WAHINE KAHA

Positive Women

TREAT YOURSELF RIGHT

Information for Women living with HIV or AIDS

POSITIVE WOMEN INC. 2009

Re-written and adapted with permission from: Positive Women Victoria and the AFAO and NAPWA Education Team..

Booklet Design: Central Station

CENTRALSTATION

Cover photo:
Funded by: New Zealand Lottery

Originally produced by: The Australian Federation of AIDS Organisations (AFAO) and the National Association of People Living with HIV/AIDS (NAPWA)
Adapted by: Positive Women Inc. New Zealand January 2009 v1

Information contained in this booklet was correct at the time of writing. However, information on HIV and AIDS is constantly being updated. The booklet is a guide only. If you are considering any treatment or therapy for HIV or AIDS, seek the advice of a qualified medical practitioner. The information in this book does not intend to promote or endorse any specific treatment for HIV or AIDS.

CONTENTS

This booklet is to provide you with information about HIV, how it affects women and what you can do about it. The most important thing is for you to be able to:

- get all the information you need;
- make your own decisions;
- know where to go for support.

You will find you have a wide range of choices, and this booklet will introduce you to some of them.

1. BEING AN HIV POSITIVE WOMAN

You may be reading this booklet because you have recently learned that you are HIV positive or you may have known your diagnosis for some time, even many years. Either way, you probably feel you need to know more about HIV, how it can be managed and what treatments are available for women.

If you have only recently been diagnosed, you may be feeling shocked, frightened, confused, angry or upset. These feelings are quite normal. Women diagnosed for many years may also continue to have these feelings.

It may help you to know that there are women from all over New Zealand and from all walks of life who are HIV positive. There are women from many different cultural and religious backgrounds, young women, older women, married women, single women, heterosexual and lesbian women, women with children and women who want to have children, women who are students, women who are carers, women in all sorts of work, and women who are unemployed or retired.

Some women in New Zealand have been HIV positive for over 20 years and still remain well and active. Nowadays more and more women with HIV are living longer, enjoying healthy and fulfilling lives, working, studying, having relationships and children, and making their own choices about treatment.

Getting information

Knowledge about HIV and AIDS and its management is increasing every year. New treatments are being trialed all the time, and there are now many drugs and therapies which have been shown to prevent, reduce or delay illness. The effectiveness of treatments means that not everyone who has HIV will necessarily get AIDS. In fact, small numbers of people with HIV don't progress to AIDS-related disease, even without treatment. Now that relatively effective treatment is available, it's possible even after being diagnosed with an AIDS-defining illness to become completely symptom-free again and even to recover some lost immune function. There is more information on treatments in section 10. Because there are so many benefits to be gained by managing your health, it is important that you start getting the right kind of information and support as soon as possible.

Getting support

There are many people who can help you make decisions about the way that you manage living with HIV. This list could include doctors and health professionals who have experience with HIV and AIDS, but may also include community organisations set up specifically to support HIV positive people. Other people living with HIV — especially other positive women — can be invaluable. It can help to hear how other women have dealt with issues such as relationships, sexuality, work, decisions about having children, telling people they are positive, treatment choices, and staying well. There are many free services, pamphlets and newsletters throughout New Zealand. You will find a list of services, resources and useful contacts at the end of this booklet.

As a woman with HIV

- You have the right to take control over your own health, and make your own decisions about how you live with HIV.
- You have the right to choose when and if you tell about your HIV status, or to keep your diagnosis confidential.
- You have the right to choose which treatments or therapies you use.
- You also have the right to refuse any treatments or therapies with which you do not feel comfortable.
- You have the right to a full and active sex life.
- You have the right to have children.
- You have the right to work, or make changes to the way you work.
- You have the right to high quality health care, support and counselling in an environment which is supportive, sensitive and free from discrimination.

2. HOW DOES HIV AFFECT THE BODY?

The Human Immunodeficiency Virus (HIV) attacks your immune system, a system of organs and cells throughout the body which usually fight off infection and keep you well. HIV affects the immune system by targeting and destroying cells which normally fight off infection. The main cells infected by HIV are called the CD4 (or T4) cells — a type of white blood cell. These cells are a major part of your immune system.

If you have been told that you are HIV positive, this means that you have been infected with HIV, and your immune system has made antibodies specifically to fight the virus. But HIV antibodies don't kill the virus. Instead, HIV continues to reproduce itself within the CD4 cells, creating 'viral copies' which cause further damage to the immune system. If your immune system is weakened, this is often described as being 'immunosuppressed' or 'immunocompromised'. This means that you are at risk of developing 'opportunistic infections' or other more serious illnesses that are associated with AIDS (Acquired Immune Deficiency Syndrome).

HIV can affect your body in a number of different ways. You may feel perfectly well, and have no symptoms of HIV or illness. You may feel tired and lacking in energy: this may be due to the effect HIV can have on your immune system or may just be because you need some rest. If you have had HIV for some time, you may have some of the symptoms of more serious immune system damage, or of the opportunistic infections which HIV can cause. Whether you have symptoms or not, it is important to regularly monitor your health for any changes in how you are feeling, and to learn how to best take care of your health.

3. WHAT YOU CAN DO ABOUT HIV

It is not easy to deal with a potentially life-threatening condition. It can help to stay optimistic and look at practical ways to improve your health and well-being. Many women have found that other positive women can help them to see things differently, to feel stronger and to be more able to manage living with HIV.

Although there is still no cure for HIV, you can do lots of things to keep your immune system healthy and to prevent illness. Studies of people living with HIV or AIDS have shown that people who take an active role in their health care and work with a doctor or health practitioner experienced in managing HIV live longer and are less likely to become ill.

There are tests which can measure how well your immune system is coping with the virus and how much HIV is in your blood .These tests are a likely to be a routine part of monitoring your health if you have HIV, and are described in detail in section 8. There are also treatments which you may choose to take which can work against HIV. The aim of these treatments, described in section 10, is to prevent or limit damage to the immune system by suppressing the activity of the virus.

Many women living with HIV find complementary therapies useful. Some people use complementary therapies to assist in managing their health and well-being. Some use complementary therapies to help reduce the side effects of antiviral treatment. Complementary therapies are explored in section 17.

Because there is no cure yet, the best way to treat HIV is to:

- monitor the state of your immune system and the activity of HIV in your body;
- prevent serious damage to your immune system;
- prevent HIV-related opportunistic infections occurring;
- treat symptoms as soon as they appear.

4. POSITIVE WOMEN'S LIVES

Does HIV affect women differently?

The differences between men and women mean that there can be a different response to HIV disease and its treatment. It's important that your doctor has this in perspective and keeps an eye on women-specific research.

Men outnumber women as participants in clinical research, and most major HIV trials involve groups of people who are predominantly male. However there has been a concerted attempt to get more women into clinical trials and to conduct sub-studies of the women in major trials where possible, in case women respond differently to men.

Some studies suggest that HIV may affect women differently, with possibly greater damage to the immune system at an earlier stage. Although other studies have not reached the same conclusions, you may have concerns about this research, or wish to discuss it further with your doctor.

There is some evidence to show that HIV does affect women differently in some respects. This may be due to physical, social or psychological differences. HIV may affect:

- hormones;
- body weight and shape;
- your reproductive system;
- menstruation and menopause;
- your lifestyle and social circumstances.

Do women respond differently to HIV?

In general, women's lives differ from those of men in a number of ways. Women are often the primary carers, responsible for the emotional and physical well-being of others in their lives and often juggling these responsibilities with paid work.

What you are entitled to as a positive woman

While women remain a minority of people infected with HIV in New Zealand, as a positive woman, you are entitled to the same quality of and access to information, clinical services and support as are HIV positive men. If you believe that you have received a lesser standard of service delivery in any of these areas, you are entitled to make a complaint.

5. TELLING PEOPLE YOU ARE HIV POSITIVE

It is hard to know how people will react if and when you tell them you are HIV positive. Many people find that family, close friends and partners are very supportive and understanding. Unfortunately, there is still some ignorance about, and stigma attached to HIV infection. Nonetheless, it is important that you do have people whom you can talk with about being HIV positive. So you may be thinking about whether to tell family or friends.

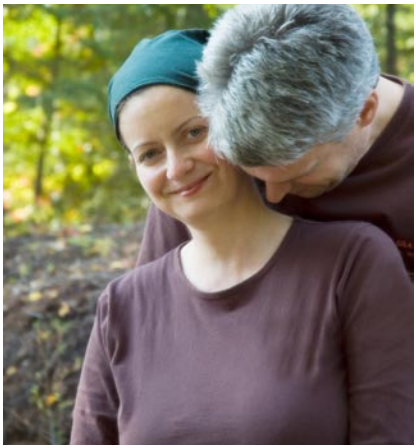
When you are thinking about whether you should tell people, and whom you might tell, it may be useful to consider the following questions.

- Can I trust this person with this information?
- Will they offer me support?
- Are they likely to judge me?
- Will they respect my confidentiality?

You may find it useful to discuss these issues with a counsellor or another HIV+ person. If you want to keep your HIV status fairly private but want to be able to discuss it with a few trusted friends, it is a good idea to give the people you tell permission to talk to another specific person. This is a practical way of keeping the information private, while recognising that a person may need to talk about it with another trusted person.

Telling partners

If you are in a relationship with an HIV-negative partner who does not know you are positive, you may want to tell them. This can be difficult, but you will probably need their support and understanding to help you to live with HIV. You may be afraid that your partner will be angry, accusing or judgmental.



Your partner may certainly be scared or confused. You might be scared that he or she will leave you. It can be as big a shock to your partner as it was for you to learn that you are HIV positive. It is often helpful to have a doctor or HIV counsellor available to support you and answer questions when you tell people close to you. Your partner may want to consider having an HIV test. You will probably find that your partner can come to terms with you being HIV positive and, in fact, it may strengthen your relationship. You may need to discuss issues about safer sex.

Telling children

It's up to you when you want to tell children that you are HIV positive. This is one of the main issues that arise for women with children after diagnosis. Talking with other positive women, particularly those with children, can be really helpful for exploring different approaches you might take. This is also an issue that you can discuss with a counsellor or health care professional if you would like some guidance on what might be best for your particular family circumstances.

Some women decide to talk to their children straight away, whereas others decide to wait until the children are older. It very much depends on the family situation and your judgment. You know your children and are in the best position to make this hard decision.

When you decide to tell your children, it may be a good idea to tell some other people who can provide support for the child – maybe an aunt or a good friend whom your child trusts. Older children may feel angry, particularly if they feel that important information has been withheld.

There are people you do not have to tell

If you are HIV positive, you do not have to disclose your HIV status to:

- your friends;
- your employer;
- your work colleagues;
- doctors, dentists or other health care professionals.

Having said this, it may be wise to tell any doctor treating you — particularly over the long term or for serious conditions — that you have HIV. To help you make the best decisions about your health, your doctor will need as full a picture as possible. It is also a good idea to tell your dentist, since HIV can affect your gums. If you do tell a doctor, dentist or any other health care provider, they cannot refuse to treat or manage you: this would be discrimination and against the law.

Circumstances in which the law may require disclosure

Generally, you are not obliged to tell anyone if you are HIV positive. However, in some unusual circumstances, the law may require that you disclose.

- HIV positive people are legally obliged to tell any sexual partner if they have unprotected sex (sex without a condom)
- The Department of Immigration requires anyone applying for permanent residency in New Zealand to be tested for HIV

If you are refused service

If you are refused any service or believe you have been treated unfairly because you are known or presumed to be HIV positive, this may be a case of discrimination. It is against the law to discriminate against people because of their HIV status. If you would like more information about how to deal with HIV-related discrimination, contact the Health and Disability Commission or an HIV support group – listed at the back of this booklet.

6. GETTING ON WITH YOUR LIFE

Work

Work has the potential to affect your health and well-being, in both positive and negative ways. Work may be boring and stressful, or merely and economic necessity. It may also be interesting, fulfilling, and a great reason to get up in the morning.

