

HIV















A New Diagnosis



+BODY POSITIVE→

· NEW ZEALAND ·
Tinana Ora Aotearoa

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“YOU may want to talk to
another HIV positive person.

Then call Body Positive on 0800 HIVLINE
or Positive Women Inc. on 0800 POZTIV

- We Are Here To Help”



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Tinana Ora Aotearoa

Positive Women



A Positive Diagnosis

You have probably been given this booklet because you have tested positive for HIV. This booklet is for any person who is diagnosed HIV positive – regardless of gender, sexuality, or cultural background. You may be feeling shocked, scared or frightened right now; however being HIV positive is no longer a death sentence in the developed world. People from all walks of life are living with HIV and many people enjoy full and active lives.

There are many services and specially trained people working at PLWHA (People Living with HIV/AIDS) organisations throughout New Zealand who can provide advice, support and further information. Some organisations have a specific focus such as ‘Positive Women Inc.’. A full list of services for people with HIV is contained at the back of this booklet.

This booklet details how the virus affects your body, offers advice on how to manage your life as an HIV positive person and provides suggestions on how to make decisions around treatments, sex, telling people and your legal rights. It will not answer all of your questions, but it may be a useful starting point. You might also find this resource useful if you have been positive for a while and would like more information.

This booklet has been written to provide you with advice that you might find useful at different times as you come to terms with your diagnosis. You might find some sections more relevant to you than others or you might decide you want to read the entire booklet to learn as much as you can about HIV.

What do I need to know?

HIV stands for the Human Immunodeficiency Virus. If you have been told you are HIV positive, it means that your body has come into contact with HIV and you have become infected with the virus. The virus infects and damages cells in your immune system known as CD4 cells (T4 cells), a type of white blood cell that makes up a major part of your immune system. HIV uses these cells to make copies of itself.

Over time, if your CD4 cells are damaged, your body is less successful at protecting you from bugs and germs that can lead to infection or illness. HIV treatments can help you to stay well for longer. (See p25 for more information about HIV treatments.)

When the immune system has been severely damaged by HIV infection, AIDS can occur. However, HIV and AIDS are two different things. AIDS stands for Acquired Immune Deficiency Syndrome. HIV can lead to AIDS when the immune system has been damaged to such an extent that it is vulnerable to other infections and diseases. These infections and diseases are called 'opportunistic' infections. The organisms that cause common AIDS defining illnesses are usually controlled by a healthy immune system. Many opportunistic infections are treatable or preventable.





What does HIV infection mean in the long term?

HIV treatments have improved dramatically over the years, this has had a huge impact on the HIV person's life expectancy of people living with.

Today, people living with HIV can expect to have a full life, if compliant with taking treatment on an uninterrupted basis

There are many factors – some related to HIV and some not related – which can determine how long a person with HIV will live.

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. If you are co-infected with viral hepatitis for instance, this might influence your treatment decisions
- Other medical conditions - for example diabetes

How will HIV change me?

Right now, you might be feeling like your life will never be the same again. You might be feeling angry, confused, guilty, depressed or shocked. All of these feelings are completely normal.

There are many people living with HIV in New Zealand today who are enjoying full and active lives. Many of these people continue to live their lives in much the same way as they did before diagnosis. You might have many identities or ways of thinking about yourself – mother, Asian man, gay man, teacher or Buddhist. Working out where your HIV status fits into your identity may take a little while, or it might be a relatively simple process for you.

Every person deals with identity differently, although there are some things that may help if you're trying to figure out where HIV fits in with your identity. Talking to other positive people about their experiences and how they coped can be useful. Body Positive or your local PLWHA organisation (see p54-55) should be able to provide information on support groups for HIV positive people in your area. Peer support groups can be helpful if you want to talk to other people about their experiences.

If the idea of peer support doesn't appeal to you or if you are finding you need more help to come to terms with your HIV status and working through any identity issues, you can also talk to a counsellor or a one on one peer worker. Body Positive can provide advice on one on one peer support or counselling.



Fact or Fiction?

- **HIV is a gay disease**

There are heterosexual, bisexual, transgender and homosexual people living with HIV. HIV does not discriminate. It affects people from all walks of life, cultural backgrounds and genders regardless of their sexuality.

- **HIV is a death sentence – I'm going to die**

There have been many advances in HIV treatments over the years and HIV is not the death sentence it was once thought to be. Most HIV positive people are living healthy and productive lives with a normal or near to normal life expectancy.

- **I don't think I am going to get through this**

Coming to terms with being HIV positive can be a difficult journey for some and each person comes to terms with their positive diagnosis in their own ways and it is important to remember that there are many people who are HIV positive leading full and active lives. There are many services that can provide you with counselling and put you in touch with other HIV positive people, and this may help you to get through this (see p54-55). There are also sections in this booklet on coping strategies, and you may find some of the ideas useful (see p19, 30, 40 and 52).

