

LIVING **WELL**

PIKI TE ORA

WITH HIV

You are probably reading this because you or someone you know has recently been diagnosed with HIV. Everyone responds differently to the news, and there is no right or wrong way to handle it. Taking everything in when you first hear about the diagnosis can be hard. You may need help to get information and answers to questions you have. Some people want to know everything immediately, others either feel uncomfortable doing this or want to learn the specifics gradually.

Remember that due to research and improved medication, living with HIV has changed a lot in the last ten to twenty years. People from all walks of life are living with HIV and enjoying full and active lives. Give yourself time to get used to the idea that having HIV will change your life in significant ways, but you will learn and have support to adapt to the changes over time.

“Some people want to know everything immediately, others either feel uncomfortable doing this or want to learn the specifics gradually.”

This booklet is for anyone diagnosed with HIV regardless of gender, sexuality or cultural background. You may want to read it all at once, or take your time – dipping in and out over days or even weeks. You may also wish to have a relative or friend read it, or you may want to discuss it with a doctor, specialist or counsellor.

For a full list of places to find help, please check out page 45 and get in touch.



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Finding out

What being diagnosed with HIV means

HIV stands for Human Immunodeficiency Virus. Being told you have tested positive for HIV means your body has come into contact with HIV and you have contracted the virus.

Even though HIV infection is serious and there is currently no cure, there are many treatment options available to you that will enable you to live a long and healthy life. Combination-drug treatments mean you can be in control of HIV, not the other way around.

HIV belongs to a group of viruses called retroviruses. These work by invading the genetic material of cells within your body. Normally, the body's immune system would fight off such a virus, but HIV stops this by infecting CD4 cells (also known as T-cells). The virus can live in the body for years without causing obvious damage, though it will continue to constantly replicate.

Over time, if your CD4 cells are damaged, your body may be less successful at protecting you from bugs and germs that can lead to infection or illness. There is more detailed information about HIV later in this booklet or online at nzaf.org.nz/HIV.

HIV services in New Zealand

There are many support and medical services available to people living with HIV. The New Zealand AIDS Foundation (NZAF) offers free counselling and support to anyone affected by HIV. New Zealand also has a network of HIV peer support groups and there are HIV specialists based at hospitals around the country. You can find more information about services on page 17, or online at nzaf.org.nz/services.



Feeling well?

You may feel fine and have no symptoms, even though you've been diagnosed with HIV. This is often referred to as 'asymptomatic infection'. For most people this lasts for several years and, for some, the asymptomatic phase can last 15 years or more.

If you are not displaying any symptoms and you feel well, it is still important to look after your health through diet and exercise. The effect of HIV is different for everyone but, generally, taking care of yourself physically and emotionally will lessen the impact of HIV on your lifestyle in years to come.

Diagnosis and symptoms

Many people don't know they have contracted HIV for many months, even years. If you have been diagnosed late, you may still feel well.

When you first contract HIV, your body begins to make antibodies. Some people say they feel like they have the flu. Doctors call this 'seroconversion illness', because this is the very first time your body is trying to cope with HIV.

Common symptoms are:

- A high temperature (fever)
- Sore throat
- A blotchy rash on the body
- Tiredness
- Swollen glands
- Joint and muscle pain

Initial coping strategies

Everyone deals with the initial diagnosis in their own way. You will have your own feelings and reactions to work through. There is no right or wrong way to respond.

Working out where your HIV status fits into your identity may take a little while, or it may be a relatively simple process for you. We all have many words we use to describe parts of ourselves; words for our gender, job, sexuality, ethnicity, race and beliefs. Taking time to work out where your HIV status fits in with your identity can be a helpful process.

When you first get the news it can be a good idea to take a few days out to relax and de-stress if you need to. Your doctor should be able to provide you with a medical certificate for work, if required. Developing strategies to deal with the news will be important. Make time to think, react and feel over the first few weeks if you can.

Having people to talk to and support you can be important. You could talk to a close and trusted friend, your partner or a relative. You may prefer to talk with people who have experiences of HIV. NZAF can put you in touch with peer support groups or people living with HIV in your area.

Alternatively, specialist counsellors can be found through NZAF online at nzaf.org.nz/counselling.

Working out how much information to take in over the first few weeks can be a tricky process. Assess how you are feeling as you digest the details and feel out whether you would like to find out as much as you can quickly, or take things a little slower. It can sometimes feel like an information overload, so find the right pace and go from there.

What does having HIV mean in the long term?

Every person is different, and there is no set answer to how HIV will affect you over time.

There are many factors that will affect your wellness. These factors include:

- How well you look after yourself emotionally and physically
- Decisions around treatments
- How well treatments work for you
- Genetic factors
- Co-infection with other illnesses such as sexually transmitted infections and hepatitis

In the last 30 years there have been dramatic advances in the treatment of HIV. Consulting with your doctor or HIV specialist is essential for finding out what treatment is right for you. For more information, see the HIV treatment section, page 19.