If you have a choice as to whether you can work or not, or whether to work full-time or part-time, it may be a good idea to think about the role of work in your life. Remember, you don't have to rush into any decisions.

The issue of work may be complicated by your health. Perhaps you are experiencing periods in which you are unwell or need regular time off for medical care. Complicated antiviral regimes may also be an issue, particularly if you are experiencing side effects (such as diarrhoea).

In these circumstances, it makes sense to take time to think about your work situation. You may wish to discuss your options with your partner, your counsellor, doctor or another health care provider.

If you are having periods in which you are unwell, it may be harder to balance the demands of work and family or personal life. It is useful to remember that the nature of the workforce is changing all the time. You may find that there are opportunities for part-time work, or for work with flexible working hours which may suit you more than full-time work. Some women like to get involved in activities such as volunteer work or study in order to keep busy, and to maintain or develop social networks and other contact.

Getting more information

Your work situation may affect things like work and income entitlements. Disability Support Officers, located at WINZ or an HIV councellor may be able to advise you further on this.

Stress and fatigue

If you're HIV positive, you may experience periods of fatigue or constant tiredness. The cause of this could be physical or psychological. Stress or depression are common causes of fatigue. However, constant tiredness may also have a physical cause, related to HIV, or to other illness.

If you feel constantly tired or stressed, think about ways in which you might reduce your work-load and responsibilities. Take time out for yourself, even if you're caring for others. Some complementary therapies incorporate relaxation techniques. Yoga or meditation are just two of the approaches many women have found helpful.

Positive Women Inc. holds free annual women's retreats and a family gathering every two years. These can be a great way to take time out for yourself, meet other positive women and perhaps learn to deal with problems like stress or depression.

It's important to keep doing the things that you enjoy in life — things which make you feel good about yourself and raise your self-esteem.

If you are feeling more than usually fatigued, or the onset of tiredness is sudden or extreme, it could be related to HIV. Talk to your doctor if you think this may be the case.

Diet and exercise

To help your immune system stay healthy and to prevent HIV-related weight loss, it is important to eat well and enjoy your food. This means eating meals which include a wide range of foods. Because people with HIV are susceptible to weight loss, it is recommended that you eat a well-balanced diet to try to maintain your normal weight. This is a diet that includes fresh fruit, vegetables, grains and protein. Avoid low calorie or low-fat diets, or 'fad' diets and eating plans which are excessively restrictive.

Women with HIV may need to eat a diet higher in protein than HIV negative women in order to conserve lean muscle mass. Some women need specific help to maintain normal blood lipids and sugar.

You may want to talk with a dietitian to help manage your specific nutritional needs. A dietitian may be able to recommend ways to manage stress, fatigue, diarrhoea, nausea, changes in body shape or weight loss. You may choose to take some extra vitamins or nutritional supplements. If you think this could be for you, seek advice froem your doctor or HIV specialist. Exercise can also improve your mood, increase your energy levels and help maintain your lean muscle mass. Even a daily walk in the fresh air can help you feel, and sleep, better.

Alcohol

A little alcohol can help you relax, feel good and increase your appetite. A glass of wine or beer or a single measure of spirits should do you no harm. Heavy drinking increases your body's requirements for certain nutrients, such as vitamin B6, and places a strain on your liver. A healthy liver is needed to process anti-HIV drugs. Some women on these treatments find that they become increasingly likely to experience a 'hung over' feeling, with even small amounts of alcohol.

Smoking

If you smoke, you may want to cut down or stop if you can. It is well known that smoking is a health hazard for everyone and may be unhelpful for someone with a damaged immune system. Smoking increases the risk of cervical cancer, also a higher risk for HIV positive women. There are programs that can help you stop smoking if you decide to quit smoking and some are available on subsidies. Ask your doctor.

Recreational drug use

Some recreational drugs interact with anti-HIV drugs, so it's important to talk honestly to your doctor about any drugs that you use, whether regularly or occasionally.

Using recreational drugs while you are on antiviral treatment can be harmful because:

- each person's body may have a different reaction;
- your immune system may be damaged through long-term use of some of these drugs;
- some recreational drugs may lower the levels of antivirals in your blood, so less of the dose is absorbed;
- some antivirals may raise the blood levels of amphetamine-based drugs to possibly dangerous levels.

If you do inject recreational drugs, it is strongly recommended that you do not share needles or injecting equipment — even with other HIV positive people. Use your own injecting equipment or use a new kit every time. This is important in order to:

- reduce the risk of becoming infected with hepatitis C or other blood borne viruses;
- prevent the transmission of HIV and other infections.

Seeking advice and support

If you use drugs, you may want to reduce your use or stop altogether. You should seek advice and support in this through your doctor, community health service, or HIV support group.

For information about interactions between HIV antiviral drugs and recreational drugs, see section 10.

7. SEX

Sex can be a really positive way to feel good about yourself and your partner. Having sex can make you feel desired and valued. Sex can make you feel happy and fulfilled.

But sometimes, during stressful times, periods in which you are unwell, or while adjusting to an HIV diagnosis, some women become less interested in sex. This isn't at all unusual. Research suggests that HIV positive women often lose interest in sex for the first year or so after diagnosis but the good news is that for most women, sexual desire does return.

Safer sex

It can be hard to feel relaxed about sex when you have HIV because you may be afraid of transmitting the virus to your partner. Learning to talk about sex and negotiate safe sex with a partner may be hard for women. Talking about your feelings to a counsellor, or to other women living with HIV, may help you find ways of exploring your sexuality safely.

Understanding the ways in which HIV can be transmitted may help you decide which sexual activities are safe, and which ones pose a risk. HIV can only be transmitted if:

- there is a route via which the virus is able to enter someone's bloodstream or lymphatic system;
- HIV is present in a high enough quantity for transmission to occur.

This second point may be confusing or misleading. You may have heard, for example, that it is impossible to transmit HIV to a sexual partner if you have a very low or undetectable viral load. Unfortunately, while low levels of virus in the blood do seem to suggest you are less likely to transmit HIV, the evidence is not clear enough to be able to make a blanket statement.

You have the right to purse a happy, safe and fulfilling sex life. That means being free to enjoy a range of sexual activities, and being free to not have sex, with the partner or partners of your choice and there are plenty of sexual activities which you and your partner can continue to enjoy.

Kissing

Kissing is extremely safe. There is not enough HIV in saliva to transmit HIV, and the mouth is not a good route into the body as saliva harms HIV.

Oral sex

Licking or sucking the vagina, or vaginal lips is considered to be relatively safe in terms of HIV. Vaginal fluids are relatively low in HIV concentration, and the mouth has very good protective immune mechanisms, including saliva. Sexually transmissible infections (STI's) such as herpes and gonorrhea, however, can be transmitted through oral sex.

There have been no documented cases of transmission of HIV from vaginal fluid in the mouth, but there may be some risk in exceptional circumstances, such as when you have

your period and your partner has an open mouth wound, or an open ulcer or lesion in or around the mouth. As a general rule, don't let someone go down on you with a cold sore or ulcer unless they use a barrier, as they may transmit something to you – such as herpes, and the risk of you transmitting HIV to your partner also increases.

Latex sheets known as dental dams or condoms slit length ways have sometimes been advocated for 'safe' oral sex, but these are considered unnecessary in terms of HIV prevention (the exception here is in the occupational context for sex workers, who often seek to minimise any microbial contact by using barriers as much as possible).

There is no danger of a positive woman infecting their partner by performing oral sex on them.

Vaginal or anal sex with condoms

If you are having vaginal or anal intercourse with an HIV negative male partner it is recommended that you always use condoms with a water-based lubricant. This could be the male condom, or the new female condom (available from most Family Planning Clinics), which are inserted into and cover the vagina. It is also important to consider condoms even if your partner is HIV positive. This protects your own health as well as that of your partner. When using condoms, it is important to choose a water-based lubricant such as KY, since oil-based lubricants like Vaseline or hand cream can damage latex, and cause the condom to tear or break.

If both you and your partner are HIV positive, you may be thinking about sex without condoms or other barrier protection. In this case, you may wish to discuss the potential risks (such as other STIs) with your partner, and weigh these up against the pleasure many people get from unprotected sex. (Insert section about re-infection here)?

Hands and fingers

There is no risk to your partner if he or she penetrates your vagina or anus with fingers or hands — unless cuts, sores or scratches are present. If there are cuts, sores or scratches on your partner's hands, he or she should consider using latex gloves for barrier protection.

Sex toys

Penetrative sex toys like vibrators or dildos should always be washed or used with condoms to prevent the spread of a range of infections. Always change the condom between users/partners.

Negotiating sex

Of course, all of the above presumes that you and your partner (regular or casual) communicate well, respect each other's rights and safety during sex, and that your partner(s) is prepared to wear a condom. But it's not an ideal world. Women may sometimes find it difficult to convince some men to use condoms. If this is the case, you could consider seeking some kind of support or counselling. If you have a regular partner, they may be prepared to be part of this process. Family Planning clinics across New Zealand may be able to help, or will be able to refer you to an appropriate service.

Menstruation and sex

Menstrual fluid is made up of blood, uterine tissue and other substances, and it does contain HIV although there has been little research about the levels of virus present. It is possible that there are increased risks of HIV transmission during menstruation, so barrier protection such as condoms and lubricant are particularly important.

For women who have hepatitis C, it is particularly important to prevent others having contact with your blood as HCV (Hepatitis virus) is easier to transmit than HIV. HCV is readily transmissible through blood.

8. CHOOSING AND WORKING WITH YOUR HEALTH CARE PROVIDERS

In the course of managing your HIV infection, you may have contact with a range of health care providers. These could include: general practitioners, infectious diseases specialists, complementary therapists, nurses, gynaecologists, physiotherapists, psychiatrists, counsellors, and social workers.

Some you may use briefly, others may form the backbone of your health care.

Choosing a practitioner (or health service) is an important process. It can be easy for some women and extremely difficult for others. For instance, many women do not live near a doctor or complementary therapist who is experienced in treating HIV, especially HIV in women. Living in a small, rural or remote community may raise other issues about local medical services, including anxiety about confidentiality. Remember, though, that all doctors and practitioners are bound by strict codes of professional conduct regarding privacy. Your doctor is not allowed to disclose information about your health, including your HIV status, to other people.

It can also be difficult to judge the knowledge and skills of particular practitioners because knowledge about HIV and how to treat it is a rapidly changing area.

A good health provider will:

- explain the risks, costs and benefits of any treatment — including any side effects;
- suggest or be open to alternative ways of treating or managing symptoms and side effects;
- protect your privacy and respect confidentiality at all times.

Attitudes, knowledge and commitment: choosing who to see

General practitioners and HIV specialists

Managing HIV infection is an increasingly complicated and rapidly changing area of health care. It is important, when choosing a doctor, to establish their levels of knowledge and commitment to working with and treating patients with HIV.

When choosing a GP, consider asking:

- do they treat other women with HIV?
- are they prepared to work with someone with HIV in a non-judgmental fashion?
- if they don't treat many people with HIV, are they willing or able to learn more about this condition in order to offer you the best care?
- are they able to prescribe HIV antiviral drugs?
- do they have the latest information about antiretroviral medicines?
- do they have a personal manner which suits your needs?

Specific issues relating to women and HIV

Many women prefer to see a woman doctor or complementary therapist as a matter of course, or particularly for gynaecological or sexual health matters. The important thing is to find a practitioner who is up-to-date about HIV and sensitive to gender and family issues.

Many women, given the choice, would prefer to see a health care provider who sees other women. You may feel that a woman is likely to be more sensitive to specific issues affecting women, such as menstrual irregularities, cervical screening, antiviral side effects, or pregnancy.

You can contact Positive Women Inc. or any support group to ask if they are able to recommend GPs living in your area who have experience with HIV. If you would prefer to see a female doctor, let them know this. If a number of women are happy with the care provided by a practitioner, it suggests that they are well-informed about HIV and sensitive to the particular needs of women. You need to choose the one that suits your needs best — and it may not be the most 'popular' practitioner, or the one with the biggest case-load.

