



## Acknowledgements

NSW Ministry of Health

Dr Katherine Brown (Director Illawarra Sexual Health Service, Senior Staff Specialist and Clinical Associate Professor University of Sydney and University of Wollongong)

Dr. Chris Bourne (Head, NSW STI Programs Unit; Senior Staff Specialist, Sydney Sexual Health Centre SESLHD; and Conjoint Associate Professor, Kirby Institute UNSW)

NSW Sexually Transmitted Infections Programs Unit

The Australasian Society for HIV Medicine

Positive Life NSW

ACON

Updated December 2020



9 [START<sub>x</sub>]

**This booklet contains information that is relevant when a person is dealing with a new HIV diagnosis.**

**All of the answers won't be found here, but this booklet will give you some basics on HIV, together with information about what to expect in the next few months.**

**It also includes advice about a range of services that may help you adjust to managing HIV within your day to day life.**

If you've recently tested positive for HIV, chances are you'll be experiencing a range of emotions.

Some people take it in their stride, while for others a positive test result can be more difficult. There's no right or wrong way to feel about a diagnosis; the important thing to remember is that you can manage HIV. You will adapt to HIV and be able to live your life the way you choose to live it.

The first thing is to allow yourself some time to work through your initial feelings and reactions, secure in the knowledge that living with HIV today is nothing like it was in the 80s and early 90s. There will be challenges, but it is important to know that help is available if you want it - no one has to deal with HIV alone.

This booklet has been written by gay men living with HIV, who have been in the same place as you are now. We've been there and gotten through it - and you will too.

*'When I was given my positive diagnosis, it was like getting the wind knocked out of me.'*

*'For two or three days I couldn't eat or talk to anyone. It took almost a week for me to experience even a moment where I wasn't thinking about the fact I was positive.'*

# Contents

HIV Today .....	02
You Can Connect.....	04
HIV - The Basics .....	08
Myths and Facts .....	11
Living With HIV .....	17
Staying Safe.....	27
Disclosure.....	31
Alcohol and Other Drugs.....	35
Conclusion .....	37
Further Reading .....	39

## HIV TODAY

*In Australia, there is a diverse range of people living with HIV.*

*The reality of what life is like living with HIV is different to years gone by. People are living well, living as long as their HIV negative peers and managing HIV within their lives.*



## HIV IS CHANGING

The arrival of HIV combination therapy in the mid-90s began to change our experience of living with the virus. Continuous improvement since then has resulted in treatments that are more effective in suppressing HIV, are easier to take, and very unlikely to cause side effects. The majority of people now take treatment - typically just one or two pills a day. People on effective HIV treatment with a sustained undetectable viral load are not infectious to their sexual partners.

Having HIV can present challenges. The impact may be different from person to person, but for most of us the reality is that HIV is a chronic manageable illness. You can expect to live a normal life, but ongoing wellness is ultimately going to be dependent on continuing HIV treatment.

It's a reality that most men living with HIV are leading rewarding and healthy lives. Taking charge of your health, being informed about treatments, and connecting to a variety of support options/services are ways in which gay men have been able to do this..

## YOU CAN CONNECT

*There's a range of services available to you through organisations such as ACON that can link you in with peer support, workshops or counselling.*

*Resources are also available online if you are not ready to connect in-person or by talking.*

## a[STARTx]

a[STARTx] is a weekend workshop for gay men recently diagnosed with HIV and a partnership project between ACON\* and Positive Life NSW\*\*.

It's peer-led and presented, which means it is run by and for gay, bisexual and other same sex attracted men who are living with HIV. The aim is to empower you with the confidence and the skills to manage HIV by drawing on your own experience and other's in the workshop.

a[STARTx] provides practical advice, information and a peer perspective on a wide range of issues that may confront you after diagnosis. There's also time set aside for sharing personal experiences, problems and possible solutions with the support and encouragement of other gay men who, like you, are experiencing or have been through a diagnosis.

### More info:

[endinghiv.org.au/treat-early/getting-support](http://endinghiv.org.au/treat-early/getting-support)

\*ACON is New South Wales' leading health promotion organisation specialising in HIV and lesbian, gay, bisexual, and transgender (LGBT) health.

\*\* Positive Life NSW works to promote a positive image of all people living with and affected by HIV with the aim of eliminating prejudice, isolation, stigmatisation and discrimination.

*'I needed to get information. I had worked out that I wanted to be in control of the situation and my health. So, I am glad I turned up to the weekend.'*

*'a[STARTx] liberated a lot of what I was scared about or had questions about, the rest was up to me to figure out.'*

*'By the end of the weekend, I was on a bit of a post-workshop high and was feeling so much better about the road ahead.'*

## NEWLY DIAGNOSED COUNSELLING

ACON provides free counselling support and information for people recently diagnosed with HIV or those affected by a diagnosis, such as partners, family or friends. Counselling offers a safe place to discuss the needs and feelings associated with a recent diagnosis and can provide links to other services. Follow up is provided within one working day and can be offered through face-to-face contact or by phone.