Words and terms you might hear – what they mean

There are many medical terms you will encounter while working with doctors and specialists. If you don't understand them, always ask.

Difference between HIV and AIDS

AIDS stands for Acquired Immune Deficiency Syndrome and is an advanced stage of HIV infection. These days, very few people living with HIV develop AIDS, largely thanks to advances in medications. AIDS can develop when HIV weakens a person's immune system to the point their body is no longer able to protect itself against infections and cancers that a normal immune system would fight off.

Window period

This is the early stage of HIV infection, when there is a lot of HIV in your body. During this window period, blood tests can give a negative result because your immune system is still reacting to the virus. This means very few antigens and antibodies are being made. It also means you will need to test again a few weeks later to confirm a negative result. This high viral load means the risk of HIV transmission is much higher at this time than at others.

CD4 cells

CD4 cells (or T4-cells or T-cells) are a subset of your white blood cells. CD4 cells are a critical part of your immune system. They are infected and destroyed by HIV. CD4 cell numbers can fluctuate on a regular basis and are influenced by a variety of factors other than HIV. For example either the presence of another infection such as the flu, or levels of stress. Sometimes, an HIV infection can deplete CD4 cells to such dangerous levels that they are unable to play their part in helping your immune system work properly.

Contact tracing

An anonymous process to find out if anyone else, for example previous sexual partners, may have been unknowingly exposed to HIV, and to alert them to get tested.

Seroconversion (seroconversion illness)

Seroconversion is the period of time during which HIV antibodies develop and become detectable. Seroconversion generally takes place within a few weeks of initial infection. It is often, but not always, accompanied by flu-like symptoms (see Diagnosis and symptoms section on page 3).

Viral load

Viral load is a measure of the amount of HIV in your bloodstream. Knowing how much HIV is present is an indicator of how active the virus is and the risk of future damage to the immune system. A blood test will determine your viral load. It is important to have a baseline viral load value to assess the response to the treatment, and a baseline resistance test to check that the appropriate drugs are used.

Immunosuppression

This refers to the suppression of the immune system and its ability to fight infection and certain cancers. Immunosuppression may result from some diseases, such as unmanaged HIV, or from certain drugs.

Asymptomatic infection

Asymptomatic infection describes HIV infection with no symptoms.

Adverse reactions

These can occur when the body reacts badly to a drug. They can manifest in many different ways, and some are quite common and benign. Make sure to ask your doctor what to expect from your medication and when to seek help.

Myths and facts

It's important to distinguish between myths and facts about HIV and what it's like to live with it. Here are a few common myths and the facts behind them:

Only gay men get HIV

Anyone can get HIV. Your race, gender and sexual orientation have nothing to do with it. Currently in New Zealand, there are people who are gay, heterosexual, bisexual, transgender and from diverse communities, cultural and religious backgrounds and ethnicities, who are living with HIV. Statistics show that gay and bisexual men are the most at-risk group of getting HIV, but they're not the only ones. Men who have sex with men in New Zealand are a relatively small community, which may make it easier for infections to spread. HIV transmission is also eighteen times more likely through receptive anal sex without a condom than it is through receptive vaginal sex without a condom.

HIV is a death sentence – I am going to die

HIV is not the death sentence it once was. People living with HIV are now able to access the right care and treatment and lead long and productive lives.

I don't think I can get through this

Give yourself time to cope with the HIV diagnosis. Everyone reacts differently. It can help to talk to a counsellor, to an HIV specialist or someone currently living with HIV. Most people living with HIV say they slowly learned to control their treatment and health. Remember that help and support is at hand and you are not alone in this.

I'm going to infect the people I love

It is important to remember, HIV cannot be transmitted by hugging, kissing, massages, sharing cups or using the same bathroom. It can only be transmitted through unprotected anal or vaginal sex, sharing needles or direct blood-to-blood contact. For sexual partners, there are many ways to prevent HIV transmission, including: condoms, PrEP (Pre-exposure prophylaxis) and maintaining an undetectable viral load (UVL/ U=U) for more than six months. It is also now extremely rare for HIV to be passed from mother to child during pregnancy or delivery if the mother is on successful treatment.

HIV only affects people living in large cities

In New Zealand, HIV affects people in cities, smaller towns and villages and rural communities.

I don't know who to tell

Think of the people you want to tell and take your time in deciding. Who and when to tell is completely your choice. There are many people you can talk to including counsellors, your doctor or other people living with HIV. These people can be a good starting point when you are trying to figure out who to tell and how to tell them.

The medication will rule my life

Although skipping pills or delaying doses may put you at risk of the HIV virus becoming resistant to drugs, most people get used to the routine requirements quite quickly (see Adherence to medication section on page 22).

Nobody will ever want to have sex with me again

Many people living with HIV receive support from their partners upon disclosure. People living with HIV have a right to a full and active sex life, but they and their sexual partners must take responsibility to ensure HIV isn't transmitted. Condoms are the most effective way to prevent both the transmission of HIV and other STIs. Pre-exposure prophylaxis (PrEP) is also very effective and is a daily pill taken by HIV negative partners to prevent transmission. Excitingly, we now know that, if a person living with HIV has an undetectable viral load and maintains this for more than six months, HIV is not transmitted sexually.

