



Newly diagnosed with HIV

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Education +
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1) After testing

You have tested positive to HIV. It may have been a complete shock to you. Or perhaps you expected it, or guessed it was a possibility. Regardless of where people are at when they have the HIV test, there is no way to predict anyone's response to a positive result.

It is likely that you experienced a range of feelings. Shock, anger, bewilderment, fear, relief, sadness, rage and grief are all common reactions to a positive test. People can also feel overwhelmed with questions.

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

What does an HIV positive test mean?

Testing HIV positive does not mean you have AIDS. 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 - do not need to be changed by an HIV diagnosis.

Living with HIV does bring changes, uncertainties and challenges. Each individual will handle it in their own way. But having emotional support, quality medical treatment and care and easy access to information will certainly help.

What's the difference between HIV and AIDS?

HIV (Human Immunodeficiency Virus) is a virus which infects the immune system and slowly damages it over time. Someone who has tested positive for HIV is referred to as being HIV positive.

AIDS (Acquired Immune Deficiency Syndrome) is a collection of severe illnesses which occurs when someone has a very damaged immune system. Without treatment, most HIV positive people would go on to develop AIDS, but this can take many years - from 2 to 20 years depending on the individual. Antiretroviral treatments prevent HIV from damaging the immune system and therefore stop AIDS from developing in many people.

How long have I got?

A positive HIV test does not mean you are going to die from AIDS or get sick. It is true that there is still no cure that eliminates HIV from an infected person. Major advances in



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HIV treatments have resulted in people with HIV living long healthy lives just like people who don't have HIV.

2) Disclosure — What about telling others?

Telling others is a complex issue. Should I tell anyone? Who can I tell? What about my privacy? How will they handle it? When should I tell them? What information will they need to know?

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)

Firstly, remember that you don't have to tell anyone. Don't rush into action, you've got time. You can leave the telling for days, months or years. A good piece of advice from positive people and HIV workers alike is to take your time, think about it, and don't tell too many people at the start before you've had a chance to sort some things out for yourself. Remember, it's impossible to 'un-tell'.

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)

Most people want to talk to at least one person immediately after diagnosis. 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 (see "Resources" for options).

Choosing people to tell: Many people find being diagnosed with HIV is an isolating experience. Talking about it with someone important to you can help. Do you have one or two people in your life that you can share this with? Ask yourself, "is there someone I think I could talk to about any issue, who I can trust and who will respect my privacy?" 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.

Family and friends: The people closest to you may have their own reaction to the news of your HIV status and they may need to talk to someone themselves. Good information can reassure them that HIV is not a death sentence and correct any misunderstandings they may have. Some of the counselling and support services listed at the end of this



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Fact Sheet can help your family, friends and others who are affected by your HIV diagnosis.

Sexual partner(s): If you are using condoms with your sexual partner(s) then you do not have to tell them you are HIV positive. You may want to think carefully before telling your sexual partner straight away. It may raise issues for them as it has for you. In Victoria, it is a legal requirement that a person with HIV does not knowingly or recklessly infect another person. This means that HIV positive people are required to use safe sex practices. NSW has specific legislation that requires that people disclose their HIV status before having sex. If you were not using condoms with your sexual partners before your HIV positive result you are now legally obliged not to pass the virus onto your partner(s). How you manage this is up to you and support is available if you need it.

It is important that others who you believe might have been exposed to HIV are informed too, so that they can be offered testing and access to treatments. This can be done confidentially via the Partner Notification Officers without involving you if necessary. Your identity will not be disclosed.

Confidentiality: Some people are more able to keep information to themselves than others. You should expect healthcare providers to abide by their professional code of confidentiality. They are required by law not to disclose any information without your consent. If you live within a tight-knit family or social group, or in a small community such as a rural town, confidentiality is often harder to maintain. If this is a concern for you, consider discussing your situation with people outside these situations, such as a trusted professional or friend in another town or city.