## ONE TO ONE PEER SUPPORT

ACON and Positive Life NSW offer peer support. Peers are guys living with HIV who are trained to support those making sense of a new HIV diagnosis or living with HIV more broadly. Peers provide one-to-one support to those men that may want to talk to someone who understands, but who may not necessarily want to speak to a counsellor. Like the a[STARTx] weekend workshop, one on one peer support helps you build knowledge and skills around topics such as HIV treatment, HIV disclosure, building resilience and provides a safe, confidential space to explore these topics.

**More info:**

[endinghiv.org.au/treat-early/getting-support](http://endinghiv.org.au/treat-early/getting-support)

## ONLINE

There is a wealth of information online and sometimes sorting through this can be a daunting experience with some information being outdated or inaccurate, so access to reliable information is key. Check out the Newly Diagnosed section on Ending HIV for useful links to websites and other services.

**More info:**

[endinghiv.org.au/treat-early/getting-support](http://endinghiv.org.au/treat-early/getting-support)

## HIV - THE BASICS

*Knowing the basics about HIV is important and can empower you to make decisions about your health, your sex life and your general wellbeing.*

*There is a lot of information out there, so understanding the basics is always a good place to start.*

## WHAT IS HIV?

'HIV' stands for human immunodeficiency virus. HIV affects the immune system - the body's defence against infection. HIV reproduces in the body, and without treatment it will gradually weaken the immune system to the point that the body can no longer mount an effective response to infections that can lead to more serious illnesses.

## WHAT IS AIDS?

'AIDS' stands for Acquired Immune Deficiency Syndrome and is rare in Australia. It's the name given to a group of potentially life-threatening infections, called opportunistic infections, and cancers, which can develop when someone has not been taking treatment for many years and their immune system has been significantly weakened by HIV. This is why it is important to start HIV treatment as early as possible.

You can't "catch" AIDS and there is no AIDS test. Untreated HIV causes AIDS and it is HIV that can be passed on.



## MYTHS AND FACTS

*Getting hold of accurate and up-to-date information is the first step towards taking control of HIV.*

*Fortunately, there are many people around to answer your questions. Knowledge is power - once you know more about living with HIV, you'll be in a better place to deal with it.*

## MYTH #1

*'This is the end of my life.'*

HIV is NOT a death sentence. Treatment has come a long way since combination therapy first became available in the 1990s. The number of pills required daily has significantly reduced and treatment has become more effective and easier to take. Before these improvements some people used to experience high levels of toxicity and severe side effects from treatments, but this is now extremely rare. Most people diagnosed with HIV today can expect to live active and satisfying lives into old age, because of the advances in treatment.

Getting the right information and being able to talk to people who have been through the same experience can be a really important part of that process.

## MYTH #2

### *'My sex life is over.'*

After receiving a positive diagnosis, for some it is very normal for sex to be the furthest thing from their mind. For others, receiving a positive diagnosis has no impact on their sex lives at all. Both of these responses are ok and normal. Disclosing your status is not easy at first so it is important to consider who you tell. It is important to find a way of disclosing that makes you feel comfortable and gives you the confidence to handle an unwanted response. This can take a little while to work out. Making contact with a peer-based organisation and speaking to someone who has gone through the same thing could help you to find ways of disclosing your status. Understanding the risk of transmission and collecting enough information, so you can answer questions that may be asked when you disclose, is also a good way of building confidence, both for you and your potential partner.

The a[STARTx] workshop or one-to-one peer support are great ways to begin to develop your skills in managing HIV disclosure. See the back of this booklet for contacts.

## MYTH #3

*'I am afraid of infecting my partner. People have told me that even if I achieve an undetectable viral load, it isn't safe!'*

Being HIV positive does not mean that you are going to infect your partner/s. You and your partner/s can have a fulfilling sex life, and you can help to ensure that they stay HIV negative. Maintaining an undetectable viral load by taking HIV treatments as prescribed stops the onward transmission of HIV from a person living with HIV to an HIV negative person. This is commonly known as 'Treatment as Prevention' (TasP) and is considered one of the most effective risk reduction strategies for preventing the transmission of HIV, alongside condoms and pre-exposure prophylaxis (PrEP). It is important to note that today the person most likely to pass on HIV is someone who doesn't know they have it.

There is more information in the 'Staying Safe' section of this booklet about how to prevent sexual transmission, which includes new technologies like PrEP.

## MYTH #4

*'I've discovered this rash on my body. Is this because something terrible is happening because of the virus?'*

Chances are, probably not. It is quite normal to become much more vigilant about your health and notice things about your body that you might not have noticed previously.

