



+BODY POSITIVE→

• NEW ZEALAND •
Tinana Ora Aotearoa

HIV & Hepatitis C Co-infection



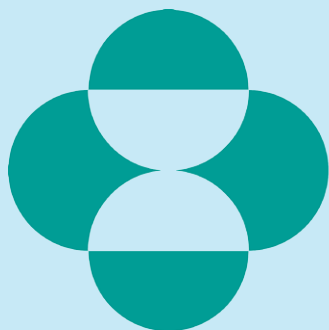
**Reproduced in New Zealand with
approval from CATIE**

(Canada's source for HIV and hepatitis C information)

**Edited for New Zealand with the assistance of
Professor Ed Gane**

New Zealand Liver Transplant Unit, Auckland City Hospital

This publication was funded by



MSD

What is co-infection?

Co-infection is when a person is living with more than one infection at a time.

This booklet provides information specific to HIV and hepatitis C co-infection. There are many other co-infections, such as HIV and hepatitis B, HIV and tuberculosis (TB) or hepatitis C and hepatitis B.

Body Positive Inc. can offer information on HIV infection as well as HIV and hepatitis C co-infection. Check out www.bodypositive.org.nz or contact us on 0800 HIV LINE if you would like further information or support.

What are HIV and AIDS?

HIV stands for human immunodeficiency virus. It is a virus that weakens your immune system, your body's built-in defence against disease and illness. Without treatment, HIV can make it harder for your body to fight off other diseases and illnesses. Over time, you can become sick with life-threatening infections. This is the most serious stage of HIV infection, called AIDS (acquired immune deficiency syndrome).

There's no cure for HIV, but with the right treatment, care and support, most people with HIV can stay healthy and live long healthy lives.

**HIV
and
hepatitis C
co-infection
means that a
person has both
HIV & hepatitis C.**

What is hepatitis C?

Hepatitis viruses infect the liver. There are five types of hepatitis viruses: hepatitis A, hepatitis B, hepatitis C, hepatitis D and hepatitis E. These viruses are different; they have different ways of passing between people, different symptoms and different treatments. This booklet focuses on hepatitis C.

Hepatitis C is a virus that infects your liver and over many years can cause damage to this important organ. This type of damage is called fibrosis in earlier stages and cirrhosis in later stages. Over time, the damaged liver isn't able to work as well. In severe cases, cirrhosis can lead to liver failure or liver cancer.

After infection with hepatitis C, the body tries to fight the virus. In some people, the body is able to clear the virus. If the virus is still in the body after six months, the infection becomes chronic and stays in the body.

There is a cure for hepatitis C; hepatitis C treatment can completely clear the virus from the body. But there is no vaccine for hepatitis C and the body does not develop protection against the virus, so it is possible to become infected again.

How do you know whether you are co-infected?

A person can be co-infected and not know it. Both HIV and hepatitis C are slow-acting viruses. People can be infected for years with either virus without having any signs or symptoms of illness.

Tests are the only way to find out for sure if you have HIV and hepatitis C. The test for HIV is a blood test. Hepatitis C is detected with two blood tests. The first test is called an antibody test, which detects antibodies made by a person who has been exposed to hepatitis C. Therefore, the hepatitis C antibody is a marker of exposure and cannot distinguish active (current) from past infection. This hepatitis C antibody test will remain positive long after the virus disappears, either spontaneously or after successful treatment. The only tests which are able to detect active infection are the HCV antigen tests (not currently available in New Zealand) and the HCV RNA test viral load test (also called a viral load test or a PCR test).

You just found out you have HIV and hepatitis C

Coping with the fact that you have co-infection can be difficult. This is true whether you have been living with one virus and then learned that you have the other one or learned about both infections at the same time.

For some people who have been dealing with one infection, whether it is HIV or hepatitis C, a second infection is not easier to handle. It can feel like an extra obstacle or a setback in adjusting to life with a chronic illness.

On the other hand, some people who have been dealing with one infection feel empowered by their experiences managing that infection and are able to adapt what they have learned to a second infection.

If you have tested positive for HIV and hepatitis C at the same time, the initial shock can be especially difficult to cope with. In addition to the information in this booklet, you may want more general information about HIV and hepatitis C.

The most important thing right now is to speak to your doctor and get as much support as you can to put yourself at ease.

Everyone reacts to the news of being co-infected in his or her own way. Still, many people ask similar questions: How can co-infection affect me? What treatment options exist and how can treatment affect me? What resources are available to support me? This booklet is meant to answer many of these questions.

Living with both HIV and hepatitis C creates a unique set of challenges related to staying healthy, making decisions about treatment and protecting yourself and others. With the help of a healthcare team, information and support, you can live a long and healthy life.

The most important thing right now is to speak to your doctor and get as much support as you can to put yourself at ease.



Will you be sicker because you have HIV and hepatitis C?

At most, only one in four (25 percent) of people who have HIV and hepatitis C clear the hepatitis C virus on their own, without any treatment. This means that most people go on to live with chronic hepatitis C, which will be lifelong unless the infected individual receives successful antiviral therapy.