Timing: Choose a time and place carefully when you plan to tell someone about your diagnosis. Try to make sure it is private and that you both have enough time to discuss your information.

Telling children: Many people living with HIV are mothers and fathers. Whether or when to tell children is a complex issue and it can help to talk about this issue with other positive parents, a counsellor or social worker.

Not telling people: Remember, you don't have to tell anyone about your HIV status, including friends, employers, workmates or health care workers. The one exception is sexual partners whilst in NSW (see Sexual Partners above).



3) What happens now?

Your current state of health often depends on whether or not your immune system has been weakened by the virus and whether you have any other health concerns or illnesses. Individuals vary greatly in how much HIV damages their immune system. The length of time you have been infected with HIV might also be a factor. Treatment for HIV generally gives your immune system a chance to recover.

What does it mean in terms of relationships? Sex? Children?

While HIV can have a significant impact on your sexual and emotional life, it won't eliminate it. At first, some people might not feel as sexually attractive after being diagnosed with HIV. This will change over time. Many people currently living with HIV are in a relationship or are sexually active.

HIV may complicate some things for some people - issues such as condom use, lifestyle changes, fear of being rejected and fear of infecting partners are now on the agenda. Most people find ways to successfully negotiate these situations, and talking to other positive people and healthcare providers can help.

For women, the possibility of having children in the future remains strong. Current medical interventions enable most women with HIV to have a child with little risk of transmitting HIV to the child or affecting their own health.

*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)*

At present, the situation for men wanting to father children is difficult in Victoria. The in vitro fertilisation technique called intracytoplasmic sperm injection can achieve pregnancy without the risk of HIV transmission. Another low risk technique is called sperm washing. Talk to your doctor about whether these procedures are suitable for you and available locally. In vitro fertilisation is not necessarily available for all people. Other options include donor sperm or foster care.



4) 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 a valuable way of handling your situation and learning from the experience of others.

*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)*

*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)*

The various peer support groups or services listed on the back pages 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 and services.

5) Making decisions about starting treatment

Many people may not need to start treatment right away. There are many new drugs available now for the treatment of HIV that are much better than drugs that were used years ago. These newer drugs have fewer side effects, are more potent and are easier to take than their predecessors. Your doctor will let you know if you need to start treatment. HIV affects individuals differently. It is important to work out just how it is affecting your system. Doctors use blood test results to help them to assess this. It is important to see your doctor every three to six months to monitor your health.

*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)*



One test is the T Cell or CD4 cell count. This test measures the function of your immune system at this point in time. A higher CD4 count means your immune system is healthy. The second test is the Viral Load test. This test measures how active the HIV virus is in your system at this point in time. A lower viral load means that the virus is less active in your body and would take much longer to cause significant damage to your immune system.

Most people start HIV treatments when the CD4 count is around 350. There is a current trend to starting treatment earlier than this because of concerns that HIV can have an affect on the heart, kidneys liver and other organs. Your doctor will discuss these concerns with you. The decision to commence treatment, or wait to start treatment is ultimately yours to make in consultation with your doctor. Talking with the Treatments Officer at PLWHA Victoria or with other HIV positive people who are currently taking antiretroviral drugs can provide some valuable, first-hand insights.

6) Working your way through the HIV system

When you were diagnosed, you should have been offered information about some of the existing HIV services. They include: medical/clinical services, HIV information, counselling, contact with other HIV positive people, practical support, help with Centrelink issues and housing, legal services and so on.

When you are first diagnosed, the 'HIV system' can seem like a maze. You may not even want to enter it for a while. If or when you do, it can help to take a friend along for support, even if it's just some of the way. A friend may help you figure out questions to ask, remember the answers you get, make appointments for you - they can just be there for you at the end of the day when you need to talk things through. Some people find it useful to write down questions that come up before they see their health professional.