This happens to many people who are living with a range of different health issues and can be a response to a new diagnosis. Rashes and other flu-like symptoms can happen to some people during the seroconversion period (the process of changing from being HIV negative to being HIV positive after exposure to HIV, which usually lasts less than month). These symptoms are rarely serious and do not happen to everyone.

If you are worried about a rash or any other symptoms speak to your doctor or another HIV health clinician who will be able to check that everything is ok.

## MYTH #5

*'My whole life will be different. Everything will change!'*

HIV brings challenges and is probably dominating your thoughts right now, but it is only one aspect of your life. As time progresses you will see that it will probably only have a limited place in your day-to-day life. People living with HIV continue to have careers, families, friends, relationships and lead fulfilling and vibrant lives.

## MYTH #6

*'I will experience side effects from HIV treatment.'*

Improvements in treatment have meant that most people living with HIV lead healthy lives, with little or no side effects from their medication. Advances in treatment mean most people need to take fewer pills than before, in most cases just one pill a day. Speaking with your doctor or peer-based organisation can give you the facts on HIV treatments today. You can find a list of contacts in the back of this booklet.

## LIVING WITH HIV

*HIV doesn't have to rule your life.  
For more and more people,  
HIV is a small, manageable part of  
their day-to-day life.*

*You will have to make choices to  
manage HIV but know that there is a  
variety of support out there,  
so you don't have to make these  
choices alone..*

## WORKING WITH YOUR DOCTOR

Forming a good relationship with your doctor is one of the most important things that you can do for your health. Finding a doctor who works well with you is crucial. It is going to be a long-term relationship and you will make some big decisions regarding your health together (primarily about treatment), so finding a doctor you can trust as well as be open and honest with is important.

HIV treatments can only be prescribed by doctors who have specialist qualifications in treating HIV. These specialists are called 'Schedule 100 Prescribers', or 'S100 Prescribers'. S100 Prescribers practice at certain hospitals, sexual health clinics, and some specialised private GP practices. In some rural areas of NSW these doctors are only accessible at sexual health clinics.

However, if you already have a doctor you like and who you are comfortable with, your doctor may consider working with an S100 prescriber to manage your HIV treatment. If you see a specialist for your HIV treatment you should also have a GP for day to day issues as most health problems are not HIV related.



It is important to inform your GP about your HIV status, as some HIV medications might interact with treatments for other common conditions, such as cholesterol or reflux, and they will need to check before prescribing to ensure there will be no effect on your HIV medication. (See page 50 of this booklet to find a list S100 prescribing doctors).

## **FOLLOW-UP TESTS AFTER A DIAGNOSIS OF HIV**

You may have questions about the tests that your doctor will be giving you - who wouldn't?

Like any chronic health condition, the management of HIV requires ongoing medical care and support. Your doctor will run some tests after diagnosis as a starting point. These provide information about your health at the time you are diagnosed. The most common of these tests are CD4 and Viral Load monitoring. There will be other tests your doctor will carry out, so don't be afraid to ask your doctor about the tests being performed so you understand what they are and why they are being done. Over time you will get used to the numbers and what they mean. The a[STARTx] workshop or speaking to a peer who is also living with HIV at ACON or the Treatments Officers (who live with HIV themselves) at Positive Life NSW can help you understand this information.

Once you have had a couple of visits, you should only need to go for regular check-ups, probably every three to six months (or as required by your doctor). It is important to monitor your health after your diagnosis and to stay connected to good medical care.

## CD4

A CD4 count is one of the ways your doctor will monitor your overall health and how your immune system is being affected by HIV. A CD4 cell (once referred to as a T Cell) is a type of white blood cell and one of the frontline defence cells in your immune system. The normal count for a CD4 cell is 500 to 1200 cells/mL.

When you first become HIV positive your CD4 count could decrease, sometimes dramatically. This is part of a typical immune response, which indicates that your immune system is recognising and attempting to control HIV. Your CD4 count will usually stabilise over a few months. However, this count will then decrease over the next few years if HIV is not treated. It's normal for CD4 counts to fluctuate over time, going up or down, which is why the doctor will test you regularly and look at trends in those levels. When a person has started treatment, their CD4 count usually returns to normal levels when the virus is suppressed.

## VIRAL LOAD

Your viral load refers to the amount of HIV in your blood. When you are first exposed to HIV, your viral load may increase to a very high level and possibly into the millions. Within six months from seroconversion, the process of your immune system developing antibodies to the virus, your viral load may reduce somewhat and stabilise.

Your viral load may range from 'undetectable' to thousands. Results are given in terms of 'copies' per millilitre (mL) of blood. An 'undetectable viral load' is when a person living with HIV has an HIV viral load of less than 200 copies/mL. An undetectable viral load is the goal of effective HIV treatments.

