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Newly diagnosed with HIV

New Diagnosis

If you have recently found out you have HIV you probably have a number of questions that you need answers to. You may know a lot about HIV already or this may be all completely new to you. The information in this fact sheet covers some of the important things to know early on. There are links to other sites for more information as well as contacts to services in Victoria.

Regardless of the reason for deciding to have an HIV test, there is no way to know how you will respond to finding out that you have HIV. It is something that each person reacts to in their own way and in their own time. It is important to know that life does not stop because you have HIV.

You can continue to have a very active and full life, including sex and relationships. Other things that are in your life plan - for instance, work, children, study, sport or travel – can still happen. Living with HIV is, at times, difficult and some things may need to change. That is where having emotional support, a good HIV doctor and easy access to information will be helpful.

We hope that this fact sheet will begin to answer some of your questions and be a useful guide to the support and information that is available to people living with HIV in Victoria.

What is the difference between HIV & AIDS?

Many people use the terms HIV and AIDS to mean the same thing, however they are not the same thing. It is important to understand the difference. HIV (Human Immunodeficiency Virus) is a virus that passes from person to person during sex, blood to blood contact or during childbirth.

Once transmitted, HIV enters cells of the immune system called CD4 cells, where it makes lots of copies of itself. In this process, the CD4 cells are killed. The immune system usually protects us from disease and infection, however HIV weakens the immune system over many years meaning it cannot fight off the infections and diseases that a healthy immune system normally could.





The term AIDS (Acquired Immune Deficiency Syndrome) refers to an advanced stage of HIV infection. Someone is said to have AIDS if they have one or more of a specific list of illnesses as a direct result of a weakened immune system. The weaker the immune system the more a person is at risk of developing AIDS.

In the past, before HIV treatment was invented, most people living with HIV would go on to develop AIDS over many years. The situation is very different today. HIV treatment, called anti-retroviral treatment (which may be shortened to *ART* or *ARVs*), radically reduces the amount of HIV in the body. This in turn reduces damage to the immune system and prevents AIDS. If someone already has AIDS, then starting on ART can allow the immune system to get better and restore health. There is more information about HIV treatments further on in this Factsheet.

Will having HIV shorten my lifespan?

Although there is no cure for HIV, with good medical care and effective HIV treatment people with HIV today are living long healthy lives, similar to people who don't have HIV. Due to the success of HIV treatment the World Health Organisation changed the classification of HIV from a terminal illness to a chronic manageable condition. This is great news and is a direct result of the effectiveness of HIV medications. The more that is known about this relatively new disease through scientific and clinical research, the better HIV medical care will become.

Telling others (disclosure)

Finding out you have HIV may be a shock, and you will probably want to talk with someone about it. Telling someone that you have HIV may also be a big step. Once you have told someone you can't undo the telling, so it is worth taking your time to decide who to tell. In thinking about telling others we recommend that you consider the 5 "W's" – who, what, when, where and how.

*I made the mistake of telling a whole lot of people straight after (diagnosis). It was like I had to spew it out, like I couldn't stop myself. But I regret it now. If I'd just waited another day, or even another week and thought about who it really was OK to tell. Those are the people who have stuck with me till today.
(Brent, 39, diagnosed 1991)*

Except for a few cases discussed below, you don't have to tell anyone. If you choose to tell someone, you may prefer to talk to someone close to





you, or someone more removed like your doctor or another health professional. Some people prefer to talk to a complete stranger at the end of the phone. The best person to talk to may not be the person you are closest to, but perhaps a person who is a good listener and will keep your information private.

Telling family and friends

In telling family or friends choose a time and place that allows for privacy, and where you won't be interrupted. Think about what you want to say. It is probably best to keep it simple and to tell only what you are comfortable with. It is a good idea to have some written information on hand as your family and friends will have questions of their own. The following links contain information written for partners, friends and family:

<http://www.afao.org.au/living-with-hiv/partners,-family-and-friends>

<http://napwa.org.au/resource/treat-yourself-right/telling-people-you-are-hiv-positive>

Talking with a counsellor or another positive person can be useful in helping you prepare to tell others.