In general, co-infection can make the effects and symptoms of hepatitis C worse.

Liver damage can happen more quickly and can be worse in a person who is co-infected with HIV, especially if someone has been HIV positive for many years and has a weak immune system (a CD4 count less than 200). Good control of HIV infection will however, slow down the progression of the liver damage to the same rate in people without HIV infection. Previous concerns that treating HIV could worsen HCV have disappeared with the availability of effective HIV therapy. Therefore, the highest priority in someone with both HIV and HCV should ALWAYS be to start effective treatment of the HIV infection. The HCV treatment is never urgent and should wait until the HIV infection is under control.

Things you can do to live better with HIV and hepatitis C

Get connected

HIV and hepatitis C services in your area can offer support and information. They can also help connect you to other people living with HIV, hepatitis C or co-infection. For information on services in your area, check out www.bodypositive.org.nz or contact us on 0800 HIV LINE.

Facing emotional problems on your own can be very difficult. Help is available. If you are feeling down or depressed, it's important to talk about it with a doctor or a counsellor. There are different kinds of counselling and therapy available. Some of these are one-on-one (where it is just you and a counsellor) and some are done in groups (where you, other people and a counsellor all meet together). The setting and type of service you receive will depend on what kind of support you're looking for and which services are available in your local area.

Get medical support

Medical support that you trust can help you live better with HIV and hepatitis C. In addition to your normal doctor/GP, you will likely also need see specialists—doctors who concentrate on a particular condition—such as an infectious disease specialist, gastroenterologist or liver specialist (a hepatologist). Other people who can support you include a pharmacist, naturopath, counsellor, psychologist, psychiatrist, dietitian or social worker. In future, it is likely that the new hepatitis C therapies could be prescribed in the community, this would improve access and remove the need to attend hospital clinics.

Some services provide support and care for both HIV and hepatitis C in one place and at the same time. Other times, people get care for their HIV, hepatitis C and other health issues in different places.

Some people who are co-infected may also use illegal drugs. Unfortunately, even in 2015, some healthcare professionals may still have negative or strong attitudes towards this, which can make it hard to build a comfortable relationship with them. If you are not comfortable with your healthcare professional it is always OK to ask to be transferred to someone else. Body Positive can help with this process if you require assistance. Ongoing drug use is associated with severe

health problems. It is very important to understand that someone with HIV and HCV who continues to inject drugs, is far more likely to die than someone who does not, from causes other than either HIV or HCV (suicide, murder, accident). Therefore, it is very important if you are using, that you discuss this with your support person or health care professional, who may arrange counselling at Community Alcohol and Drug Services or another rehabilitation centre such as Higher Ground, Odyssey House, the Bridge, WINGZ, or Pittman House.

Remember, every person has the right to good, respectful medical care.

It is always important that any healthcare professionals treating you are aware of anyone else you are currently seeing. This will insure all of your health information is up to date and will also help you and your healthcare professionals share relevant information with each other.

Get the right tests

Your specialist will likely recommend a variety of tests to check (monitor) how HIV and hepatitis C are affecting you, your immune system and your liver. You and your specialist will decide how often you have each of the tests.

An **HIV viral load test** measures the amount of HIV in your blood. The viral load test measures the number of copies of HIV in a millilitre of blood. Generally, the higher the viral load, the faster HIV will attack the immune system.

There is also a **hepatitis C viral load test** to measure the amount of hepatitis C virus in your blood. This test is sometimes called an RNA test or a PCR test. Unlike HIV and the immune system, a higher or lower hepatitis C viral load does not imply more or less liver damage.

HIV and hepatitis C virus naturally make copies of themselves (replicate) at different speeds. The average value for hepatitis C viral load is between 1 and 10 million, but don't be alarmed by hepatitis C viral loads that are a lot higher than your HIV viral loads.

There is no point checking hepatitis C viral loads regularly as these do not reflect liver damage. Viral load testing is mostly used before starting treatment. With the current PHARMAC-funded treatment, viral load is also checked during therapy. However, this will not be needed in future when we move to the new all-oral treatments.

Your **CD4 cell count** will give you and your doctor a rough idea of how strong your immune system is. Generally, you should be getting your CD4 count checked every three to six months. It may make sense to check it more often if you've been stressed or sick.


Liver tests are used to look at the health of the liver. Many specialists recommend liver tests every three to six months when you're co-infected with HIV and hepatitis C. These tests may include:

- Blood tests (some check the levels of liver enzymes, such as ALT and AST, and some measure liver function, such as bilirubin, prothrombin time and albumin). These are useless markers for assessing hepatitis C injury but should still be performed annually in someone of HIV therapy to check for toxicity from HIV medications.
- Fibroscan (which measures how stiff the liver is; it is also called transient elastography). This has replaced liver biopsy in most countries including New Zealand because it is more accurate, cheaper, has no side effects and provides an immediate result. The new portal Fibroscan machines can easily be transported to community clinics which removes the need to go to hospital. Fobroscan should be repeated every 3-5 years until the person is cured.