The initial diagnosis

After the initial diagnosis, it is important to take some time to think and relax. You don't need to rush out and tell people straight away, but you may find it helpful to have some supportive friends and family around you. You might have friends living with HIV who could be a good source of support.

Following your initial diagnosis, you will be offered an opportunity to see an HIV specialist. You may find you have more questions or want more information over time. Start making a list of any questions you think of in the next few weeks.

Finding support

NZAF offers free counselling and support to anyone affected by HIV. There is also a network of HIV peer support groups, and HIV specialists around the country you can get in touch with.

If you're feeling overwhelmed you can visit NZAF's website www.nzaf.org.nz or call free on 0800 802 437 to chat to a support person or book an appointment to speak to one of the counsellors in person.

Talking about your diagnosis

Some people experience a feeling of isolation when they find out they are living with HIV. Being diagnosed with HIV is a personal experience, and it's up to you to decide when and who you feel confident to disclose your HIV status to.

You don't have to tell your friends, employers or work colleagues if you don't want to. New Zealand has a robust human rights framework that protects people living with HIV (you can find out more about HIV and the law on page 29).



Telling others of your diagnosis is easier if you have given yourself time to feel ready. Under New Zealand law, you are not obligated to tell your sexual partners your HIV status as long as you are using condoms every time.

When deciding who to disclose to, you may wish to ask yourself these questions to help you decide whether you can trust someone with the information that you're living with HIV:

- Will they offer me support?
- Will they judge me?
- Will they respect my confidentiality?
- Will it help me if they know?

If the answer to any of these questions is no, the person you are considering telling may not be the best choice. Try to find someone you feel sure will be supportive, non-judgmental, discreet and helpful. A counsellor or peer-support person may be able to help you make the best decision.

Once you have decided who to tell, you might find it useful to let them know who else you have told so that they can support each other, as well as you.

Telling your doctor or healthcare professional

It is important to develop a good relationship with your doctor, and to talk to your GP or health professional about your status. Monitoring your health and making sure you have the right treatment options available to you will increase your wellbeing.

It is wise to tell health professionals you are seeing for other conditions that you are living with HIV. However, you do not have to disclose your HIV status to every doctor, dentist or other healthcare professional.

Letting them know will give them a clear picture of your health and be able to help you make decisions about your health. Your healthcare provider cannot reveal your HIV status to anyone, except in extreme and unusual circumstances (for example, if someone else's safety is involved, such as some cases of non-consensual sex brought to the attention of the police), and they should inform you first.

If you don't feel comfortable with your doctor for any reason, talk with them

about your concerns. If you are still not satisfied, remember you have the right to choose a different doctor that you trust and feel comfortable with, or who has more knowledge about HIV. NZAF can help you to find doctors or health professionals who have HIV expertise and experience.

Contact tracing

After an HIV diagnosis, you will be asked about your recent sexual partners. This is called contact tracing, a process to find out whether anyone else may have been unknowingly exposed to HIV and to alert them to get tested. It's important to be honest here so those people can get tested. Don't worry – your identity cannot be disclosed by your doctor and your recent partners will be contacted anonymously.

Telling your partner

If you are in a relationship with someone who is HIV negative, or if you have multiple casual partners whose HIV status you may or may not know, you may want to tell them.

It can help to have a counsellor experienced in working with HIV issues available to help you if and when you decide to tell your partner(s). There are no set rules about telling your partner(s), regardless of their HIV status, and you may feel scared or uncomfortable telling them. Despite the fears you might have, many people have found they received support when they shared the news. It may even strengthen your relationship.

Your partner(s), husband or wife might also want to consider testing for HIV, especially if you have been having sex without condoms or sharing injecting equipment.



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Counselling

NZAF offers free and confidential counselling in a safe space. Services are available for people living with HIV, their friends and whānau and anyone affected by or at risk of contracting HIV. To make an appointment, call 0800 802 437 or book online at www.nzaf.org.nz.

Counselling is also available through Sexual Health Services around the country.

Counselling is provided at Body Positive in both Auckland and Wellington to members via the Positive Health Scheme. Body Positive is a group founded by and run for people with HIV.

Peer support groups for people living with HIV

Facilitated peer support groups and other support for people living with HIV are offered by NZAF, Body Positive, Positive Women Inc and INA. These are a great opportunity to meet other people living with HIV, hear and share experiences and provide support in a confidential and safe environment. Contact details for other organisations are on page 45, or you can visit nzaf.org.nz/supportgroup to find the right support for you.



HIV treatment

Registering with an HIV specialist

There are an increasing number of options available to you for treating HIV. Registering with an HIV specialist is essential in order to find out what options are best for you. This is free through public hospitals and Sexual Health Services. If you contact NZAF they can put you in touch with an HIV specialist in your area.