- **I am going to infect the people I love**

Many people have this fear when they are first diagnosed, but just because you are HIV positive does not mean you are going to infect the people you love. HIV can only be transmitted through unprotected sex, from mother to child usually at delivery, breast milk and direct blood contact. It is not passed on by hugging, kissing, sharing cups, touching, rubbing or massage. (See p49 for information on transmitting and preventing HIV)

- **I don't know who to tell**

It's advisable not to rush out and tell people straight away; however, you may wish to tell your partner, friends or family. There are many people you can talk to including Peer Support Workers at Body Positive, your doctor, or other HIV positive people. These people can be a good starting point when you are trying to figure out who to tell and how to tell them. (See p54-55.)

- **HIV only affects people living in cities**

HIV does not only affect people living in large cities. There are people living with HIV in small towns, rural communities and major cities in New Zealand.

- **I'll never be able to have children**

People living with HIV have the right to have children. In fact, there are many HIV positive women and a growing number of HIV positive men who have made the decision to have children. Thanks to the advances in our knowledge of HIV, there are ways that the risk of transmission can be reduced from mother to child and ways that HIV positive men can father children without passing on the virus.

- **Nobody will ever want to have sex with me again**

People living with HIV have the right to a full and active sex life. Being HIV positive does not mean that your partner or a potential partner will automatically reject you. In fact many people say that when they shared the news, they received support and it led to a greater level of intimacy in their relationships (see also p33-35).



Who should I tell?

You do not need to rush out and tell people you have HIV. Sometimes it might be helpful to take some time to adjust to the news yourself before you decide to tell your friends or family.

It can help you decide who you might like to tell if you take some time to think about how people might react to your news. You might find it useful to ask yourself:

- Who can I trust with the information that I am HIV positive?
- Will they offer me support?
- Will they judge me?
- Will they respect my confidentiality?

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.

You do not have to disclose your HIV status to:

- Your friends
- Your employer
- Your work colleagues
- Every doctor, dentist or other health care professional

It is wise, however, to tell health professionals you are seeing for other conditions that you are positive so that they have a clear picture of your health and can help you to make decisions about your health. Your health care provider cannot reveal your HIV status to anyone, except in extreme and unusual circumstances.

Telling your partner

If you are in a relationship with someone who is HIV negative (known as a serodiscordant relationship), or if you have multiple casual partners whose HIV status you may or may not know, you may want to tell him or her. You may be frightened of their reaction or you might be comfortable telling them the news. There is no easy way to tell your partner, or partners, and no set rules – regardless of your partner's HIV status. It can help to have a counsellor who is experienced in working with HIV issues available to help you when and if you decide to tell your partner. Your partner, husband or wife might also want to consider testing for HIV, especially if you have been having sex without condoms or sharing injecting equipment.

Despite the fears that you might have, many people have found that they received support when they shared the news. It might even strengthen your relationship.

Telling your children

If you have children you might find it hard to find the right time to tell them. You might not even be sure you want to tell them. Some people have found that talking to other people living with who have HIV children is helpful in making this decision. Contact Body Positive or other suitable groups near you.



Your rights

Although you are not obliged to tell anyone your status, the law may require you to tell people under certain circumstances. In New Zealand you are not legally required to tell any sexual partner as long as you are practicing safe sex using condoms and not putting your partner at risk.

The law also states HIV positive people cannot donate blood, semen, eggs or any other body tissues. The Department of Immigration requires anyone applying for permanent residency to provide the results of an HIV test.

You may be asked about your HIV status if applying for life insurance or by your superannuation fund. Some companies may refuse to insure you if you have HIV or if you refuse to tell them your status.

As a person living with HIV, you have many legal rights that protect you from discrimination. You cannot be refused a job, housing, medical services or dental services just because you have HIV. Discrimination based on HIV status is illegal throughout New Zealand under the Human Rights Act. It is illegal to discriminate on the grounds of employment, education, the provision of goods, services and facilities, accommodation, buying or selling property, club membership and sport. The law also protects people who are believed to be HIV positive and people who associate with HIV positive people.

For further details on your rights contact Body Positive or your local PLWHA organisation.

What can you do if you have been treated unfairly?

If you feel you may have been discriminated against or if you would like more information about the various laws covering HIV positive people, contact Body Positive or your local PLWHA organisation.

A list of organisations to contact in relation to issues regarding your rights and discrimination can be found on p54-55.

Coping Strategies:

The initial diagnosis

People experience a range of emotions when they find out they are HIV positive. Some people may feel shock, anger, horror or disbelief and others may cope better with the news. All of these reactions are completely normal and it helps to remember that you are NOT going to die tomorrow. Most HIV positive people live long and healthy natural lives.

When you first get the news, some people advise that you don't rush straight out and tell people or make any major life changes such as quitting your job or leaving your partner, husband or wife. It can help 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 you need it.

If you do want to talk to your partner, a friend or your family, think about how they might react and if they would be willing to support you. You might have HIV positive friends who could be a good source of support. If you are not sure how your partner, friends or family will react to the news, consider talking to a peer support worker at Body Positive or a counsellor.

Following initial diagnosis, it's useful to make a follow up appointment to see your doctor in the next few days.

You may have more questions or want more information in a week's time. Start making a list of any questions you think of in the next week or two. Some people also decide to undergo another HIV test in the week or two after their diagnosis to be sure that the test is right.