- Ultrasound (which takes a picture, like a photograph, of the liver to measure how much damage there is). This is only needed if the person has cirrhosis on the Fibroscan and is repeated 6 monthly to check for complications of cirrhosis.

In severe cases, cirrhosis from hepatitis C can lead to liver cancer. Finding cancer in its early stages can lead to more successful treatment. Talk with your specialist about your risk for liver cancer and a screening schedule that makes sense for you.





Take simple steps towards healthy living

You can help stay healthy, keep your immune system strong and lower your risk for liver damage with some key health habits. However, it can be hard to always make healthy choices because other things in your life may be more important.

Do as much as you can, and remember that every healthy choice helps your liver, your immune system and your overall health.

- **Quit or cut down on alcohol.** The process of breaking down alcohol in the body puts an extra strain on the liver and can cause more damage. Also, treatment for hepatitis C has a better chance of working if you can cut back on or stop drinking alcohol.
- **Quit or cut down on using cannabis.** There are cannabis receptors in your liver which cause rapid scarring in heavy users

(equivalent to at least three joints per day).

- **Quit or cut down on smoking.** Smoking tobacco can put an extra strain on your liver and can lead to other health issues such as heart disease, cancer and breathing problems.
- **Quit or cut down on illegal drugs.** Some drugs may affect your liver or your ability to take certain HIV or hepatitis C medications. It may become harder for your liver to break down the drugs and there's a higher risk for overdose. For information on safer drug use, consider talking to a doctor or Body Positive.

- **Consult with your doctor or pharmacist before taking painkillers and other medications, vitamins, herbs and supplements.** Some are more liver friendly than others. If you are on treatment for HIV and/or hepatitis C, speak with your doctor about possible interactions.
- **Lose weight if obese.** Fatty liver has been shown to increase the liver damage in people with hepatitis C. Lifestyle interventions are the most important interventions in obese people with chronic hepatitis C, including:
 - I) **Exercise, rest and relaxation are all important.** Find the right balance for you. A health professional can give you advice for your situation.
 - II) **Eat a healthy and balanced diet.** Choose fresh foods over salty, sugary, fatty and fried foods whenever possible. Drink plenty of water.
- **Get tested for hepatitis A and B.** Both of these viruses also infect the liver and can make liver damage worse if you already have hepatitis C. There are vaccines to protect against hepatitis A and B. If you have never been vaccinated, it's something to consider, especially if you travel or have multiple sexual partners because both hepatitis A and B can be easily transmitted through sex.
- **Get regular check-ups to monitor your overall health.** When thinking about health, it's important that we don't focus only on liver health and CD4 cell counts—there are other health issues that are linked to HIV, hepatitis C and co-infection. Let your specialist and doctor know about any problems you are having, changes you notice or if something feels different. These changes may or may not be related to HIV or hepatitis C.



Drinking less alcohol is one of the best things you can do for your health when you are co-infected with HIV and hepatitis C. If you want to make this change in your life, try different strategies to discover what works for you. You might:

- Set a drinking goal and try to stick to it. For everyone with hepatitis C with no or mild scarring of the liver, total alcohol intake should be less than the current ALAC recommendations of no more than six drinks for men and four for women on a single occasion, and no more than 21 for men and 14 for women a week, plus at least two alcohol free days a week. For anyone with moderate liver scarring or cirrhosis, then the recommendation is for no alcohol at all.
- Space out alcoholic drinks with non-alcoholic drinks such as water.
- Switch to smaller drinks or drinks with lower alcohol content (three percent instead of five percent, for example).
- Seek support through a support group, addiction treatment or counselling.

Body Positive offers more information on how to live better with HIV and hepatitis C. See www.bodypositive.org.nz or call us on 0800 HIV LINE.

Learn about the treatments for HIV and hepatitis C

Treatments are available for HIV and for hepatitis C. You and your specialist will decide on how to best treat the two viruses. The treatments are different in several ways. (See 'Different viruses, different treatments' on the next page for more information.)

Different viruses, different treatments

Since treatment information can be complicated and changes quickly, this is a general introduction to major treatment issues related to HIV and hepatitis C co-infection. However, as you begin to make treatment decisions, you may want more detailed and current information than this booklet provides.

Treatment is available for HIV and for hepatitis C.

HIV and hepatitis C treatments are different: they have different goals, work in different ways and have different regimens.

HIV treatment means taking a combination of anti-HIV drugs—usually at least three—every day. Treatment is usually taken once or twice a day and some drugs are combined into one pill so that there are fewer pills to take.

There are more than 20 different anti-HIV drugs, and experts recommend specific first-time combinations because they are safe, effective and generally easy to take. However, other factors, such as the type of virus that you have, your other medical conditions or your other prescription drugs, may mean your specialist will decide on a different combination for you.