Medication

Depending on a number of different considerations, your doctor will recommend a course of treatment. Medication, known as antiretroviral treatment, works to stop or reverse any damage to your immune system, control symptoms and improve your quality of life.



Doctors will use a combination of different anti-HIV drugs to stop the virus from replicating and to protect your immune system. There are currently several classes of antiretrovirals and they all work in different ways against HIV.

NRTIs

Nucleoside reverse transcriptase inhibitors, and Nucleotide reverse transcriptase inhibitors, also known as 'nukes'. The HIV virus uses enzymes to make copies of itself in your body, NRTIs work to stop the replication of the virus.

NNRTIs

Non-nucleoside reverse transcriptase inhibitors, or 'non-nukes'. These work by binding with the same enzyme to block it through a different mechanism.

CCR5 inhibitors

These work by stopping HIV locking on to immune system receptors called CCR5.

Protease inhibitors

HIV uses the protease enzymes to break up big protein chains known as poly proteins, which are then used to assemble new viral particles. Protease inhibitors are drugs that block the activity of the protease enzyme.

Entry inhibitors

These are rarely used, currently. They block the virus from entering the target cells.

Integrase inhibitors

These stop HIV from integrating into the DNA of the cells it infects.

Fixed-dose combinations

Fixed-dose combinations allow you to take fewer pills. The fixed dose is a combination of two or more drugs in a single tablet. This line of treatment is advised depending on your existing health and whether you're already living with other health conditions. In some cases, being on separate pills is a better option so the levels of certain drugs can be altered to suit your health needs.

Starting treatment

Evidence shows there are significant health benefits to starting HIV treatment as soon as possible. Starting early also means your viral load may become undetectable sooner - once this happens, HIV is no longer transmitted sexually (see page 35). In New Zealand, people can access publicly funded treatment as early as they wish to.

Adherence to medication

Starting treatment for HIV is a long-term commitment. Though being on daily medication may feel like a constant reminder of your HIV status, it is important to stay on track with treatment - this is because if you stop taking medication, or take it irregularly, the virus may become resistant to it. This means being consistent with medicines and not missing any pills or appointments.

You may have to take a number of pills, and needing to take them at strict times may affect your lifestyle, but this is something people get used to over time. Living with HIV does mean an adjustment, but medicines are just a part of life post-diagnosis. Your attitude towards medicines will determine your long-term health, and your body's ability to cope with HIV.

Not only is adhering to your prescribed medications the best way to ensure you live a long and healthy life, but it can result in achieving an undetectable viral load. Which we now know means HIV can not be transmitted sexually.

Side effects

Any drug can cause side, or unwanted, effects. These can be divided into different types:

- Allergic reactions and short-term side effects
- Ongoing side effects
- Long-term toxicities or effects that can develop over a number of years

Not everyone experiences side effects from their drugs and not everyone experiences the same side effects. In fact, many are quite rare. It's hard to know how often people develop different side effects, as estimates and studies show varying figures.

Some HIV treatments are known to cause diarrhoea, headaches and gastrointestinal upset to some degree, but these side effects are often easily managed and, in most cases, reduce over time. If you start treatment with a low CD4 count or high viral load, side effects may be more of an issue and you may need help pre-planning for effective management.

Wherever a drug has been shown to potentially cause adverse reactions, it will be accompanied by a warning. Your doctor will also advise you about it and what to do if something like a hypersensitivity rash occurs.

Direct reactions to the drugs can cause a range of, sometimes ongoing, side effects. These can vary from mild headaches or occasional diarrhoea, to more serious side-effects, such as a slow decline in kidney function. There are also some problems, which may develop over time, like numbing of the fingers and toes, abnormalities in liver function or abnormal redistribution of fat throughout your body. Most of these problems tend to happen with the older drugs, however. With the newer drugs, there are far fewer reported side effects to worry about.

Allergic reactions

Allergic reactions to a drug are unpredictable – a few people may suffer them, but the majority won't. Allergic reactions can occur when the immune system reacts badly to a drug and the symptoms are usually a rash or fever. Often, these symptoms will resolve themselves, but if you develop a rash when beginning a drug, seek medical advice – on rare occasions some allergic reactions can be dangerous. Your doctor may be able to treat the rash with antihistamines or by slowly increasing your dose as your body gets used to the drug.





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Different stages of HIV

Acute HIV infection/Seroconversion

When you first contract HIV, your body begins to produce antibodies. Some people say they feel like they have the flu. Doctors call this 'seroconversion illness' because this is the very first time your body is trying to cope with HIV. Common symptoms may include a high temperature (fever), sore throat, a blotchy rash on the body, tiredness, swollen glands and joint and muscle pain. However, you may not experience any of these.

'Window period'

Blood tests confirm there is HIV in your body by picking up the antigens and antibodies your body produces in reaction to the virus. In the early stage, there is a lot of HIV in your body (high viral load). However, during this window period some of the blood tests can actually give a negative result. This is because your immune system is still reacting to the virus and very few antigens and antibodies are being made. In reality, this high viral load means the risk of transmission is much higher now than at other times.