It's important to develop a good relationship with your doctor. You have the right to ask questions and make decisions about your health. 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 who you can trust and feel comfortable with, or if you feel they don't know enough about HIV, ask for a referral to a doctor with more knowledge and experience. Shop around if you need to as having an ongoing and comfortable relationship with a doctor you can trust is important for managing your life as a person living with HIV. Body Positive and Positive Women Inc. can refer you to doctors who have done HIV training.

Checklist

- You don't need to rush out and tell people straight away
- Make a follow up appointment to see your doctor in a week or two
- Make a list of questions so that you can remember to ask your doctor about these things



Life with HIV

The stage of infection you are in when you are diagnosed will have an impact on decisions around treatments. You may have been diagnosed at the point of seroconversion (the events that occur rapidly when the virus first enters your body) or you may have been living well with HIV for some time. You may also have been diagnosed in the later stages of infection, with an AIDS defining illness. This section provides information on the point of diagnosis and what this may mean in terms of HIV treatments.

Seroconversion

Seroconversion means converting or changing from being HIV negative to HIV positive. This occurs when you first pick up the infection. During seroconversion, HIV enters the body and begins to multiply. Your body will not have seen HIV before and levels of the virus initially grow rapidly, reaching high levels in the blood, semen, vaginal fluids and breast milk. Between 50% and 80% of people experience what is known as seroconversion illness. Common flu like symptoms may include lethargy and tiredness, fevers, night sweats, an unusual rash, diarrhoea, and nausea, which usually last a week or two. There are clinical trials investigating whether newly infected patients benefit from treatment in the long term. Generally treatment at the time of seroconversion is reserved for those with a low CD4 cell count, or people who may be experiencing an HIV opportunistic illness, e.g. pneumonia.

Talk to your doctor about starting treatment and when the time might be right for you. Remember once you start — it's permanent for life.

Feeling well

You may have received a positive diagnosis, yet feel quite healthy with low viral loads and CD4 counts above 500 (a normal level). This is often referred to as asymptomatic infection. For most people this lasts for several years, but for some people, the asymptomatic phase can last 15 years or more. If you are not displaying any symptoms and you feel well, it can help to look after your health through diet and exercise. At this stage of infection it is important to have regular contact with your doctor three or four times a year for physical examinations and blood tests to detect any subtle changes in your immune function. This can help you stay well by taking treatment before you have serious damage to your immune system. It can also be beneficial to your long term health if you try to avoid any infections such as sexually transmitted infections as they may impact on your immune system (see p50 for more information). If these infections do occur, it is important that they are treated as soon as possible.

Late diagnosis

If you present with an opportunistic infection or you have a very low CD4 count, your doctor may recommend that you start treatments straight away. The symptoms of immunosuppression you might be experiencing could include diarrhoea, minor skin conditions, a lack of energy or swollen glands. The severity of these symptoms can indicate how well your immune system is coping. You might also be advised to take medication for particular opportunistic infections. Commencing HIV treatments at this time can help you to gain greater control of your health and prevent any further damage to your immune system. If you have a CD4 count below 250, your doctor might also recommend prophylaxis (medications) that can prevent some opportunistic infections from occurring. These medicines can be stopped when your immune system recovers. For more information about how the point at which you are diagnosed can impact on treatments decisions making, contact Body Positive or your local PLWHA organisation. Further contacts on where you can go for more information can be found at the back of this booklet.



Treating HIV

There is a wide range of drugs or treatments that can be used to control the amount of HIV in your body. They work to slow the damage caused to your immune system. HIV treatments are known as antivirals or antiretrovirals. Their job is to stop the HIV virus from replicating, which protects your immune system from damage. There are currently six classes of antivirals. They all work in different ways against HIV..

The classes of drugs are:

- nucleoside reverse transcriptase inhibitors (or 'nukes' or NRTIs) - nucleoside analogues, and nucleotide reverse transcriptase inhibitors (also known as NtRTIs)
- non-nucleoside reverse transcriptase inhibitors ('non-nukes' or NNRTIs)
- protease inhibitors
- fusion inhibitors
- integrase inhibitors

Commonly used combinations include two nucleoside reverse transcriptase inhibitors, in combination with either a non-nucleoside reverse transcriptase inhibitor, a protease inhibitor or an integrase inhibitor.

When to start

International guidelines recommend that HIV treatment should be offered within seven days of an HIV diagnosis. If people are ready to begin treatment it should be available on the same day as diagnosis. With the removal of the CD4 Threshold in New Zealand on 1st July 2017 there are no longer any barriers to accessing treatment.

Modern HIV treatments are far less toxic, have fewer side effects and are far better at fighting the HIV virus than they once were. A critical new piece of research - the START study - recently found that getting on treatment reduces the chances of HIV-related health complications by up to 50%. Also, we now know that treatments make reaching an undetectable viral load possible for many positive people, which drastically reduces the chances of HIV being passed on.