Complementary therapists

Many complementary therapies are widely used by women with HIV and reported to be safe and effective. However, because this area is largely unregulated, it can be confusing or difficult to work out whether an alternative therapist is appropriately qualified. Many complementary therapies have professional bodies and associations which can be some guide as to the reliability and qualifications of the therapist (though unfortunately, it is not a guarantee). Be wary of any complementary therapist who claims to be able to 'cure' HIV or AIDS.

Positive Women Inc or another HIV support group should be able to refer you to qualified practitioners who work with and are sensitive to people with HIV.

Working with your health care providers

Do they respect your decisions and wishes?

Some women with HIV have reported experiencing pressure from their doctors to start or continue with antiviral therapy or other forms of HIV-related treatment.

A good doctor will appreciate that most people don't make HIV treatments decisions lightly, and that an individual woman will generally have carefully considered her reasons for starting or changing any form of treatment.

If you are experiencing side effects from your HIV medications, don't be ashamed or afraid to talk to your doctor about this. You don't need to suffer in silence. Some side effects can be managed fairly simply, but you may need more support when dealing with very severe or problematic side effects. Your doctor should be clear about the potential side effects of your HIV drugs. If you feel side effects may be a problem, you could ask your doctor about whether it would be appropriate to have some simple remedies on hand (like Imodium for diarrhoea) when you start taking the drugs.

Often, women don't tell their doctors if they are using any complementary therapies because they are fearful the doctor will be judgemental, and not support them in this

choice. Some doctors have a less co-operative attitude when it comes to complementary therapies than others. But many doctors are prepared to work with complementary therapists to ensure that the patient is getting the best quality care. If you are interested in complementary therapies, it may be a good idea to be upfront about this, and establish whether your doctor is prepared to work co-operatively with other therapists.

Every treatment decision is yours, and yours alone, to make. It is up to you to consider the information given to you, weigh it in the balance, and make your decision.

If you do feel that your doctor or health care provider is pressuring you into making a decision, or placing stress on you in any other way, consider going to see another practitioner. Alternatively, you could try taking a friend or advocate along to your consultations.

Are they happy to refer you to other practitioners?

Good health practitioners will support you in seeking a second opinion if you are making a difficult decision. They will understand that it can be useful to have another viewpoint, or to seek confirmation of their assessment. Your GP should also have a list of people to whom they can refer you for assistance in other areas, such as emotional or psychological support.

What are their fees or charges?

It's important to consider whether you can afford the treatment options you choose. Most HIV services are offered free of charge through public hospitals or clinics. Private specialists (such as gynaecologists) will charge so it's important to ask about the cost prior to a consultation.

Money is often an issue with complementary therapies. HIV support groups may also offer cheaper access to alternative therapies such as massage. You may be able to negotiate a discount if you are on a pension or a low income earner however if this is not the case, you may have to pay full price.

What if you want to change your practitioner?

If you are unhappy about the service you are getting, you might want to exercise your consumer rights, and change practioners. If this is the case, you can arrange to have your medical records transferred to your new doctor. This requires a signed permission form, your clinic receptionist should be able to provide you with this.

What if you have a complaint?

There are complaints procedures in place in most hospitals and health practices. You can gather more information about complaints procedures from Positive Women Inc., telephone advisory services, and the Government Ministry of Health and the Health and Disability Commission. See the back of this booklet for contact details.

9. MONITORING YOUR HIV

How are you feeling?

When you had your HIV test, you should have had counselling before the test and when you received the test results. If you were not given any counselling, or feel the counselling was inadequate, ask Positive Women Inc. to suggest someone you could talk to.

How you are feeling at any given moment may be related to your HIV status, or to your general sense of physical and emotional well-being. If you are feeling unwell, it could be directly related to HIV or some other illness, or it may be that emotional or psychological stresses are playing a major role.

The section looks at the various ways in which HIV can be monitored an managed. Monitoring your HIV (or 'keeping an eye' on the course of the virus) may involve a series of steps including regular general check-ups, and tests which can look at how much HIV is in your body at any time, and how this is affecting your health and immune system.

Some people living with HIV have experienced very little illness, while others have had periods of illness and have spent time in hospital. Each person living with HIV is unique and no-one can know exactly how the virus will affect them.

There are HIV treatment officers available. They can provide you with up-to-date information and will spend time — face to face or by phone — discussing any matters that concern you.

How do you know what's happening to your body?

Even when you are feeling well, it is recommended that you keep a check on your immune system. The two tests that are most useful for finding out how your immune system is coping with HIV are CD4 counts and viral load tests.

These two tests are the most important tests in terms of ongoing health monitoring. They may be used as a guide so you can understand:

- how much HIV is in your body at any time;
- how this is affecting your immune system;
- whether you are at risk of opportunistic infection;
- whether you should start treatment;
- whether your current treatments are working.

These tests will also have a role in terms of other decisions, for example, if you are considering pregnancy.

Viral load tests and CD4 (T-cell) counts

CD4 (T-cell) counts

This is a blood test which can tell how many CD4 cells (also called T-cells) you have. A person with a healthy immune system can have between 500 and over a thousand of these important white blood cells.

CD4, or T-cells, are important because they help make the immune system work efficiently to deal with, or get rid of, any unwanted bugs, viruses or organisms. But unlike other viruses, HIV actually invades and destroys the CD4 cells. The immune system cannot function well without these cells. Eventually, if it goes unchecked, HIV will begin to destroy the CD4 cells at a faster rate than the body can actually produce them. When this begins to happen, the number of CD4 cells drops, and because the immune system cannot do its job, it is slowly overwhelmed.

Interpreting CD4 cell counts

If your CD4 count is 500 or less and you are experiencing ill-health you may be advised to consider starting antiviral treatment. If your CD4 count is 200 or less, treatment will be highly recommended.

If your CD4 count is 200 or less, this may indicate that serious damage has occurred to your immune system. This may place you at risk of serious illnesses related to HIV, called 'opportunistic infections'. If you have between 250-350 CD4 cells or less, you need to consider not only antiviral therapy (to control HIV), but also think about treatments called prophylactic treatments, which can minimise the likelihood of your becoming ill with particular infections. Discuss this with your doctor.

Viral load tests

HIV multiplies — by 'copying' itself — within your body. Viral load refers to the amount of HIV in your blood at any given time. You can also measure viral load in other body fluids like vaginal fluid, but routine viral load tests usually just look at how much virus is in your blood.

The reason this is important is because the amount of virus in your blood is a direct indication of how much damage HIV may be doing. The higher the amount of HIV, the greater the risk of your immune system being damaged, and the greater the risk of serious HIV-related illness. Viral load test results are expressed in terms of the amount of HIV per millilitre of blood.

What factors affect viral load?

A number of factors can affect viral load. Viral load can go up and down in response to: your general health, antiviral drugs (and whether they are working), changes in treatment, the presence of other infections, vaccination (e.g. hepatitis B), and the strength of your immune system.

Viral load and treatment decisions

You and your doctor need to decide if and when to start ARV (anti-retroviral) treatment. You may want to use the results of your CD 4 and viral load tests over time to inform these decisions.

Currently, the T-cell or CD4 counts are more often used to make a decision regarding commencing ARV, but the viral load results may also be taken in to account when making that decision.

What does viral load test entail?

A viral load test is a simple blood test but generally isn't checked every time you have your CD4 test unless your specialist needs to specifically monitor this.

Interpreting the results

Viral load tests may show a great range in the amount of virus the blood, varying wildly between individuals from millions of copies to as few as twenty. Your doctor will want to keep an eye on how your viral load is changing over time. This will be a pretty good indicator of how well you are doing on treatment, or if you are not on treatment, it may suggest whether your health is stable

In general, the following understandings of viral load are used:

- more than 30,000 copies — high viral load;
- 10,000 to 30,000 copies — moderate viral load;
- 3,000 to 10,000 copies — low viral load;
- 500 to 3,000 copies — very low viral load;
- under 500 copies — "undetectable" viral load.

But it is important to see viral load tests as part of an overall picture, and not get too 'freaked out' by the result of any single test. For example, if your first viral load test showed HIV was in the millions, and it is now down into the thousands, this is a pretty good indicator that HIV is not out of control.

An important note about 'undetectable' viral load

If your result comes back as 'undetectable' this does not mean that there is no HIV in your blood. Unfortunately, the term "undetectable" can be very misleading. It means that the amount is less than 400-500 copies of HIV per ml of blood.

Viral load in blood and viral load in vaginal fluids

Research shows that there is usually a relationship between levels of HIV in the bloodstream and levels of virus in other body fluids like vaginal secretions. In other words, if your blood viral load is low it is likely that the level of virus in vaginal fluids will also be low. However, this is not always the case. It is important to know that some studies have been unable to demonstrate a relationship between blood and vaginal fluids, finding low levels virus in blood and higher levels of virus in vaginal secretions. The best that can be said is that if you have low levels of virus in your blood you are most likely to also have low levels of virus in your vaginal fluids, but that a small number of cases will not reflect this pattern. It is not clear what factors affect this relationship, and why differences between viral load in blood and in vaginal fluids may sometimes occur.

Other common tests

Pap tests (Pap smear)

Cervical cancer is one of the leading cause of death in NZ women. Women living with HIV or AIDS are advised to have a Pap smear every twelve months. A pap smear is a simple procedure in which a sample of cells is swabbed from the cervix (at the top of the vagina), to test for an unusual changes, which may suggest the risk or presence of cancer. It is not uncommon for women to have a condition that is called 'cervical dysplasia', regardless of HIV status. This means that your Pap smear result shows some abnormal cells. In some women, these abnormal cells can lead to cervical cancer if they are not treated.

In general, HIV negative women are advised to have pap smears every 12-24 months. The reason that HIV positive women are advised to have pap tests every 12 months is that cervical dysplasia, or the presence of abnormal cells, is more common in HIV positive women. The presence of abnormal cells does not mean you have, or will get cancer. However, in a small number of cases, they can suggest pre-cancerous conditions.

It is possible that progression from cervical dysplasia to cancer may be more rapid in positive women. If you have a pap smear and cervical dysplasia is found, ask your doctor whether you should have a colposcopy. This is a slightly different test, in which cells are taken from the cervix for further examination.

Cervical cancer, which is described in more detail in section 14, can be difficult to treat. However, it can be prevented if abnormal cells are found early enough by routine testing.

Pap tests are available from any general practitioner (GP) or nurse practitioner or through Family Planning and Sexual Health clinics.

Other tests you may need

There are other tests which you may feel you need, or may be asked to consider, as part of managing HIV. These could include:

- tests for any other sexually transmissible infections (STI's);
- liver function tests (particularly if you are positive to hepatitis B or C);
- tests to see if you have been exposed in the past to viruses (for example, cytomegalovirus or CMV), which can recur in people with lowered immune systems.

10. HIV TREATMENTS

There is no treatment or drug yet which can totally clear the body of, or eradicate, HIV. However, there are a range of approaches which can be used to treat and manage HIV, and limit the amount of damage it can do to your health. These are:

- drugs which directly target HIV itself, and inhibit its ability to reproduce (called antiretroviral drugs) otherwise known as ARV's,
- treatments which can delay or prevent the onset of HIV-related opportunistic infections (called prophylactic treatments);
- treatments which help to restore, rebuild or maintain the function of your immune system (called immune-based therapies); and
- complementary or alternative therapies, which may help improve your energy, and manage or alleviate symptoms and drug side effects.

In the last 10 years, HIV treatments have improved immeasurably. New drugs are becoming available, and new approaches continue to offer hope. Combinations of ARV drugs have improved life expectancy for many people living with HIV or AIDS, dramatically slowed disease progression, and have helped reduce the rates at which AIDS-related illnesses and deaths have occurred. The incidence of some life-threatening illnesses has declined by as much as 90 percent since combination antivirals were widely used.

However, the new treatments have not been without some cost, with side-effects and often difficult dosing requirements raising a new set of issues and dilemmas which are explored in this section.