Chronic infection phase

A few weeks after the initial infection, if you've been ill, you may start to feel better and symptoms will disappear. HIV is, however, still present in your body and causing harm to your immune system – it can also still be transmitted to partners through unprotected sex. This is called the 'chronic HIV infection phase'. How long this phase will last is, again, different for each person and for some, it can be several years.

Doctors use two key ways of finding out how active HIV is in your body and its impact – CD4 count and viral load. The CD4 count will give an idea of the damage done to your immune system, if any. The viral load test indicates the number of copies of the virus in your body. These tests give you and your doctor useful information to plan your treatment. If you have any questions about when you should start treatment you should discuss this with your doctor. Over time, your CD4 count is likely to decline and this is a sign that your immune system is getting weaker.



AIDS

AIDS stands for Acquired Immunodeficiency Syndrome and nowadays, with effective HIV treatment and management, a vast majority of people living with HIV never develop AIDS. We talk about AIDS when people develop diseases which normally do not occur in individuals with healthy immune systems. Most of these conditions are cancers or opportunistic infections caused by bacteria, viruses, fungi

and parasites that are normally controlled by the elements of the immune system that HIV damages. With the right treatment and care, people diagnosed with an AIDS-related illness can recover.

You may have a number of different illnesses. This is why AIDS is referred to as a syndrome – a collection of signs and symptoms caused ultimately by the same virus, HIV.

Your legal rights and responsibilities

People living with HIV have the same human rights as everyone else, including the right to health, privacy, non-interference from the state and non-discrimination. No one can refuse you a job, housing, medical services or dental services because of your HIV diagnosis. In fact, it is illegal in NZ to discriminate based on HIV status under the Human Rights Act and you can complain to the Human Rights Commission if you feel you have faced discrimination.

If you think you have been discriminated against, the first step is to contact the Commission's InfoLine team: freephone 0800 496 877 or email info@hrc.co.nz – or you can send a letter or use the complaint forms available at www.hrc.co.nz.

This right to non-discrimination extends to your partners, family, friends, colleagues and other people associated with you. No one can treat people unfairly because of their relationship with you.

In New Zealand, although you are not obliged to tell anyone your status, the law may require you to disclose your status under certain circumstances. If you want to donate blood, semen, eggs or organs, then it is quite important to disclose your HIV status to doctors.



For some things, it is quite straightforward. For example, the Department of Immigration requires most people applying for permanent residency to New Zealand to provide the results of an HIV test.

You might encounter unexpected problems sometimes. If you're thinking of applying for life insurance, some companies may ask you about your HIV status. Some might refuse to insure you if you're living with HIV or if you refuse to tell them your HIV status. There are exceptions in the Human Rights Act that may allow this, though you can check with the Human Rights Commission if you're not sure.

As far as relationships go, the decision to tell or not to tell sexual partners is yours to make. Under New Zealand law, everyone has a legal duty not to endanger the life, health or safety of others. In law, this means that people living with HIV must take 'reasonable precautions' to avoid transmitting HIV to sexual partners. 'Reasonable precautions' would mean participating in sexual activities that involve a very low risk or no risk of transmission, for example, masturbation, oral sex and kissing, and using condoms for anal and vaginal sex.

The legal consequences of having undetectable viral load have not been tested in New Zealand courts. In this case, even though there is no risk of sexual transmission, it is recommended to use condoms with partners who are unaware of your positive status.

People living with HIV who disclose their HIV status to their sexual partners before having consensual sex avoid legal liability. There are some considerations to be mindful of here. [Find out more at nzaf.org.nz/rights](http://nzaf.org.nz/rights)

Donating blood, organs, semen or eggs

Blood donations are screened for HIV for everyone. It gets risky if you donate in the window period of infection, because the test may not actually pick up the presence of HIV in your blood. It's different if you want to donate organs, semen or eggs.

Travelling overseas

With a little planning you'll easily be able to avoid any hassle while travelling. You'll need to carry your medication with you, so ask your doctor for a letter explaining that you need to take it regularly and that it's for personal use. The letter doesn't have to discuss your HIV status.

For more information, please visit nzaf.org.nz/travelling or positivewomen.co.nz/resources/booklets

Pregnancy and childbirth

There are many parents living with HIV who are raising healthy, happy kids. If you think you might be pregnant or want to get pregnant, there are different ways to make it possible and reduce the risk of transmission. Talk to your doctor sooner rather than later. Positive Women Inc also has excellent resources on HIV and pregnancy.

For more information, please visit nzaf.org.nz/pregnancy

Work and employment

People living with HIV are protected against discrimination by the same laws that protect people living with disability. In most work and employment scenarios, you are not required to disclose your HIV status. In fact, your employer is accountable and has to take all reasonable steps to protect you from harassment at your place of work.

For more information, please visit nzaf.org.nz/employment



Finances

Living with HIV doesn't mean an end to having and meeting financial goals. Many say that once they've sorted through their treatment plan and are feeling well again, they carry on as normal. There is nothing stopping you from buying a house or saving for a pension, for example.