The viral load might also be taken into consideration when planning treatment decisions. If the viral load is greater than 100,000, this might prompt your doctor to recommend treatment earlier. Though an unexplained and significant upward trend in viral load over a number of tests may be a stronger indicator that you should consider changing or starting treatments than a single, detectable result in isolation. In addition, some authorities are starting to recommend treatment on diagnosis. This is a discussion you should have with your doctor.

You may have plenty of time to consider your options before rushing in. It's advisable to have a good think about whether or not you want to start because once you start treatments, it is important to take all the doses of the drugs as HIV can become resistant to the treatment if you miss doses frequently.

Starting antiviral therapy is a serious commitment because it generally means taking treatments for the rest of your life. Taking treatments long term may affect your quality of life, particularly if you develop side effects or find daily pill taking a burden. It's important to realise that starting treatment is your decision and something you should consider with regard to your lifestyle, general health and whether or not you feel ready for treatment. Some of the things you might like to consider when deciding on whether or not to start treatments and what treatments to take include:

Your lifestyle

There may be aspects of your lifestyle to consider before deciding on treatments, if you travel a lot for instance. Or if you like to skip breakfast, it might not suit you to take treatments that need to be taken in the morning with food. Quality of life is important and you should try to make sure that you can fit a treatments regimen into your lifestyle.

Storage of the drugs

If you have young children or live with people who don't know that you have HIV, something you need to consider. Alternatively, if you need to store your drugs at work and you are worried about people finding out; you might want to consider this when making a decision about treatment combinations that may suit your lifestyle. However most treatments are only once or twice daily.

At what stage of HIV disease you are diagnosed

Any treatment decision needs to be discussed fully with your doctor, taking into account not only CD4 (and viral load) but most importantly, your ability to integrate combination therapy into the way you live.

Side-effects

Any drug can cause side-effects, or unwanted effects. These can be divided into different types: allergic reactions and short-term side effects; ongoing side-effects; and long-term toxicities or effects which can develop over a number of years. Not everyone gets side-effects from their drugs and not everyone experiences the same side-effects, many are quite rare.

It's hard to estimate how often people develop different side-effects as estimates and studies show varying figures. Some anti-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 need pre-planning for effective management.

Allergic side-effects or 'adverse reactions' to a drug are both unpredictable and uncommon – a few people may suffer them, but the majority won't. Adverse 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 as on rare occasions some allergic reactions can be dangerous. You may be able to treat the rash with antihistamines, or by slowly increasing your dose as your body gets used to the drug.

However, 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 which can vary from mild (headache or occasional diarrhoea) to more serious. 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 side-effects to worry about.

Your doctor may prescribe other medicines (like anti-diarrhoea or nausea medications) to help deal with some of these. Many people report that some simple complementary therapies are useful in controlling side-effects: talk to

an HIV-experienced dietician for advice. Referrals will be available through your doctor, Body Positive or your local PLWHA network (see p54-55).

Some side-effects to HIV drugs can develop over the long-term. Now that we know more about these drugs, doctors are increasingly monitoring and checking for signs of these problems, and may advise you to change drugs if you are at risk. These include:

- Peripheral neuropathy, or nerve damage causing pain in hands or feet;
- Blood sugar changes;
- High cholesterol or blood fats;
- Body shape changes like fat wasting or developing a belly, paunch or enlarged breasts (lipodystrophy);
- Muscle inflammation;
- Anaemia;
- Hepatitis and pancreatitis (inflammation of the liver or pancreas); and
- Mouth ulcers.

The earlier you detect any changes, the easier it is to make changes to diet, exercise or the medications themselves, which can all help improve, or in some cases reverse these effects.

Where can you find out more?

'HIV Tests and Treatments' provides more information on the current antiviral drugs for the treatment and management of HIV, as well as common tests used to monitor the health of people with HIV. **'Managing Side Effects'** details the side effects of HIV & antiviral treatments, and suggestions for their management. Both booklets are available from Body Positive or can be downloaded from www.bodypositive.org.nz.

Coping Strategies:

A few weeks later

A few weeks after you receive your diagnosis, it's advisable to go back and see your doctor. You may have a list of questions or you might want to have another test to make sure your initial test results were right. If your doctor recommends treatments, remember that you do not need to make any decisions straight away. Ask questions and try to learn as much as you can before making any major decisions. Body Positive and other PLWHA organisations in New Zealand can provide a wide range of useful information.

A few weeks after the initial news, some people notice they start to feel bad about themselves. If you start feeling like this, try to do nice things for yourself. If you haven't told anyone yet, have another think about the people in your life that you can trust and who will support you. If you can't think of anyone you can tell or if it still seems too soon, consider talking to a peer support worker at Body Positive or your local PLWHA Organisation or a counsellor. They may also be able to help you work out who to tell and how to tell them or to support you until you feel ready to tell others.

It can help you to stay focussed if you set some short - term goals. These goals might change over time. Maybe you want to join the gym or take up yoga classes? You might also want to consider your long-term goals and ask yourself how you feel about these things now. You may be starting to think about sex again. People react differently but you do have the right to a healthy and active sex life. New Zealand law does not require an HIV positive person to disclose their HIV positive status providing they are practicing safe sex. It is important to always have safe sex. People have been charged and jailed for recklessly endangering life where not disclosing their HIV status and not practicing protected sex. (See p18 for more information on your rights.)

