

TALKABOUT

WHERE WE SPEAK FOR OURSELVES

Annual Magazine 2019

The best of Talkabout

A compilation of the
year's most popular
contributions.

Today it's not
hard to take care
of yourself and
live life to the full
with HIV.

Fresh options
with choices and
changes around
HIV are greater
than ever!

Sydney in the 70s
was a cool place
to explore your
sexuality, it was
adventurous.

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imply any status, sexuality or behavioural characteristics.

PositiveLifeNSW
the voice of people with HIV since 1988



A magazine for and by people living with HIV

Talkabout is the flagship publication for Positive Life NSW. It's an expression of the personal, social and political viewpoints of PLHIV and aims to represent our community in a way that is within our control.

Talkabout has a long history in our community, finding it's feet in 1988. And now, this new annual printed format brings you the most popular articles from today's online editions.

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If you'd like to know more about contributing or being interviewed, please contact the Talkabout Editor.

Opposite page: Twin brothers, Tim and Jonathan Vincent, Talkabout cover Dec/Jan 1997/98 photographed by C.Moore Hardy. "You can't kill the spirit that helps us all handle this epidemic. In many ways, we support each other and motivate ourselves to overcome the obstacles that HIV throws in our way."



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It's time to speak up and speak out

This edition explores themes
of freedom in an environment of
change as we live with HIV.



Craig Cooper

CEO, Positive Life NSW

Welcome to the first printed annual edition of *Talkabout!*

As we arrive at the final year of the ambitious NSW Health strategy to virtually end HIV transmission in NSW by 2020, *Talkabout* is making a comeback on an annual basis. Published from 1988 until 2014 when it moved into the online space as an electronic magazine, this edition of *Talkabout* holds the most popular articles from the online version of *Talkabout* as we explore themes of freedom in an environment of change as a people living with HIV (PLHIV).

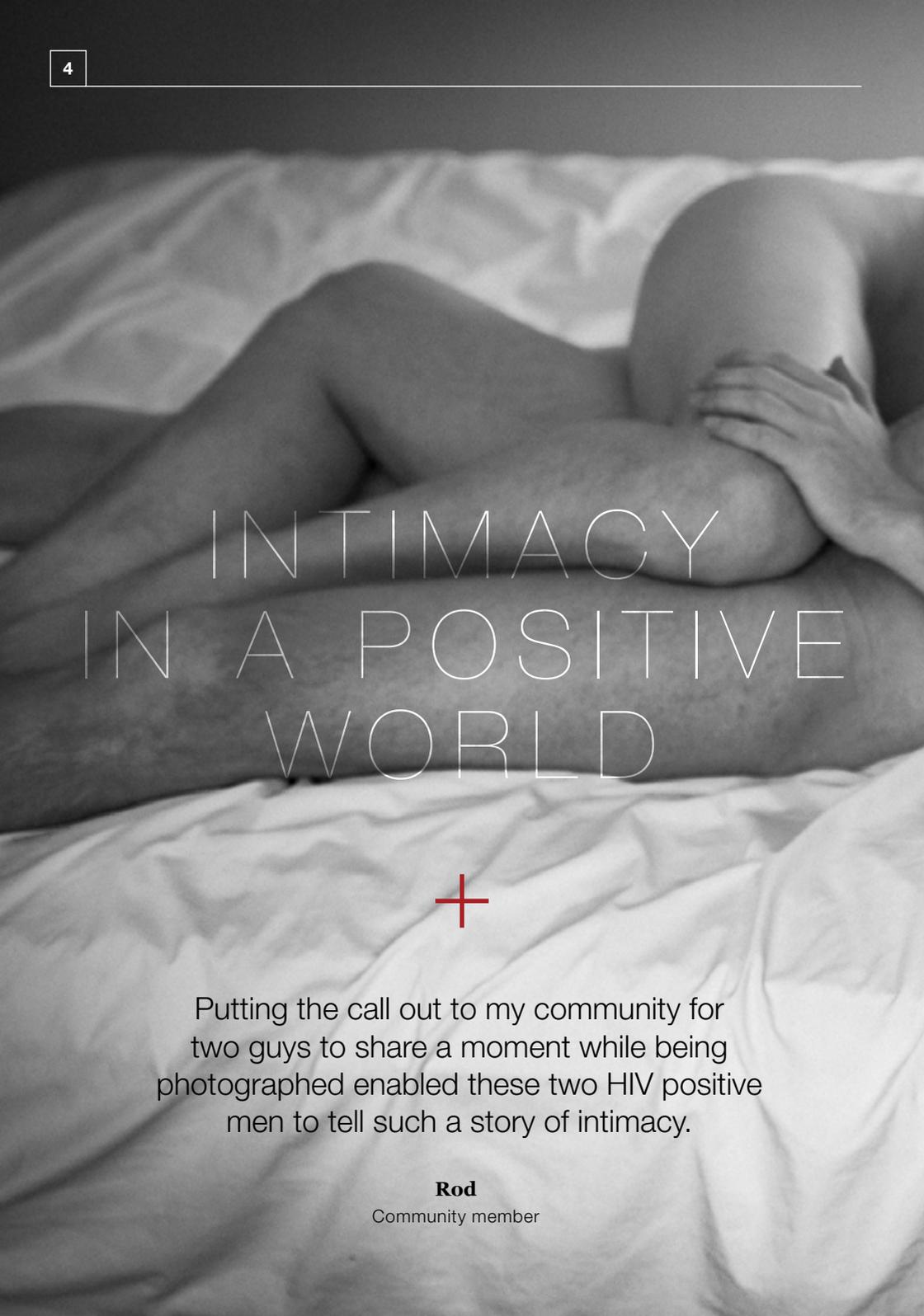
'Intimacy in a positive world' (page 4) celebrates the freedom we have today in an era of Treatment as Prevention (TasP), Zainab shares the freedom she's found through her journey with HIV (page 8) while Adrian (page 58), Roy (page 76) and myself (page 42) write how increased options around medication today frees us to make choices and decisions that work for us.

Our voices in this edition reflect on the ever-present influence of change

in our lives especially how the conversation about living with HIV is changing (page 20), changes in how doctors communicate with us (page 78), and how taking action on behalf of ourselves still inspires courage and effects change (page 66).

The impacts of HIV on the intersectionality of gender (page 26), poverty (page 76), substance use (page 30), cultural (page 44), linguistic and trans (page 14) experiences emerge as strong voices from our personal stories. If one thing has not changed, this is not a time for silence (page 54). Even today, our voices must continue to be raised, in this time where silence still equals invisibility or even death (page 10). The voices of those of us free from HIV, find that speaking up in the prevention and testing space ensures the best choices for our health.

I encourage you to share our voices in this copy of *Talkabout* and raise awareness amongst your friends and family, that we are still here loving and living with HIV. 