*I had a good counsellor right from the start. She told me that you don't have to tell anyone, or particular people, like your family and stuff. I waited for a while. And it wasn't that hard cos I had the counsellor to talk to anyway. Then I did it one at a time, and only when I felt safe.
(Michael, 29, diagnosed 1996)*

Telling sexual partner(s)

While laws in other states differ, in Victoria there is no law that requires you to tell sexual partners that you have HIV. However, you may be guilty of a crime if you place another person at risk of catching HIV. While there have been very few actual convictions related to the spread of HIV, it is important to be aware of your rights and responsibilities. Safer sex practices are the best way to avoid placing others at risk.

While treatment and an undetectable viral load have been shown to reduce the risk of sexual transmission, it is not currently known if being on treatment is a legal defence against a criminal charge.

It is up to you if and when you tell new partners. Some people decide to be upfront and tell all new partners; other people decide not to tell. The



decision is yours. This may be hard for some people and support is available if you would like to talk with someone about this (see Contacts).

Be aware that laws around telling sexual partners about your HIV status are different in each state. In some states, the law says you must tell a person that you have HIV prior to having sex, even if you practise safe sex. Ensure you are aware of the law in your state by contacting the local state HIV/AIDS organisation.

See <http://www.livingpositivevictoria.org.au/living-with-HIV/HIV-law>

Telling previous sexual partners

It is important that you think about past sexual partners who you believe may be at risk of HIV so that they can be contacted and offered testing. Think about partners in the period between your last negative HIV test and this positive test result. Contacting previous partners can be a difficult thing to do and support is available. There are health workers who can do this for you without telling others who you are. Talk with your doctor about this.

Do I have to tell my employer?

Unless your work puts you in a situation where you are at risk of passing on HIV to other people, such as health care workers who perform certain risky procedures, you do not have to inform your employer of your HIV status. Certain industries require HIV testing, such as the Australian Defence Force and the legal sex industry in Victoria. (It is illegal to do sex work in Victoria if you have HIV.) Apart from these exceptions, your employer does not have the right to ask your HIV status and you do not have to tell. For information about HIV and specific industries, contact the Victoria AIDS Council's legal assistance service (see listing).

Telling health care workers

You do not legally have to disclose your HIV status to health care providers, however in most cases it is recommended that you do. The medical procedure or treatment could impact your health, or your HIV medications and related conditions could affect your medical treatment. For example, some of the ARTs affect drugs used during operations. If the anaesthetist does not know your medications and gives you the standard sedation for many minor procedures, it may take a very long time for you to wake up after the procedure. Seek advice from your HIV doctor about disclosure if you are having medical treatment.



Confidentiality

It is important to know that your health information will remain confidential (private) and healthcare providers are required by law not to disclose any information without your consent. This may be more of a concern if you live within a tight-knit family or social group, or in a small community such as a rural town. If this is a concern for you, you might consider seeking support in another town or city.

Relationships

Intimate partners

Adjusting to living with HIV can take time, and feeling comfortable with sex may be difficult early on. Having sex may be the last thing on your mind at the moment. "What if I infect my partner?" is a common concern for people who are newly diagnosed and talking with others who have gone through this can be helpful. You can contact Living Positive Victoria who will put you in touch with someone to talk with. Many people living with HIV say that while it was difficult early on, their relationships became stronger and closer over time.

If your partner is also HIV positive you may wonder if it's safe for you to have unprotected sex together. Talk with an HIV specialist doctor about this, as there are different types of HIV that you may be at risk of, as well as other sexually transmitted infections.

Other relationships

You may be concerned about infecting others in your life that you are close to, such as family members and children. Talk with your doctor or HIV nurse about transmission if you have concerns. HIV **cannot** be transmitted by hugging, kissing, sharing cups, knives and forks, shaking hands, toilet seats or general social interactions.