*I question what doctors have to say and I ask them questions - lots of them. And I decide what I'm going to do or what I'm not going to do.
(Sarah, 36, diagnosed 1994)*

If you need to access a range of services, it may help to have a health professional, such as a social worker who is working in the HIV field, coordinate this process.

Choosing a doctor

Having a doctor or medical team that you trust is important. You can receive medical care from an HIV specialist GP, the Melbourne Sexual Health Centre or some hospital clinics. Note that only specialist GPs and physicians that have trained in HIV medicine are able to prescribe antiretroviral drugs.



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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 back pages) is available to link people living in rural locations with GPs and other health providers.

Remember, you can change doctors, or have more than one doctor. This practice is common among people who have been diagnosed with HIV. Some doctors have a particular specialty, such as assisting women who want to become pregnant or others who specialise in gay health. Some are supportive of their patients using complementary therapies.

Complementary treatments

Over half of people with HIV use complementary therapies such as vitamin and mineral supplements, massage and acupuncture to enhance health or deal with the side effects of antiretroviral treatments. There are a small number of natural therapists with expertise in treating people with HIV. More information about referrals can be obtained from HIV organisations.

7) Know your rights

Did you know:

- ◆ There are laws designed to protect people with HIV against discrimination in health, employment, housing and education situations.
- ◆ You do not have to tell your employer that you have HIV. There are a small number of exceptions, including the armed forces.
- ◆ It is against the law for doctors, nurses and health care providers to tell anyone you are HIV positive without your consent.
- ◆ Health professionals cannot treat you differently because of your HIV status. You are entitled to good quality care and respectful behaviour.
- ◆ You have the right to make decisions about any treatments offered and you have the right not to agree to any medical treatment offered.

Get to know all your rights and be informed about all your health issues.
Organisations listed below can help with any specific information you might need.



8) Services

Medical Treatment

Specialist clinics

<p>Victorian HIV Service Infectious Diseases Outpatient Clinic The Alfred Hospital Commercial Rd Prahran. 3181 Phone: 9076 6081 www.alfredhealth.org.au/id/ <i>Phone first. No referral is necessary.</i></p>	<p>Monash Medical Centre Infectious Diseases Unit 246 Clayton Road Clayton. 3168 Phone: 9594 4564</p>
<p>Victorian Infectious Diseases Service HIV Service – Outpatients clinic 9th Floor Royal Melbourne Hospital Grattan St Parkville. 3050 Telephone: 9342 7212 Email: vids@mh.org.au www.mh.org.au/vids/</p>	<p>Melbourne Sexual Health Centre Referral Clinic 580 Swanston St Carlton. 3051 Phone: 9341 6214 Freecall 1800 032 7000 www.mshc.org.au</p>

GP Clinics

<p>Northside Clinic 370 St Georges Road Fitzroy North VIC 3068 Phone: 9485 7700 Fax: 9486 5718 www.northsideclinic.net.au/</p>	<p>Centre Clinic (VAC) Darebin Community Health Service 42 Separation St Northcote. 3070 Phone: 9403 1206 www.nican.com.au/service/darebin-community-health-centre-northcote-site</p>
<p>Prahran Market Clinic Prahran Central Corner Commercial Road & Chapel Street Prahran 3181 Phone: 9514 0888 Email: info@prahranmarketclinic.com</p>	<p>Centre Clinic (VAC) Rear 77 Fitzroy Street (above Guardian Chemist) St. Kilda. 3182 Phone: 9525 5866 www.vicaids.asn.au</p>



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Legal Services

<p>HIV/AIDS Legal Centre Victoria (HALC) VAC Positive Living Centre 51 Commercial Rd Prahran. 3181 Phone: 9525 4455 Freecall: 1800 622795</p>	<p>Equal Opportunity Commission Victoria Level 3, 380 Lonsdale St, Melbourne. 3000 Enquires line: 03 9281 7100 Fax 03 9281 7171 Toll free country calls 1800 134 142 TTY 03 9281 7110 www.eoc.vic.gov.au</p>
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Counselling/Support Services

Most of the services listed below work not only with HIV positive clients, but also their partners, family and friends. These agencies charge no or minimal fees.