If you're in a relationship and haven't told your partner, husband or wife yet, you might like to think carefully about how and when to broach the subject. A peer support worker, doctor or HIV counsellor can help to work through this and can be on hand to assist with any questions that might arise. You could suggest that your partner seeks support via a peer support group if they are having trouble coping with the news or would like to meet other people who have been through this. If your partner, friends or family are questioning any change in your behaviour recently, try not to panic. It can help if you prepare a believable story that will satisfy them until you're ready to share the news.

Checklist

- Ask questions and try to learn as much as you can before making any major decisions
- Set some short term goals
- Try to do nice things for yourself



Sex and Relationships

You'll probably have a lot to deal with when you receive an HIV positive diagnosis. Maybe sex is the last thing on your mind or you might choose to have a lot of sex. You might feel "infectious", angry or depressed, and this may result in a loss of sex drive, regardless of your partner's HIV status. However you are feeling right now, your feelings about sex will probably change over time. It's also important to remember that people living with HIV have the right to enjoy a healthy and active sex life. There are many people out there who will find you desirable regardless of your HIV status.

If you're in a relationship with someone who does not have HIV, you might not want to have sex because you're afraid of infecting your partner, husband or wife. These feelings are completely normal. You might also be feeling frightened and scared of getting sick, which can have an effect on your libido. It might help to talk to your partner, husband or wife about your feelings, which could lead to greater intimacy. It's worth pointing out that many people who have chosen to tell their partner, husband or wife have received support.

If you are not ready to have sex, there are many other intimate sexual activities you can enjoy that involve little or no HIV risk such as kissing, massaging, mutual masturbation and oral sex. If you are planning to have penetrative anal or vaginal sex, the safest way to prevent transmission of HIV is to use condoms and water-based lube. Condoms can also protect you from other STIs. Dams and gloves can also be used for protective sex (see p34 for more information). If you're considering having casual sex with someone you don't know, you might have similar concerns about whether or not to disclose your status.

Some people choose not to tell people they have sex with. Others decide to tell people up front. The choice is an individual one. Deciding how and when to tell someone you're HIV positive – whether it is a long-term partner or a casual partner – is a personal and sometimes difficult decision. There is no easy way to disclose your HIV status. Talking to a counsellor, peer support worker or other HIV positive people can be helpful.

What is safe sex?

People living with HIV have the right to a full and active sex life. You can still enjoy sex regardless of your HIV positive status. Safe sex is any sex that avoids semen, blood or vaginal fluid from getting into the bloodstream of another person. HIV is not transmitted through kissing, sucking, touching, rubbing, massaging or using hands or fingers to penetrate your anus or vagina providing the person has no cuts, sores or scratches on their hands. If they do have any cuts, sores or scratches, it's advisable to use latex gloves.

Using condoms during insertive anal or vaginal sex can help to minimise the risk of passing the virus on to another person. It is recommended that condoms are always used with a water based lubricant such as Wet Stuff or KY. Oil based lubricants like Vaseline or hand cream can damage the condom and should not be used.

There is a very low risk of passing on the virus through oral sex. However, if you have HIV and are the insertive partner, the safest oral sex involves using a condom because any cuts or ulcers in the mouth of your receptive sexual partner can allow the virus to enter their bloodstream. Oral sex for women also poses little risk. There is not much HIV present in women's vaginal fluids and dental dams (thin square pieces of latex to cover the vagina or anus during oral sex) are not necessary for protecting against HIV unless you are menstruating. However they may protect from other sexually transmitted infections which may be common and adversely affect people with HIV.

If you and your partner both have HIV, you may not want to use protection, however there is debate around the risks posed by people who have HIV when having sex and exposing their partner to a different strain of HIV. Becoming infected with a different strain can result in reinfection (super-infection) which may limit your treatment options if you get a drug-resistant strain. Talk to your doctor or contact Body Positive or Positive Women Inc. for more information about the different strains of HIV and how this may impact on the decisions you make around sex.

Sex and menstruation (monthly bleeding or periods)

HIV is present in menstrual fluid. Having sex when you have your period can increase the risk of HIV transmission so it's a good idea to consider using condoms during anal or vaginal sex or dams during oral sex at this time (the risk of passing on HIV during oral sex remains very low, however).



What does HIV mean for women?

Women of all sexualities, cultural backgrounds and ages are living with HIV. Many of these women are leading healthy and full lives. Some of these women have chosen to have a family while others have made different choices about how they wish to live their lives. As a woman living with HIV, you have many rights. You have the right to have children, you have the right to love and be loved, the right to have a full and healthy sex life, the right to take control of your own health and make decisions around treatments.

Women living with HIV may face many unique issues. Women are generally the primary care givers of children and others in families, which might mean you have to juggle your family's needs with your own needs. It can help to talk to other positive women about their experiences. Contact Positive Women Inc. to talk to other women about issues you might be facing – either now or in the future.