For more information, please visit nzaf.org.nz/finances

Support organisations for people living with HIV

Organisations such as NZAF, Body Positive, Positive Women, Sexual Health Services and INA (a support organisation for Maori and Pacific people living with HIV) are available for support and guidance. NZAF also provides support to African communities (see pages 45-46 for contact details).

Relationships and sex

Safer sex

Research has shown that using condoms during sex is one of the most effective ways of preventing the transmission of HIV and many other STIs.

We now know that, for people living with HIV who reach an undetectable viral load (UVL) and maintain it for more than six months by adhering to their medication, HIV is not transmitted through sex. You may have heard the term **Undetectable = Untransmittable (U=U)** being used, which is one of the ways this important message is being spread.

PrEP (Pre-Exposure Prophylaxis) is another option for preventing HIV for those who struggle with condom use with casual partners. PrEP is medication that is taken by HIV negative people to prevent HIV. When taken as prescribed, PrEP builds up in a person's system and significantly reduces their chances of HIV infection.

It is important to remember that neither PrEP nor UVL prevent the transmission of other STIs. So, consider keeping condoms in the mix with casual partners.

If you're not ready to have intercourse, there are many other intimate sexual activities that you can enjoy that involve little or no risk, such as kissing, massaging, mutual masturbation and oral sex.

Condoms and lube

Condoms and lube are an effective way to protect you and your partner from contracting HIV or STIs during sex. When condoms are used consistently and correctly, the latex acts as a barrier that HIV can't pass through.

Using lube will help stop the condom from ripping or coming off. It's important to use water-based lube, as oil-based lubricants may damage the condom.

Supplies can be obtained free via Ending HIV at nzaf.org.nz/condoms

Frequently asked questions

When do I have to disclose to sexual partners?

In New Zealand, as long as you're using condoms every time you have vaginal or anal penetrative sex, you are not legally obligated to disclose your HIV status.

According to New Zealand law, everyone has a legal duty not to endanger the life, health or safety of others. Legally, this means that people living with HIV must take 'reasonable precautions' to avoid transmitting HIV to sexual partners. Condoms are an effective way of preventing HIV transmission as HIV cannot pass through latex. The use of PrEP by a partner not living with HIV or the partner living with HIV having an undetectable viral load are effective in preventing HIV, too.

However, so far in New Zealand there has not been a test case in the courts to determine if use of PrEP or undetectable viral load would constitute as reasonable precautions and a legal defense.

Can I still transmit HIV sexually if I have an undetectable viral load?

No, see page 35.

Do my partner or I have to wear a condom during oral sex?

Giving or getting a blowjob has a very low risk of transmitting HIV. Some things you could do to further minimise the risk are to avoid brushing your teeth for at least one hour before oral sex, visit a dentist at least once a year to make sure your gums and teeth are healthy, check your mouth for ulcers, cuts or bleeding sores and avoid ejaculation into the mouth.

If both my partner and I are living with HIV, can we have sex without condoms?

There is a small chance that if you're already living with HIV and are exposed to HIV repeatedly, it can lead to exposure to a different strain of the virus (not if you both have UVL). This may result in resistances to the treatment you are on. See the super/co-infection section for more (page 35).

If I'm not having penetrative sex do I need to worry?

HIV is not transmitted through kissing, touching, rubbing or using fingers to penetrate the anus or vagina. However, if your hands or your partner's have bleeding cuts, sores or scratches, it's advised to use latex gloves and waterbased lubes. Menstrual blood contains HIV - you can use dams during oral sex to minimise transmission risk.

Undetectable viral load and HIV transmission

If you are living with HIV and are taking your medication as prescribed, you may achieve an undetectable viral load. Which, evidence shows, if maintained for more than six months, means there is no risk of HIV transmission through sex. HIV treatments are very effective at suppressing the HIV virus when taken daily as prescribed, although it is important not to assume that you are undetectable just because you're on treatment. Getting a regular viral load test is important for your own health and that of your sexual partners.

When considering the role of undetectable viral load in preventing HIV it is important to remain consistent in taking medications and continue to keep your specialist appointments. This ensures you are equipped with the knowledge and confidence to make these decisions.

Super/co-infection

When a person living with HIV is infected again through exposure to a different strain, it is known as super-infection. This may sometimes lead to the person becoming resistant, or not responding, to the combination of anti-HIV drugs they're on. This reduces their options for treatment. Risk factors for super-infection are a detectable viral load, having a concurrent sexually transmitted infection and, most of all, unprotected sex. There is no risk if both partners have undetectable viral loads.

Sexually transmitted infections (STIs)

STIs are bacterial or viral infections that are transmitted from person to person during unprotected anal, vaginal and oral sex. Research has shown that infection with an STI may also increase the likelihood of HIV being acquired or transmitted.

Your nearest NZAF centre provides STI tests for HIV and syphilis. There are STIs that are preventable by vaccines – hepatitis A, hepatitis B and human papillomavirus (HPV) – although, the vaccines may not be funded. It is best to discuss this with your doctor.