Making decisions about treatment

Deciding which, if any, treatments to take can be very complicated. It may at times seem stressful, confusing or frightening. And the treatments that you might use are likely to change over time, influenced by factors like:

- your general well-being;
- changes in your viral load or CD4;
- side effects;
- your lifestyle;
- the availability of new treatments and approaches;
- your attitudes to medicine.

When considering treatments, it may seem overwhelming, because you will be expected to take in quite a lot of information, a lot of which is complicated or even contradictory. Doctors may say one thing, and other positive women, or your friends and family, may say something else.

The important thing is not to be rushed into any decision before you are ready for it. In the end, which drugs you do or don't take is up to you.

Women and antiviral drugs

Deciding when and if to take HIV antiviral therapy can be especially complicated for women, because there is not a great deal of information which specifically focuses on how antivirals affect women's bodies and lives. Fortunately, this is changing, and knowledge in this area is increasing. But it can be hard to find clinical information which explains how these drugs may work differently in women. For example, some doctors believe that the standard doses of some antiviral drugs, which are calculated on body weight but have been far more frequently tested in men, may be too high for many women, and so side effects may be more severe.

What are antiviral treatments?

Antiretroviral (ARV) drugs stop HIV from replicating and infecting new cells in your body.

There are different classes (groups) of HIV antiretroviral drugs. These are:

- Nuclecoside and nucleotide reverse transcriptase inhibiters (NRTIs, sometimes called nuclcoside analogues, or nukes);
- Non-nucleoside reverse transcriptase inhibitors (NNRTIs, sometimes called non-nukes);
- Protease inhibitors (PIs);
- Fusion inhibitors and entry inhibitors;
- Integrase inhibitors (still experimental at time of writing).

Each of these classes of drugs works in a different way to interfere with the HIV life cycle and makes it difficult for the virus to reproduce. There is a range of different drugs in each of the classes and while drugs in the same class share some common characteristics, there are differences. Some are more effective at stopping HIV replication, and some are less likely to have certain side effects.

What is combination antiretroviral therapy?

Combination therapy is the use of two or more HIV antiretrovirals at the same time, as part of a treatment plan or strategy. Most commonly people take a combination of drugs from the classes listed above. The reason for using antiretroviral drugs in combination is to prevent drug resistance.

First line-therapy

Your first combination of antiretroviral drugs will usually include two drugs from the nucleoside/nucleotide analogue class, together with either an NNRTI or a protease inhibitor. The protease inhibitor may be 'boosted' by the addition of a small dose of another protease inhibitor, ritonavir.

The World Health Organisation HIV treatment guidelines recommend using a drug from the NNRTI class as the third drug in the combination, as these are less likely to cause side effects. However, under New Zealand and US guidelines, the use of either an NNRTI drug or a protease inhibitor should be determined by an assessment of the individual.

The precise drugs chosen should be the ones least likely to cause you side effects in the short and long term, with a convenient dosing schedule for you. It is important that the combination of drugs is potent enough to reduce your viral load to undetectable levels.

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What are the different kinds of antiviral drugs and how do they work?

Drug Class	What drugs are in this group?
Nucleoside/nucleotide	AZT (Zidovudine or Retrovir)
	ddI (Didanosine or Videx
	d4T (Stavudine or Zerit)
	3TC (Lamivudine)
	Abacavir (Ziagen)
	Tenofovir (Viread)
	Emtricitabine (FTC, Truvada)
Non-nucleoside reverse transcriptase inhibitors (NNRTIs or 'non-nukes') Protease inhibitors	Nevirapine (Viramune)
	Efavirenz (Stocrin)
	Indinavir (Crixivan)
	Ritonavir (Norvir)
	Saquinavir (Invirase, Fortovase)
	Lopinavir/Ritonavir (Kaletra)
	Atazanavir (Reyataz
Entry inhibitors (fusion inhibitors, receptor blockers)	Fuzeion (enfuvirtide or T-20)

Co-formulations

Some drugs are formulated together in order to reduce the number of pills that you have to take.

Co-formulated drugs

- Combivir (AZT/3TC);
- Kaletra (Lopinavir/Ritonavir);
- Kivexa (Abacavir/3TC)

It is important to note that these may have changed from time of printing.

Treatment options

Everyone is affected by HIV differently, so therefore everyone must be treated uniquely. Your HIV specialist should work with you to tailor and monitor suitable treatments.

When is the best time to start antiviral treatment?

There is no definite consensus on when is the best time to start antiviral treatment. There are no easy answers and many issues to consider. Often doctors themselves do not agree, and information about this issue can change regularly when new research becomes available.

However, there are guidelines about when to start antiviral treatment which you and your doctor need to discuss. If you do start on any of the combination therapies, you need to know that this may affect a future pregnancy. If you are thinking about getting pregnant in the future, you should talk about it with your doctor so that your treatment can be planned with this in mind.

Managing your treatments

When ARV drugs first became available, many people were taking drug combinations that really did make life very complicated, but since then there has been considerable research into the ways of combining treatments to allow better dosing schedules, such as once or twice a day. If you find it hard to remember to take pills, talk to your doctor about prioritising once-daily dosing when considering your treatment options. Current evidence suggests that once you start taking ARV medications you will need to keep taking them for life. Therefore, you need to be very committed to the decision before you start (although the drugs in your combination may change, as different agents are developed).

Research shows that missing or skipping pills puts you at high risk of developing drug-resistant HIV.

You may need frequent medical appointments at first, to check how the treatment is working. Some women find this difficult to manage at work or within their family, if they have not disclosed their HIV status. You might like to speak with your doctor or Positive Women Inc. about practical strategies for coping with all of this.

Your state of health, lifestyle and personal preference will be factors when choosing which drugs to take. Together with your doctor, you should consider any symptoms you may have and any other drugs you are taking.

If you are resuming HIV treatment after stopping therapy for any reason:

- Ask your doctor to conduct resistance testing to choose drugs that will work well for you;
- Discuss the reasons that you stopped therapy to help choose the agents that will best suit your lifestyle.

Treatment decisions are likely to be influenced by your general well-being; changes in your viral load or CD4-cell count, side effects, your lifestyle, whether you are planning pregnancy, the availability of new treatments and approaches, and finally your attitudes to medicine.

There is a lot of information around about treatment but you don't have to tackle it all at once. Don't be intimidated. Explain to your doctor that you need a reasonable timeframe for making decisions. Depending on circumstances, you many have several months or several weeks to make a decision about the way forward. You can also ask for referral to material that can help you make up your mind, such as plain-language written material to take away and consider.

Side effects

A side effect is a reaction, problem, or condition which arises as a result of taking a particular drug. The term usually refers to negative events, like nausea, diarrhoea, or nerve damage. These events are sometimes call adverse effects. The likelihood that a drug will cause some of these problems increases when you take very powerful medications. HIV antivirals are powerful drugs, so this means the potential for side effects is high.

You may find some side effects are relatively minor, and can be dealt with fairly simply (for example, there are some medications which can be prescribed for diarrhoea and nausea). However, others may be more serious.

There are three categories of side effects;

Short-term side effects are problems which arise acutely on using the drug, but which often subside over time — usually within days or weeks. Rashes and vomiting are examples of these.

Persistent side effects are those that are ongoing while taking a particular drug or drugs. They either need to be controlled by other medications or, if the side effects are unendurable, you will need to change your antiretrovirals. Diarrhoea is a common example of a persistent side effect that is treatable, and another is changes in your central nervous system (disturbed thinking, feeling 'nervy' and nightmares), which usually is not treatable.

Long-term side effects (sometimes called long-term toxicities) are those conditions which develop over a long period of time using a particular drug. Examples of this are peripheral neuropathy (a kind of nerve damage) and lipodystrophy (a fat distribution problem which can lead to changes in your body shape).

Before going onto any antivirals, you should make sure your doctor is clear with you about potential side effects. Ask your doctor written information if possible. If you are concerned, ask whether you can also be given something to have on hand in case you do experience one of the more common side effects (like diarrhoea).

The question of long-term side effects is more difficult. Often, it is not clear who is at risk of these effects. And because the drugs are new, there may be others we don't know about.

Side effects you may experience

When you are on antiviral treatment you may experience:

- no side effects;
- mild or unpleasant side effects;
- difficult but manageable side effects;
- side effects you are unable to tolerate;
- serious side effects (rarely).

Two out of three women will experience some side effects.

The most common side effects experienced by women

- Tiredness;
- Nausea;
- Vomiting;
- Diarrhoea;
- Muscle pains;
- Headaches;
- Changes in menstrual patterns;
- Skin rashes;
- Nightmares;
- Peripheral neuropathy (tingling and numbness in hands and feet);
- Changes in body shape (lipodystrophy) over a long period, and
- Changes in blood sugar and cholesterol levels

Coping in the first few weeks

Side effects that are difficult to manage at first can disappear after a couple of months so it may be worth persevering if you can. Because the first two weeks on a new treatment is the most difficult you might consider planning to take time off work or organising child care.

Make sure that you have told your HIV doctor about all the other drugs you use. Some side effects may occur because your combination therapy is interacting with other drugs you are taking.

Lipodystrophy (changes in body shape)

A significant side effect linked to antiretroviral treatments is a condition known as lipodystrophy. The term refers to the unusual or abnormal distribution of fat throughout your body and is linked to particular classes of drugs – protease inhibitors are associated with fat accumulation (lipohypertrophy, where fat accumulates around the trunk of the body, the breasts and sometimes the upper back) and nucleoside reverse transcriptase inhibitors are linked with lipoatrophy (fat loss from limbs, face and buttocks).

Increasingly the two patterns of fat changes (loss in some areas and gains in others) are seen as distinct. Not everyone taking drugs from these classes will get the conditions (the estimation is that about 20% of people with HIV will experience this, and women are more likely to than men), and certain drugs are more closely associated with the conditions than others. Fat accumulation tends to appear more quickly than fat loss, but both syndromes tend to emerge relatively slowly.

The strongest associations with specific drugs are d4T with lipoatrophy and ritonavir with lipohypertrophy. The drug d4T is very rarely prescribed now in New Zealand because of this association and because there are other drugs available that can give the same antiviral control without this side effect. Ritonavir, however, is very widely used in small doses as a 'booster' of other drugs in the protease inhibitor class and fat accumulation is likely to occur over time, particularly if the drug that ritonavir is boosting is also associated with changes in fat distribution.

Older protease inhibitors such as indinavir and saquinavir are commonly associated with fat accumulation, while the older nucleoside analogues including AZT and ddI are related to fat loss. If you are taking any of the drugs in this list you may want to be monitored for signs or symptoms of body fat changes. The NNRTI drug efavirenz has also been associated with lipodystrophy, particularly with breast enlargement.

Managing mild or moderate lipodystrophy

In some cases, there are things you can to help manage or control lipodystrophy. If you have changes in your body shape which concern you, talk to a physiotherapist experienced in HIV, who may be able to recommend an exercise program to build and strengthen your muscle tone. This kind of program may involve something like regular weight training. Improving your muscle mass and tone may mask some of the physical symptoms.

If you have high blood fat or cholesterol levels, consider modifying your diet. A dietitian or your doctor may be able to advise on this. It is important that you consult a practitioner about this because the idea is not to lose weight, or to decrease the total amount of calories in your diet: this can be dangerous in women with HIV. However, it makes sense to swap saturated fats like butter for more 'heart-friendly' kinds of fat, and to increase the amount of lean protein, vegetables and whole grains in your diet.

Severe lipodystrophy

In a small number of cases, lipodystrophy may be very severe. If this is the case, you may need to try going off protease inhibitors altogether, and switching them with another kind of drug, like a non-nuke. Research is currently being done to see whether the effects of lipodystrophy can be reversed if you stop taking protease inhibitors.

Drug Resistance

When HIV reproduces, it makes thousands of copies of itself. Some of these copies can have mistakes or 'mutations', and these changed copies will go on to reproduce further copies of themselves. Sometimes, HIV changes in such a way that it can escape the control of antiviral drugs. These copies can then go on multiplying, unchecked by the drugs, leading to a whole new population of virus which is resistant to one or more of the drugs in your combination.