INTIMACY IN A POSITIVE WORLD

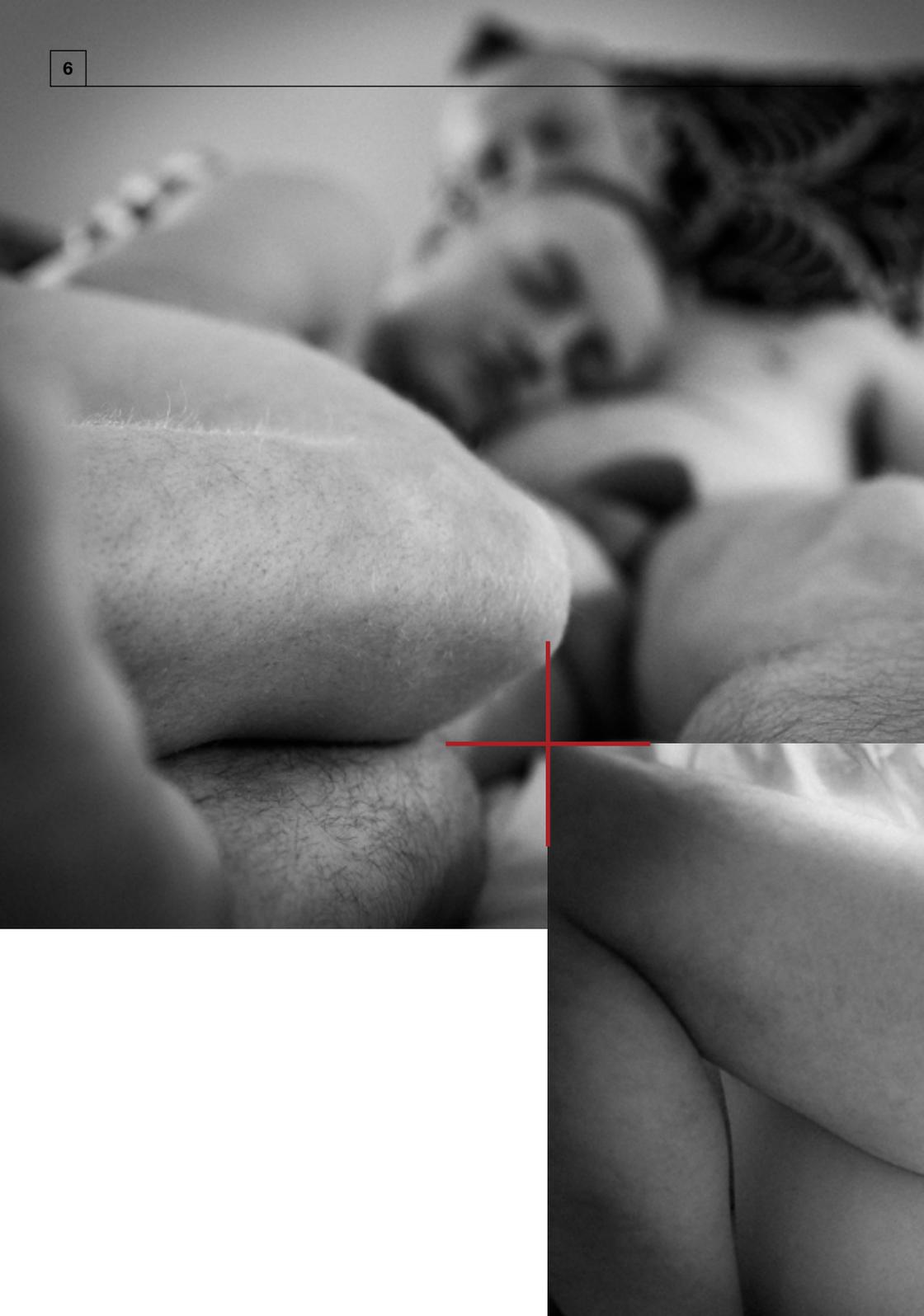


Putting the call out to my community for two guys to share a moment while being photographed enabled these two HIV positive men to tell such a story of intimacy.

Rod

Community member





Living with HIV currently means leading a full life with all the adventures and possibilities life can throw at us.



Some could see this as bravery, others as a statement of “this is life. I'm OK – get over it”.

May we vale the Grim Reaper campaign to the ignominy that it belonged to in the first place. Living with HIV currently means leading a full life with pretty much all the adventures and possibilities life can throw at us. Stigmatisation and fear of rejection for being HIV positive are not completely a thing of the past, but a broader understanding of a life living with HIV which leads to less intolerance.

Treatment as Prevention (or TasP) is used by people living with HIV to live healthier lives and reduce transmission of the virus. Today it is recommended that anti-retroviral treatment be started immediately after diagnosis to reduce the viral load to ‘undetectable’. Many recent studies have shown that a continuous undetectable viral load means transmission of the HIV virus has proved to be basically zero. 



Muslim and living with HIV

Refugee, mother, alone and living with HIV.
Zainab shares her journey out of shame.

Zainab

Community member

About twenty years ago, I never would have thought I'd be alive today. I was thirty two, and a mother, when I was told I was HIV positive at the refugee detention centre.

I associated HIV with death, and death alone. Nothing else came to my mind. I refused to accept the diagnosis, believing that I didn't fit the HIV stereotype. "I was only married twice, and they were both healthy," I sobbed to the doctor. I underwent a second medical check-up and the result was the same.

The questions asked by the medical professional were too confronting for me and I couldn't hear or answer what was said. Although I was a very late diagnosis and had AIDS dementia, I only had a detectable viral load count of 8,000. "That's why you are still alive," the doctor said to me. Based on the few questions I was able to answer,



it became clear that I was most likely infected with HIV when I was young.

I was told that I'd be dead within two to five years if I didn't start medication as soon as possible, as I had a very low CD4 count. At this point all I could think was "what about my children", "how will I deal with this?" and "how will I tell my family?" Fear of rejection, being discriminated against and shame overcame me. Unfortunately, these fears came true. I was humiliated, abused, bashed and called all sorts of horrible names.

Somalia, my country of origin, is the only nation with a 100 percent Muslim population. It is also a predominantly patriarchal nation. I had an arranged marriage when I was twelve years old and my first child when I was thirteen. At the age of six, I underwent Female Genital Mutilation (FGM) with four other girls from the neighbourhood. The same blade was used over and over, without any anaesthetic. Looking back, I can see the risks and my vulnerability.

People still found it easy to point their finger at me when I rejected the man chosen for me. They said I must be a whore to run away from him. The reality is as a woman in the Islamic world, it is a sinful thing to disobey a husband who has been chosen for her.

I could hardly handle the stress of being in the detention centre as a refugee and being diagnosed with HIV, so I isolated myself. After I was released from the centre, I was in and

out of hospital and at the same time I needed to raise my two children, who were both under ten years of age. During this period, I never thought I'd live to this day. My arranged husband passed away about 13 years ago from an AIDS-related illness, yet all of my children, conceived during this marriage, are healthy.

After many years of humiliation and soul searching, I'd finally had enough of being mistreated. To move on, I knew I had to accept the situation I was in and stop feeling guilty. So I joined Positive Life NSW and they trained me to become a public speaker. This experience has been liberating.

Being HIV positive has changed my life in so many ways. I have vowed that no girl should have to experience what I went through and I am doing my best to improve the lives of women in my community. Child bride marriages and FGM are no longer practiced amongst my family and friends. I speak at schools and in the community and I have inspired many. I have gained so much knowledge, met so many different people and made so many friends.

Today, I am not ashamed of being HIV positive. I am my own woman and I deserve to live my life accordingly. I am much happier and much healthier than I have ever been, so why should I be ashamed of being HIV positive? 

AIDS SILENCE



INVISIBILITY

Craig Cooper
CEO, Positive Life NSW

The truth be told, there are still people dying of AIDS in NSW and Australia. I know this is a shocking truth, but my concern is the continued silence and lack of visibility about this sobering fact in our community and more broadly, in our society.

In 2016, the World Health Organisation reported Global Health Observatory data that one million people died of HIV related illnesses. For people diagnosed with advanced HIV disease, there's a chance they'll receive an AIDS diagnosis. We have absolute clarity about what it is like for people receiving an AIDS diagnosis or a diagnosis of advanced HIV disease. Their family and friends and the clinical staff involved in their treatment and care know this is shocking and difficult, and how scary and saddening this is for everyone involved.

As a negative side effect of improved treatments, the prevailing assumption is that a HIV diagnosis is easily managed by commencing treatments, achieving viral suppression and there is nothing else to worry about. This is true in most instances and for most people receiving a diagnosis. On the 12 July 2016, in the lead up to the International AIDS Society conference in Durban South Africa, AFAO led the charge in their media statement 'AIDS is no longer a public health problem in Australia'. This may be seen as plausible from a population health perspective. However, people in NSW receiving a diagnosis of AIDS and advanced HIV disease with a CD4 count 200 and below, continues to be a reality.

People in NSW receiving a diagnosis of AIDS and advanced HIV disease continues to be a reality.

In response to AIDS invisibility, I wrote to our Federal Health Minister, Greg Hunt MP about the lack of visibility and data nationally regarding AIDS deaths in Australia following a World Hepatitis Day speech, on 28 July at ACON in Sydney. In the letter I asked for improved data collection and surveillance so we could monitor how many AIDS deaths are occurring in our community.

More specifically, I asked that quality measures be introduced as a part of the national surveillance program. These measures were: transmitted drug resistance through phylogenetics, aligned with the antiretroviral prescribing guidelines; the reasons for PLHIV hospitalisation; the causes of PLHIV deaths; and quality of life, including stigma, as patient reported measures. I am yet to hear back from Minister Hunt's office.

Therefore, the question arises, how do we reach and engage with people who are considered to be 'late presenters', so that we can reduce the risk of an AIDS diagnosis or death in Australia? And, what do we know about people living with undiagnosed HIV? Late diagnosis is understood as: a CD4 count less than 350 or an AIDS defining illness or death due to AIDS within three months of diagnosis, in the absence of a laboratory confirmed negative HIV test in the 12 months prior to diagnosis.

Advanced HIV disease is defined as a CD4 count less than 200 or an AIDS defining illness. When reviewing the annual NSW HIV data report, between

How do we reach and engage with people who are considered to be 'late presenters' so we can reduce the risk of an AIDS diagnosis or death in Australia?

2010 and 2016, the total number of people classified as having advanced HIV disease (the old definition of AIDS) was 391, or on average 56 people per year. This means there is a significant number of people at risk of AIDS death, who will struggle to rebuild their immune systems and are at risk of a variety of serious associated diseases and health conditions. The fact that this continues to happen in 2017, with all the advances in prevention, testing and treatment, is truly shocking, unacceptable and heart breaking.

