questionnaires and life insurance applications, or 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.

Ross reminds us you have control over who you choose to tell:

**Ross:** I only tell people my condition if they really need to know. I've told all the people who are important to me. It was on a need to know basis.

## Living with HIV and hep C: a summary

- Become better informed about choices that affect your health.
- Consider both HIV and hep C, and carefully plan your treatment with your doctors (find a doctor who is knowledgeable about hep C and HIV).
- Reduce stress and improve both quality of life and general health: exercising or using relaxation techniques such as meditation can help.
- Plan for treatment. Access up-to-date information, ask questions and get support. For example, you might want to talk to a social worker about how to deal with side effects such as depression or contact Centrelink to find out what financial support is available while you are on treatment.
- Take into account what else is going on in your life (e.g. work or study commitments), whether you are emotionally and physically ready for hep C treatment.
- Peer support, support from family, friends and/or social worker before and during hep C treatment plays a key role in coping with the difficult parts of treatment. Support can also help you to adhere to your treatment regime and plan.
  - Identify people in your life who will be a good source of support
  - Talk with other people who are living with hep C and HIV co-infection
  - Join a support group. Groups can provide structure and the ability to talk about experiences and to learn from others.
- Regular exercise, a healthy diet and reducing alcohol intake can improve your ability to cope with hep C.
  - A nutritionist or your doctor can help you plan a healthy diet.
- Hep C can be more serious and progress faster in people with HIV, so regular monitoring is even more important.
- If you are co-infected with both HIV and hep C get vaccinated for hep A and B if testing shows no evidence of previous infection and/or protection. This will protect your liver from further damage.

## Where can I get more information on treatment, clinics and support?

### Information and support

- **Hepatitis C Council of NSW** provides information, support and referrals via the Hep C Helpline. Ph 9332 1599 (Sydney) or 1800 803 990 (regional NSW). A range of topics can be discussed including hep C treatment, testing, disclosure, symptoms and lifestyle management. Referrals may also be made to doctors and other health care workers. Visit [www.hepatitisc.org.au](http://www.hepatitisc.org.au) or email: [hccnsw@hepatitisc.org.au](mailto:hccnsw@hepatitisc.org.au)
- **Hep Connect** is a free and confidential phone based peer support service, which links people with hep C to others who have personal experiences of living with the virus and treatment.
- **Multicultural HIV and Hepatitis C Service** offers support and information for people living with hepatitis C and HIV. Ph 9515 5030 (Sydney) or 1800 108 098 (regional NSW) or visit [www.multiculturalhivhepc.net.au](http://www.multiculturalhivhepc.net.au)
- **Positive Life NSW** is a community organisation representing the interests of people with HIV in New South Wales. Positive Life provides information, educational resources, advocacy and referral. Ph (02) 9361 6011 or 1800 245 677 (NSW only) or visit [www.positivelife.org.au](http://www.positivelife.org.au)

It aims to reduce isolation, provide support and ease the difficulties often associated with hep C treatment. To organise a time to speak with a volunteer call the Hep C Helpline on 9332 1599 (Sydney) or 1800 803 990 (regional NSW) and mention Hep Connect.

## Clinics: treatment and monitoring

There are clinics in every Area Health Service. Contact the Hepatitis C Council of NSW for information regarding clinics in your local area.

### For the Kings Cross/Darlinghurst area:

- **Kirketon Road Centre (KRC)** offers hepatitis C information, counselling, screening, monitoring of liver function and PCR testing (for hep C, viral load and genotype) as well as a regular hep C specialist clinic. Ph (02) 9360 2766.
- **St Vincent's Viral Hepatitis Clinic Darlinghurst** offers services such as PCR testing (for hep C, viral load and genotype), hepatitis C information, monitoring of liver function and follow-up are available. Ph (02) 8382 3707 or (02) 8382 1111.

## Community Health Centres

**Community Health Centres** exist in most towns and suburbs. They provide different services, including counselling, crisis support and information on local health and welfare agencies. Look in your White Pages under Community Health Centres.

## Food and nutrition

**Accredited Practicing Dietitians (APDs)** work in hospitals and community health centres where there is usually no charge for their services. Alternatively, private practitioners are listed in the Yellow Pages. For information on healthy eating and referral to local dietitians phone Dietitians Association of Australia 6282 9798 or 1300 658 196 or visit [www.daa.asn.au](http://www.daa.asn.au)

- **Albion Street Centre** for dietary needs. Ph (02) 9332 9600 or freecall 1800 451 600.
- **Food Distribution Network** is a not-for-profit community co-operative offering home delivery of boxes of fresh fruit and vegetables (or both). Eligibility is based on health grounds, not financial. If you wish to become a member of the cooperative phone (02) 9699 1614 or email [fdn@ihug.com.au](mailto:fdn@ihug.com.au)

## Alcohol & Other Drug Services

- **NSW Health Services** have a number of Drug and Alcohol Clinics set up around the state offering confidential advice, assessment, treatment and referral for people who have concerns about their use of drugs and alcohol. The services are free. Ph: Alcohol & Drug Information Services (ADIS) on (02) 9361 2111 or 1800 422 599, or contact your local hospital or community health centre who will also be able to advise you on your nearest clinic.
- **NUAA (NSW Users and AIDS Association)** is a peer based organisation which provides information, education and support to people who use illicit drugs. They also run a NSP (Needle and Syringe Program) where you can get all your injecting equipment free. Ph (02) 8354 7300 or 1800 644 413 (NSW only), email [nuaa@nuaa.org.au](mailto:nuaa@nuaa.org.au) or visit [www.nuaa.org.au](http://www.nuaa.org.au)

## Financial assistance

- **Bobby Goldsmith Foundation (BGF)** provides practical, financial and emotional support to people living with HIV. Ph (02) 9283 8666/ freecall 1800 651 011, email [bgf@bgf.org.au](mailto:bgf@bgf.org.au) or visit [www.bgf.org.au](http://www.bgf.org.au)
- **Centrelink** for more information on Newstart or other financial assistance. Ph 13 2850 or visit [www.centrelink.gov.au](http://www.centrelink.gov.au) and click on 'A-Z'.

## References

- 1 NSW Health (2007:1) *Communicable Diseases Factsheet, Hepatitis C*.
- 2 If you have more than one virus this is called co-infection.
- 3 Grunhage F. et al. (2008). *No difference in liver fibrosis in a cohort of HIV/HCV-co-infected patients on HAART compared to HIV-negative HCV-patients assessed by transient elastography*, Fourth International Workshop on HIV and Hepatitis Coinfection, Madrid, Abstract 8.

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Participant names have been changed.

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