You may be able to change to another combination that can work against these resistant copies of HIV. In some cases the HIV in your body can develop resistance to other drugs belonging to the same group. This is called cross-resistance.

Avoiding resistance

It is more difficult for HIV to become resistant to drugs if they are taken at the right time, and in the right amounts. This is because the drugs need to get into the body at optimal levels to fight the virus effectively. If your drugs have specific food requirements, you need to observe these because that also affects drug levels.

For this reason, 'drug holidays', or sporadically stopping and starting therapy, can seriously increase the risk of resistance. It is important that you do not stop taking any antiviral drugs without discussing it with your doctor because there is a danger that your body will develop resistance to drugs that you have been using.

If you do have to change your drugs because of resistance, ask your doctor about adding at least two new drugs which you have not used before, to help better control the virus.

Drug Interactions

A drug interaction refers to possible effects from taking different drugs at the same time. Often, this is not an issue. But some drugs react together in potentially dangerous ways. Some drugs affect the way other drugs work in your body. They may also cause other drugs to be absorbed at lower, or higher, levels.

Drugs are broken down (metabolised) in the body by the liver. A drug that affects the way the liver functions means it will change the level of other drugs work in your body.

Prescription drugs and antiviral treatment

If you are taking any other medication with your HIV drugs — whether prescription or over-the-counter, make sure you check with your doctor that the combination will not be harmful.

The contraceptive Pill

Some HIV medications interact with the pill and make it less effective as a contraceptive. You may have to change the type or dose of contraceptive pill, or use other methods of contraception.

Other interactions

There is not an extensive amount of information about drug interactions between HIV antivirals and other prescription drugs. But there are some things we do know, and some risks to be aware of.

HIV drugs may interact with:

- medication for hepatitis C;
- methadone;
- some medications for psychiatric illness;
- some kinds of anti-depressants (Valium, Rohypnol);
- over-the-counter antihistamines which contain terfenadine (eg. Teldane) — these drugs should not be used with antivirals.

Vaccinations

If you need to be vaccinated before travelling overseas, ask your doctor to make sure you are not given any live vaccines (such as yellow fever, TB or measles) if you are immunosuppressed (that is, you have a low CD4 count).

Recreational drug use

If you are taking antivirals, or considering starting antiretroviral therapy, it is important to inform your doctor about any other drugs you may take, including recreational drugs. We do not know a lot about the possible interactions between antivirals and recreational drugs. There is some evidence that using other recreational drugs — such as heroin, cocaine, amphetamines, or ecstasy — can have negative effects on your immune system. Some drugs, like ecstasy, can also damage your liver.

Pharmaceutical companies recommend HIV antivirals not be used with recreational drugs. Remember that the composition, strength and quality of recreational drugs will vary, which makes it even more difficult to make blanket statements about interactions. However, the following information may be a guide.

Marijuana

Some people find marijuana increases their appetite and helps symptoms of nausea which may be associated with HIV. While smoking anything is not good for the lungs, some women find that the benefits of smoking marijuana can outweigh the risks in certain circumstances. If you are taking any anti-HIV treatments that make you feel a little disorientated (for example, the antiviral drug efavirenz), it is possible marijuana may exacerbate these feelings.

Ecstasy and amphetamines

There is some evidence that protease inhibitors, particularly ritonavir, can interact dangerously with amphetamines. The interaction between ritonavir and ecstasy has been linked to the death of at least one man in the UK. It is thought that ecstasy and ritonavir are metabolised through the same pathway in the liver, so concurrent use of the two drugs can potentially push levels of ecstasy in the blood to toxic levels. It is also believed that combining other amphetamines — like speed — with protease inhibitors could cause potentially fatal interactions. If you use amphetamines, consider halving or reducing the amount of the drug, and do not take ecstasy and ritonavir too closely together. Other drugs with which protease inhibitors may have adverse effects include Valium, Rohypnol, anabolic steroids and ketamine (Special K).

Cocaine

It is not clear how, if at all, antiviral drugs interact with cocaine.

Heroin

There is very little literature available on this subject. It does not appear that protease inhibitors increase levels of heroin in the blood. Caution is suggested if using heroin while on antivirals. Do not share needles or injecting equipment.

Prophylactic treatments

If your immune system is not functioning well, you can be left vulnerable to a range if illnesses. There are some effective ways of preventing some of these conditions. A healthy lifestyle can improve your well-being and resistance to minor infection. Regular testing and monitoring the effect of HIV in the body is also an excellent prevention strategy.

Some prevention is achieved through medication and therapies. These are often called prophylaxis or prophylactic treatments. A prophylactic treatment is a drug or therapy which is taken to prevent an infection or condition or to prevent something from recurring.

If you have a CD4 count less than 250, it is advisable that you consider prophylactic treatments, regardless of whether you are using antiviral treatments, complementary therapies or nothing at all. You will need to discuss this with your doctor.

A more detailed explanation of common opportunistic infections, and prophylactic drugs, is given in section 15.

Clinical trials

If you are taking antiviral treatments at some point you may be asked to participate in a clinical trial of a new anti-HIV drug. New treatments have to be tried out on volunteers before they can be approved for general use. This process is known as a 'clinical trial'. Trials of new drugs take place all the time.

A lot is known about the ways to reduce viral load in the human body to prevent the immune deficiency, opportunistic infections and death. However, there are still some grey areas: it is still not known when the best time is to start treatment, what the best drug combination is, and how best to reduce side effects for all people. In instances where there is no direct evidence as to what would be the best possible treatment for your individual situation, your doctor may suggest they you could participate in a clinical trial. It is very important that the research is explained very clearly to you, and that you have the opportunity to discuss it with other people such as Positive Women Inc.

New drugs and new ways of using old drugs are studied in clinical trials. For example, trials can look at whether interruption treatment for periods of time is as successful in controlling viral load in the long-term as taking drugs continuously, or they can look at whether a combination with a new generation protease inhibitor (with other drugs) is better or worse in terms of control of viral load and side effects, like changes in body fat. Trials can also evaluate whether treatment 'vaccines' in combination with antiretrovirals offer any advantage. The point of a trial is that the outcome is uncertain- it is hoped that the new agent will offer an improvement, or that a new strategy will offer benefit, but no one knows for sure.

11. COMPLEMENTARY THERAPIES

Many women with HIV or AIDS use complementary or alternative therapies. Most complementary therapies operate from the perspective of seeing the body as a whole – taking a 'holistic' view. This means the practitioner takes into account the inter-relationship of all body's systems, as well the influence of mind, emotions and environment, when looking at an individual's health concerns.

Many kinds of therapies come under the heading of 'complementary' or 'alternative' therapies, including :

- acupuncture;
- Western herbal medicine;
- homoeopathy;
- traditional Chinese medicine;
- massage; Shiatsu
- body work or re-alignment techniques such as osteopathy, chiropractic or Alexander Therapy
- Ayurvedic
- Reiki

A survey of HIV positive women found the most commonly used alternative therapies included massage, herbal medicines, meditation and visualisation, and vitamin supplementation.

Women use these therapies for a range of reasons, including:

- health maintenance;
- to strengthen the immune system;
- to improve energy, tiredness or sleep difficulties;
- to help deal with the side effects of antiviral treatments;
- to help manage stress and anxiety;
- to assist with the relief of some HIV-related conditions such as pain in hands and feet or changes in menstrual patterns;
- as an alternative to conventional medical treatments.

Many women will use both conventional (or 'allopathic') and complementary treatments at some point.Sometimes alone and sometimes in combination with each other.

Are they effective in dealing with HIV?

There is an ongoing debate among positive people, community advocates and health practitioners about the usefulness, even the safety, of some complementary therapies. There are people strongly opposed to complementary health approaches, and others who will not use anything but these kinds of holistic approaches.

It is important, if considering complementary therapies, to seek as much information as possible about any approach you may try. This information may come from practitioners themselves, or other positive people. You may want independently seek out clinical research or trials (though this may be difficult). It is important to establish that any information about a particular therapy is reliable, since some complementary therapies may be potentially harmful or dangerous.

To date, there is no evidence that any complementary therapies, like herbs, have proven anti-HIV effects, and you should be wary of anyone who makes this claim.

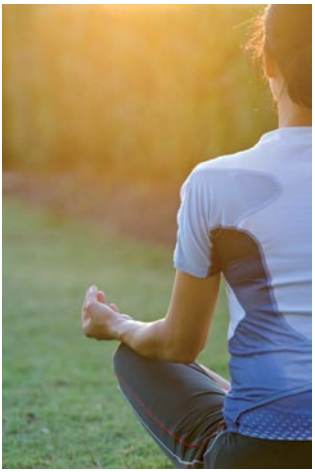
Trials and research

It can be hard to find reliable information about complementary therapies. Often, they have not been the subject of formal clinical investigation in the same way as pharmaceutical drugs. If studies have been conducted overseas, the information may not always be accessible or translated.

Studies of complementary therapies are often disputed. Formal clinical trials such as those conducted on new drugs need to follow strict guidelines. It is argued that this approach may not suit the evaluation of some alternative therapies. For instance, preparations of Chinese herbs are individually mixed by the practitioner, according to the practitioner's individual assessment. This contrasts with HIV antiviral drugs, where a specified dose is prescribed, and recommended as standard for all. These differences in the approach can make it difficult to formally say whether alternative approaches are effective.

Nonetheless, as long as a therapy remains untested in formal clinical trials it cannot be labelled as useful, nor dismissed as ineffective.

Often positive women rely on the anecdotal stories of others living with HIV, or advocate a particular therapy based on their own personal experience. An up-to-date, HIV-experienced practitioner should also be able to inform you of approaches known to be useful in the treatment of HIV conditions or showing promise in trials.



Are there side effects or drug interactions?

Not all natural therapies are safe for everyone, or free of side effects. Some substances can be quite potent, so you should be sure to notice any changes that happen to your body and discuss these with your health practitioner(s). For example, some herbal mixtures can be quite toxic on the liver, and could potentially interact with antiretroviral drugs or cause other problems.

You should tell your GP or HIV specialist about any alternative medicines you are using (like herbs), and talk to your complementary therapist about any antiretroviral or other drugs you may be taking.

12. MENSTRUAL IRREGULARITIES

Menstrual irregularities are not uncommon in women, regardless of HIV status. If you are HIV positive and experience menstrual irregularities, it is important to remember that HIV or HIV treatment may not always be to blame. Often, the problems are caused by hormonal changes that occur naturally in most women over time. They may also be due to conditions not related to HIV. However, HIV and antiviral drugs may have some effects on your menstrual cycle. Although the effect of HIV on female hormone function has not been extensively studied in HIV positive women, it is thought that changes in the immune system could cause hormonal changes and lead to menstrual irregularities.

A number of menstrual problems are reported by some positive women. These can include:

- heavier than usual bleeding (called hypermenorrhea);
- lighter than usual bleeding (called oliogomenorrhea);
- periods which are more painful than usual (dysmenorrhea);
- a worsening of premenstrual symptoms;
- irregular or 'breakthrough' bleeding.
- no bleeding at all (amenorrhea)

Amenorrhea is common in women who have been diagnosed with a chronic illness, or who have had severe weight loss. This may be something experienced by women with serious illness such as AIDS. Women who miss their periods may experience pelvic pain, swollen breasts or hot flushes.

It is possible that there may be other causes (for example, if you do not have a period, you could be pregnant). It's important to report any changes in your menstrual cycle to your doctor, or health practisioner. Your health practitioner should take a full gynaecological history, a pelvic examination, and some blood tests may be necessary. Menstrual problems can affect your physical and psychological well-being, but they are usually readily diagnosed and treated.

Can menstrual problems be related to HIV treatment?

Many women report changes in their menstrual cycle when they commence conventional drug treatments for HIV. Antiviral drugs including AZT, ddI, ddC and d4T have been known to cause menstrual problems in some women. However, little research has been done on the effects of treatment on a woman's menstrual cycle, and much of the information available is inconclusive. In other words, it may be difficult to know whether the problem is directly related to treatments, or has some other cause.