Through a review of the information we have in NSW, we discovered that people are typically over 50 years old, born overseas and diagnosed in a hospital. There are women and men, gay and straight people within this population. There has previously been an assumption that people diagnosed with advanced HIV disease and considered to be late presenters, had no engagement with the health system or community messaging about HIV prevention, testing and treatment. This is not true. There are regular and numerous examples of women attending GP clinics with symptoms, and the question 'could it be HIV?', just wasn't asked. Alternately, gay men who are community involved and regularly attending health services, are disengaging or deflecting their need for a HIV test.

So, why are people continuing to die from AIDS in NSW? If this is an informed decision "not to know" based on individual agency, I have to respect the person's choice not to test and not to know their HIV status. However, if

people are not being tested or don't know they're living with HIV as a result of fear, misinformation or due to barriers within the health system, I feel we have an obligation to support undiagnosed people living with HIV. Together, I believe we can break through the fear and reduce the number of people each year who are diagnosed as a 'late presenter', with advanced HIV disease or dying from AIDS.

As a part of the Queer Film Festival, I went to see Tom of Finland in the city. I had stupidly assumed the movie was going to be a wild gay romp about an iconic elder within

We need to break through the fear of receiving a HIV diagnosis and stop the silence about AIDS deaths.

our community. Instead, I had a sinking feeling of doom and dread as the AIDS era in our collective history was woven into the story toward the end of the movie. Broken hearted, with tears streaming down my face, I found it difficult to breathe. I managed to hold it together to get out of the movie and my friend Kim held me as I sobbed outside Event Cinemas on George Street.

My tears were not only about the movie, but following a conversation that very day with another friend about yet another man diagnosed with advanced HIV disease and AIDS and a CD4 count of 16. He died of AIDS within two days of the diagnosis. The death of this man is not an isolated incident in NSW. After working in the health and community sectors since the early 90s and the HIV sector for more than a decade, I hear stories of HIV and AIDS deaths with regularity and frequency. Some are friends, others are not. Whether I personally know these people is irrelevant, these are our people and we must stop AIDS deaths in this country.

Slogans, like 'Ending HIV', 'HIV doesn't discriminate, do you?', 'Know Your Status', 'Could it be HIV' are failing to break through the fear and reach our people, the very ones we need to be engaging with and supporting through fearful and difficult times. We need to break through the fear of receiving a HIV diagnosis, and stop the silence about AIDS deaths in contemporary Australia once and for all. 



Being transgender and HIV divergence

Sannyasi

Community member

In April 2008, my Thai transgendered partner and I were both diagnosed with AIDS in Thailand a day apart, skipping HIV completely. While I lay dying in a Bangkok hospital with AIDS related PCP pneumonia in July, she died in her family home in Wanon Niwat without me on August 17 that year. My weight had dropped to 48kgs and my CD4 count was 23. She died, I lived, that's how it went. Over the following two years my life was a revolving door of strange illnesses, rashes and hospital visits, including two bouts of deep vein thrombosis. The cheap anti-retroviral drugs I was taking damaged my body as much as the virus.

After more than 10 years in Thailand, I decided to go back to Australia, which by then was an alien country to me. As a coming home present, the government gave me a \$20,000 fine, and on top of

that, transgender-me could not find work or housing. Rejected by my family, I spent a cold Melbourne winter living in disused railway carriages in Newport, and was bashed, robbed and sexually assaulted twice. I got a break in 2013 when I moved to Sydney.

That's where I'm coming from sharing my personal observations and views on why transgender women are statistically over represented in the HIV data.

While I don't have the answers, I can give plenty of reasons why this may be the case from this Australian transgender woman's perspective.

Fact: Transgender women are statistically way over-represented in the HIV data.¹ Why is this the case? Overall, HIV transmission rates amongst 'at risk' groups have been in decline for a number of years, yet for transgender women we're going for gold as far as contracting HIV. Again, why? For races, countries and cultures outside the sphere of white western privilege, the HIV figures for transgender women just get worse and worse.

I would love to be able to give you some reliable statistics for HIV rates among Australian transgender women, but there are none. We exist only, if at all, as a subset-category under 'gay' or 'bisexual' men. See the problem here?

The issue is not around testing, diagnosis or safe sex practices per se. I'm suggesting in the case of transgender women, it's the ever narrowing life options we have to develop meaningful lives for ourselves.

Poverty, stigma, drug use, lack of family and social support, homelessness and discrimination, are all factors that impact on our identity and self-acceptance. I felt I had little choice than to do sex work to survive financially.

In Australia and most of the western world, there are three main misperceptions of transgender women; we are 'easy', drug addicts, sex workers, or some combination of the three. So-called 'tranny' porn comes in second as being the greatest misrepresentation of transgender women. It's men's idea of what it is to be transgender and accordingly we are treated as fetish objects and dehumanised as 'things'.

Let me count the times men have hit on me. Are they interested in how many degrees I have? What my career has been? Hobbies, likes etc., etc. The answer, no, no and no. The only thing going on in their heads, is what is or not between my legs and how they can get it. These men, the 'chasers' who objectify us, are the ones creeping in the shadows. I for one, choose to live in the light.

For anyone who is HIV+, disclosure remains an unnamed form of anxiety. To disclose or not to disclose; that is the question. Here is my take; for several years I carried the guilt of being responsible for the AIDS related death of my one true love, while I somehow survived. Though neither my partner nor her family ever held me responsible, the survivor guilt was in

1. <http://www.aidsmap.com/Transgender-people-are-at-high-risk-for-HIV-but-too-little-is-known-about-prevention-and-treatment-for-this-population/page/3042613/>



Poverty, stigma, drug use, lack of family and social support, homelessness, discrimination are all factors that impact on our identity and self-acceptance. I felt I had little choice than to do sex work to survive financially.

itself self-destructive. In an epiphany one day, I decided that being HIV+ was but a small part of whom I am as a person, and if someone chooses not to accept me being HIV+, too bad, their loss.

God forbid, should I ever be fortunate enough to find myself attracted to someone enough to want to jump into bed with them, I would disclose. No one likes rejection. The first time I did disclose my HIV status it was like walking on eggshells. I broached it with an attitude of being informed and of the implications of having sex with me. How many times have I ever been rejected in an intimate situation? Zero, zip, nada... Caveat: my family view my HIV status as akin to having Ebola and I have been rejected by them ever since

I disclosed my status. If you happen to be transgender, this is a familiar story. Being ostracised from family seems to be the rule, rather than the exception.

Given the accumulative social stigma transgender women have to live with, no wonder HIV rates amongst transgender women are so high, which also brings with it a plethora of life negating activities and associations depending on how deep down the rabbit hole you go. I am highly educated and I still have to put up with this shit constantly. Treating me with less than the respect I or anyone else deserves, only brings out the rude fucking bitch in me. After all, if you can't respect yourself, how can you expect others to respect you?

To paraphrase an oft used quote: 'If you tell/treat someone continually in a particular way they will eventually become that person'. Regardless of the anti-discrimination laws, transgender women are still discriminated against in employment, access to housing, medical services and in relationships.

In a post-diagnosis situation, the focus turns to health management and taking medication. Going from just having a roof over your head, paying your bills and enough to eat, to survival. Most trans-women I have met have at one time had to fall back on sex work to survive. I would note here that for the most part, transgender sex workers are far more informed and responsible in their HIV testing than their clients.

As I said in the beginning, I don't have the answers to fix these accumulative wrongs. As a transgender HIV+ woman I am uniquely positioned as one who has lived with these wrongs to say, something has got to change. In closing, I encourage my sisters to embrace your uniqueness, more akin to the goddess we are. For all the difficulties and obstacles I have faced during my transition, I would not choose to be anyone but the person I am today. Being transgender, I have transcended gender, sexuality and convention.

One with the divine am I, unique and complete. I am HIV+ [+U]. 

For all the difficulties and obstacles I have faced during my transition, I would not choose to be anyone but the person I am today.



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- ✓ HIV meds at local chemists
- ✓ Protect yourself with PrEP or PEP

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The Choice is Yours is a Positive Life NSW digital resource promoting choice to people living with HIV (PLHIV) when accessing their HIV medication in NSW.

It provides information for PLHIV who are Medicare ineligible to access affordable HIV medication, supports local NSW chemists and pharmacies who dispense HIV medications and much more.

PositiveLifeNSW
the voice of people with HIV since 1988

OUR *changing* CONVERSATIONS

Peter Schlosser

Positive Speakers Bureau Presenter

**The Positive
Speakers Bureau
two decades on**

As a Positive Speakers Bureau (PSB) presenter of twenty one years for Positive Life NSW, I have been privileged to hear stories and see lives transform from bleak to hopeful, through a time of fear, illness death and anger. I have been a witness to this transition out of ominous black storm clouds, to clouds of grey with patches of blue and rays of sunshine breaking through.