You and your specialist will also decide when is the best time for you to start treatment. Because co-infection can increase how fast liver damage happens, the sooner you start HIV treatment the better it is for your liver and overall

health. The lower your CD4 count, the more seriously you should think about HIV treatment. People with higher CD4 counts can monitor their counts and, together with a specialist, weigh the benefits and challenges of starting treatment.

At this time, HIV is a lifelong infection and HIV treatment is a lifelong commitment. Stopping treatment, even for a short time, is not recommended because there is a risk of serious health problems, including more liver damage. These short breaks from treatment can also cause your anti-HIV drugs to stop working.

Many people who are co-infected consider **hepatitis C treatment** when they have early signs of scarring (or fibrosis) on the liver.

At this time, hepatitis C treatment for someone who is co-infected with HIV generally lasts for about one year. Sometimes, if treatment is not working or if you have too many side effects, your specialist may stop your hepatitis C treatment early.

Your hepatitis C treatment options and how well you respond to hepatitis C treatment depends on many factors. Among the most important is the type (called the strain or genotype) of hepatitis C virus you have. Some strains are harder to treat than others. A hepatitis C genotype test can tell which type you have.

HIV

Hepatitis C

What is the main goal of treatment?

The goal of HIV treatment is to lower the HIV viral load to an undetectable level and keep it there. This allows the immune system to retain (or rebuild) its strength and keep you healthy. There is no cure for HIV infection—at least, not yet.

The primary goal of hepatitis C treatment is to prevent the ongoing liver inflammation which results in progressive scarring and eventually cirrhosis and its life threatening complications of liver cancer and liver failure. The only way to do so is to eradicate the virus from the body. This will prevent the need for liver transplantation and prolong survival. Eradicating the virus can also be called a viral cure or a sustained virological response (SVR). It means that a person does not have hepatitis C any more.

Are there other goals?

Treating HIV can also improve the health of many other systems in your body, including your heart, kidneys and liver. A healthier liver can better handle hepatitis C. Being on treatment and having an undetectable viral load lowers the risk of HIV passing to other people.

Treatment may improve the overall health of the liver.

By improving liver health, hepatitis C treatment can also reduce the risk of liver-related complications with HIV treatment.

Do I have to go on treatment?

Almost everyone with HIV needs to start HIV treatment eventually.

A few people clear the virus without treatment and, for some others, liver damage happens slowly enough that they do not need treatment.

Treatment of hepatitis C should never be prioritised over treatment of HIV. Only when HIV is adequately treated, should the emphasis be moved to HCV treatment. In most people with HIV/HCV co-infection, current treatment should be deferred until the newer oral treatments (Harvoni, Viekira Pak) are funded by PHARMAC

Deciding to start treatment for HIV or hepatitis C

Things to think about before starting treatment

Starting treatment for HIV or hepatitis C is a big decision. This is because there are benefits and challenges to each treatment. Before starting either treatment, there are many issues, both medical and non-medical, to consider, including:

- **Side effects**, both short term and long term, and if you feel strong enough and supported enough to manage them. Learning as much as you can about the side effects of treatment and how to cope with them beforehand will help you make better decisions. (See **'Dealing with side effects'** on page 21 for more in-depth information.)
- Your **ability to stick to** (adhere to) the treatment regimen. Adherence is important for the drugs to work. This is particularly true for HIV therapy, which is a lifelong commitment. If HIV keeps making copies of itself when exposed to low levels of anti-HIV drugs, it will eventually figure out how to make copies of itself even when it is exposed to the proper drug levels.


For many years, the standard treatment for hepatitis C has been a combination of two drugs: pegylated-interferon and ribavirin. Interferon is given by a once-a-week injection and ribavirin is taken twice a day in pill form.

New drugs for hepatitis C are being developed— some work in ways that are different from current drugs. Over the next few years, we can expect new treatments that do a much better job of treating hepatitis C.

Both the Gilead **Harvoni** and AbbVie **Viekira** regimens are now approved in NZ and likely to become funded within the next 1-2 years. These have a 95% cure rate in patients with HIV/HCV co-infection after only 12 weeks and are extremely well tolerated because of the lack of interferon. Drug interaction with the HIV medications are also easily managed.

If you have HCV infection then you should have a Fibroscan to see how much scarring you have on your liver. If there is not much scarring, then you can consider waiting until these new treatments are funded here in New Zealand.

For more information on HIV treatment, check out Body Positive's booklet **HIV Tests & Treatments** online at www.bodypositive.org.nz or call 0800 HIV LINE to order your free copy.



Then your drugs will no longer work for you.

Thinking about how taking medications every day may affect your life can help you stick to your treatment once you start taking it. Common issues that come up include managing side effects, handling taking pills in different situations of daily life, remembering to take pills on time and even understanding your feelings towards the medications.

If you are at a point in your life where, for whatever reason, you are not able to take your medications regularly and as prescribed, take a clear and honest look at what's giving you trouble. Solving these problems is a very individual matter. Your pharmacist, clinic nurse, social worker, Body Positive or friends who have been on treatment can often help you.