New research has indicated that menstrual irregularities, in particular unusually heavy bleeding, may also be a side effect of some protease inhibitors, such as ritonavir. It is important to identify such abnormally heavy bleeding, since it can lead to anaemia. Anaemia means that your blood is unable to transport sufficient oxygen to the body's

tissues. It can be caused by an abnormally low level of red blood cells. Unusually or extremely heavy bleeding can deplete the numbers of these crucial cells. Anaemia can cause serious complications, especially for HIV positive women. If you experience excessively heavy menstrual periods, tell your doctor as soon as possible and get a full blood count taken, and have your iron levels checked as well.

Menstruation and pregnancy

If you are having irregular or problem periods, it may be difficult for you to become pregnant. If bleeding is occurring at irregular times it will be harder to monitor your menstrual cycle and to predict when ovulation (egg release) will occur. If you are trying to get pregnant check with your doctor that the irregularities you are having are normal, and will not interfere with getting pregnant.

13. PREGNANCY

Many women with HIV both in New Zealand and worldwide are choosing to become mothers. You are able to reduce the chances of your baby acquiring HIV to below 2% by taking antiretroviral (ARV) drugs, and by not breastfeeding. Without these interventions, the rate of HIV infection from mother to infant is between 24-30%.

HIV can be transmitted very rarely from mother to infant in the womb. The more risky periods are during delivery or after delivery through breast milk. Without any treatment or other intervention, about one in four women with HIV will transmit HIV to her infant.

There are several key factors affecting the likelihood of transmission: your health, your viral load and your immune status. Generally speaking, the lower your viral load the less likely you are to transmit HIV to your baby.

More detailed information is available in a free booklet "HIV, Pregnancy and Women's Health" produced by Positive Women Inc. Contact Positive Women Inc. if you would like a copy.

Planned pregnancy

A planned pregnancy gives you the greatest range of options and can minimise stress, leaving you time to discuss issues with your doctor, switch drugs if necessary or to take a treatment break prior to conceiving. It also gives you a chance to sort out your maternity leave entitlements and financial arrangements if you're in the paid workforce.

But life doesn't always go to plan, and you may find yourself accidentally pregnant.

Unplanned pregnancy

An unplanned pregnancy can range from being an unpleasant shock to a welcome surprise, with many other emotions, some of them conflicting, in between. You have every right to consider all your options.

You may want a baby. You may definitely not want a baby. You may want a baby sometime in the future, but the timing might not be right – your health, your work situation or your relationship status might make having a baby just too hard right now.

It is your right to decide whether to continue with the pregnancy or to have a termination. You may wish to seek expert advice about HIV and pregnancy before you decide, or your decision may have nothing to do with your HIV status. Pregnancy counselling is available through Family Planning clinics.

Most terminations are performed at a clinic or hospital between seven and 12 weeks after the first day of your last period. If you decide to continue with the pregnancy, talk to your HIV specialist as soon as possible about how to reduce the risk of transmitting HIV to your baby.

Pregnancy check list

- Get screened for any genital infections and, if necessary, treated. Repeat at 28 weeks if you are sexually active and your partner/s haven't been treated.
- Learn about your treatment options and make a plan, with different options in it according to how well your viral load is controlled during your pregnancy.
- Learn about your delivery options and get a referral to a doctor with experience in HIV and pregnancy, and an obstetrician.
- Make a delivery plan with options according to how well your viral load is controlled during pregnancy
- Read the Positive Women Inc. booklet on "HIV, Pregnancy and Women's Health"
- Have a baby shower and get lots of presents

Do I need to take antiretrovirals?

Taking ARV drugs reduces the likelihood of your baby becoming HIV positive, but you have some options. Many women take combination ARV throughout their pregnancies; others opt to delay ARV until the second trimester.

For women who have already started taking ARV, provided their particular medications are safe for pregnancy, it is generally recommended that they continue with the ARV throughout the pregnancy. However, if you have not yet been on ARV, your doctor will assess the situation and recommend a pregnancy-safe ARV combination for the final trimester of the pregnancy.

It is sometimes recommended that you take combination ARV, plus AZT as an intravenous infusion during delivery, and that your baby is treated with AZT for four weeks after birth.

You do not have to take medication against your will. If you choose not to take any ARV during pregnancy or delivery however, this does increase the likelihood of your baby acquiring HIV even if your viral load is undetectable.

Does my baby have to take ARV?

Whether or not you have taken any ARV during pregnancy or during delivery, you will be required to have your baby treated with ARV for a period of 4-6 weeks to improve his or her chance of being HIV negative. This treatment is called PEP or post-exposure prophylaxis, and it can prevent infection by 'mopping up' infectious HIV particles to which your baby might have been exposed. It is not fail-safe but it increases the likelihood of avoiding infection.

The treatment prescribed for your baby may be AZT alone, or if you have AZT resistance, a combination ARV therapy.

Your baby may experience side effects like anaemia and neutropaenia, but many babies do not experience any side effects. If side effects are severe, your baby may require blood transfusions or need to stop therapy.

Can I breastfeed?

Breastfeeding may place your baby at risk of HIV infection, so where infant formula is available and the water supply is clean, formula feeding is advised for all women with HIV.

There is ongoing research looking for ways of reducing mother-to-infant transmission through breastfeeding because in many countries infant formula is not affordable, not available or there are serious issues of water quality. Interventions have included exclusive breastfeeding followed by immediate weaning and the prolonged use of ARV to treat infants. In 2003 a third of the infants infected with HIV worldwide were infected through breast milk. No studies so far have shown infection rates as low as can be achieved by no breastfeeding at all.

If my viral load is undetectable, can I transmit HIV through breast milk?

The lower the viral load, the lower the likelihood of transmission. But there are still significant risks in breastfeeding your child regardless of the number of HIV copies circulating in your blood.

Unfortunately viral levels in breast milk do not always correspond to levels of virus measured in the blood. Research has shown that levels of virus in breast milk fluctuate unpredictably, even varying from left breast to right breast on the same woman. The speculated cause is that small infections or inflammations of the breast tissue and milk ducts (sub-clinical mastitis) are very common and this then increases HIV replication and shedding.

What about heat-treating breast milk?

Two different forms of heat-treating breast milk – 'Pretoria pasteurisation' and flash heating - have been tested with promising results.

Flash heating is where a container of breast milk is placed into water and the water and milk are heated together until the water reaches a rolling boil, after which the milk is removed from the water to cool. Pretoria pasteurization is where a container of water is heated to boiling and removed from heat, then a container of breast milk is immediately placed in the hot water for 20 minutes, after which it is allowed to cool to 37 degrees centigrade.

Recent experiments showed flash heating to be the more effective option for removing HIV, but it must be emphasised that these techniques are being developed for women without good access to infant formula or clean water. Heat-treating milk may affect nutritional and immunological components of breast milk.

Infant formula is nutritionally as close to breast milk as possible. There is no need to 'graduate' to special formulas after six months. These follow-on formulas have added iron but your baby should be able to get iron from food at this stage, and iron-enriched formula is very constipating and largely a marketing ploy.

Does bottle-feeding mark me as HIV positive?

Many women in developed countries struggle with breastfeeding so opt to bottle-feed. Difficult deliveries, prior breast surgery (specially breast reduction), post-natal stress, low milk supply, breast and nipple pain, needing to take certain medications and smoking are all common reasons for not breastfeeding.

You do not have to disclose that you are HIV positive to justify not breastfeeding, and no-one has the right to make you feel bad about this.

If you feel a sense of grief or loss from not breastfeeding your baby, talking to a counsellor or to other positive women may help.

Might advice about breastfeeding change?

Research into ways of reducing HIV transmission through breast milk will continue because it is incredibly important for infant welfare where breast milk substitutes are not viable. In some contexts treating an HIV-uninfected baby with ARV for relatively long periods while breastfeeding may be a good alternative. But in the New Zealand context, the risks of the extended ARV exposure would outweigh the benefits because of the ready availability of infant formula and a safe water supply.

14. GYNAECOLOGICAL CONDITIONS WHICH CAN AFFECT POSITIVE WOMEN

Vaginal thrush (candidis)

Candida albicans is a naturally occurring yeast which lives generally in harmony with its human host in the gut, the folds of the skin, the anus, the mouth and the vagina. Thrush occurs when the balance of this yeast is disturbed, and it multiplies out of control.

Risk?

There is always some candida albicans living in the vagina, but it can 'multiply' to above normal levels when there is a change in the vaginal environment (for example, in sugar or pH levels). Generally, the yeast co-habits happily. But if the immune system is not working well, the candida can start to behave like an infection. Vaginal thrush is an exceptionally common infection in all women, regardless of HIV status. However chronic, or very frequently recurring vaginal thrush is the most common gynaecological disorder in women with HIV. Thrush can also occur in other parts of the body (the mouth and the oesophagus). This is more common when the immune system is weaker.

What are the symptoms?

Vaginal thrush is very common in all women but occurs far more frequently, and with greater severity, among HIV positive women. Symptoms include crotch-itch, tiredness, and a furry, white, usually odourless vaginal discharge.

Prevention

Women being treated for thrush may be re-infected by male partners during unprotected sex because thrush can be found under the man's foreskin.

How is it treated?

Topical antifungal agents

There is a range of topical antifungal agents, some of them natural therapies, which may assist in treating vaginal thrush. These include:

- live yoghurt which contains the bacteria lactobacillus acidophilus—some practitioners maintain that the bacteria in commercial acidophilus yoghurt is ineffective;
- broad-spectrum anti-fungal creams or powders such as Canesten. These are available from your chemist. You won't need a prescription, but you will have to pay for these products.

Systemic treatment for recurrent thrush

For more serious thrush, antifungal drugs may be used.

Some other medications — for opportunistic infections, for example — can also cause liver problems in the case of HCV. These include an antifungal drug called ketaconazole.

Ketaconazole is often used to treat severe or recurring vaginal candidiasis, or thrush. Severe candidiasis is sometimes reported in HIV positive women. Fluconazole, another antifungal drug, has also been associated with liver failure. It is extremely important to discuss this thoroughly with your GP, and if possible, find an alternative treatment to these two drugs.

HPV Human Papillomavirus (Genital Warts)

Genital warts are an extremely common STI. Warts are caused by the HPV (human papillomavirus), which has over 200 different strains, but many people who are infected with HPV do not have any symptoms. (i.e. actually no warts)

Many women who are or who have been sexually active have been infected with one or more strains of HPV (human papillomavirus). Some strains of this virus have been shown to cause pre-cancerous changes in the cervix.

The most common manifestation of HPV is genital warts, but most people who have HPV have no symptoms. An estimated 80% of all sexually active men and women have been exposed to HPV.

There are now vaccines (Gardasil, Cervarix) for HPV that have been proven effective in clinical trials of adolescents and women up to the age of 45. However, it is thought that these products would have less utility in people already exposed to the virus, as most positive women have been. The place of these vaccines for women with HIV is still to be determined.

Cervical cancer

Cervical cancer is a preventable condition, and if diagnosed at an early stage, can be cured. Cervical cancer and cervical cell abnormalities affect many women regardless of their HIV status but evidence suggests that the kinds of cervical cell abnormalities that can lead to cancer are more common in HIV positive women.

Not all cervical cell abnormalities (a condition called cervical dysplasia) mean you have cancer or are likely to get it. However, more severe kinds of dysplasia are associated with the development of cancer.

These possibly pre-cancerous changes are graded into three tiers according to their severity: CIN 1, CIN 2, and CIN 3. (CIN stands for cervical intraepithelial neoplasia).

- CIN 1 means there are some mild changes, with a small risk of developing cancer (about 7 percent);
- CIN 2 changes have about a 50 percent chance of becoming cancerous;
- CIN 3 changes are severe, and may mean cancer is already present and active.

If you have a pap smear which shows such high-level dysplasia, your doctor should immediately refer you for further tests. An examination of the cervix called a colposcopy may be recommended. The cervix is closely examined under a microscope, and cells may be taken for testing. There have been some arguments that this test should be routine in all HIV positive women, but others disagree, saying it is unnecessary unless pap smear results are abnormal. Some women can find colposcopy invasive and painful.