Pre-exposure prophylaxis (PrEP)

Pre-exposure prophylaxis or PrEP refers to the using of certain HIV medications as an HIV negative person in the prevention of contracting HIV. When taken on a daily basis, taking PrEP ensures there is enough of the medication in the system to significantly reduce the risk of contracting (up to more than 99%) if exposed to HIV during unprotected sex. Also, PrEP is now funded here in NZ, head to the link at the end of this section for more information about PrEP and whether you meet the funding criteria.

There are a few key things to be aware of when it comes to PrEP:

- PrEP works by maintaining a certain level of drug in the body that can prevent HIV establishing an infection. This means that people must take the pill every day to maintain this level of drug. Studies have shown that if it is taken every day as prescribed it reduces the risk of getting HIV by at least 92% and up to more than 99%.
- PrEP does not provide protection from any other STIs like syphilis or gonorrhoea which can increase the possibility of HIV infection. So, it's important to keep condoms in the mix and test at least every three months for these other STIs.
- It's important to test for HIV before starting PrEP and every three months while a person is on it – if someone uses PrEP when they already have HIV it can cause the virus to develop resistance and reduce their options for HIV treatment.
- PrEP can affect kidney function, and has other potential side effects. People on PrEP need to have their kidneys checked before they go on PrEP and regularly once they start the medication.

For more information, please visit nzaf.org.nz/prep

Post-exposure prophylaxis (PEP)

PEP is a short course of anti-HIV medication that may be able to prevent infection of someone who has recently been exposed to HIV. If your partner is HIV negative and is exposed to HIV during sex, they should visit the emergency department of their local hospital as soon as possible.

PEP needs to be taken within 72 hours of exposure to be effective and the sooner you start it, the more effective it is. Evidence shows that while PEP can reduce the chance of contracting HIV, it is not as effective as using condoms and lube for sex.



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Monitoring your health

Relationship with your doctor

A trusting relationship with your GP or HIV specialist is a key part of maintaining wellness. If you don't feel comfortable, first talk to them and, if that doesn't change things, find someone else. The more comfortable you feel to share all aspects of your lifestyle with your doctor, the better they can help you.

There are some simple things you can do that can make doctors appointments easier:

- Beforehand, make a list of questions you want to ask so you won't forget
- Remember, you can always take a support person with you
- Take a pen and paper to make notes of everything the doctor tells you. This helps you to have the information handy when you want to think through your options later
- Ask the doctor how many times you will need to meet them and make your next appointment.

If you're living with HIV and seeing a doctor for a non-HIV related condition, it is a good idea to disclose your status to them – and to tell them what antiretrovirals you are taking – so they can give you the right medicines and treatment. Anything you say to your doctor is kept confidential.

Viral load

Viral load is the amount of HIV in your blood. So, the more HIV present in your blood, the higher the viral load. A viral load test shows the number of copies of the HIV genetic material detected in a millilitre of your blood. Viral load affects how quickly your immune system is attacked by HIV and will affect the CD4 cell count.

The latest science proves that if you are able to maintain an undetectable viral load for more than six months, then there is no risk of HIV transmission during condomless sex. Keep in mind, having an undetectable viral load removes the risk of HIV transmission through sex, but it does not protect from the acquisition or transmission of other STIs like syphilis and gonorrhoea.

For more information, please visit nzaf.org.nz/viralload



CD4 count

CD4 cells are a type of white blood cell in the blood. CD4 cells are also sometimes called T4 cells or helper cells and they organise your immune system's response to infections. Measuring CD4 cells is a way to understand how healthy your body's immune system is and how efficiently it will protect you from secondary infections. The number of these cells in one microlitre of your blood is your CD4 count.

For more information, please visit nzaf.org.nz/CD4

Exercise and eating

Exercising, watching your diet and ensuring a good intake of vitamins and minerals will help strengthen your immune system.

Regular exercise will improve your wellbeing. Depending on your overall health, your doctor will recommend how much or how little exercise you need. Generally, moderate exercise helps to strengthen the immune system.

HIV can interfere with the way your body uses food and energy. Sometimes you may need to eat more than usual or eat certain types of food in order to maintain a healthy body weight. You may want to consider working with a nutritionist who has experience with people living with HIV, as a part of your treatment plan.

Some older HIV medications have a side effect called lipodistrophy where you can lose or gain fat in different parts of your body, but these medications are not used very often.



Alcohol, drugs and cigarettes

Although alcohol doesn't necessarily interact in any major way with antiretroviral medicines, heavy drinking and any associated damage to your liver may interfere with HIV treatment. Enzymes present in the liver may be necessary for the effective processing of certain drugs, including protease inhibitors.

We still don't know everything about how HIV treatments interact with illicit or recreational drugs, though research is being constantly updated. HIV specialists advise against the abuse of alcohol and illicit drugs when living with HIV. University of Liverpool has created a database of HIV treatment interactions which you can find at: www.hiv-druginteractions.org

For more information visit alcohol.org.nz and drughelp.org.nz.