It was 1996. A tide of people had flowed down Oxford St and College St to The Domain in Sydney. It was my first Candle Light Rally and my first talk as a Positive Speaker. I stepped out of this ocean of humanity onto the stage. I faced thirteen thousand people. Thirteen thousand candles lit in honour and remembrance of those who'd died of AIDS.

As a 33-year-old man living with HIV, I was overcome with awe, fighting back tears. The unifying glow of love and support radiating from this large and diverse sea of people was both heart rending and exhilarating, sad and

beautiful. It was a time of urgency and crisis; more people were dying of AIDS than ever before. My partner had died at the end of 1994 and I was on prophylaxis for multiple AIDS defining illnesses.

After the eternity that was my five minute talk of thanks and remembrance, I stepped off the stage alone and into the dark. I was overwhelmed by the scale of the event. Blinded by tears, I sobbed my heartbreak onto the ground.

Slowly at first, members of the nearby crowd stood and left anonymity behind to personally embrace and console and thank me. Young and old, mums, dads, siblings, partners friends, carers, positive and negative, one after another. In my thanks to the angels in the crowd I had not anticipated the impact or amazing response to my story, a common story of that time. I felt so honoured and privileged.

In those days our talks were simply presented. Our stories, our lives, our humanity, shared with the broader community in the hope of bringing about

compassion for and acceptance of those living with HIV/AIDS. Meanwhile along with us, our supporters, advocates and doctors endeavoured to improve conditions for people living with HIV/AIDS (PLWHIV/AIDS).

From the very beginning of the HIV/AIDS pandemic in Australia, conditions were not good for those with HIV. Little was known about HIV and misinformation and misunderstanding were rife. This led to fear, stigma and discrimination, even within those communities most heavily impacted by this disease.

The 'Grim Reaper' advertisements brought broad community attention to the need to practice protected sex, yet it was so frightening it only served to increase the fear, stigma and discrimination exhibited towards those with HIV. It did nothing to educate or dispel the myths about HIV. Basically it said 'AIDS kills' and thus the inference was that we were killers and blame raised its ugly head. I remember often hearing the joke "what does GAY stand for... got AIDS yet?"

Tales of rejection by family and friends were commonplace. Being turned away from medical and dental care really happened. Eviction from rental accommodation and loss of jobs, was also occurring. Bashings and even murders were in the media. Often very negative assumptions were made about your character or sexual behaviour. It was your own fault and you were to blame, if you got HIV.

Meanwhile we were dying horrible deaths, fighting for something to be done, for treatments or a cure to be found. Our time was precious and limited. Sadly some gave up and ended their lives before disease could. A sense of urgency impacted all that we did.

Activism and advocacy, angry desperation, hope and despair, were the tone of the 1980s. To say that we were living with a heavy black cloud over us barely expresses the feeling of having this disease. In 1984 I remember being told a cure would be found in five years. Five years later I was told the same thing. Ten years later I was told the same again. I was scared and angry. We didn't even have adequate treatments! A generation of people were dying. Those were years of desperation and waiting.

As the Positive Speakers Bureau grew and matured, we speakers came to realise that our stories had the

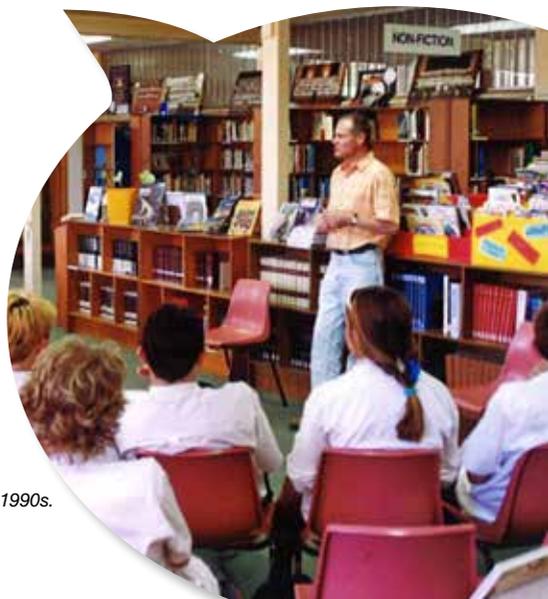


Image: PSB Speaker Paul Maudlin at a high school circa late 1990s.

power to make real change. Societal changes beyond that of acceptance and compassion. Our stories could inform and educate, turn apathy and disinterest into action. We could impact the social, medical and political. Most of all we could impact and improve our own lives and the lives of those to come.

Our stories started to weave in information addressing misconceptions, modes of transmission, HIV progression, AIDS, stigma, discrimination, loss, grief, joy, resilience, support, friendship, sex, relationships, HIV services, work, health care and advocacy. Health care was a protracted and desperate campaign. We were demanding and hopeful for a cure. We also needed treatments for the rare health conditions that we were getting

as our immune systems failed. This was a slow process for those with HIV. As a cure seemed less and less likely, we were fighting for the development of HIV treatments. In the meantime, people died.

In the face of death, resilience often presented itself as humour. Between 1990 and 1997, I was a breath from death on five occasions. I'm still here but many aren't, and I was fortunate to be witness to their final days. In those years I spent a great deal of time in the HIV/AIDS ward at St Vincent's Hospital and watched as many dealt with illness and mortality. One of my dearest friends, Gordon, had a T-Cell count of two. He had named them Yin and Yang. I remember the day he



www.mhahs.org.au



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 - community engagement projects
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told me with a laugh and a smile that “Yin and Yang had gone on holiday.”

Always and foremost was our personal and honest stories of the impact of HIV on our lives; the human face if you will.

Today our PSB presentations are more positive with the advent of good treatments. They are also more sophisticated, targeting the differing needs of our clients, be they held at other NGOs, universities, schools, health care workers and more. Our talks are always focused on our lived experiences and as rounded, diverse and unique as each of us is, so too are our stories.

Our equally powerful secondary messaging arises from the fact that HIV does not happen in isolation and our experiences of it can be affected by our gender, sexuality, age, culture, ethnicity, co-morbidities, employment or not, mental health, social and regional isolation, homelessness, socio economics, religion, family, friendships, relationships, interests and self-esteem, to name a few.

By addressing these in conjunction with HIV, we portray the reality and diversity of PLHIV, and broadening our target audiences and perceptions, as to who has HIV. We can fit the speaker to the audience and client needs. We use our voices, our faces, and our experiences, to address stigma, discrimination, our concerns, and our needs. In doing so, we empower ourselves and elicit change.

Our talks are always focused on our lived experiences and as rounded, diverse and unique as each of us is so too are our stories.

Through all of this, there has always been a sense of hope, humour, joy and gratitude for that which remains. The positive and dramatic changes in treatments and prevention strategies are normalising our lives. The picture is less dire. Sunshine is replacing the storm clouds of the past. HIV is a chronic condition like diabetes, they say. Diabetes though does not come with moral judgement, fear, stigma and discrimination. Let us not forget the small number of those for whom life with HIV is still a struggle, who will not live the ‘one pill a day’ dream, for whom medication is failing, or for whom the damage is done.

Attitudes have changed for the better and prospects have vastly improved. There is still no cure and we still have much to do, not just in regard to stigma and discrimination, but policy, law and equality as well. The overriding theme of our stories always has and will always be resilience, hope and empowerment.

The conversation must continue. 

For more information about the Positive Speakers Bureau

 1800 245 677 (freecall)  www.psb.positivelife.org.au

Finding the confidence to get back out there

Steven

Community member

Once you become poz, then what? Do you stop having sex, have judgmental thoughts, be unhappy, overthink, not go out and feel rejected, fearful and anxious?

All you wanted to do was go out and enjoy yourself, have some great sex and meet new people. When I was diagnosed with HIV, I was 21 years old and had lived three years in Sydney. Around this time, I'd split with my boyfriend who was 21 years older than me, and I wanted to try things sexually with different people. I was a normal sexually adventurous 21 year old, but nothing out of control.

Today, at 22 years old, it has taken some time to deal with my diagnosis. I knew I couldn't run from being HIV positive. I told the three or four friends that I already felt sure of and they've been a great support to me.

My fears, anxiety, hurt, worries about the unknown or rejection, wondering if hot guys would still want to touch me, all haunted me. I wondered what would happen in the future and if everyone would say



“no” to me or never want to meet up. Of course that can happen anyway for many reasons other than being HIV positive. We all get rejected at times – positive or not. Fears about being unloved and being anxious about rejection are common emotional experiences, and I wonder if we use HIV as an excuse? I think maybe we do at times.