- **Other health problems**, like heart disease, diabetes, anemia, obesity or mental health issues such as depression. These conditions may affect the specific drugs you take or how you can prepare

for the side effects of treatment. For example, some people with depression start antidepressant medications a few weeks before starting hepatitis C treatment.

- How fast **liver damage** is happening. Your liver might not get worse or it could get worse very fast. Monitoring your liver health will give some information about how fast the disease is happening. Severe liver damage can make hepatitis C and HIV more difficult to treat and can also limit which HIV medications you can take.
- Your **support network**. Joining a support group and talking with family and friends can all play an important role throughout all phases of treatment.
- If you are **pregnant** or your partner is pregnant, or if either of you wants to have a baby, see the section '**You can have a healthy baby**' on page 27 for important information.

Your specialist can help you consider all of these factors and come to a decision that is best for you. The most important thing is to start treatment when you are ready.

Which treatment to take first?

If you have never been on HIV or hepatitis C medications before, the decision about which condition to treat **first is almost always HIV**. This will raise CD4 cell counts, improve your immune system, which slows down the rate of liver injury.

Already on HIV treatment? If your HIV is under control with HIV treatment, you might consider taking hepatitis C treatment while staying on your anti-HIV drugs. Your specialist may recommend changing the specific HIV medications you take to avoid interactions with hepatitis C medications.

Taking on two treatment routines and two sets of side effects at the same time can be difficult, but many people say that the experience of taking HIV treatment actually helped to prepare them for hepatitis C treatment. For example, strategies for remembering to take your anti-HIV drugs or tips for

coping with side effects can be used when taking hepatitis C treatment.

Some people, especially people with HIV who visit their doctor regularly, learn they have hepatitis C when the infection is caught early (in the **acute phase**). If this is the case for you, your doctor might recommend waiting a few weeks to see if the body clears the hepatitis C virus on its own. If it seems that the body will not clear the virus by itself, your doctor might recommend starting hepatitis C treatment right away.

Acute hepatitis C is easier to treat than chronic hepatitis C; the treatment may be simpler, length of treatment may be shorter and the success rate is higher.



**Starting
treatment
for both
viruses at the
same time is not
recommended.**

Making sure your drugs work together

Sometimes when people take medications for more than one condition at the same time, these medications react with each other. This reaction is called a drug-drug interaction. Drug-drug interactions can cause more side effects or change how effective a particular medication is.

It is important to be aware that some of the medications commonly used to treat HIV and hepatitis C can interact with one another. Other medications that you may be taking, including methadone, can also interact with certain anti-HIV or anti-hepatitis C medications.

Talk to your specialist about the different medications you are taking so that he or she can help you avoid drug interactions. Getting your different

prescriptions filled by a single pharmacy can also help avoid unexpected interactions.

Another type of drug interaction is when an existing medical condition such as hepatitis C changes how effective or safe a medication is. Many anti-HIV drugs are broken down by the liver and this can put an extra strain on the liver and cause more damage to it. Your specialist may recommend switching to more liver-friendly anti-HIV drugs or lowering the dose—the effects on the liver usually go away after these changes are made.

If you are taking HIV treatment, regular blood tests to monitor your liver health will help to identify possible problems. This is true whether or not you are also taking hepatitis C treatment. This way, most people can be on a treatment that is safe and effective.



Once you've started treatment for HIV or hepatitis C

How to know whether treatment is working

HIV treatment slows down the production of HIV in your body. This leads to drops in your HIV viral load.

The goal is to have your HIV viral load become undetectable.

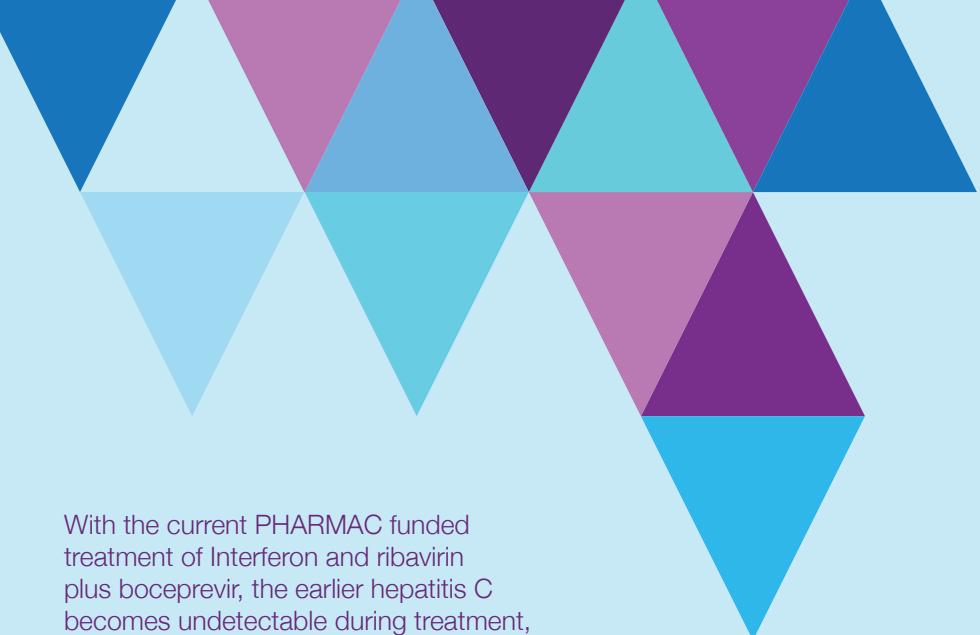
HIV viral load usually becomes undetectable within three to four months, depending on how high it was before treatment. Don't be alarmed if your viral load doesn't become undetectable right away. Talk to your specialist about how long it could take in your case.

