

POSITIVE WOMEN VICTORIA

Women and HIV Media Guide



"I think sometimes we stigmatise ourselves because of the past. We think, 'oh yeah, how are they going to perceive me', and stuff like that. It's (stigma) within us as well."

Gugumela*, member, Positive Women Victoria



PositiveWomen

Support and advocacy for women living with HIV



CONTENTS

Reporting on HIV	3
Issues Faced by Women Living with HIV	4
U=U and Ending HIV Stigma	6
Effects of HIV Stigma	7
HIV and the Law	8
Interviewing Women Living with HIV	9
Preferred Terminology	10
Published News Articles	10
About Positive Women Victoria	11

*names changed to ensure privacy.

Images throughout this guide by Kate Disher-Quill and LDV Photography.

REPORTING on HIV

The *Women and HIV Media Guide* provides journalists with information that enables accurate and sensitive reporting of stories about women living with HIV. We encourage journalists, researchers and other people who may be asking women with HIV to tell their personal stories to read this guide.

This resource is designed to help you understand the role you can play in challenging outdated and stigmatising myths about HIV, and raising awareness across the community of important developments in HIV treatment and prevention.

Among the key messages you will find in this Media Guide, there are two facts that are especially important and are explained here:



HIV can be effectively treated. With effective treatment, people living with HIV are able to live healthy, productive lives.

These important developments together challenge the misinformation and myths that are behind HIV stigma.



Effective treatment can reduce levels of the replication of HIV in peoples' blood to levels too low to be detected by standard blood tests, a state known as undetectable viral load. A person with an undetectable viral load is unable to transmit HIV to their sexual partners. This development is sometimes referred to as: Undetectable = Untransmittable (or Untransmissible) or U=U.

Your role

With this media guide — and as a journalist, writer, researcher or interviewer — you have the power to use these facts to challenge outdated myths, and help all people with HIV, including women living with HIV, live free of the burden of stigma, judgment and discrimination.

"We were sure that there must be other women out there facing the same things, so we decided to set up a group for positive women."

Bev Greet OAM, HIV activist and Co-founder, Positive Women Victoria



ISSUES FACED by Women Living with #IV

There are an estimated 750–800 women living with HIV in Victoria with an estimated 3,370 women in Australia (as at the end of 2018). This is around 12 percent (of the approximately 28,000) of people who are living with HIV in Australia.

In Victoria in 2018, 28 women were newly diagnosed with HIV, representing approximately 10 percent of those newly diagnosed in Victoria.

While PrEP (pre-exposure prophylaxis) — a drug available in Australia that can be taken to prevent HIV transmissions occurring — is helping to reduce new HIV diagnosis among men who have sex with men, HIV transmissions among heterosexual people are not declining, and many heterosexual men and women may not realise that they are at risk of HIV.

Heterosexual sexual contact continues to account for 25 percent of people newly diagnosed with HIV nationally.

Positive Women Victoria (PWV) engages with a diverse group of women living with HIV. Some of our members are newly diagnosed, and for many, their diagnosis was unexpected. For others, their contact with Positive Women Victoria was the first step in connecting with and seeking support from the community of women living with HIV.

Prior to their diagnosis, many women living with HIV had little or no prior knowledge of HIV, treatment options and support. Women are at risk of being diagnosed at a late stage of infection, because they may not realise that they have been exposed to HIV. Sometimes, doctors can contribute to the myth that women are not at risk of HIV because they do not necessarily think to offer a HIV test, or may even incorrectly reassure women who ask for testing that women are not likely to be at risk.

PWV works with agencies to demystify and destigmatise HIV testing, and encourages testing to be viewed by doctors as a routine part of sexual health care.

"It is not until people start feeling unwell that they may discover they have HIV ... or until a HIV test is required for a job, life insurance, a test during pregnancy or in some cases, like me, for a visa for travel. Or it could be because they are very sick and it is a late stage diagnosis and they have an AIDS defining illness."

Heather Ellis, Peer Project Leader and member, Positive Women Victoria

750–800

women living with HIV in Victoria



In Victoria in 2018, 28 women were newly diagnosed with HIV



Around the globe, over half of all people living with HIV are women. Our membership reflects this, and is very diverse in age, cultural background and personal stories told, with many different languages spoken by our members.

Among the most common questions asked of our peer support workers are: Am I going to die? Will I be able to have children? Is my family or partner at risk of HIV? Will I experience treatment side effects?

Women living with HIV can also be dealing with a range of other complex issues. These include: other health concerns or diagnoses, including mental health concerns; financial, employment or housing insecurity; immigration or residency issues; family or intimate partner violence.



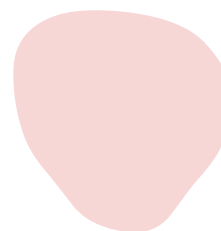
Around the globe over half of all people living with HIV are women



"I attended an HIV function in Melbourne and was asked by a man who realised I was HIV positive: 'How did you get it? Did you sleep with a gay man?' I was flabbergasted by his naiveté.