It is important to know that recent advances to tests that detect HIV in the blood can now be as sensitive as to count as few as 20 copies/mL. Despite this, a person living with HIV who has an HIV viral load of less than 200 copies/mL is still considered 'undetectable' and at zero risk of passing on HIV to their partners once they have been on stable treatment for six months.

An undetectable blood result doesn't mean you have zero or no HIV in your blood - but rather, that treatments have dramatically reduced the level of HIV in your

blood to extremely low levels, detectable only by very specialised and sensitive pathology tests.

When you start HIV treatment your viral load will typically fall to undetectable levels (or close to it) and remain there while you continue to take your medication as prescribed. Some people may experience an occasional short-term increase (sometimes called a 'blip') when on treatments, where their viral load may become detectable at low levels. It is not clear why this happens. It could just be that at the time that the blood was taken, you may have had another virus or the test counted broken pieces of the virus. It can also happen if you have missed doses of your treatment. If this happens, your doctor usually says it is nothing to worry about despite it having a bit of an emotional impact on you. Usually your next test will return to 'undetectable.' However, if the count begins to rise over time the doctor may want to check that you are on the right medication. Having a 'blip' doesn't mean you are more likely to pass on HIV, but it is worth monitoring. Always discuss any concerns you may have with your doctor.

## Sexual Health

Regular check-ups for sexually transmissible infections (STIs) should be part of your routine. If you are sexually

active it is important to have an STI screen. You may choose to simply do this each time you go to see your doctor for your HIV monitoring and check-up. If you have been having a lot of sex, more frequent testing is recommended.

It is important to know if you have an STI. If you are not on treatment, some STIs can increase the HIV viral load in cum, pre-cum and anal mucous. For a man living with HIV who is not on treatment, an increased viral load means your immune system is having to work harder and also makes passing on HIV more potentially more likely. An STI does not affect your viral load or increase your risk for passing on HIV if you are on antiretroviral treatment

A sexual health check is easy to have. When you visit your doctor for your CD4 and Viral Load check-up, ask for a sexual health screen as well. You should have STI tests of your urine, throat, arse/rectum and blood for a complete sexual health check at least once a year. You are already at the clinic so why not get everything looked after in the same visit? It will save you a lot of time. If you do get an STI, your doctor can assist you with contact tracing your previous sexual partners anonymously.

**More info:**

[endinghiv.org.au/sti/let-them-know](http://endinghiv.org.au/sti/let-them-know)

[thedramadownunder.info](http://thedramadownunder.info)

## TREATMENT

HIV medications or “HIV Antiretrovirals (ARVs)” are commonly referred to as “treatment” and is the only effective way of controlling the virus in your body. Some people become anxious when considering treatment as they think they are becoming unwell or are concerned about side effects. Neither is necessarily true. Treatment will assist you to manage your HIV, prevent passing on HIV to your sexual partners and most importantly, give you the opportunity to lead a healthy and long life. With the right information and support it is easy to find a combination that works for you.

Advances in HIV knowledge mean that treatments are easier to take and side effects are uncommon. HIV treatment is made up of three different drugs that are usually combined together into one pill. This is sometimes known as your ‘Combination’ or ‘Combination Therapy’. A wider choice of medications allows people to change their combinations if they do experience side effects, and newer combinations are much more effective against the virus, easier to take, and usually require only one to two pills to be taken once each day.

Treatments work best when you take them correctly. Your doctor will explain HIV treatments to you and provide guidance on taking treatments the right way. Taking your medication correctly is also called 'adherence'. It is important to create a routine that you have found that works best for you, such as taking your treatment each day with your breakfast, as an example. If you are regularly missing a lot of your medication or finding it hard to take treatment as has been prescribed talk to your doctor or a peer about finding a better way to remember taking your medications. Irregular adherence can lead to your current treatments losing effectiveness to control the virus. While there are many other options to replace one that has stopped working, changing your treatment can be stressful.

Modern treatments are also highly effective at reducing the amount of HIV in your blood to 'undetectable' levels. In addition to greatly benefitting your personal health, having a sustained undetectable viral load for over six months means there is zero risk of passing HIV on to another person during sex, even when condoms or PrEP aren't being used.

Accessing treatment in Australia is becoming more convenient. There are now three ways you can collect HIV meds.

1. Hospital Pharmacies
2. Local Chemists
3. Online Pharmacies

For more information about picking up your treatments speak with your doctor or visit The Choice is Yours which outlines the range of options to access HIV Treatments. Alternatively, you can talk to ACON or Positive Life NSW, with contact details in the back of this booklet.

**More info:** [thechoiceisyours.positivelife.org.au](http://thechoiceisyours.positivelife.org.au)

HIV Difference is a digital resource which aims to normalise and illustrate how sero-discordance is understood and negotiated in relationships between all people of HIV-difference.