Women and treatments

Compared to men, women, have some particular issues, including the effect on menstrual patterns. If you do decide to begin treatments, it's important to tell your doctor about any other medications you are taking, including the contraceptive pill and implants, as some HIV medications make the pill less effective as a contraceptive.

Having children or women who have HIV

Women living with HIV have the right to have a family. In fact, many women living with HIV in New Zealand have chosen to have children. Due to the advances in HIV treatments and our knowledge of HIV, there are many strategies that can be used to minimise the risk of passing HIV on from mother to child. The risk of passing HIV from mother to child is very low (under one per cent) if your viral load is undetectable, your CD4 count is high and you use treatments during pregnancy and delivery to reduce viral load. Other ways of reducing the risk of transmission from mother to child includes vaginal births, choosing not to breastfeed and accessing good obstetric care. Caesarean births used to be routinely recommended, but nowadays many women are choosing to have a vaginal birth if their viral load is undetectable.

‘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.

The back section of this booklet also provides further contacts on where you can go for more information.



Coping Strategies:

A little while on

As time passes, you may be more comfortable with the news that you have HIV or you may be feeling ambivalent. You may also be feeling shock, anger, guilt, shame or depression. These feelings are normal and for most people, they pass in time.

You may be ready to find out more about what it means to be living with HIV. Along with this booklet, there are many other resources and booklets available from Body Positive and other PLWHA organisations throughout New Zealand. You can also take a look on the Internet. Several good sites include:

- Australian Federation of AIDS Organisations (AFAO - Australia)
www.afao.org.au
- National Association of People Living with HIV/AIDS (NAPWA - Australia)
www.napwa.org.au
- The Body (United States)
www.thebody.com
- Medscape (United States)
www.medscape.com
- Australasian Society for HIV Medicine (ASHM - Australia)
www.ashm.org.au

As time goes on, many people feel they are in a better position to start making decisions about work, life goals and social connections. Some people decide to make major changes while others are happy to continue as before. If you have been seeing a counsellor, attending a peer support group, talking to a peer worker or your partner, friends or family, it's good to keep talking – even if you are feeling a little bit better. Issues might come up over the coming weeks or months and you may be better placed to work through these issues if you keep talking.

Your doctor will probably want to see you again after a few weeks to see what is happening with the virus and your immune system. It's good to get into a pattern of regular health monitoring. Hopefully, you have developed a good rapport with your doctor by now. If not, you could consider finding someone who you feel more comfortable with.

If you have started taking treatments, ask how they are working for you:

- Have you made the right choice?
- Are the side effects subsiding?
- Are the treatments fitting into your lifestyle?

If not, you might want to consider changing to a more suitable treatment regimen. You have the right to stop taking treatments if you are not happy with how things have been working, but be sure to talk with your doctor about this decision as treatment breaks can be harmful to your health – in the short and long terms. Always discuss the ramifications of choices with your doctor so you can make an informed choice.

If you haven't started treatments, your doctor may be encouraging you to begin. Take your time and learn as much as you can about the pros and cons before making up your mind. Body Positive and other PLWHA organisations can be a good start for information on treatments decision making. (See p25-29 for more information on treatments decision making.)

Regardless of whether or not you are on treatments, talking to other positive people about their experiences can help you with things like commencing treatments, adherence (sticking with treatments), or side effects.

Checklist

- Regular health monitoring can help you manage HIV
- Talk to other positive people about their experience with treatments



Looking after your health: *Viral load and CD4 count*

People living with HIV can benefit from regular tests designed to monitor how their immune system is coping. Most people feel well until their immune system is so low they get a severe infection. Two ongoing and regular tests are recommended for positive people – viral load and CD4 count. The results of these two tests looked at over time can help predict when your immune system needs help, before you get a severe infection. This allows you and the doctor to discuss preventive medicine and start this so you do not become ill unexpectedly.

Viral load – what do you need to know?

A viral load test is a simple blood test that measures 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. The test can also determine how well your treatments are working or whether you might like to consider starting treatments.

Viral load – what do the results mean?

a) 'Undetectable' viral load

One result you can get back from a viral load test result is 'undetectable'. This means that HIV is present in very small amounts (below the capacity of current commercial tests to accurately measure; below 20-40 copies). The virus at such levels is replicating so slowly that little, if any, damage will be happening to your CD4 cells and immune system and there is also less chance of developing resistance. It is important to remember that you can still pass HIV through sharing needles or having unprotected sex.

Viral load tests tell you how much virus is in your blood. But HIV is also present in other body fluids, including semen, vaginal fluids and CSF (cerebrospinal fluid)—the fluid which protects your brain. The level of virus in your blood is often different to the amounts in other body fluids. This difference can be caused by a number of factors.

For this reason, blood viral load tests should not be used to judge the likelihood of HIV transmission. It is possible to have low or undetectable blood viral load, but higher levels in semen or vaginal fluids.