I replied: 'How do you think most people get HIV? By having sex without a condom with someone who does not know they have HIV'."

Susan Paxton, HIV activist and member, Positive Women Victoria



U=U AND Ending HIV Stigma

The Undetectable equals Untransmittable (U=U) message, endorsed by more than 20 years of scientific evidence, is a global call to action to change public opinion on HIV transmission and end HIV stigma.

U=U is both transformative and liberating for women living with HIV because it proves that people living with HIV on antiretroviral treatments with an undetectable viral load (meaning the virus is not detected in a blood test), cannot transmit HIV.

While the evidence base has been growing for many years, the U=U concept was launched in the United States in 2016 by the Prevention Access Campaign.

When HIV is successfully treated (with one of many potent and well-tolerated antiviral drug options now available) and a person obtains an undetectable viral load, the risk of transmission to sexual partners, or to a baby during pregnancy or childbirth, is removed.

Quite simply, this means women living with HIV who are maintaining successful treatment can confidently look forward to the prospect of pregnancy and motherhood.

There is also recognition that in many instances, women who are living with HIV can consider breastfeeding their newborn as a potential option.

In developing countries, the WHO (World Health Organisation) supports breastfeeding noting water quality is a concern. In some developed countries, like the UK and Switzerland, women living with HIV with an undetectable viral load and with supportive medical care can choose to breastfeed.

In Australia, breastfeeding guidelines have been developed by medical professionals with input from Positive Women Victoria (PWV) and other HIV sector organisations. PWV believes that with the right information and the support of a doctor, breastfeeding can be a legitimate choice open to women living with HIV.



"Every day for a month, we measure out an antiretroviral solution into a syringe. It smells like jelly beans, and my baby son gulps it up greedily.

A hard-won moment of sleep is thwarted by an alarm reminding me to take my own meds. This show, too, must go on. But it gets easier.

Tests come back negative. He puts on weight. He's happy. He's healthy. He's still beautiful. Together with my specialist, I work through those fears. She helps me to understand. 'Just enjoy him', she urges me. She's a mum too. She knows her stuff."

Brittney*, member, Positive Women Victoria

EFFECTS of HIV stigma

Stigma hinders people living with HIV from reaching their full potential and can cause social isolation, mental health conditions such as depression, and can lead to drug and alcohol abuse.

Women living with HIV face many specific gender-based aspects to stigma and discrimination including: assumptions made about HIV transmission; judgemental attitudes to women with HIV who are mothers; sexual violence and discrimination against transgender women; discriminatory attitudes in the health care setting; the 'dual stigmas' of injecting drugs and sex work; racism for Aboriginal and Torres Strait Islander women, those born overseas, or those from culturally or linguistically diverse backgrounds.

"With an undetectable viral load, it's my choice if I tell someone my status before sex, especially with casual partners. There is no risk of me transmitting HIV and when you realise that, you don't need to say anything. This gives you a lot of confidence in your own sexuality. You need to trust the science."

Sarah, member, Positive Women Victoria

Due to fears over rejection, and in some cases violence, women living with HIV may also close themselves off from dating. Many suffer anxiety about telling their potential intimate partners they have HIV because of the ignorance about HIV and its transmission and especially about U=U. Supporting women, through peer-led efforts, to feel safe and confident to tell family, friends and intimate partners is crucial to building resilience.

For more information on U=U visit [PositiveWomen.org.au](https://www.positivewomen.org.au).

Or view the booklet, [Understanding U=U for women living with HIV](#) (ICASO Community Brief, September 2018).



HIV and the Law

There is no legal requirement in any Australian state or territory for a person to tell someone they have HIV before sex, provided the person living with HIV takes reasonable precautions to prevent HIV transmission. However, 'reasonable precautions' are not defined by law and these public health laws are still catching up with the scientific research that supports U=U.

People living with HIV may not want to tell a sexual partner for a number of reasons such as being subjected to stigma, emotional and physical abuse, their HIV status being shared with other people without their consent, and blackmail. Women especially fear violence, when they tell a potential sexual partner. This is another reason the U=U message is important and empowering.

For the latest information on HIV and the law visit [Living Positive Victoria](#).

"In the past, I struggled to share my story about living with HIV because of the stigma. I am originally from Africa and being in Australia, I have witnessed that many women, especially women from migrant backgrounds, still do not feel comfortable talking about their HIV status because of the shame and guilt associated with it.

We still have a long way to go to break down the silence. One of the most effective ways of challenging stigma is the visibility of people with HIV."

Heather M, Peer Engagement & Research Coordinator and member, Positive Women Victoria



"Support from other HIV positive women gives us strength to move past it being a large part of our lives, to HIV being a very small part of each of us; something that does not define us.