**More info:** [hivdifference.positivelife.org.au](http://hivdifference.positivelife.org.au)



## BENEFITS OF EARLY TREATMENT

We now know that starting treatment immediately or as early as possible after a HIV diagnosis is one of the best decisions to ensure good long-term health. Key findings of a recent study (START study) show that early treatment of HIV extends life expectancy and prevents serious illnesses from developing, including major cardiovascular events (heart disease, stroke), cancer, renal and liver disease. Start talking early on with your doctor about commencing treatment.

Once you start treatment you will be taking it for the rest of your life. If you think this will be a problem, talk to your doctor who will have some tips to help you stay on track with your health and HIV.

To learn more about treatment benefits.

**More info:**

[thechoiceisyours.positivelife.org.au/immediate.html](http://thechoiceisyours.positivelife.org.au/immediate.html)

ACON and Positive Life Evidence Brief for Immediate Update of HIV Treatment.

**More info:** [bit.ly/Evidence-Brief](https://bit.ly/Evidence-Brief)

## LONGER LIFE EXPECTANCY AND QUALITY OF LIFE

Starting treatment immediately or within a few weeks of diagnosis will result in a higher CD4 count and a stronger immune system. Life expectancy for someone diagnosed with HIV today is very similar to someone who does not have HIV.

Anxiety and sometimes depression can come with HIV as a diagnosis can be overwhelming. Talk to your doctor about counselling or contact one of the organisations listed at the back of this resource for help. You do not have to go through this alone.

## REDUCED INFLAMMATION THAT LEADS TO OTHER ILLNESSES

When the immune system detects any infection, including HIV, it commences what's known as an 'inflammatory' response. This is your immune system releasing chemicals that cause inflammation to help control infection. This response is helpful in the short term - for example if you have the flu. But when you have untreated HIV, these chemicals are released continuously over time. That inflammatory response continues while your HIV remains untreated and it can cause damage to the heart, liver, kidneys and brain, which is another reason why it's important to start as early as you're ready.

Starting HIV treatment early can reduce inflammation and chances of damage to your body. For other ways to reduce inflammation, discuss with your doctor.

## STAYING SAFE

*Just because you are HIV positive,  
doesn't mean you have to give up  
your fulfilling sex life.*

*There are many ways you can have a  
rich and full sex life and prevent the  
transmission of HIV.*

*Getting the right information about  
risk and prevention strategies can  
give you the confidence you need to  
ensure your sex life is fun,  
safe and fulfilling.*

## RISK OF TRANSMISSION

HIV is transmitted by bodily fluids like semen (cum - including pre-cum, the fluid present before ejaculation), and mucous from the lining of the arse, or blood passing from a person with HIV into the bloodstream of someone who doesn't have HIV.

There are a range of prevention and risk reduction strategies to brush up on to stop transmission occurring.

## PREVENTING TRANSMISSION

### CONDOMS

If you are not on treatment, condoms are an effective barrier to prevent passing on HIV and are also the best way of reducing your chances of picking up or passing on other sexually transmissible infections (STIs). Condoms, when used correctly with plenty of water-based lube, can prevent fluids passing from one partner to the other when having sex. This makes sex using a condom and water-based or silicon-based lube safe for both partners. If used properly, condoms are extremely reliable.

Wrapped or Raw - a Positive Life NSW digital resource supporting the choice of gay, bisexual and other men who have sex with men (GBMSM) in NSW living with HIV around negotiating sex while minimising risk, maximising pleasure, enabling disclosure and having great sex with other men of all HIV statuses.

**More info:** [wrappedorraw.positivelife.org.au](http://wrappedorraw.positivelife.org.au)

### U=U or UNDETECTABLE = UNTRANSMISSABLE

When a person living with HIV has an undetectable viral load sustained over six months or more, they are unable to pass on HIV to sexual partners. This is referred to as U=U, or “undetectable = untransmissible”. Research from the Partner Study and the Opposites Attract Study showed that there were zero cases of HIV transmission in approximately 58,000 acts of condomless sex where one person had an undetectable HIV viral load and the other person was HIV negative. These two studies show that achieving and maintaining an undetectable viral load is a safe HIV prevention strategy, known as treatment as prevention, or TasP. It is now clear that people living with HIV with an undetectable viral load (below 200 copies/mL) cannot transmit HIV sexually.

An undetectable viral load does not have any effect of protecting you against the transmission of other STIs. If you're not on treatment, having an STI may raise your viral load, potentially increasing the risk of HIV transmission. Getting an STI screen is easy and this can be done as part of your regular testing routine. If you have any STIs, it's important to get them treated.

## OTHER RISK REDUCTION STRATEGIES

'Risk reduction strategies' is a term given to the range of ways used to reduce the risk of passing on HIV.