Once your HIV viral load becomes undetectable, it should stay there provided you continue to take your medication. If your HIV viral load becomes detectable again, you may need to change your combination of anti-HIV medications.

CD4 counts don't usually increase as quickly as HIV viral load drops, especially if you're co-infected with hepatitis C. Once HIV is under control, your immune system should become stronger.

Changes in your hepatitis C viral load show whether **hepatitis C treatment** is working. Your hepatitis C viral load will be measured at different times during treatment.

Ideally, the hepatitis C viral load will become undetectable, though this is not always the case.



With the current PHARMAC funded treatment of Interferon and ribavirin plus boceprevir, the earlier hepatitis C becomes undetectable during treatment, the higher the chance of clearing the virus. Treatment sometimes works more slowly for people who are co-infected. Small drops in hepatitis C viral load at the beginning of treatment do not always mean that treatment is not working or will not work. If this happens, don't be discouraged. Be patient and hang in there!

In contrast, the speed at which the hepatitis C virus disappears from the blood is irrelevant with the new all oral therapies of Harvoni and Viekira Pak – everyone will have undetectable virus within the first 6 weeks of treatment.

If the hepatitis C viral load becomes undetectable during treatment, it will be measured again twelve weeks after treatment is finished. Hepatitis C is cleared from the body when the virus is undetectable six months after the end of treatment. This is called a sustained virological response (SVR).

Unfortunately, hepatitis C treatment does not work for everyone. Sometimes, if treatment is not working, your specialist may stop your treatment early. (See the section **'After hepatitis C treatment'** on page 23 for more information.)

Undetectable, cleared and cured: three important words

An **undetectable** HIV viral load means that the amount of HIV is so low that the test used to measure HIV viral load can no longer detect the virus in the blood. An undetectable HIV viral load allows your immune system to rebuild itself and for you to remain healthy. It does NOT mean that HIV is gone from your body. You are still HIV positive. Currently, there is no cure for HIV.

With hepatitis C treatment, hepatitis C viral load can also become **undetectable**. If hepatitis C viral load remains undetectable six months after you have finished treatment, the hepatitis C virus is cleared from the body.

If the virus is **cleared** from the body, treatment has **cured** hepatitis C. This stops the damage to the liver. However, treatment itself cannot repair the damage that hepatitis C has already done to the liver. In many people, the liver is able to heal itself over time.

Dealing with side effects

In general, people who are co-infected and taking treatment for HIV, hepatitis C or both experience the same side effects as people who are living with one virus and taking one treatment. The main difference is that some side effects may happen more often or feel more intense among people who are co-infected. The PHARMAC funded treatments of interferon, ribavirin and boceprevir are each associated with common and sometimes severe side effects, including mood changes (depression, anxiety, agitation), fatigue, skin rashes, loss of appetite and flu-like symptoms.

The good news about anti-HIV drugs is that newer drugs are much easier for the body to tolerate than older drugs with little or no side effects.

Work with your specialist to plan for side effects before starting treatment.

Planning for side effects means understanding what side effects you might experience and thinking of ways to manage them. For example, there are medications your doctor can prescribe to help manage diarrhoea during the first few weeks after starting HIV treatment. Or you can reduce the flu-like symptoms of hepatitis C treatment by taking over-the-counter medication the day of the interferon injection.

Natural health products

Natural health products are vitamins and minerals, herbal remedies, homeopathic medicines, ancient systems of healing, probiotics and supplements.

Talk to your doctor and pharmacist about any natural health products you take or are thinking of taking as part of your treatment plan.

From managing drug side effects to boosting your immune system, there are many reasons why people take natural health products. For example, antioxidant supplements (such as vitamins A, C, and E, N-acetyl- cysteine (NAC), co-enzyme Q10 and alpha-lipoic acid) are popular among people with HIV because they help protect and heal the body's cells from damage caused by HIV. However, no natural health product has proven to be effective as a treatment for HIV itself or as a treatment for hepatitis C.

While natural health products do not require a doctor's prescription, they have benefits and side effects, just like other drugs. Some natural health products can also interact badly with anti-HIV or anti-hepatitis C medications. This is especially true for herbs. For example, St. John's wort, a herb used to treat depression, can cause problems with anti-HIV medications. Milk thistle, a herb that some people believe may improve liver health, can also cause problems with many medications, including anti-HIV and anti-hepatitis C medications.