Starting a family

Whether you are a man or a woman with HIV, you can still plan for a family. There are several things that can be done to reduce the risk of a positive woman passing HIV on to her baby. Men with HIV can also father children and there are special techniques to reduce transmission. If starting a family is something you would like to do, talk with your doctor.



Victoria has a specialized Service that helps couples where one partner is HIV positive and the other is HIV negative, to safely become pregnant. The Chronic Viral Illness Program is located at The Women's Hospital, and your doctor can refer you to that clinic.

PEP

If your partner has been at risk of HIV advise them to seek PEP – a 28 day course of HIV medications that helps to prevent HIV transmission. The medication is unlikely to work if it is not started within 72 hours of the time when you may have been exposed to HIV, and should be started as soon as possible. It may have been a broken condom, unprotected sex, shared injecting equipment or something else that you feel is high risk. Call the PEP Phonenumber for advice and referral to the closest PEP clinic, on 1800 889 887 or visit the following site: <http://www.getpep.info/>

Finding an HIV specialist doctor

HIV specialists are doctors trained in HIV medicine and are experts in looking after people living with HIV. It is recommended that people newly diagnosed with HIV visit an HIV specialist doctor at least every 3 months.

You will soon become familiar with terms such as “CD4 count” (a measure of how healthy your immune system is) and “viral load” (the amount of HIV in your blood). It is important that you feel comfortable with your HIV doctor as you will develop a close relationship over time and they will help guide you in important decisions such as when to start HIV treatments. HIV specialists are located at major public hospitals, the Melbourne Sexual Health Centre and at some GP clinics throughout Victoria. For a list of HIV specialist doctors call Living Positive Victoria (see Contacts).

People living in regional or rural towns may find it difficult to find a doctor with specialist knowledge about HIV in their area. They may also have concerns about privacy. Most HIV expert doctors are in Melbourne, but they can provide support for your local doctor to manage your health issues. The Victorian HIV Consultancy (see Contacts) is often able to link people living in rural locations with GPs and other health care providers.

Starting on HIV treatments

HIV treatment, called *antiretroviral medications* (ARVs), is medication which reduces the amount of HIV in the body and allows the immune system to stay healthy. Over the years treatment for HIV has improved a





lot, and today it is so effective that it has transformed HIV from a fatal disease to a chronic manageable condition. HIV treatment can be started at any stage. Current research shows that starting treatment early is good for your health in the long term, and it reduces the risk of passing the virus to others.

The right time to start HIV treatment is different for everyone. It is best started *before* there is a lot of damage to the immune system (before the CD4 cell count declines below a certain level) and/or the amount of virus in the blood rises to a high level (viral load increases). For some, the right time to start HIV treatment may be when there is no apparent damage to the immune system, but their partner is HIV negative, and they do not want to pass on HIV to their partner. It has recently been shown that transmission of HIV rarely occurs if the person with HIV is on ART and their viral load is below 500 copies/ml.

Commencing treatment is also a big step that requires thought and planning and talking with your doctor. Once started, treatment must be continued for life. Stopping or changing treatment without your doctor's advice can be dangerous to your health and it can also stop your medication working properly in the future.

Depending on the stage of HIV infection when you were diagnosed, starting on HIV treatment may or may not be something that you have to think about at the moment. There is plenty of information available about HIV treatment and talking with someone at Living Positive Victoria or with other HIV positive people who are currently on treatment can give you a good idea of what it may be like. For more information about HIV treatment visit: <http://napwa.org.au/treating-hiv>

I started on antiretrovirals soon after I was diagnosed. Since then my health has been 100% better, partly because of taking the medications, but also because of eating healthy foods, positive thinking and looking after myself. In 2005, I changed my medications because one of the drugs wasn't working. My new regimen has meant my viral load has become undetectable again and CD4 count normal. (Emilio, 40, diagnosed 1998)

Complementary treatments

Many people living with HIV use complementary therapies such as vitamin and mineral supplements, massage and acupuncture to enhance health or manage side effects of antiretroviral treatments. If you are considering taking herbal medication it is important to discuss this with





your HIV doctor, as some herbal medications interact with HIV medication.