### **More info:**

[endinghiv.org.au/stay-safe/risk-calculator](https://endinghiv.org.au/stay-safe/risk-calculator)

[thechoiceisyours.positivelife.org.au/prevention.html](https://thechoiceisyours.positivelife.org.au/prevention.html)

## PEP

PEP (Post Exposure Prophylaxis) is a course of anti-HIV medications taken over a four-week period. If someone is exposed to HIV, PEP can prevent an HIV infection occurring, particularly when started soon after possible exposure. People are encouraged to start treatment as soon as possible after 'the event' but within 72 hours (three days) at the very latest.

### More info:

[1800 PEP NOW \(1800 737 669\)](tel:1800737669)

[thechoiceisyours.positivelife.org.au/pep.html](http://thechoiceisyours.positivelife.org.au/pep.html)

## PrEP

PrEP (Pre-Exposure Prophylaxis) is a new means of reducing the risk of acquiring HIV. It involves people who are HIV negative taking antiretroviral medications. When taking PrEP, the medication builds up in a person's system to the point where it is effective in breaking the replication cycle of the virus, which can prevent the virus taking hold in the body and becoming an infection.

### More info:

[endinghiv.org.au/prep](http://endinghiv.org.au/prep)

[thechoiceisyours.positivelife.org.au/prep.html](http://thechoiceisyours.positivelife.org.au/prep.html)

[wrappedorraw.positivelife.org.au](http://wrappedorraw.positivelife.org.au)



## DISCLOSURE

*Telling people your HIV status can be tricky. Sometimes it'll be beneficial to share this information with people like doctors and friends, and at other times you would prefer to keep it private.*

*Disclosure to family and friends will always be a personal choice for you.*

## DISCLOSURE

In 2017 the Public Health Act in NSW changed, no longer requiring the disclosure of HIV status prior to sexual intercourse. The law does require, however, that someone who knows that they have HIV, takes 'reasonable precautions' against transmitting the virus to others.

Reasonable precaution refers to minimising the risk of passing on HIV to other people through the following precautions:

- using a condom during sexual intercourse; or
- the HIV positive partner seeks and receives confirmation from a sexual partner that a sexual partner is on HIV pre-exposure prophylaxis; or
- the HIV positive partner has a suppressed HIV viral load of less than 200 copies/mL

ACON and Positive Life recommends that people living with HIV consult their doctor about the best ways to protect their sexual partners in their specific circumstances.

ACON and Positive Life encourage that the responsibility for discussing and disclosing HIV status belongs to every individual - not just people living with HIV.

\*It is important to note that the information provided only pertains to the Public Health Act in NSW. If you are travelling or reside outside of NSW, you should be aware of the different legalities in regard to HIV disclosure in the states and territories.

For more information on HIV disclosure in regard to the Public Health Act in NSW, please see:

**More info:**

[health.nsw.gov.au/phact/Pages/pha-s79.aspx](http://health.nsw.gov.au/phact/Pages/pha-s79.aspx)

HIV Difference is a digital resource which aims to normalise and illustrate how sero-discordance is understood and negotiated in relationships between all people of HIV-difference.

**More info:** [hivdifference.positivelife.org.au](http://hivdifference.positivelife.org.au)

## SHARING YOUR STATUS WITH OTHERS

It is understandable that you may want to tell friends and family about your HIV diagnosis. You may want their support or just someone close to talk to. When thinking about opening up to friends or family about your diagnosis carefully consider these few points before you do.

1. Why are you telling them? Be sure and at ease with your motive before disclosing.
2. Once it's out there, you can't take it back. Be sure that the person you are telling is someone you can trust not to share your information with others.
3. Not everyone understands what HIV is like today. Some people may be misinformed and may worry about your health. You may have to provide them with some support and information when disclosing (having this booklet with you may help), which might be too much for you at this time.

If you need to 'unload' right away, perhaps just to talk things through with a willing listener, there are understanding and knowledgeable people you can talk to in strict confidence either on the phone or face-to-face. Services can be found in the back of this booklet.

## WHAT ABOUT EMPLOYERS?

There is no obligation by law to disclose anything about your diagnosis to your employer. Before you disclose to your employer it is advisable to seek legal advice particularly if you are unsure of your working conditions. If you do disclose to a manager, they are required by law to keep this confidential and provide the right support for you in the workplace. It is illegal for an employer to discriminate against you within the workplace. There are severe penalties for an employer disclosing your status without your consent.

**More info:** [halc.org.au](http://halc.org.au)

# ALCOHOL AND OTHER DRUGS

*A diagnosis of HIV does not mean that you cannot use alcohol and other drugs; however there may be some new things for you to consider.*

Partying frequently or for long periods can make sticking to HIV treatment more complicated and can cause you to miss treatment doses. It's important to plan ahead effectively so that you continue to take your HIV treatment on time, even if you're partying for a long time.