If you do use illicit drugs, here are some ways to minimise risk:

- Avoid taking HIV treatments and other drugs at exactly the same time: wait at least a couple of hours between doses.
- Some HIV drugs, such as Ritonavir and possibly other protease inhibitors, may cause dangerous, even fatal interactions with ecstasy, P and other types of methamphetamines. HIV drugs also slow down the elimination of recreational drugs from your system.
- Start with a smaller amount of any illicit drug and monitor any unusual responses.
- Seek emergency medical help if you experience dizziness, sudden drowsiness, blurred vision, heart palpitations, vomiting or any other severe or unexpected effect.
- Methamphetamines and ecstasy can make eating difficult; which can be a problem for people who need to take treatments with food.
- Drink plenty of water.

If you smoke cigarettes, cutting back or quitting will improve the effectiveness of treatment and will ease stress on your immune system. Smoking is damaging to everyone's health, but if you are living with HIV all the risks of smoking (including but not limited to lung cancer, heart attacks, strokes and abnormal clotting in the legs and lungs) are significantly increased. For support to quit smoking visit quit.org.nz or call Quitline on 0800 778 778.

Staying connected

You're not alone

Coming to terms with an HIV diagnosis and learning to live well with it is not something you need to go through on your own. There are counsellors, peer support groups, specialists and doctors you can access for free at any time. Though it may feel difficult at first, telling partners, relatives and close friends can help you feel supported and make decisions about treatments, lifestyle changes and how to keep healthy.

There'll be good and bad days

Particularly to begin with, the way you feel about your HIV diagnosis may change depending on the day. This is a natural reaction to stress, shock and change. Some days you may feel like you are mourning and, to some extent, you may be. For most people, getting used to a future that includes living with a chronic manageable illness can provide some ups and downs. Take each day as it comes and know that gradually you will adapt to this change in your life.

It helps to talk

Many people feel they can only talk about the big, important medical or life-and-death issues. Yet you might notice little fears creeping in, or you might have questions you think are silly. Remember, there's no such thing as a stupid question. The more you feel like you can talk about anything to your spouse, counsellor, friend or doctor, the easier you will find it to move on with living well with HIV.

HIV-related stigma still exists and is often fuelled by misconceptions and fear around HIV. Having honest conversations about experiences of stigma is vital to feel supported. Stigma adds to isolation, fear and misinformation about HIV. If you are scared of or feel you are experiencing stigma, talk to someone about how to deal with it.



Where to get help

New Zealand AIDS Foundation

The New Zealand AIDS Foundation provides HIV tests, free counselling, HIV prevention and HIV research.

nzaf.org.nz
[0800 802 437](tel:0800802437)

Sexual Health Services

Sexual Health Services are available from all DHBs across the country. They are a specialist service offering free and confidential sexual health care. Some Sexual Health Services employ HIV specialists.

nzshs.org/clinics

Body Positive

Body Positive is an organisation founded by and run for people with HIV/AIDS. Body Positive provides a broad range of services in an attempt to break down the sense of isolation HIV+ people often experience and build a sense of community and wellbeing.

bodypositive.org.nz

Positive Women Inc.

Positive Women Inc. is a support organisation for women and families living with HIV and AIDS. They are also involved in HIV advocacy, awareness and destigmatisation.

positivewomen.org.nz
[0800 769 848](tel:0800769848)

INA Māori, Indigenous and Pacific Island HIV/AIDS Foundation

INA is an organisation working with Māori, Indigenous and Pacific Island communities to raise awareness and advocate for people living with HIV/AIDS.

ina.maori.nz

UNAIDS

UNAIDS is the joint United Nations programme on HIV/AIDS, an innovative partnership that leads and inspires the world in achieving universal access to HIV information and prevention.

unaids.org

Ministry of Health

The Ministry of Health provides information about HIV and AIDS in New Zealand. Information includes answers to frequently asked questions, recommendations for HIV testing of adults in healthcare settings, research and publications.

health.govt.nz/our-work/diseases-and-conditions/hiv-and-aids

AIDSmap

NAM/AIDSmap work to change lives by sharing information about HIV and AIDS. They provide independent, clear and accurate information on HIV free of charge.

aidsmap.com

District Health Board: Infectious Disease Service

HIV specialists are available in certain District Health Boards that have an Infectious Disease Service for a particular region. Consult your GP or NZAF to find out where your nearest HIV specialist is based.

Youthline

Youthline is a free phone, email and text service providing support for young people and their families.

youthline.co.nz
[0800 376 633](tel:0800376633)

OUTLine

OUTLine is a free, confidential telephone counselling service for the LGBTIQ+ community. They also provide face-to-face counselling services.

outline.org.nz
[0800 688 5463](tel:08006885463)

“Having HIV
has made me
stronger & more
compassionate
than I have
ever been.”



Charlie

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NZAF
Te Tūāpapa Mate
Āraikore o Aotearoa

Image: Nick Diamantidis