I know I can't hide, suppress or ignore HIV. What now? My first step was to find a doctor I felt comfortable and confident with. I went to a few doctors and found they didn't fit very well with me, but now I've found a great HIV specialist who seems right for me.

Counselling has also been really helpful to me. Finding a HIV specialist counsellor to help talk things through with you can help find a way forward, or finding a support group of other people in similar shoes to you. I also needed to build some confidence within myself and looked for a general life coach who has been really helpful to give me some structure to help me move forward. She looked at my good points and suggested some action steps to follow. We started with small steps and built on that. The major thing she explained was that being positive is not the worst thing in the world. People are still going to like me for myself, and if they don't, she suggested I just let them

go, as they are not worthy of my time! I discovered that HIV showed me a new way of finding myself, mentally, emotionally, sexually and spiritually.

Then there was the online world. Where do you start? Being honest always worked for me, whether in my

profile, during a conversation, or just before meeting someone. Sometimes an online interaction doesn't give me what I'm looking for, but I remember it's

Fears about being unloved and being anxious about rejection are common emotional experiences, and I wonder if we use HIV as an excuse? I think maybe we do at times.

only an online exchange through a computer screen. I do what I can to move things into the real world and meet up with people, go to social groups, meet over coffee, at the gym, in the club or out and about. Sure, there are some people who are still frightened to hear the word HIV but there is no need to beat yourself up over becoming positive. Accept, acknowledge, be aware and move forward.

So, how do you move forward? Some simple tools that have helped me are being honest and loyal to myself. To think through what my values are and what I look for in someone else. You will find people who like you and want to be with you. Good foundations are a good start, and I think it helps to take your time to find out what works and makes you happy. ☐



How gender impacts the lives of women living with HIV

LIFTING THE IGNORANCE AND INVISIBILITY
IN THE ELIMINATION OF HIV IS A TASK FOR
BOTH MEN AND WOMEN.

Jane Costello

President, Positive Life NSW

As a heterosexual woman living with HIV for the past 25 years, I am acutely aware that the lived experience of women with HIV today is still mired in ignorance and invisibility. Many people in the general community and some health care providers still think that HIV is not an issue for heterosexual people, particularly for women. I know of more than one heterosexual woman who on asking their GP for an HIV test was told “oh you don’t need that” or asked “why?” Sadly several of these women have subsequently been diagnosed HIV positive.

Thankfully, Australian society has effectively maintained the HIV response for our priority populations – gay men, other men who have sex with men, sex workers and people who inject drugs. However, based on new diagnoses of HIV, Australia has all the alarming signs of a gradual “epidemiological shift”. Over the past five years in Australia, HIV transmission related to heterosexual contact has increased by 10 per cent, with a 14% increase between 2016 and 2017 and in 2017, 25 per cent of new HIV diagnoses in Australia were transmitted through heterosexual sex.

There are gender differences in HIV in Australia. Unlike gay men and men who have sex with men, very few women in Australia are diagnosed with newly acquired

HIV. Today, when a woman is diagnosed with HIV, she tends to find out after years of living with HIV. By then her immune system has been significantly damaged. She has probably been admitted to hospital as a “late presenter” with a serious often life-threatening advanced HIV disease which is defined as an AIDS-defining illness. In this state of health, this woman has missed out on the benefits of early diagnosis, and any immediate advantage anti-retroviral treatment could have given her long term health. She will also experience greater complications around her reproductive health which then also impacts the health of her family and her own psychological health.

About 10 per cent of people living with HIV in Australia are women, yet they continue to be invisible in the HIV prevention message. If we are serious about working towards eliminating HIV, then we need to talk about the different ways HIV affects and impacts the lives of women.

There is a dearth of images in public health campaigns designed to educate the community about HIV. Imagery that includes a young woman, a transgender woman or even a heterosexual couple is conspicuously lacking. We must open the conversation about HIV to reduce the silence and secrecy around women living with HIV.

THE POSITIVE AND
DRAMATIC CHANGES
IN TREATMENTS AND
PREVENTION STRATEGIES
ARE NORMALISING
OUR LIVES.

Compared to gay men and men who have sex with men, women are less likely to test for HIV. Women will gain only limited benefit from advances in treatments while they continue to present late and with advanced HIV disease. While well-meaning clinicians challenge women who pro-actively ask for HIV testing and tell them they don't need to be tested, they and the wider community continue to promote the misguided assumption that HIV is not an issue for women.

Lastly, there are gaps in the research data into HIV and gender differences that are specific to the female body. This lack of information feeds into misunderstanding about the efficacy of anti-retroviral treatments in relation to women,

their hormonal differences and the impact these differences have on the side-effects of HIV treatments for women. HIV also plays into the experience of women intersectionally through poverty, in rural and regional locations, access to treatment and medical care, and mental health factors – all aspects either unacknowledged, disregarded or overlooked.

Thanks to the recent hard work of Femfatales, the National Network of Women Living with HIV, there is some ongoing support and advocacy into the issues faced by women with HIV and the ways the virus impacts on their health and quality of life. The recent publication *Living Well – Women With HIV* developed by the Australian Federation of AIDS Organisations (AFAO) and the National Association of People Living with HIV (NAPWHA) in consultation with HIV-positive women provides information and helpful guidelines about key aspects for women living with HIV. The specific issues and concerns of women with HIV are detailed in both a hard copy publication and an online website www.womenlivingwell.org.au

The National Day of Women Living with HIV Australia also plays a part to raise awareness amongst women about their risk for HIV and their need to test for HIV. Normalising the reality of HIV as a virus that impacts women in Australia is a task for us all - both men and women, in the elimination of HIV in Australia. 

Alcohol and Other Drugs: NSW Treatment Lines

Thinking about changing the ways you use drugs or alcohol? Or do you just want to talk to somebody about what support is available? Every Local Health District (LHD) in NSW has different options for people looking for treatment. To make it easier for you, the **NSW Users and AIDS Association (NUAA)** has put together this map of LHDs and a directory of treatment lines.



Central Coast - (02) 4394 4880

Northern Sydney - 1300 889 788

Sydney - (02) 9515 6311

Western Sydney - (02) 9840 3355

Far West - 1300 662 263

Illawarra Shoalhaven - 1300 652 226

South Eastern Sydney - (02) 9332 8777 (Northern); (02) 9113 2944 (Central)

Northern NSW - (02) 6620 7600; (07) 5506 7010 (Tweed Heads)

Nepean Blue Mountains - 1300 661 050

South Western Sydney - (02) 9616 8586

Hunter New England - 1300 660 059

Mid North Coast - 1300 662 263

Murrumbidgee - 1800 800 944

Southern NSW - 1800 809 423

Western NSW - 1300 887 000

**Want to find out more about treatment and
safer using? Contact NUAA today!**

Phone: (02) 8354 7300 | 1800 644 413 (free-call)

nuaa.org.au | @nuaaNSW



Injecting crystal, harm reduction & HIV

'Caleb'

Community Member



The glorious, chemically fuelled sex that I was having half a decade ago changed my life and my HIV status. Looking back on my sex life, not much has changed in the intervening period between my diagnosis and today.

I'm certainly more careful, but I still love sex with drugs (and rock-n-roll in moderation). I don't buy into the overhyped media reaction to gay guys using 'Tina' and 'Gina', and the responses that seem to inform any online discussion these days are a quagmire of fear based on misinformation.

Drug use has been a strong theme woven throughout my life and it certainly hasn't been the end result of trauma, pain, or any other negatively associated trope. Substance use was a key that unlocked a higher dynamic range of pleasure than I ever thought possible.

From the early days dancing all night at Hand in Hand parties, through to the intense emotional and physical pleasure of engaging in sex with other

men and being high as a kite while at it, it had all the magnificent intensity I wanted! Of course it's not a lifestyle that is for everyone, and it's certainly not something I suggest everyone try.

Injecting crystal was something that I started doing over a decade ago, and I was lucky to have been shown and taught how to do it safely. In today's need for more instant gratification offered by Scruff, Grindr and other social media cruising apps, there is no reason why harm reduction can't be part of the language of hooking-up.

It's not hard to take care of yourself when using drugs with sex and staying safe when injecting. Transmission of any blood borne virus can happen with more activities than just through butt sex. Use new and sterile equipment every time, and try to keep the areas where you're mixing up as clean as possible and free of lube. Wash your hands before you inject, and always swab.

One thing that has now changed substantially is my life outside the bedroom. These days I'm more connected, caring, associated with community, and far happier.

I have found sincerity in being genuinely interested in the health and welfare of my poz mates who I have surrounded myself with. And for me? That's a huge positive! 