While research suggests an undetectable viral load reduces the risk of HIV transmission, an undetectable viral load has not yet been proven to completely eliminate the risk of transmitting the virus. **The use of viral load in prevention is not a substitute for safe sex.**

HIV infects cells which remain inactive or ‘resting’ in lymph glands and has also been shown to infect small amounts of other types of cells. This HIV is not measured by plasma viral load. This HIV is not reached by treatments; as long as it remains in the ‘resting cells’ in lymph glands, it does not reproduce nor do any damage. To totally cure or eradicate HIV, you would need to also eradicate the virus in these ‘resting cells’. So far, this has not been possible.

b) Detectable viral load results

You will often be told that your viral load result is ‘high’ e.g. more than 100,000, ‘moderate’ e.g. 10,000 to 100,000 or ‘low’ e.g. less than 10,000 copies. On their own your viral load results are no cause for alarm. For example, a high viral load result does not mean that you are going to be sick tomorrow.

Your viral load level is a rough guide to the likelihood of future damage to the immune system. So if your viral load is high it means that future damage is more likely. If it is low or undetectable it means future damage is less likely.

CD4 Count

The other test that is critical in managing HIV and understanding how it is affecting you and your body, is the CD4 or T-cell count.

CD4 cells are a critical part of your immune system. They are infected and destroyed by HIV. The numbers of CD4 cells vary on a regular basis and are influenced by a variety of other factors apart from HIV e.g. in the case of another infection such as the flu or levels of stress. Sometimes, in HIV infection they can be depleted to such dangerous levels that they are unable to play their part in helping your immune system work properly.

A CD4 count test looks at the effect of HIV on your immune system and can tell you how much damage has been done to your immune system. If a significant amount of damage has occurred, you could be susceptible to opportunistic infections.

A general guide to CD4 test results is:

- 500 to 1,350 CD4 is the “normal” range for adults;
- Between 500 and 250 CD4 cells indicates some damage but it is unlikely you will be at risk of major opportunistic infections; and
- Less than 250 CD4 indicates more serious immune system damage and suggests that you could be at risk of serious opportunistic infections.

CD4 percentages measure the proportion of CD4 cells in every 100 lymphocytes (white blood cells that include T-cells and B-Cells). The CD4 number is calculated by determining the percentage of total lymphocytes that are of the CD4 type and then calculating that number. The percentage can indicate how stable the CD4 count is in relation to changes in the total lymphocyte count. Together with viral load and actual CD4 cell tests, it's another result that is used by your doctor to assist in determining your optimal treatment strategies.

Looking after your health: *HIV and Recreational drugs*

Many people know that HIV damages and weakens the immune system over time. A damaged immune system makes it difficult for your body to fight off disease. Using ecstasy, Crystal/Ice and other types of methamphetamines and other party drugs is likely to further suppress your immune system. The effects can be harmful for both the short and longer term. In addition to the drugs, the partying lifestyle itself can weaken your immune system. Staying up for long periods of time, not eating enough, or not eating the right foods can damage the immune system of any person, even if they are in great health.

There's not a lot known about how HIV treatments interact with illicit or recreational drugs, though this is changing. However, if you are on HIV treatments and use recreational drugs, there are some common cautions you could follow:

- Avoid taking HIV treatments and other drugs at exactly the same time: Wait at least a couple of hours between doses.
- Ritonavir and possibly other protease inhibitors may cause dangerous, even fatal interactions with ecstasy, Crystal/Ice and other types of methamphetamines. We know that these HIV drugs slow down the body's elimination of recreational drugs.
- Drink plenty of water.
- 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.

Clinical trials

Your doctor might discuss the idea of participating in a clinical trial. Clinical trials are used to test the safety and effects of new drugs, combinations of drugs, and/or drug dosing strategies. Before you agree to participate in a clinical trial, you should have adequate written and verbal information about the purpose of the trial, the procedures involved, the benefits and any potential risks. You do not have to agree to participate in a clinical trial even if your doctor recommends it. You have the right to decline and your standard of health care should not be affected if you decline.

Some of the reasons people might decide to become involved in a clinical trial include:

- Participating in research has helped in New Zealand's response to HIV/AIDS and led to advancements in the treatment of HIV/AIDS.
- Participants may receive a new treatment before it is widely available.
- The health of people participating in a clinical trial is closely monitored by HIV/AIDS experts who may have more knowledge or experience than their regular doctor.

Some of the things to consider before involvement in a clinical trial include:

- New treatments often have unknown side effects or toxicities.
- Some participants enter trials involving a placebo, meaning they don't know until the end of the trial if they were getting the new drug or not.
- The treatment may be helpful for a short period, but may not make any difference to long-term health.

Someone at Body Positive or a local PLWHA organisation might be able to discuss some of these considerations with you in greater detail to help you make a decision about whether or not to get involved in a clinical trial.



Transmitting and preventing HIV

HIV is present in semen (cum), pre-cum, blood, vaginal fluid and breast milk. It is also present in the fluid lining of the rectum and anus (this may also contain small amounts of blood). The most common ways it can be transmitted are through unprotected sex (sex without a condom) and sharing needles. HIV is also present in some other body fluids including saliva and tears, but not in the amount necessary to transmit the virus to another person. Neither urine nor sweat contain HIV. It is not passed on through kissing, hugging, sharing cups or plates, touching, rubbing, massage, or from toilet seats.