Some treatments make the effect of recreational drugs, like ecstasy and crystal meth, stronger than they would be normally. If you are going to use, talk to your doctor or a healthcare professional first about their interactions; taking smaller amounts first to gauge the strength is advisable.

This website gives detailed information about which HIV medications interfere with different recreational drugs:

**More info:** [hiv-druginteractions.org](http://hiv-druginteractions.org)

If you want to speak to someone about HIV treatments and alcohol and drug use, information is available from the alcohol and other drugs contacts at the back of this booklet. If you feel that drinking or drug use is a problem, there are good services available that can help you make decisions about what to do. See the back pages of this booklet.

## CONCLUSION

*This booklet has covered some of the basic information about HIV.*

*You may have more questions as you are just getting started. It is important to take things slowly and build your knowledge gradually.*



Hopefully this booklet has given you some practical information about being diagnosed with HIV today. It is manageable and you will get through this time. Support is out there if you need it, or if you just need more information, that is out there too. HIV has changed from years gone by, modern treatments mean that you can lead a long and full life.

The next few pages list other booklets, websites, support services and people you can talk to in confidence.

### **Remember**

- + You are not alone
- + Modern treatments are highly effective
- + It can be useful to talk to other people living with HIV who have been where you are right now.

## FURTHER READING

*This is a list of booklets for people recently diagnosed with HIV.*

*You can get these from support services or call your local ACON office for copies to be posted to you.*

## ENDING HIV (ACON)

An initiative to end new HIV transmissions by the year 2020. Doing this is possible by Testing More + Treating Early + Staying Safe.

[endinghiv.org.au](http://endinghiv.org.au)

## SUPPORT SERVICES

Meeting other people living with HIV who understand what you are going through can be a great way of gaining reassurance and finding answers to your questions. Although they will have different experiences around their diagnosis, they remember what it was like for them and what helped them get through this period. Confidential support from a professional can also be invaluable. Most of these services and groups are in Sydney, but ACON regional offices offer support across NSW, and can also tell you about other services available in your region.

## ACON

ACON is New South Wales' leading health promotion organisation specialising in HIV and LGBTI Health.

ACON offers services in Sydney and throughout NSW.

1800 063 060

[acon.org.au](http://acon.org.au)

## COUNSELLING SUPPORT

Post-test counselling support for people recently diagnosed with HIV and others affected, including partners, family and friends.

(02) 9206 2000

## a[STARTx]

Weekend long, non-residential workshop for gay and bi men recently diagnosed with HIV, run by other men living with HIV. a[STARTx] covers topics such as HIV treatments, HIV disclosure, building resilience and managing your sex life while living with HIV.

[astart@acon.org.au](mailto:astart@acon.org.au)

[endinghiv.org.au/treat-early/getting-support](http://endinghiv.org.au/treat-early/getting-support)

## PEER SUPPORT

People living with HIV (peers) who provide one-on-one peer support to gay men living with HIV who want someone who understands, but don't necessarily want to speak to a counsellor.

(02) 9206 2000

[astart@acon.org.au](mailto:astart@acon.org.au)

## ACON'S ALCOHOL AND OTHER DRUGS PROGRAM (AOD)

Provides support services and health promotion programs to people who use illicit (illegal) and licit (legal) drugs.

(02) 9206 2000

[acon.org.au/what-we-are-here-for/alcohol-drugs/](http://acon.org.au/what-we-are-here-for/alcohol-drugs/)

## SUBSTANCE SUPPORT SERVICE

ACON's Substance Support service provides free short-term face to face, phone or Skype counselling of up to 12 sessions with the ability to re-enter as required. Counsellors assist people to better manage their use, cut down or quit. ACON also provides counselling for partners, friends and family affected by a loved ones' AOD use.

(02) 9206 2000

[intake@acon.org.au](mailto:intake@acon.org.au)

## POSITIVE LIFE NSW

Works to promote a positive image of people living with HIV, including their partners, family and friends. Positive Life NSW provides information and targeted referrals, and advocates to change systems and practices that discriminate against people living with HIV in NSW. They have Treatments Officers who also live with HIV themselves, who can also provide you with assistance.

Positive Life offers a Work Ready program for people living with HIV who want some support to engage or reconnect in life through study, training, paid (casual, part-time or full-time) or voluntary work.

Positive Life has a Housing Support Officer to support people living with HIV access, achieve and maintain stable accommodation, including risk of homelessness.

Positive Life also offers a Peer-led partner notification service (also called contact-tracing) which provides support from someone else who has been through the process of notifying our sexual and injecting partners that they have potentially been put at risk of an infection.

[positivelife.org.au](http://positivelife.org.au)

## HIV/AIDS LEGAL CENTRE (HALC)

Free legal advice, information and referral for people living in NSW with an HIV-related legal problem.