Depression is a very common side effect of hepatitis C treatment. It deserves attention because about one out of every three people treated for hepatitis C can develop mental health problems, including depression. The good news is that there are ways to lower the risk of depression. Some doctors start their patients on medications to lower the risk of depression a month before starting them on hepatitis C treatment.

If you are using substances, you may want to talk to your doctor or Body Positive about how to get help for dependence on alcohol or illegal drugs. These changes will make it easier to take treatment and make you healthier.

Some people are tempted to stop their treatment early because of side effects. But, for the treatment to work, it is important to take all doses exactly as prescribed. If you experience severe side effects, you should talk to your doctor or nurse about ways to reduce them.



After hepatitis C treatment

If treatment cleared the virus:

If you have cirrhosis before you start treatment, your specialist may want to continue monitoring for liver cancer. He or she may recommend an annual screening test, for example. You may also continue to experience some symptoms of liver damage, such as tiredness or difficulty concentrating. For many people, the liver heals itself over time.

The body does not develop protection against the hepatitis C virus and it is possible to become infected again. Understanding how hepatitis C can pass from person to person will help you take steps to protect yourself in the future. (See ***'Protecting yourself, protecting others'*** on page 24.)

If treatment did not clear the virus:

People can have many different emotions when hepatitis C treatment did not clear the virus. You may want to talk about your feelings with someone such as a friend, family member, counsellor, support worker, nurse, Body Positive or your local hepatitis organization.

Focus on doing what you can to reduce liver damage and to live and feel well. (See ***'Things you can do to live better with HIV and hepatitis C'*** on page 5.) Continue to follow up with your specialist to monitor your liver. There may be other options for you, such as trying treatment again, especially when new anti-hepatitis C drugs become available.

Protecting yourself, protecting others

How do HIV and hepatitis C pass from one person to another?

A major reason why co-infection with HIV and hepatitis C is common is that both viruses often pass the same way.

Both viruses can pass through blood-to-blood contact (when blood carrying the virus gets into another person's bloodstream). HIV can also be spread through semen (cum, including pre-cum), vaginal fluids, anal fluids and breast milk.

Neither HIV nor hepatitis C can pass through dry kissing or casual contact such as hugging, shaking hands, sharing clothes or eating together.

During sex

The chance of HIV passing during sex depends on different factors, including:

- The kind of sex you're having – HIV passes most easily during unprotected anal sex and unprotected vaginal sex. The risk of HIV passing during oral sex is usually very low. Cuts, sores or inflammation in the mouth or throat or on the genitals can increase the risk during oral sex.
- HIV treatment and viral load – if you're on HIV treatment and have an undetectable viral load, the risk of HIV passing to a partner is much lower.
- If either partner has another sexually transmitted infection (STI) – STIs can affect the genitals, anus, mouth and throat. Having an STI can increase the chance of HIV passing during sex.

Although sexual transmission of hepatitis C is rare, it can happen, especially during unprotected anal sex. Being co-infected with HIV and hepatitis C increases the risk of hepatitis C passing during unprotected sex. Using drugs during sex also increases the risk of transmitting hepatitis C

Safer sex involves thinking about the kinds of sex you want to have, learning about the risks and using different strategies for lowering the risk of HIV, hepatitis C and other STIs.

Looking for some safer sex tips to get you started?

- **External (male) condoms and internal (female) condoms** are an effective form of protection against HIV, hepatitis C and most other STIs. Using a water-based lubricant with condoms can decrease the chances of the condom breaking. For information on how to use a condom, talk to a healthcare or community worker.
- You can reduce your risk of getting other STIs by **learning how different STIs pass between people, getting tested regularly and treating any infections right away.**
- Sharing sex toys can allow HIV, hepatitis C and other STIs to pass. **Putting a condom on the toy and changing it whenever a sex toy is passed from partner to partner or from one body opening to another**—mouth, anus or vagina—can lower this risk.
- **Good oral hygiene**, such as preventing sores in and around the mouth, can lower the risk of HIV, hepatitis C and other STIs passing during oral sex. Not brushing or flossing for at least 30 minutes before sex will also lower this risk.

Do you have to tell your sex partner(s) that you have HIV and hepatitis C?

In New Zealand people living with HIV do not need to declare their HIV status when condoms are properly used during sex, nor do they need to declare their status when oral sex is performed. There have been several court proceedings and convictions against people living with HIV in New Zealand who have not used condoms and also not declared their HIV status before having sex.

People with hepatitis C should undertake a reasonable precautions against transmitting the infection, however there is no legal duty to disclose their hepatitis C status before sex.

Together with your partner(s) you can make decisions about the level of risk and the strategies that are right for you.



When using drugs

Sharing or borrowing equipment for preparing, injecting, smoking and snorting drugs can spread HIV and hepatitis C. This is because used equipment can have blood on it and even small amounts of blood carrying HIV or the hepatitis C virus can spread these viruses when there is contact with another person's bloodstream.