If you are having penetrative anal sex (receptive or insertive) or vaginal sex, using condoms and water-based lube is the most effective way to prevent passing on HIV to your partners.

If you use needles, always using a clean kit and never share mixing equipment including spoons, filters, rinsing water, tourniquets or glasses to avoid passing on HIV. Clean kits are available at needle exchanges. You can also contact Body Positive or other PLWHA organisations to find out about where to get clean kits in your area. If you cut yourself, it is a good idea to clean up any blood and cover the wound.

Where can I get more information?

Contact Body Positive or other PLWHA organisations for more information. Alternatively, there are many good websites providing information on HIV including:

- Australian Federation of AIDS Organisations (AFAO - Australia)
www.afao.org.au
- National Association of People Living with HIV/AIDS (NAPWA - Australia)
www.napwa.org.au
- The Body (United States) **www.thebody.com**

Sexually transmissible infections

A sexually transmissible infection (STI) is an infection that is passed on through close body contact or sex. Even if you do not notice any changes in your body, it's still possible that you could have an STI without knowing it. Some of the more common STIs include chlamydia, gonorrhoea, syphilis, herpes, genital warts, hepatitis A and B, crabs (pubic lice).

If you have HIV, it's advisable to take extra care of your health, including trying to protect yourself against STIs. As with any infection that places stress on the immune system, an STI can allow HIV to produce more copies of itself with the result that more damage occurs to the immune system. Prompt detection and treatment of curable infections such as chlamydia and gonorrhoea will remove extra stress from the immune system and allow it to function as well as possible to control HIV.

Some STIs make it easier to transmit HIV to a negative partner, even when you have no symptoms. If you are sexually active, you should have regular sexual health check-ups. Extra check-ups are advised if you experience any rash, sores, irritation, or genital discharge following sexual contact. Condoms can protect you from most, but not all STIs so even if you always use condoms having regular checks should be discussed with your doctor. As a general guide the more partners you have the more often you need check-ups.



Coping Strategies:

Time passes

You've probably come a long way since your initial diagnosis and you should acknowledge this. That's not to say that life is suddenly easy for everyone. Continue to set small achievable goals and take time out for yourself. If you feel ready, you might like to set some long-term goals or review any previous goals you might have set.

Fitting HIV into your life can be time consuming. You may find it difficult to juggle work, your social life, doctor appointments and remembering treatments. It's normal to feel overwhelmed and time pressured by the new demands that HIV places on your lifestyle.

As time passes, you might find you start thinking more about sex and you may feel ready to have sex again. Or perhaps you never stopped having sex since your diagnosis. Some people say they feel frightened of rejection because of their HIV status and this holds them back from a healthy sex life. However, every person – regardless of his or her HIV status – has the right to a full and active sex life.

If the fear of rejection concerns you, it can help to remember that you've probably faced and had to deal with rejection in the past for many different reasons.

Newsletters and magazines such as '**Positively Positive**' by Body Positive Inc. and '**Positive News**' by Positive Women Inc. may be good sources of information.

If you are in a relationship and it is starting to feel rocky now that the initial shock has passed, consider talking to a counsellor or seeking out a couple's counsellor if you both want to work on the relationship. You have been through a major life change and you need to give yourself credit for all the steps you've taken so far. Try to remember that this is an adjustment you both need to make in your relationship.

For people taking treatments, it may be a good time to take another look at how you've been going. Are you happy or finding it difficult? You have the right to make decisions about starting or stopping treatments. If you're not taking treatments, continue to learn as much as you can so that you are well informed about any future decisions you make.

It's advisable to start thinking about your long-term health. Good eating patterns and regular exercise can be beneficial to your long-term health and will put you in a good position to manage living with HIV. Dietitians are available at most public hospitals to help you improve your diet if this is an issue.

Checklist

- It's normal to feel overwhelmed by the increased time pressures that HIV places on you
- Good eating patterns and regular exercise can benefit your long-term health
- You have the right to a full and active sex life

PLWHA Support Services Contact Details

Body Positive New Zealand

www.bodypositive.org.nz

Free Call: 0800 HIVLINE (0800 448 5463)

- Auckland (09) 309 3989
- Wellington (04) 801 5484



Positive Women Inc.

www.positivewomen.org.nz

Free Call: 0800 POZTIV (0800 769 848)

Tel: (09) 309 1858



INA Foundation

(Maori, Indigenous and Pacific Island Support)

www.ina.maori.nz

Tel: (07) 883 9084



PLWHA Support Services Contact Details

Auckland Sexual Health Service

www.ashs.org.nz

Free Call: 0800 739 432

- Central Auckland (Greenlane) (09) 630 9770
- North Auckland (Glenfield) (09) 443 9580
- South Auckland (Mangere) (09) 255 5172
- West Auckland (Henderson) (09) 836 0838

Community HIV Team Infectious Diseases Dept.

Auckland Hospital

Tel: (09) 307 4949 ext 22960

New Zealand AIDS Foundation

www.nzaf.org.nz

Free Call: 0800 80 AIDS (0800 80 2437)

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



Services for Sex Workers

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

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