<p>Positive Counselling at Williams Rd. Family Therapy Centre 3 Williams Rd Windsor. 3181 Phone: 9530 2311 www.williamsroad.vic.edu.au/</p>	<p>Victorian AIDS Council 6 Claremont St South Yarra. 3141 Phone: 9865 6700 Freecall: 1800 134840 www.vicaids.asn.au</p>
<p>HIV Social Work Team The Alfred Commercial Rd Prahran. 3181 Phone: 9076 3026</p>	<p>Catholic HIV/AIDS Ministry Archdiocese of Melbourne PO Box 171 Clifton Hill. 3068 Phone: 9417 7829 Email: mhayescam@netspace.net.au</p>
<p>Melbourne Sexual Health Centre 580 Swanston Street, Carlton. 3053. Phone : 9347 0244 Freecall: 1800 032 7000 www.mshc.org.au</p>	<p>Lifeline 131114 24 hour telephone counselling service</p>



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<p>Education and Resource Centre (HIV, Hepatitis and STIs), The Alfred, Fairfield House, Moubray Street, Pahran. 3181 Phone: 9076 6993 Email: erc@alfred.org.au www.hivhepsti.info</p>	<p>People Living With HIV/AIDS (PLWHA) Victoria Suite 1, 111 Coventry Street Southbank Victoria 3006 Phone: 03 9863 8733 Fax: 03 9863 8734 www.plwhavictoria.org.au</p>
<p>Straight Arrows Suite 1, 111 Coventry St Southbank Phone: 9863 9414 Email: support@straightarrows.org.au www.straightarrows.org.au <i>For heterosexual men, women and children and their families</i></p>	<p>Positive Women Level 1, 210 Lonsdale Street, Melbourne VIC 3000 Phone: 9921 0860 Fax: 9076 6092 E-mail: info@positivewomen.org.au www.positivewomen.org.au <i>Support and advocacy group for women with HIV/AIDS</i></p>
<p>Positive Living Centre (Victorian AIDS Council) Peer Support Workers 51 Commercial Rd Pahran. 3181. Phone: 9863 0444 Freecall: 1800 622795 Email: plc@vicaids.asn.au www.vicaids.asn.au</p>	<p>Haemophilia Foundation Victoria Suite 5 Ground Floor 860 Nepean Hwy, Hampton East. 3188 Phone: 9555 7595</p>
<p>Breaking the Chains Phone: Jeffrey on 5562 8216 Glen on 5561 6257 <i>A Warrnambool and district support and education group for HIV or Hepatitis C positive people, their friends, families and supporters</i></p>	



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For information about rural services in Victoria contact:

Victorian HIV Consultancy The Alfred Commercial Road Prahran. 3181 Phone: 9076 3658	Country Awareness Network (CAN) 34 Myers Street Bendigo. 3552 Phone: 5443 8355 Email: can@can.org.au www.can.org.au
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Useful Websites

Victorian AIDS Council (VAC) www.vicaids.asn.au	Australian Federation of AIDS Organisations (AFAO) www.afao.org.au
Project Inform <i>National community-based organisation from the U.S.</i> www.projinf.org	The Body <i>A service of Body Health Resources Corporation (New York)</i> www.thebody.com
Education and Resource Centre (HIV, Hepatitis and STIs), The Alfred. www.hivhepsti.info	

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Acknowledgement

This fact sheet was compiled with the contribution of a number of staff from The Alfred and external agencies, service providers and support organisations. The ERC would like to thank you all for your time and effort.

Disclaimer

This information is provided for educational purposes only and is done so without liability or recourse. This information is not intended to replace professional health care advice. We strongly recommend that you discuss any issues concerning your health and treatment with your health care provider before taking action or relying on the information.



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Fact Sheet

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