Today when we get together it's to celebrate: marriages, births, graduations, our achievements, living well with HIV or just to have some fun. And we certainly have a lot of fun when we are together."

Emma, member, Positive Women Victoria

INTERVIEWING

Women Living with HIV

A media interview should be an empowering experience and should not leave the interviewee uncomfortable, unhappy or traumatised.

When interviewing a woman living with HIV, the question 'How did you get it?' can sound judgemental especially if this is asked at the very start of the interview.

Often, this question will be answered as the interview progresses as it is part of a woman's journey in living with HIV. It is the beginning.

Positive Women Victoria requires the following to be observed when interviewing a woman living with HIV:



The interviewer must provide an idea about the questions to be asked.



The interviewee can terminate the interview at any time if they feel uncomfortable.



If a translator is required, care should be taken not to misinterpret quotes.



The interviewee and Positive Women Victoria requests to view the story before publication.



The interviewee has the right to protect her identity if she chooses.

Since the beginning of the HIV pandemic, stigmatising language has sometimes been used when reporting on HIV issues.

You can help us challenge HIV stigma by using preferred language when reporting about HIV and interviewing women and other people living with HIV.

For a full list of preferred language, please visit [The Well Project](#).

PREFERRED Terminology

Journalists can help challenge the outdated information, myths and stereotypes that reinforce stigma.

By using factually accurate and clear language when writing about HIV, you will help avoid clichés and judgemental or emotional terms.

Here, we suggest alternative terminology to some commonly-used terms.

For further information on preferred language visit [The Well Project](#).

Stigmatising	Preferred
Sufferer Victim	Woman (or person) living with HIV
Infected	Contracted Acquired Diagnosed with HIV HIV transmissions
AIDS virus (acquired immunodeficiency syndrome) refers to a number of illnesses acquired when HIV destroys the immune system	HIV
Death sentence Life-threatening condition	HIV is a chronic manageable health condition when people are on antiretroviral treatment

PUBLISHED News Articles

The following are examples of accurate and sensitive reporting on women living with HIV.



You Can't Ask That "HIV Positive"
ABC TV, Season 5, Episode 5



U=U and dating in 2020
Positive+ Living magazine, NAPWHA



What it's like living with HIV
ABC Life



HIV misconceptions leading to delayed diagnosis
ABC News



Thinking positive: what it's like living with HIV today
Vogue



For more details on accurate and sensitive reporting on HIV issues, please refer to the [HIV Media Guide: Information For Journalists](#) produced by AFAO (Australian Federation of AIDS Organisations).

ABOUT

Positive Women Victoria

Positive Women Victoria (PWV) is the only community-based HIV organisation in Australia that is funded to provide peer support, information and advocacy specifically for women living with HIV.

PWV was founded in 1988 by two women (Bev Greet and Deborah Gillies) as a result of their isolation following their positive HIV diagnoses. It was a time when HIV was so stigmatised and women were a minority within a minority, making them all but invisible in an epidemic that was overwhelmingly affecting men who have sex with men.

PWV continues to respond to the changing needs and emerging issues affecting women living with HIV and recognises the impact gender has on the way women experience HIV.

PWV is funded by the Victorian Department of Health and Human Services with some funding from grants, bequests and donations. We work closely with a number of HIV sector and other community organisations, including Living Positive Victoria, a community-based organisation supporting people who live with HIV, and Thorne Harbour Health, a leader in health promotion

for gay, lesbian, bisexual, trans and gender diverse communities. We are also an associate member of the National Association of People Living with HIV Australia (NAPWHA).

Our vision is that all women and girls living with HIV in Australia are free from stigma, and supported in their unique journey. Our mission is to support, represent and promote effective change for women and girls living with HIV to enable their needs to be met.

Dr Kirsty Machon, Executive Officer, says PWV provides a safe space for woman living with HIV to gain personal support and to be referred by peers into pathways to access treatment, care and referral without discrimination or barriers.

Contact information:

Dr Kirsty Machon, Executive Officer
Positive Women Victoria

E | kirsty@positivewomen.org.au

M | 0478 827 217

"The Australian community needs to know and see that women are living with HIV, and that women with HIV have relationships, sex, children and families, careers, and rich and rewarding lives.

Since the 1980s, HIV has changed so much and it continues to change as new treatments are continually being developed. This is fantastic, but we are also still focused on ultimately finding a cure, too."

Dr Kirsty Machon, Executive Officer,
Positive Women Victoria



Positive Women Victoria
Coventry House
Ground Floor, 95 Coventry Street
Southbank VIC 3006

E | info@positivewomen.org.au
W | PositiveWomen.org.au
PH | (03) 9863 8747

Positive Women Victoria acknowledges the lands on which we work are on the traditional lands and waterways on the Kulin Nations.

We pay our respects to Elders both past, present and emerging, and acknowledge their continued spiritual relationship and connection to their country.



PositiveWomen

Support and advocacy for women living with HIV