Neil Fraser
Program and Peer Support Officer
Positive Life NSW

You may have heard or seen the U=U campaign online in your social media feeds or heard discussions and conversations where this is a feature.

U=U is a HIV awareness campaign that refers to the reality that if you have an undetectable viral load (in Australia, this is less than 20 copies of the HIV virus per millilitre of blood)* you cannot transmit HIV through sexual contact. In other words, undetectable means untransmittable.

The science about ‘untransmissible’ began to emerge in 2008, when the Swiss National AIDS Commission issued what is called ‘The Swiss Statement’. Shortly thereafter, Positive Life NSW was the first community organisation in Australia that mentioned the science from the Swiss Statement, in our Sero-Disco magazine. The PARTNER study in 2016 and the Opposites Attract study in 2017 also found zero HIV transmission to their partners from virally suppressed people living with HIV (PLHIV) on effective Anti-Retroviral Therapy (ART). Around the same time PLHIV in NSW have been sharing this message as something to celebrate. The impact of PLHIV knowing there is zero risk of transmitting HIV to our sexual partners has been profound. The abating of anxiety and liberation from feelings of guilt has added to our levels of confidence and motivation regarding ART.

Recently the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM), who educates the healthcare workforce in HIV, viral hepatitis, other BBVs and sexually transmissible infections (STIs), have taken the position to support GPs and other clinicians about the strength of the science behind undetectable and the impact of effective ART for PLHIV and our partners, lovers and fuckbuddies.

Today, while everyone can be confident in the science, questions remain for many PLHIV with a more traumatic lived experience of HIV. If you have been living with HIV like myself for just a few years, chances are your experience in contrast to someone living 20 or 30 years with the virus is significantly different. I haven’t lived with an overwhelming fear of transmitting HIV to my fuck-buddies or lovers nor have I experienced handfuls of my friends



U=U is a HIV awareness campaign that refers to the reality that if you have an undetectable viral load you cannot transmit HIV through sexual contact.

Unfortunately, U=U won't automatically reduce stigma and discrimination in the wider community.

or fucks dying from a mystery disease suddenly and unexpectedly.

Recently I had a discussion with 'John', a community member who understood the message of undetectable equals untransmittable (U=U). John was well informed on the science and understood how maintaining viral suppression meant there was not enough of the virus to transmit. He could articulate the nuances of the terms and language well. The part that he found challenging was where this messaging impacted decades of fear he had been living with and dismissed his experience of living with HIV. Intellectually, he just couldn't switch this off.

The impacts of fear and stigma are very real on people who experience them and live with them daily. Fortunately, for most of us, these feelings subside with time and contact with other PLHIV. Health

promotion activities that engage and activate our capabilities and strengths and engagement with resilient communities also act to reduce stigma.

It is critical, as it was 30 years ago, that we leave no one behind when discussing all the positive aspects of science and modern treatments. Given the 30 to 40 years of health promotion, community development and engagement activities that has targeted sexually active, queer or gay men, many feel liberated and affirmed by the U=U message.

Unfortunately, however, for others living with HIV, U=U is received as a simplified alphanumeric equation, especially those who haven't had appropriately targeted campaigns to develop their capabilities and health literacy. The message is lost on the young mother living with HIV who still hears conflicting information about breast feeding. This is only amplified with the daily struggle of the nexus (and gossip) of kids, schools, neighbours, and even family members. It is also lost on people with limited education and cognitive impairment.

The use of the word 'undetectable' demands a communal understanding of the word. Otherwise it risks leaving those with less health and sexual education behind or confused. While undetectable equals untransmittable is a good news story for all PLHIV and has the potential to ameliorate HIV fear, phobia and stigma, it is not an inclusive message that is

meaningfully understood by all PLHIV. It has the potential to create a further divide between people living well with HIV and those who are still struggling with multi-morbidities or achieving viral suppression.

Unfortunately, U=U won't automatically reduce stigma and discrimination in the wider community. I have seen PLHIV unexpectedly blindsided with stigma and discrimination when other people still react with fear about HIV regardless of being told they are undetectable. For other members of our community, this messaging has the unfortunate side effect that sets people up for anxiety when they have a viral blip or evidence of ART resistance. This hopeful message is meaningless and isolates those of us who experience a range of complications including illness or cancer treatment.

An unexpected hidden consequence of this messaging sees the weight of responsibility shifted onto PLHIV to be compliant, good patients with our medications. When we focus on discussions of HIV prevention (a 'prevention narrative') the needs of PLHIV are often overshadowed by the needs of those at high-risk of HIV acquisition. Using a prevention narrative positions PLHIV as 'the vectors of disease' which fuels HIV stigma and discrimination. As PLHIV we have always been doing our

fair share of the work in preventing the onward transmission of HIV by maintaining high levels of engagement in health and remaining on effective antiretroviral therapy. We are not the risk!

More than ever, undetectable and untransmissible is a conversation we need to unpack and question in all its complexity. Treatment as prevention (TasP) is just one of many positive aspects of effective treatment. In NSW, PLHIV have achieved so much as we work together as a community. We have used science and logic to remove stigma from the public health act. PLHIV advocated for universal access to medications and we are on track to being one of the first places in the world to achieve zero locally acquired infections. Zero risk of HIV transmission is good news for all PLHIV and our partners and compliments our commitment to ending HIV in NSW.

We need to remain mindful and vigilant as PLHIV now more than ever of the language we use when discussing treatments. We are an ageing population and increasingly our needs are becoming as diverse as the communities we live in. As we approach Ending HIV, and zero transmissions, let's make sure our conversations are inclusive and respectful and no individuals nor groups are left behind. 

*The PARTNER study in 2016 an undetectable viral load (UVL) was defined as having a viral load with less than 200 copies/mL.

talkabout

Where we speak for ourselves

November 2003
The Magazine of People Living With HIV/AIDS NOW Inc.

September 1999

about

With HIV/AIDS NOW Inc.

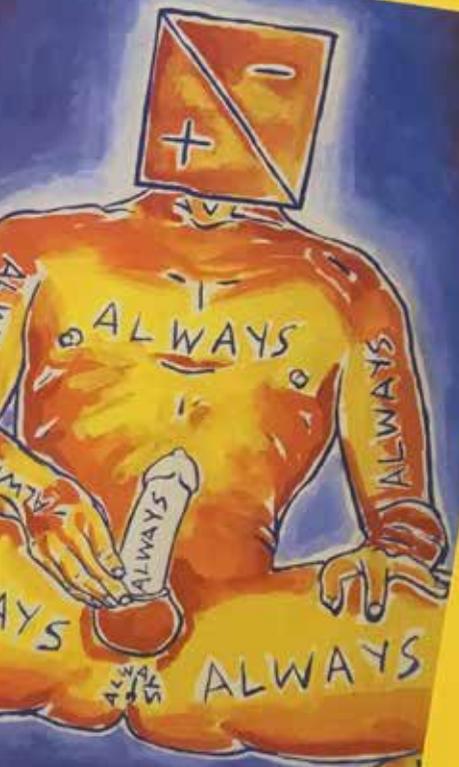
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Where we speak for ourselves

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ISSUE #100

The Magazine of People Living With HIV/AIDS NOW Inc.

...e women:
...e not alone



Dancing
shoes
positive tale
from the
Mardi Gras
party

Talkabo

No. 92 February

The Newsletter of People Living With HIV/AIDS NOW Inc.
Where We Speak for Ourselves

A tribute to Talkabout

The first edition of Talkabout came out in December 1988, as the newsletter '*Where We Speak for Ourselves*'. Talkabout has sought to be a voice for anything and everything that might be relevant to living with HIV. Publishing the most up-to-date information for people who tested positive to HIV – such as personal stories living with the virus, Olga's Personals, handling disclosure, combatting discrimination and conference reports – Talkabout shaped how we thought about living with HIV in those early years.





Above: ACT UP protest freeze in Castlereagh Street, Sydney on 24 May 1991 to draw attention to treatments access. Published in Talkabout July/August 1991.

Right: Twin brothers, Tim and Jonathan Vincent photographed for Talkabout Cover December/January 1997/98

Below: PLNSW Treatments working group.



Right: PLNSW Craig Cooper (CEO) and Jane Costello (President).



