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## Newly diagnosed with HIV

### New Diagnosis

If you have recently been diagnosed with HIV you probably have a number of questions that you are seeking information about. You may know a lot about HIV already or this may be all completely new to you. The information provided below covers what we consider to be the most important things to know early on. There are links to other sites for more detailed 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 predict anyone's response to being newly diagnosed. An HIV diagnosis 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 be achieved. Living with HIV does, at times, bring challenges and may require some lifestyle adjustments. That is where having emotional support, quality medical care and easy access to information will be helpful.

We hope that the information below will begin to answer some of your questions and provide a useful guide to accessing the support and information available to people living with HIV (PLHIV) in Victoria.

### What is the difference between HIV & AIDS?

Many people use the terms HIV and AIDS interchangeably, however they are not the same thing and it is important to understand the difference. HIV (Human Immunodeficiency Virus) is a virus that is transmitted from person to person via sexual activity, blood to blood contact or during childbirth. Once transmitted, HIV enters cells of the immune system (CD4 cells) where it reproduces itself, killing the CD4 cell in the process. The immune system usually protects us from disease and infection, however HIV weakens the immune system over many years meaning it cannot fight off other infections and diseases that a healthy immune system would normally be able to.





The term AIDS (Acquired Immune Deficiency Syndrome) refers to a more advanced stage of HIV infection. Someone is said to have AIDS if they are diagnosed with one or more of a specific list of infections/conditions 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 effective HIV treatment was available, most people living with HIV would go on to develop AIDS over many years. The situation is very different today. HIV medications, called antiretroviral medications (ARVs), significantly reduce the amount of HIV in the body, which in turn reduces damage to the immune system and prevents progression to AIDS. If someone already has AIDS, then starting on ARVs can allow the immune system to recover and restore health. There is more information about HIV treatments further on in this Factsheet.

### **Will having HIV shorten my lifespan?**

Although there is currently no cure for HIV, with good medical care and effective HIV treatment, people with HIV today are living long healthy lives similar to those who don't have HIV. Due to success of HIV treatments 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?**

Receiving an HIV diagnosis is big news and you most likely will want to talk with someone about it. Telling someone that you have HIV is also big news. 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 disclosure 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)*





With a few exceptions 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 with no disruptions. 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 link contains information written for partners, friends and family:  
<http://www.afao.org.au/living-with-hiv/partners,-family-and-friends>

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)*

### Sexual partner(s)

The law in Victoria requires that a person with HIV does not “knowingly or recklessly infect another person”. This means that if you have HIV you are required to use safe sex practices (using condoms) that prevent the transmission of HIV. In Victoria if you are having safe sex with your current sexual partner(s) then you do not legally have to tell them you are HIV positive.

It is up to you if and when you tell new partners. Some people decide to be upfront and tell all new partners, whereas other people decide not to tell. The decision is yours. This may be challenging for some people and support is available if you would like to talk with someone about this (see Contacts).





NSW has specific legislation that requires that people living with HIV disclose their HIV status before having sex, even if the sex is safe. If travelling to NSW this is important to know. All other states in Australia have similar requirements to Victoria, although laws vary slightly from state to state. The website of the Australian Federation of AIDS Organisations (AFAO) provides more information about disclosure in other states: <http://www.afao.org.au/living-with-hiv/legal-issues#disc>

### **Previous Sexual Partners**

It is important that you think about past sexual partners who you believe might have been exposed to 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 specialist health workers who can do this on your behalf without involving you or disclosing your identity. 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 transmitting HIV, such as health care workers who work with exposure prone procedures, you are not obliged 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. Apart from these exceptions, your employer does not have the right to ask your HIV status and you are under no obligation to disclose. For information about HIV and specific industries talk with someone at the HIV/AIDS Legal Centre (see Contacts).