If you use drugs, there are things you can do to lower the chance of HIV and hepatitis C passing to others and to protect yourself from other infections.

The steps you can take are forms of safer drug use, also called harm reduction.

- If you inject drugs, including steroids, you can lower the risk by not sharing needles, syringes, and other injecting equipment (cookers, filters, water, swabs and ties) and by attending needle and syringe exchange outlets for sterile equipment and good advice.

- If you smoke drugs, you can lower the risk by using your own equipment (pipes, mouthpieces) and trying not to share with other people.
- Pyrex pipes with mouthpieces are safest because they don't break down as easily or get as hot as other materials when heated. This can prevent cuts, burns and sores on the lips, helping to stop HIV and hepatitis C from passing.
- If you snort drugs, you can lower the risk by using your own equipment and trying not to share with other people. Consider items that you can use once then throw away, such as a rolled-up Post It note or a plastic straw.

If you don't have access to new needles, you can clean your own needles and syringes before each time you use them. Still, you should not share these with other people. To clean the syringe, flush it twice with clean water, twice with bleach and then twice with new water. Each flush should last 30 seconds. This will kill HIV, but bleach is NOT effective at killing hepatitis C in needles or syringes.



You can have a healthy baby

Many people living with HIV and hepatitis C want to have children.

Healthy pregnancies and healthy babies are possible for people living with HIV and hepatitis C.

Although HIV can pass to a foetus or baby from an HIV-positive mother, advances in HIV treatment and care mean you can have an HIV-negative baby. For more information, ***'HIV Pregnancy & Women's Health'*** and ***'Treat Yourself Right: Information for Women living with HIV or AIDS'*** are two booklets aimed specifically at women living with HIV. They provide information on pregnancy, and on a wide range of topics with a focus on health maintenance and treatment information, and are both available from Positive Women Inc. or alternatively can be downloaded from www.positivewomen.org.nz.

When it comes to **hepatitis C**, transmission between mother and baby is not common (less than 1 in 20 chance). The chance increases when a woman is co-infected with HIV (1 in 5 chance).

Some women want to try to clear the hepatitis C virus before becoming pregnant. It's important to be aware that ribavirin, one of the drugs commonly used to treat hepatitis C, can cause severe birth defects if taken at the time of conception or during pregnancy. Both male and female partners should wait at least six months after finishing hepatitis C treatment before trying to get pregnant. Hepatitis C treatment should never be started in a woman who is not using reliable contraception, is pregnant or is breast feeding.

Breastfeeding is generally not a risk for hepatitis C transmission. However, it is a risk for HIV transmission. Guidelines strongly encourage HIV-positive mothers to use baby formula.

For more information

For more information about something you read in this booklet, contact **Body Positive Inc.** or one of the other organizations listed below:

Body Positive Inc.

www.bodypositive.org.nz

0800 HIV LINE (0800 448 5463)

- Auckland (09) 309 3989

Positive Women Inc.

www.positivewomen.org.nz

0800 POZTIV (0800 769 848)

- Auckland (09) 309 1858

INA Foundation

(Maori, Indigenous and Pacific Island Support)

www.ina.maori.nz

- Waikato (07) 883 9084

New Zealand AIDS Foundation

www.nzaf.org.nz

0800 80 AIDS (0800 80 2437)

- Auckland (09) 309 5560
- Wellington (04) 381 6640
- Christchurch (03) 379 1953

The Hepatitis Foundation of New Zealand

www.hepatitisfoundation.org.nz

0800 33 20 10

- Whakatane (07) 307 1259
- Tauranga (07) 579 0923

Hepatitis C Resource Centre

www.hepcnz.org

0800 22 HEPC (0800 22 4372)


- Christchurch (03) 366 3608
- Otago (03) 477 0407

Needle Exchange Programme

(Outlets throughout New Zealand)

www.needle.co.nz

- Christchurch (03) 366 9403



The New Zealand Liver Unit

- Auckland (09) 307 4949 ext 22920

New Zealand Prostitutes Collective

www.nzpc.org.nz

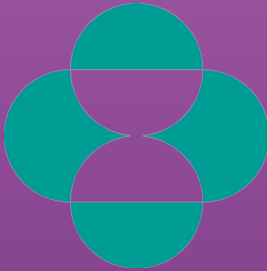
- Auckland (09) 366 6106
- Wellington (04) 382 8791
- Christchurch (03) 365 2595
- Dunedin (03) 477 6988
- Tauranga (07) 571 0640
- Waikato (07) 839 5519
- Taranaki (06) 758 6228
- Hawkes Bay (06) 835 1400
- Palmerston North (06) 357 3150



+BODY POSITIVE
• NEW ZEALAND •
Tinana Ora Aotearoa

Auckland Head Office: 1/3 Poynton Terrace, Newton, Auckland
Tel: 09 309 3989 | **Email:** office@bodypositive.org.nz

Freephone: 0800 HIV LINE
www.bodypositive.org.nz



MSD