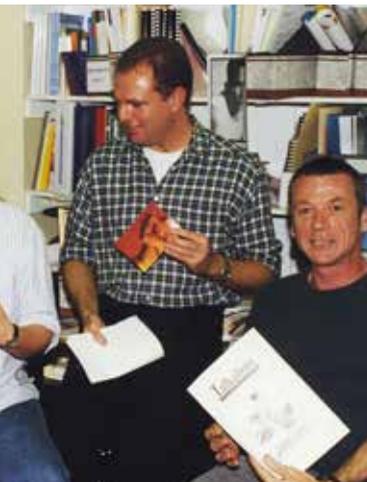
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Talkabout

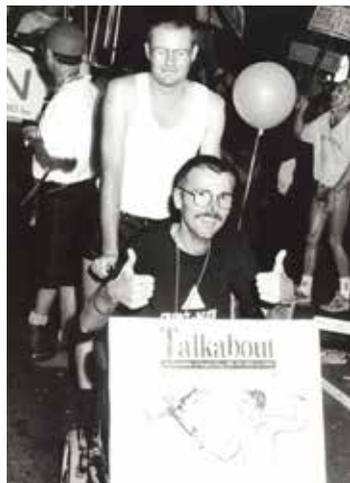
The Newsletter of People Living With HIV/AIDS Inc NSW

◆ Where We Speak for Ourselves ◆

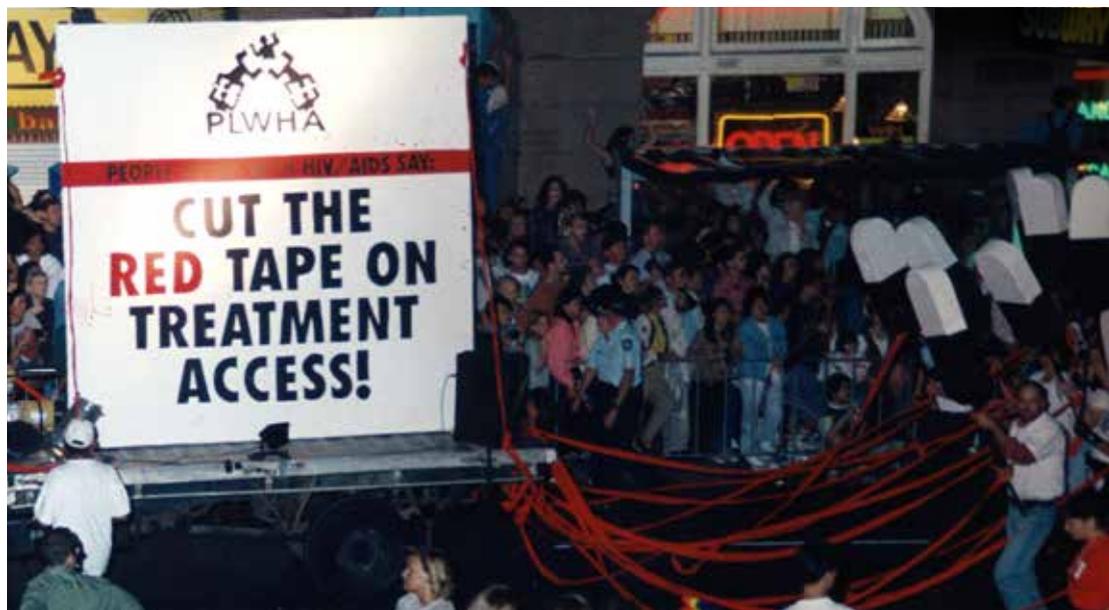
SEX



Right: Alan Brotherton pushing Matthew Bradshaw, one of the first coordinators of NPLWAC (now NAPWAH) in the 1992 Mardi Gras Parade. Published in Talkabout February 1994.



Below: Scenes from People Living with HIV/AIDS Mardi Gras 1996 float, Oxford Street. Published in Talkabout April 1996.



If I could arrange for my illness to strike on certain days it would be easier to hold down a job.

Jane Costello

Through unity comes strength and in strength we become empowered.

Aboriginal and Torres Strait Islander panel member

The centrality of the positive voice has and always will remain a key to the HIV response in NSW. There should be nothing about us without us.

Jonothan Street

When I'm feeling really positive (no pun intended), I think AIDS changed the visual arts and that art can change lives.

Peter Du Ruyter

Talking about ...

Our contributors have had a lot to say over the years. Here's a few of the Talkabout voices.

*AIDS is everyone's business,
it doesn't discriminate and it
isn't going away.*

Georgina Harman

“Welcome to the first edition of Talkabout, the newsletter of People Living with AIDS (NSW). The aim of the newsletter is to provide a voice for the people most often unheard in the AIDS crisis – the people infected and affected by HIV themselves. Talkabout is your voice: a means of getting in touch with others, expressing your opinions, concerns and demands; asking question; sharing your experiences and knowledge; hearing news relevant to us – the people living with AIDS.”

*Talkabout edition #1,
November/December 1988*

*Before there was 'we'
there has to be a 'me, then
there can be an 'us'.*

**Aboriginal and Torres Strait Islander
panel member**

*“One common theme I came
across [in the peer support
work I did] was the need
for people to feel a sense of
dignity getting on with their
lives as positive individuals.”*

Peter Du Ruyter

*I decided that being HIV
positive was but a small part
of who I am and if someone
chooses not to accept me ...
to bad, their loss.*

Sannya Si



The Red Tree

After a round of viral non-clearance, Craig describes his balancing act to stay motivated and active as he waits for improved treatments.

Craig Cooper

CEO, Positive Life NSW

One of my favourite books is *The Red Tree* by Shaun Tan. *The Red Tree* is captivating, evocative and inspiring. It's about a little girl who finds herself depressed, alone and dragged down by life, yet at the end of the book, she finds a beautiful magical red tree in her bedroom; her sanctuary. The imagery and essence of the story for me mirrors my relationship with and understanding of HIV and my health. My HIV trade-off at the moment is medication with better CNS penetration versus insomnia, anxiety, gut problems and weight gain.

My previous HIV medication regimen resulted in a year's disturbed sleep and weight gain.

I would be lucky if I slept two to three nights a week for up to seven hours.

A typical night sleep was three to four hours of broken light sleep.

After continuous disturbed sleep patterns, I adjusted to functioning on a daily basis as if I were walking through a haze.

This would trigger regular headaches and migraines and concurrently impacted on my ability to exercise. When my weight became a problem for me, I talked with my doctor and asked for a medication review, explaining what was happening. Around the same time, I noticed I was having problems saying words, recalling the name of things and generally becoming increasingly forgetful. This lasted for about five years.

We chose medication that had better CNS penetration and it took almost twelve months for me to notice a difference and to fully recover from the previous drugs neurologically, having improved sleep and weight loss. Unfortunately, this only lasted two years and I've begun to experience similar symptoms to what I had previously. This time however, migraines have been a regular feature, up to three to four a week. What triggered this was a diagnosis of hepatitis C in February 2016. I commenced treatment (Harvoni) immediately and unfortunately three months after treatment completion, I was unable to achieve a sustained virological response. I had a reaction to the medication and became manic, with a side-order of a protracted flat-affect. Another way of describing it would have been an occasional elevate mood, with a regular dose of fatigue and an inability to feel happiness. When notified of my treatment failure for hepatitis C, I became depressed and withdrawn, isolating from my friends and the world.

I was told there are no side effects from the new hepatitis C drugs. Not for me! I was told the clinical trials reveal a superior product. Not for me! I was told 'you'll be cured.' Not me! I was told 'you'll be okay.' I wasn't! I felt there was something wrong with me and there was. I was one of the small proportion of people that do not achieve hepatitis C cure from the new medications. Worse than that, I was borderline psychotic and depressed. I lost all hope, confidence and felt like a total failure.

Since my hepatitis C viral load reactivated, I have gained weight, suffered insomnia and managed constant migraines. Regular bouts of insomnia have been a constant feature of my life now for more than a decade, I'd be lucky if I can establish a reasonable sleep pattern for up to six months at a stretch. I became dependent on codeine while taking Harvoni, just to manage the headaches and fatigue. I didn't want to return to my reliance on codeine to manage the migraines so have eliminated processed foods, sugar and sodium, meats, dairy products (apart from goats' cheese and some butter) and have reduced my alcohol intake. While I re-introduced regular massages and acupuncture, unfortunately that strategy didn't turn everything around. The migraines have ceased, but all else remains. I spoke with my doctor and named my concerns, but the decision was to stay on my current HIV meds, because of the CNS penetration and neurological benefits.

I guess for me, the older I get and longer I live with multiple infections and diagnosed conditions, it all just feels like a balancing act, with regular trade-offs and compromises. I am now in a holding pattern while I wait for the *AbbVie pangenotypic* meds to be introduced into Australia. Remaining motivated and engaged in my health takes energy, focus and is a full time job.

The little girl in *The Red Tree* gives me hope and acts as a constant reminder that there is beauty and magic in the world. ☐



A bittersweet relationship with HIV

Sama
Community Member

I remember the day I found out I had HIV. I was at the doctor with my niece who knows English better than me. The doctor sat across from us and looked nervous. He said to me, "I have to tell you, you have AIDS." He gave some papers to my niece and asked her to explain it to me. I was in shock.