### **Telling health care workers**

You do not legally have to disclose your HIV status to health care providers, however in some cases it is advisable to disclose if the medical procedure/treatment could impact on your health, or your HIV medications and related conditions could affect your medical treatment. Seek advice from your doctor about disclosure if you are having medical treatment. The HIV/AIDS Legal Service (HALC) has a booklet that covers legal issues of disclosure and can be found at: <http://www.halc.org.au/downloads/Disclosure.pdf>





## Confidentiality

It is important to know that your health information will remain confidential 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 sexual intimacy may be challenging 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 amongst people who are newly diagnosed and talking with others who have gone through this can be helpful. You can contact PLWHA Victoria who will put you in touch with someone to talk with. The experience of some other positive people is that, after an initially challenging period post diagnosis, their relationship actually strengthened and developed greater levels of intimacy.

If your partner is also HIV positive this may bring up questions for both of you around whether to have unprotected sex in your relationship. Talk with an HIV specialist doctor about this as there may be issues of re-infection with a different strain of HIV and the impact of sexually transmitted infections on HIV.

### 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. With advances in HIV treatments and other medical interventions the risk of a positive woman passing HIV on to her baby has been significantly reduced and with appropriate medical treatments, the risk of transmission is very small. Men with HIV can also father children and there are special techniques to minimise transmission. If starting a family is something you would like to do, talk with your doctor.

*My partner and I did the research about safe sex, and we made a decision. Of course, you sometimes think about the possibility of infection, it can be scary. But we've done the learning and the talking. We feel good about the decision. (Angela, 26, diagnosed in 1995)*

## NPEP

If your partner has been at risk of HIV advise them to seek NPEP – a 28 day course of HIV medications that helps to prevent HIV transmission. They have 72 hours in which to start, but act quickly because the sooner that NPEP is started the more effective it is. It may have been a broken condom, unprotected sex, shared injection equipment or something else that you feel is high risk. Call the NPEP Phonenumber for advice and referral to the closest NPEP clinic 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 managing the health of people living with HIV. It is recommended that all people living 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 PLWHA Victoria (see Contacts).





People living in regional or rural towns may find it difficult to access HIV expertise in their area, or have concerns about confidentiality. Though HIV clinical expertise is largely concentrated in inner Melbourne, these specialists 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 treatments, called antiretrovirals (ARVs) are medications which reduce the amount of HIV in the body and allow the immune system to stay healthy. Over the years ARVs have improved significantly, and today they are so effective that they have transformed HIV from a fatal disease to a chronic manageable condition. HIV treatments are generally commenced when the immune system declines below a certain level (CD4 cells decrease) and/or the amount of virus in the blood rises significantly (viral load increases).

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 treatments and talking with someone at PLWHA Victoria or with other HIV positive people who are currently on treatment can provide some valuable, first-hand insights. For more information about HIV treatments 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 regime 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 are 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. There are over 3,000 people in Victoria 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, 29, diagnosed 1996)*

There are HIV support services in Victoria specifically for gay men, heterosexuals and women which can assist you in meeting other positive people. 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. PLWHA Victoria produces a newsletter called Poslink which you can view on-line to find out what is happening:

<http://www.plwhavictoria.org.au/living-with-HIV/poslink.php>

We hope that you have found the information contained within this factsheet helpful. Please see the list on 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

### **People Living with HIV/AIDS Victoria**

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

Programs include workshops (Phoenix) for newly diagnosed  
9863 8733

<http://www.plwhavictoria.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/>

### **Victorian AIDS Council/Gay Men's Health Centre**

Information and support for all gay men (positive and negative)  
9865 6700

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

### **Positive Living Centre**

A community centre for all people living with HIV  
9863 0444

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

### **HIV, Hepatitis & STI Education + Resource Centre**

Education and information for the Victorian community  
9076 6993

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

### **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>





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

## Newly diagnosed with HIV

### **Victorian HIV Consultancy**

Information about rural HIV services  
9076 3658

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

### **Melbourne Sexual Health Centre (Green Room)**

Free HIV & sexual health clinic  
9341 6200

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

### **HIV/AIDS Legal Centre (NSW)**

HIV related legal advice  
02 9206 2060

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

### **The Body**

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

<http://www.thebody.com>

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### **Disclaimer**

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