Some researchers have suggested that progression to cervical cancer may be faster in HIV positive women. Invasive cervical cancer is an AIDS-defining illness.

Other risk factors

- Some kinds of the human papillomavirus, a sexually transmissible infection which causes genital warts, are strongly linked with cervical cancer. You may have been exposed to this virus even if you've never had warts. A blood test will tell you this.
- Smoking appears to be a risk factor.
- The risk of developing cervical cancer also increases with age: women may be at increasing risk from their mid-30s.

Effectiveness of treatment

The main reason why it is important to detect cervical cancer or pre-cancer early is that it appears current treatments may have a higher likelihood of failure in HIV positive women, especially women who have a low CD4 count. In addition, abnormal cells which have been treated (eg. through laser surgery) may be more likely to recur.

Importance of testing

The main message for HIV positive women in terms of cervical cancer is that early detection is critical. This should include:

- regular six-monthly pap smears;
- further referral if your pap smear shows abnormal cells;
- aggressive treatment in the case of severe dysplasia.

You may want to consider blood tests if you think you may have been exposed to HPV or genital warts.

Pelvic Inflammatory Disease (PID)

PID is an inflammation of the pelvic area usually caused by untreated sexually transmitted diseases like gonorrhoea or chlamydia. Some women have PID without knowing or without noticing any symptoms. Untreated PID becomes increasingly painful and can cause infertility. PID seems to be more common and more severe amongst HIV positive women. The symptoms can be mild, moderate or severe:

- pain or cramps in the lower back and abdomen
- pain during intercourse
- deep pelvic pain
- pain going down to the top of the legs
- bleeding between periods
- vaginal discharge that is smelly but itchy
- high temperature
- fatigue.

If you notice any of these symptoms or have any concerns about PID, talk with your doctor. PID must be treated by antibiotics. In severe cases women may need to be admitted to hospital.

15. OTHER STI'S

Herpes

Herpes infections are caused by a virus. There are a number of different herpes viruses. The most relevant and common are herpes simplex I and II, and herpes zoster (also called the varicella zoster virus). Herpes simplex I is the virus which causes cold sores. This virus does not usually cause genital herpes (though rarely, it can). Genital herpes is usually caused by the herpes simplex II virus.

Are you at risk?

Herpes simplex II is a sexually transmissible infection. Transmission occurs through contact with the herpes sore or infected fluids. Condoms for vaginal or anal sex, and the use of barrier protection like dams, can help prevent this.

Symptoms

May include:

- Itching and tingling in the genitals
- Painful sores or blisters around the vagina/anus
- Burning/pain when urinating
- A feeling of 'pressure' in the pelvic area

Herpes and HIV

The frequency and severity of outbreaks of genital herpes may increase if the immune system is weakened by HIV. It is also possible for undiagnosed herpes infections, which have not cause symptoms in the past, to be 'reactivated', and cause symptomatic illness.

Treatment

Medical educators urge the aggressive treatment of herpes infections in people with HIV. It can be treated with a drug called acyclovir (Zovirax). Recurrent outbreaks may be treated with famiciclovir (Famvir).

Reducing stress, eating a healthy diet and taking care of yourself can all help reduce the recurrence of herpes.

Hepatitis B

Hepatitis refers to the inflammation of the liver. There are number of viruses which can cause this condition, including hepatitis B.

Are you at risk?

Hepatitis B is transmitted in similar ways to HIV so risk factors include unprotected anal or vaginal sex, and injecting drugs where equipment is shared between users, or genital contact. Unprotected oral sex where ejaculation occurs can also, though more rarely, result in transmission of hepatitis B.

Symptoms

Symptoms of hepatitis B infection usually show up between one and six months after exposure to the virus. They may include: a mild, flu-like illness, loss of appetite, abdominal pain and discomfort, vomiting and nausea, pale faeces, aching joints, jaundice (can be recognised by yellowing of the eyes). People with hep B virus can suffer recurring symptoms, including serious liver damage. A blood test will determine a diagnosis.

Prevention

Using condoms and dental dams during sex, and avoiding risk behaviours like needle sharing can minimise the risk. But the only truly effective preventative measure is vaccination. The vaccination can be safely used even if you're HIV positive. But a good response to vaccination is more likely if you have a strong immune system.

Hepatitis B and HIV

Hepatitis affects the liver. So the ability to tolerate HIV treatments, which also affect the liver, may be reduced.

Shingles (herpes zoster)

Shingles are caused by the varicella zoster virus. Anyone who has had chicken pox has been exposed to this virus, and could have an outbreak of shingles. Symptoms can include: skin rash, pain along nerves (usually face, chest or abdomen, painful, fluid-filled blisters). Shingles is also treated with Ayclovir.

Other STIs

Sexually transmissible infections (STIs) like chlamydia, gonorrhoea or syphilis may affect any women. But since HIV can affect the severity and course of some infections, and ongoing infection can be a burden on the immune system, it's important to be aware of the risks. Often, protected sex will be a sensible and practical preventative measure. A regular checkup is also a good idea. Many STIs can be quickly and easily dealt with if they are picked up quickly.

16. CO-INFECTION WITH HIV AND HEPATITIS C

The term co-infection means that a person has another infection, as well as being HIV positive. Research suggests that one in three women with HIV may also be infected with the Hepatitis C virus (called HCV for short).

What is hepatitis C?

Hepatitis is a general medical term which describes the inflammation of the liver. It is commonly caused by the viruses of the same name (the hepatitis viruses, including hepatitis A, B and C). However, hepatitis, or liver inflammation, can also be caused by other factors such as alcohol use.

The hepatitis C virus was first identified in 1989. Before that, it was called 'non-A, non-B hepatitis'. In other words, they'd worked out that it was a different virus, but hadn't been able to identify it exactly. The virus which causes hepatitis C is related to a group of viruses called flaviviruses. It is not related to HIV.

How is hepatitis C transmitted?

Hepatitis C is transmitted through blood to blood contact. The highest risk activity, in terms of transmitting HIV, is the sharing of needles, syringes, or other drug injecting equipment like tourniquets. It can also be transmitted in other ways: for example, receiving a tattoo or body piercing with non-sterile or shared equipment. Some people developed HCV through blood transfusions, before the virus was identified and screening programs were available.

HCV is actually much more infectious than HIV. For example, it can be transmitted via blood-contaminated skin. (For this reason, HCV prevention measures should include hand washing). Research also suggests that HCV may be sexually transmissible, though with considerably less frequency than HIV or hepatitis B. The Hepatitis C virus can frequently be found in menstrual blood, suggesting that safe sex has a role to play.

What does a hepatitis C diagnosis mean?

There is a lot of mythology and stigma associated with hepatitis C infection. However, testing positive for HCV does not necessarily mean you are going to become seriously ill. In some cases, people live well with hepatitis C infection for a long time, and a small but significant percentage of people even go on to eliminate the virus from the body.

Many people, though, will have chronic or ongoing hepatitis C infection, and often, this can cause liver damage over a long period of time.

It is currently thought that for every 100 people who have HCV:

- between 15 and 20 will clear the virus altogether (though continue to have antibodies)
- between 80 and 85 will have long-term or persistent viral presence

Of these people with chronic infection:

- between 60 and 65 are at risk of developing long-term liver damage — including the possibility of cirrhosis, or even cancer — over a period of many years of infection.

In other words, in a small number of cases, there is a very real risk of HCV infection making you quite ill. However, this generally happens over several decades. And as research into the field continues, new standards of treatment are being developed. It can take a while to work out the best way of managing HCV infection. You could use drugs and medications. Other people prefer to look at alternative strategies: looking after your health, or the use of complementary therapies like acupuncture or herbs.

Testing for hepatitis C

There are a number of tests which might be of use for determining if you have HCV.

- An antibody test is used to detect antibodies to hepatitis C in your blood. Antibodies are generated by the immune system in response to specific infections. If you have hepatitis C antibodies, it means you have been exposed to the virus. However, once you have antibodies to hepatitis C, you will always have them. So antibody testing will not tell you whether you have chronic infection, or whether the virus is doing any damage at a particular time.
- A hepatitis PCR test may also be used to detect hepatitis C, though usually, it is not used first up as a diagnostic test. A HCV PCR test is really a viral load test, only for hepatitis C rather than HIV. Like a HIV viral load test, it measures the amount of virus circulating in your blood.
- To take testing a step further, and work out whether HCV is causing any damage to your liver, you may need to test for a substance called ALT. (The technical term for this is alanine aminotransferase). ALT is released into the blood by the liver. If your ALT levels are unusually high, it may indicate that your liver is stressed out or damaged: this would suggest that liver inflammation is occurring.

Treatment

The approved treatment for hepatitis C infection in New Zealand is a drug called alpha interferon, an injectable drug that is an immune modulator. This means it stimulates the immune system to help it deal with HCV.

It is important to know that interferon is far from effective in all cases of hepatitis C. In fact, only about 25 percent of people will 'clear' HCV infection through interferon alone, and it is unclear as to how long you need to keep taking it for it to be effective.

In some cases, interferon will have side effects, and they can occasionally be severe. Tiredness and flu-like symptoms have been reported. Tiredness is common.

You may find, if you talk to other people with HCV infection, that there are very mixed views on interferon. However, as with treating HIV, new research suggests that a much greater effect is being seen with combination treatment, using a drug called ribavirin. Ribavirin is not yet licensed in Australia for treating hepatitis C. However, it is available through a special access scheme at some major teaching hospitals and centres. There are particular parameters around access, and you may find there are some problems. However, moves to make the drug more accessible are underway. Ask your doctor if he or she can refer you to a gastroenterologist who treats patients with HCV.

Does HIV make hepatitis C worse?

This is, understandably, a common question, but it is difficult to answer. It seems there is some evidence that HIV can cause a more rapid progression to liver damage in people with HCV. This is because HIV appears to increase hepatitis C viral load. It is less clear what effect HCV has on HIV infection. Studies have produced conflicting results, and some studies have indicated that having hepatitis C does not necessarily cause people with HIV to "do worse" or get sicker more quickly.

HIV treatment options and hepatitis C

One area where HCV may have a serious impact, however, relates to HIV treatments. There are no big controlled studies that have scientifically looked at what HIV treatments should be used with hepatitis C, but there are some common cautions.

For a start, there are a number of anti-HIV drugs which can themselves be toxic on the liver, and these may be best avoided in people who have abnormal liver function tests, or evidence of inflammation. These include:

- nevirapine;
- ritonavir;
- d4T (cases of fatal liver failure have been reported: people with hepatitis are considered at higher risk of these liver problems).

Prescribing information for most HIV antivirals suggests they be used with some caution in people with hepatitis. In some cases, information about possible liver complications is sketchy. Ribavirin may also cause AZT and d4T to be absorbed at less than optimal levels. So it seems d4T is one drug to be avoided if you have hepatitis C.

Nonetheless, it makes sense that HIV be kept under control, possibly with antiviral therapy, if you are also hepatitis C positive. Regular liver function tests, which are important in terms of antiviral therapy, are particularly important if you also have HCV.

Hepatitis C treatment options

In general, treatment for hepatitis C is not used unless you have regular abnormal liver function tests, suggesting that the virus may be doing some damage. In the case of HIV, it may make sense to reserve treatment unless really necessary because of the potential for interferon to stimulate an immune response, and push up HIV viral load.

A number of states now have co-infection clinics for people with both HIV and hepatitis C. These can be a useful way of co-ordinating your treatment options.

Alternative therapies

Not surprisingly, many women with hepatitis C are interested in alternative therapies. Alternative therapies may be a very useful and positive way of assisting your body and immune system to cope with both the physical and psychological impacts of HIV and HCV. It also makes sense to consider modifying your diet, reduce consumption of alcohol, avoiding binge-drinking if you have active hepatitis, and doing some exercise. This may help overcome problems like tiredness, reported by many HCV and hepatitis C positive women.