There is a small number of natural therapists with expertise in treating people living with HIV. Talk with the Positive Living Centre who can provide access to natural therapists in Victoria (see Contacts).

Support from others with HIV

Most people find that they want to talk to someone who has been through what they are going through. In Victoria, there are over 6,000 people living with HIV. Talking to another person with HIV can be very helpful, not only when newly diagnosed, but for ongoing support.

Talking to other pos people made the difference. It took me a while cos I was just in shock and didn't want to go anywhere, go to work even, let alone sit in a group of strangers. But when I did it was such a relief. Mainly what I heard them saying at the beginning was 'its OK, you won't die, but shit we know just how scary it is, we've been there...' I started to feel kinda 'normal', pretty funny eh!

(Brent, 39, diagnosed 1996)

There are HIV support services in Victoria specifically for gay and bisexual men, heterosexuals, and women, and they can assist you in meeting other people who are living with HIV. They offer one to one contact, informal social occasions, as well as group support and information sessions (see Contacts).

My doctor gave me the number and eventually I rang Positive Women. The voice at the other end was so friendly, and relaxed and caring, that I burst into tears. Really they were tears of relief. I didn't ring a lot over the time, but I knew that someone was there for me when I needed anything, like information or just a chat.

(Martha, 56, diagnosed 1997)

You can become as involved as you choose to with HIV organisations. Living Positive Victoria produces a newsletter called Poslink which you can view on-line to find out what is happening:

<http://www.livingpositivevictoria.org.au/>

We hope that you have found the information contained within this factsheet helpful. Please see the list of contacts over the page. These are the main HIV information services in Victoria. Please make use of these services – they are there for you.





Contacts

Victorian AIDS Council/Gay Men's Health Centre

Information, advice, support and services for issues surrounding HIV/AIDS infection and prevention.

9865 6700

<http://www.vicaids.asn.au/>

Living Positive Victoria

Education, information and representation for all PLHIV in the State of Victoria

Programs include workshops (Phoenix) for newly diagnosed

9863 8733

<http://www.livingpositivevictoria.org.au/>

Positive Women Victoria

Support and information for HIV positive women

9863 8747

<http://www.positivewomen.org.au/>

Straight Arrows

Information and support for HIV positive heterosexual men, women, parents and their families.

9863 9414

<http://www.straightarrows.org.au/>

Positive Living Centre

A community centre for all people living with HIV

9863 0444

<http://www.vicaids.asn.au/community-centre>

HIV & Sexual Health Connect Line

Confidential and Anonymous service which provides Information, support and referral for Victoria

1800 038 125

<http://www.connectline.com.au>

Victorian HIV Consultancy

Information about rural HIV services

9076 3658

<http://www.alfred.org.au/Department.aspx?ID=406>





A free and confidential service for people seeking information about HIV/AIDS, hepatitis and sexually transmissible infections (STIs).



Country Awareness Network (CAN)

Support Education Resources and Advocacy for people in rural areas

03 5443 8355

www.can.org.au

Melbourne Sexual Health Centre (Green Room)

Free HIV & sexual health clinic

9341 6200

<http://www.mshc.org.au>

HIV, Hepatitis & STI Education + Resource Centre

Education and information for the Victorian community

9076 6993

<http://www.hivhepsti.info/>

Victoria AIDS Council's legal assistance service

Assistance with legal issues around HIV

Phone: (03) 9863 0406

Email: legal@vic aids.asn.au

<http://www.vic aids.asn.au/plc-legal-assistance>

The Body

US site with extensive information for people living with HIV including "Ask the experts" and HIV blogs

<http://www.thebody.com>

Produced by Education + Resource Centre (HIV, Hepatitis, STIs)

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