(02) 9206 2060

[halc@halc.org.au](mailto:halc@halc.org.au)

[halc.org.au](http://halc.org.au)

## MULTICULTURAL HIV/AIDS AND HEPATITIS C SERVICE (MHAHS)

The Multicultural HIV and Hepatitis Service (MHAHS) works with culturally and linguistically diverse (CALD) communities in NSW to improve health and well-being in relation to HIV, hepatitis B and hepatitis C.

The service works with more than 20 language groups and implements a range of health promotion, community development and media initiatives, as well as offering individual assistance to people living with HIV through emotional support, liaising with case managers or other health care workers, and discussions about treatment options. Services are also available to partners and family members.

(02) 9515 1234 or 1800 108 098

[info@mhahs.org.au](mailto:info@mhahs.org.au)

[mhahs.org.au](http://mhahs.org.au)

## The Australasian Society for HIV Medicine (ASHM)

S100 DOCTORS For a list of S100 prescribing doctors in NSW see fact sheet online.

[ashm.org.au/images/prescriber/ashmprescribers.pdf](http://ashm.org.au/images/prescriber/ashmprescribers.pdf)

## SEXUAL HEALTH CENTRES

Your local Sexual Health Centre (often attached to a public hospital) may also have confidential counsellors available. Contact your local 'sexual health clinics for your nearest location, including regional clinics.

[endinghiv.org.au/nsw/where-to-test](http://endinghiv.org.au/nsw/where-to-test)

## NSW SEXUAL HEALTH INFOLINK

The Sexual Health InfoLine is a NSW Ministry of Health funded information and referral telephone line and website. InfoLink has been in operation since 1989 and is staffed by specialist sexual health nurses from 9:00am to 5:30pm. InfoLink provides sexual health information and referral to community members and provides specialist clinical support and information to nurses, doctors and other professionals who are treating clients with sexual health issues.

1800 451 624

[shil.nsw.gov.au](http://shil.nsw.gov.au)



## THE INSTITUTE OF MANY

The Institute of Many (TIM) is a peer-run group for people living with HIV, who meet online and socially.

[theinstituteofmany.org](http://theinstituteofmany.org)

## GLOSSARY OF TERMS

In this section: Common terms that a newly diagnosed person may come across.

### **AIDS (Acquired Immune Deficiency Syndrome)**

Acquired Immunodeficiency Syndrome is a condition in which HIV has severely weakened someone's immune system making them vulnerable to life-threatening infections and cancers.

### **Antiretrovirals**

The name for the type of treatments that fight HIV (which is a retrovirus). Different antiretrovirals work at stopping the virus at different stages of the HIV life-cycle.

### **ART (Antiretroviral Therapy)**

Anti-retroviral therapy, also known as HIV treatment, is the use of a combination of different drugs for ongoing treatment of people living with HIV.

### **CD4 Cells**

The body's white blood cells that help fend off infections. In regard to HIV, these are targeted and destroyed by the virus, subsequently weakening the immune system.

### **CD4 Count**

A measure of the number of CD4 cells (or T-helper cells) in someone's blood. CD4 cells are a type of immune system cell in the body that HIV attacks and kills over time. The lower the CD4 count, the weaker the immune system.

**Contact tracing**

Contact tracing is the process of identifying all sexual contacts and anyone who have shared injecting equipment who need to be made aware of their HIV risk.

**Drug resistance**

When a drug's effectiveness is reduced. This can lead to treatment failure for people living with HIV.

**HIV (human immunodeficiency virus)**

Human Immunodeficiency Virus is a virus that attacks the body's immune system. HIV can be transmitted by bodily fluids, such as blood and semen, during sex. There is currently no cure or vaccine for HIV.

**Opportunistic Infections**

A type of infection that occurs in people with a weakened immune system. People living with HIV are at greater risk of acquiring these.

**Replication**

This is the process whereby HIV makes multiple copies of itself, using the body's CD4 cells.

**Viral Load**

A term used to describe the amount of HIV in someone's blood. The higher the viral load, the more HIV present.

**UVL**

Undetectable viral load. When someone living with HIV takes treatment, they can lower their viral load to be 'undetectable'. This provides health benefits for the individual, as well as preventing onwards transmission.

# Memo

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

# Memo

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

# Memo

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

# RECENTLY DIAGNOSED?

ACON offers counselling or peer support services for men who are recently diagnosed or needing support with their experience living with HIV.

## NEWLY DIAGNOSED program

Counselling support and information for people recently diagnosed with HIV or affected by a HIV diagnoses including partners, family and friends.

## a [START<sub>x</sub>]

a[START] peer navigators  
a[START] Workshop

Connect with guys who have lived experience of HIV, to share and gain information and support.

Follow up is provided within one working day and assistance can be offered through face-to-face meetings or by telephone.

**Find out more contact us on**

02 9206 2000

[astart@acon.org.au](mailto:astart@acon.org.au)

[acon.org.au](http://acon.org.au)