Some herbal formulations, however, could actually be a problem. While it is often thought that herbs are always ‘safe’ and ‘natural’, this is not always so, and there have been reports of some herbal medications actually causing liver damage. As with alternative therapies for HIV, make sure you find a qualified, reliable practitioner for any alternative therapy you may wish to use. Research is currently being conducted into a Chinese herbal mixture called CH100. Contact your local hepatitis support organisation for more information about this research.

HCV treatment during pregnancy

The use of the HCV drug ribavirin is definitely not recommended if you are pregnant or are considering pregnancy.

Breast feeding

Breast-feeding is not associated with a high risk of transmitting HCV to a child. However, HIV positive women are generally recommended not to breast-feed.

Seek advice and support

The emotional and physical effect of a diagnosis of both HIV and HCV on any woman should not be underestimated. You may find it extra stressful or daunting because there are no ‘black and white’ or clear-cut answers about how to manage both conditions together, and some of this information is contradictory. It is important to allow yourself the psychological and emotional space to deal with these issues. There are support groups and organisations around for people with hepatitis C. Your doctor, hospital or sexual health centre may also be another source of referral for further information about treatments or counselling.

17. GLOSSARY

CD4 cells
Cells of the immune system; the system that usually works to fight infection and keep you well. Also known as T-cells or T4 cells

Lipoatrophy
Fat loss from limbs, face, buttocks

Lipodystrophy
Change in fat distribution in the body

Lipohypertrophy
Where fat accumulates around the truck of the body, the breasts and sometimes the upper back

Prophylaxis
Preventive treatment

Viral Load
The number of copies of HIV in each ml of your blood

Acronyms

AIDS
Acquired immune deficiency syndrome

ART
Anti-retroviral therapy

ARV
Anti-retrovirals

BMI
Body mass index

CIN
Cervical intraepithelial neoplasia; pre-cancerous changes in cells of your cervix

GP
General Practitioner; community doctor

HAART
Highly active anti-retroviral therapy; treatment of HIV infection using several different drugs together

HIV
Human Immunodeficiency Virus

FPA
Family planning association

HBV
Hepatitis B Virus

HCV
Hepatitis C Virus

HDL
High density lipoprotein; the 'good' cholesterol

IUD
Intra-uterine device; a copper and plastic device inserted into the uterus for contraception.

IUS
Intra-uterine system; small T-shaped device inserted into uterus, similar to IUD but unaffected by use of other drugs.

LDL
Low density lipoprotein; the 'bad' cholesterol

NNRTI
Non-nucleoside reverse transcriptase inhibitor

OI
Opportunistic infections; a number of illnesses, infections and conditions which occur in people whose immune systems have been damaged due to HIV and AIDS

PEP
Post-exposure prophylaxis; treatment taken after possible exposure to HIV to minimize likelihood of acquiring the virus.

PGL
Persistent generalised lymphadenopathy

PID
Pelvic inflammatory disease

PLWHA
People living with HIV/AIDS

S&M
Sadomasochism; a sexual practice

STI
Sexually-transmitted infection

SVR
Sustained virologic response; when a viral load is undetectable 6 months after treatment

UTI
Urinary tract infection

18. OTHER RESOURCES AND INFORMATION SOURCES

There are many resources available through Positive Women Inc., The New Zealand AIDS Foundation and the Ministry of Health which explore issues raised in this booklet in further detail. Some of these include:

Legal issues (including disclosure)

Pregnancy

HIV, Pregnancy and Women's Health (2007: Positive Women Inc.)

General Information Websites

www.positivewomen.org.nz (New Zealand)
www.i-base.info (UK)
www.TheBody.com (USA)

HIV and/or AIDS organisations and support groups

Positive Women Inc

Freephone: 0800POZTIV (0800 769 848)
Street address: 1/3 Poynton Terrace, Newton, Auckland 1010 Phone: (09) 309 1858
Email: positivewomen@xtra.co.nz
Website: www.positivewomen.co.nz

Absolutely Positively Positive

A support community on the Web
Website: www.app.org.nz

Body Positive Inc

Street address: 2/3 Poynton Terrace, Newton, Auckland 1010
Postal address: PO Box 68 766 Newton, Auckland
Phone: (09) 309 3989 Fax: (09) 309 3981
Email: office@bodypositive.org.nz
Website: www.bodypositive.org.nz

Auckland (Head Office)
Covers Northland and Auckland Districts
Contact details as above

Waikato
The Waikato region covers the central North Island, Bay of Plenty, Gisborne, Thames and Hamilton districts.
Email: lance.d@xtra.co.nz

Wellington
Email: errolgreaves@gmail.com

Body Positive Canterbury Inc
A separate organisation has been established in the Canterbury area.
Postal address: P.O. Box 24-155, East Linwood, Christchurch.
Phone: (03)942-6647 (Please leave a message)
Email: bpcanterbury@paradise.net.nz

New Zealand AIDS Foundation (NZAF)

Free 24 Hour AIDS hotline: 0800 802 437
Street address: 31-35 Hargreaves Street, College Hill, Ponsonby
Postal address: PO Box 6663, Wellesley Street, Auckland
Phone: (09) 303 3124 Fax: (09) 309 3149
Email: contact@nzaf.org.nz
Website: www.nzaf.org.nz

Auckland: Burnett Centre
1/3 Poynton Tce, Newton, Auckland
Phone: (09) 309 5560 Fax: (09) 302 2338
Email: contact.burnett@nzaf.org.nz

Hamilton : Te Puawaitanga o te Ora
11 Ohaupo Rd, P O Box 41, Hamilton
Phone: (07) 838 3557 Fax: (07) 838 3514
Email: contact.hamilton@nzaf.org.nz

Wellington : Awhina Centre
New address needs to go in here
Phone: (04) 381 6640 Fax: (04) 381 6641
Email: contact.awhina@nzaf.org.nz

Christchurch : NZAF South / Te Toka
269 Hereford St, PO Box 13-618,
Armagh St, Christchurch
Phone: (03) 379 1953 Fax: (03) 365 2477
Email: contact.tetoka@nzaf.org.nz

Northland AIDS Network Charitable Trust

Postal Address: PO Box 1778 Whangarei 0140
Phone: (09) 4361473 or (09) 435 0187
Fax: (09) 435 5462
Website: http://www.northlandaids.org.nz/

Nelson HIV/AIDS Support Network

Email: kevin@ts.co.nz

Hepatitis C Support Group (NZ)

Freephone: 0800 224 372
Street address: 1st Floor Liston House Patricks Square, Cnr Wyndham & Hobson Sts, Auckland
Postal address: PO Box 90 563 Auckland
Phone/Fax: (09) 377 8500
Email: admin@hepc.org.nz
Website: www.hepc.org.nz

Sexual Health Contacts

Family Planning Association of NZ

Freephone: 0800 FPA LINE (0800 372 5463)
Street Address: Level 6 Southmark House, 203-209 Willis Street, Wellington
Postal Address: PO Box 11-515, Wellington
Phone: (04) 384 4349 Fax: (04) 382 8356
Email: contact@fpanz.org.nz
Website: www.fpa.org.nz

Auckland Office
Postal Address: Private Bag 99 929, Newmarket, Auckland
Phone: (09) 522 0120 Fax: (09) 522 0130

Christchurch Office
Postal Address: PO Box 40113, Christchurch
Phone: (03) 379 0514 Fax: (03) 365 5757

Auckland Sexual Health Service

Freephone: 0800 739 432

Central Auckland
Located in: Building 7, Level 3, Greenlane Clinical Centre, Greenlane West Road
Postal Address: Private Bag 92024, Auckland
Phone: (09) 630 9770 (for bookings and enquiries) or (09) 630 9782 (for management team) Fax: (09) 630-9783

West Auckland
Located on: 2nd Floor, Westpac House, 362 Great North Road
Postal Address: PO Box 21-518, Henderson, Auckland
Phone: (09) 836-0838 Fax: (09) 836-0839

South Auckland
Address: 12 Waddon Place, PO Box 43202 Mangere, Auckland (Next to the Mangere Health Centre)
Postal Address: PO Box 43202, Mangere
Phone: (09) 255-5172 Fax: (09) 255-5178

North Shore
Located at: 418 Glenfield Road,(cnr Glenfield & Peach Rds) Glenfield, Auckland
Phone: (09) 443-2544 Fax: (09) 443-2554

Hamilton Sexual Health
Website: http://www.waikatodhb.govt.nz/wdhb/default.asp?content=973

Other Sexual Health Clinic phone numbers

Whangarei (09) 438 6123
Hamilton (07) 839 8732
Tokoroa (07) 886 7239
Tauranga (07) 579 8130
Whakatane (07) 307 8818
Rotorua (07) 349 7918
Gisborne (06) 868 9005
Napier (06) 834 1812
Hastings (06) 878 8109
Taupo (07) 378 3895
New Plymouth (06) 753 7757
Wanganui (06) 348 1234
Dannevirke 0800 808 602
Palmerston North (06) 350 8602
Levin (06) 368 9199 ext. 809
Masterton (06) 378 9029
Wellington (04) 385 5996
Nelson (03) 546 1537
Blenheim (03) 577 1913
West Coast (03) 768 0499 ext. 874
Christchurch (03) 364 0485
Ashburton (03) 308 4149

Timaru (03) 684 3089 ext. 8768
Dunedin (03) 474 7919
Invercargill (03) 214 5768
Gore (03) 208 9090

Advocacy

Human Rights Commission

Freephone: 0800 496 877
Fax: 09 377 3593 (Attn: InfoLine)
Email: infoline@hrc.co.nz (for general enquiries)
TTY (teletypewriter) access number: 0800 150 111
Website: http://www.hrc.co.nz

Auckland
Street Address: Level 10, Tower Centre, 45 Queen Street, Auckland
Postal Address: PO Box 6751, Wellesley Street, Auckland 1141
Phone: (09) 309 0874 Fax: (09) 377 3593

Wellington
Street Address: Level 8, Vogel Building, 8 Aitken Street, Thorndon, Wellington
Postal Address: PO Box 12411, Thorndon, Wellington 6144
Phone: (04) 473 9981 Fax: (04) 471 6759

Christchurch
Street Address: KPMG at Cranmer (Ground Floor), 34-36 Cranmer Square, Christchurch
Postal Address: PO Box 1578, Christchurch 8140
Phone: (03) 379 2015 Fax: (03) 353 0959

Health and Disability Commissioner

Freephone: 0800 11 22 33
Email: hdc@hdc.org.nz
Website: http://www.hdc.org.nz/

Auckland Office
Street Address: Level 10 Tower Centre 45 Queen St
Postal Address: PO Box 1791 Auckland
Phone: (09) 373 1060 Fax: (09) 373 1061

Wellington Office
Street Address: Level 13 Vogel Building, Aitken Street
Postal Address: PO Box 12 299 Wellington
Phone: (04) 494 7900 Fax: (04) 494 7901

Women's Health Action

Postal Address: Women's Health Action, PO Box 9947, Newmarket, Auckland
Phone: (09) 520 5295 Fax: (09)520 5731
Email: info@womens-health.org.nz
or jo@womens-health.org.nz
Website: www.womens-health.org.nz

Other

E-mail Contacts

New Zealand Quilt Project - nzquilt@hotmail.com
Circle of Friends - quattro@xtra.co.nz
ADIO (Auckland Drug and Intravenous Users Organisation) - adio@ihug.co.nz

Relationship Services

Freephone: 0800 RELATE (0800 735 283)

African Health Promotion Programme (AHPP)

Kudakwashe Tuwe (National Co-ordinator) and Rumishael Masanga (Health Promoter)
Street Address: 31-35 Hargreaves St, Ponsonby, Auckland
Postal Address: PO Box 6663 Wellesley St, Auckland
Phone: (09) 303 3124 Fax: (09) 309 3149
Email: k.tuwe@nzaf.org.nz
or rumishael.masanga@nzaf.org.nz

Positive Women

POSITIVE WOMEN INC
1/3 POYNTON TERRACE, NEWTON, AUCKLAND 1010
PHONE: (09) 309 1858
FREE PHONE: 0800 POZTIV (0800 769 848)
EMAIL: positive women@xtra.co.nz
WEB: www.positivewomen.co.nz