I thought I would be dead very soon. I thought I had the flu working too hard. No-one told me I was having an HIV test.

I never thought this could happen to me. In my country we thought only people who use drugs and people who are sex workers could get it. I've learned a lot more about HIV now.

That was four years ago. My life changed a lot after that day, including the way I think about myself. I realise the doctor was wrong to do it like that and I don't think he knew much about HIV.

The doctor and the nurse at the clinic where I go now are good. They help me a lot and I can talk to them. They help me understand how I can live with this HIV.

Today, my niece and I don't talk about it. I don't think she told anyone. Although she did change after that and became more distant. I have always been worried I might give it to someone else, like my grandchildren. At the clinic they tell me about being 'undetectable' and about the 'virus load'. Those sorts of things. I know I can't infect anyone or make my family sick, but I worry about it all the same. It's a big stress, but I'm glad I'm not dead.

My family are everything for me and all the time I have to keep my secret. All the time I try to make sure they never see my tablets or see me going to the clinic. I always worry if people can tell I'm HIV positive when I am at the church or the shops.

My family are everything for me and all the time I have to keep my secret. All the time I try to make sure they never see my tablets or see me going to the clinic. I always worry if people can tell I'm HIV positive when I am at the church or the shops.

Sometimes I really want to tell my children and my sister. But I am so scared what they will think. I don't think they will accept me.

Sometimes I wonder, what did I do to get this thing?

The nurse at the clinic told me maybe I got it from my husband. I don't like to think about that. He died after we came to Australia. I miss him. 

TALKABOUT



Talkabout Online

Talkabout is also an online hub 'where we speak for ourselves' with four editions published each year. You can read personal stories and experiences by and for people living with HIV at www.talkabout.positivelife.org.au

Anti-retrovirals and HepC

Roy Christopher

Community Member

The decision of when to start on anti-retroviral treatment for me was a no brainer and also taken out of my hands, I had presented to the hospital sicker than I'd ever been in my life.

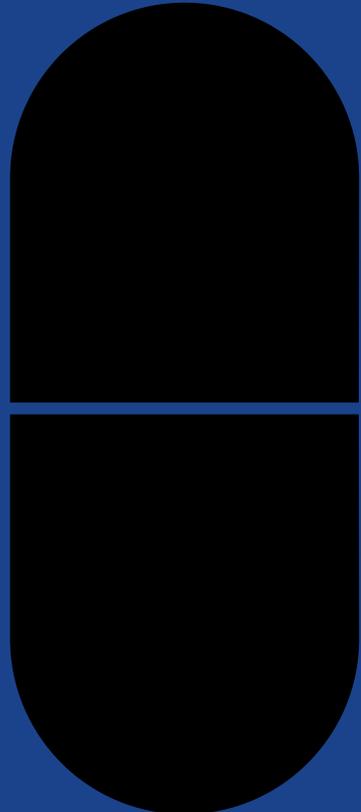
Further investigation resulted in me being told that I was HIV positive and that I had developed a condition known as PCP (pneumocystis pneumonia).

After having taken medications for almost six months, my HIV Doctor was baffled as to why I could not record an undetectable viral load. After more blood tests I returned a positive result for Hepatitis C. Unfortunately the combination of anti-retroviral medications that I was on was making my liver sick which in turn reduced the effectiveness of ART on my HIV.

My doctor and I decided that I should change my HIV medications and it was with this change of

medications that we discovered that I am allergic to certain types of anti-retroviral drugs. More blood tests were undertaken and we eventually found a combination which worked well with keeping the HIV at bay whilst having a minimal effect on my liver.

This was an at times painful journey and the one message that I would like for other people to take away from my experience, is to make sure that you are fully aware of your Hep C status before beginning your treatment for HIV. 



Remember the Swiss Statement?

Geoff Honnor

Distinguished PLNSW Member

In one sense it was just a bureaucratic missive about risk assessment from the Swiss AIDS Commission, issued in January 2008, directed mainly to that country's legal fraternity, insurance risk and liability assessors.

But in another sense, it was the 'shot heard round the HIV world' and the harbinger of the new prevention era in which we're now immersed. It raised a range of challenges, the resolution of which has provided an inspirational backdrop to our times, though reading the current commentary you'd think we'd missed the biggie: "What about condoms for other STIs." Puzzled? Read on.

The Swiss Statement offered an expert, evidence-based perspective on the risk of

an HIV positive individual with treatment suppressed virus transmitting HIV to a negative partner during unprotected sex. Based on findings from the Rakai Community Cohort Study in Uganda and observation in practice, the Statement's authors advised that a person in this situation was not sexually infectious, providing he was taking his medication, had maintained an 'undetectable' level of virus for at least six months and had no STIs. Media picked the news up from the Commission's initial press release, a firestorm of international controversy followed and our world has not been the same since.

Much of the initial controversy focussed on the 'no risk' advice in the Statement and the Commission later advised its regret in not positioning the statement 'where we live' so to speak:

a world where risk is a constant and where the objective is to reduce the risk to a point where for the vast majority of us it becomes a worst case scenario, is very unlikely to happen.

The second point of criticism was the lack of a randomised control study derived evidence-base to prove the Commission's concept, and the third was the prospect of HIV positive people suffering 'risk disinhibition' i.e. throwing the condoms away and getting stuck right into it on receiving this dangerous news. At the time, hearing one's partners in the World's Most Successful Partnership-Based HIV Response (TM) expressing this degree of mistrust in their community partner, did give pause for thought.

In fact, Australia led international opposition to the Swiss Statement and a modelling study conducted by the then National Centre for HIV Epidemiology and Clinical Research (now the Kirby Institute), published in the Lancet later that year,

suggested that HIV transmission among serodiscordant monogamous couples in which the HIV-positive partner had an undetectable viral load due to effective treatment might rise fourfold over a decade if condom use was abandoned.

AIDSmap reported on the modelling study as follows: On the basis of the data presented here, the modelling researchers concluded, "we believe that the Swiss Statement is not a sensible public-health message because its logical outcome would be the abandonment of condoms by people with effectively treated HIV infection... As a population strategy, treatment as prevention has the potential to reduce HIV epidemics only if consistent condom use is maintained. Indeed, our analysis suggests that there is large potential for more harm than good."

It was the 'shot heard round the HIV world'.

Treatment is as effective in halting viral progression as it is in greatly reducing the risk of HIV transmission.

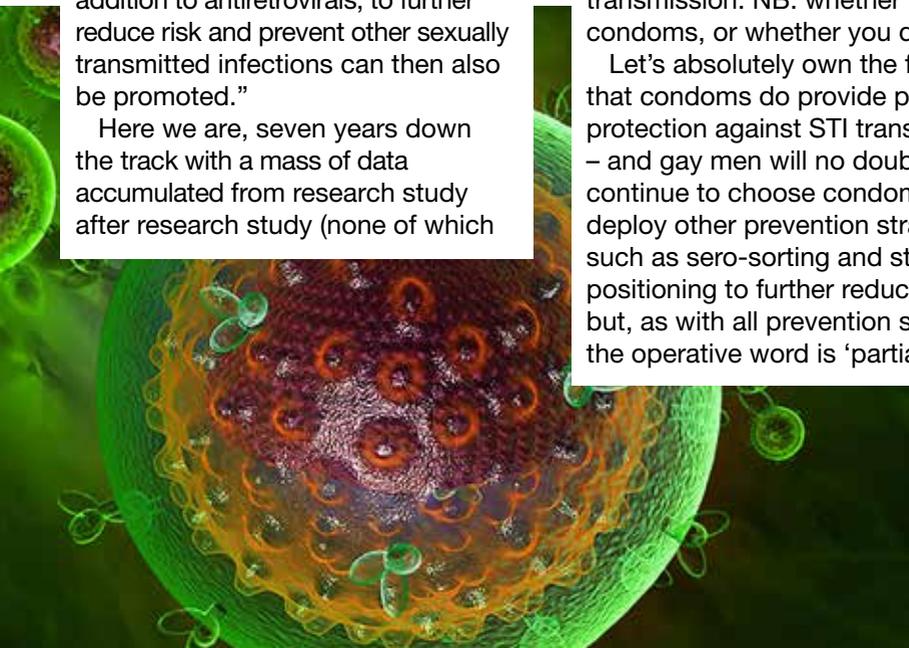
The Lancet editorial commentary on the findings by eminent Professors Garnett and Gazzard was more measured: “Denying an effect of treatment on risk of transmission would be dishonest and futile, because well-informed patients will assume an effect,” they wrote.

Their commentary was also more welcoming of the ‘teaching moment’ embedded in the Swiss Statement: “In many ways, the Swiss Statement provides the opportunity for positive public-health messages, by promoting adherence to treatment and concern over other sexually transmitted infections. The use of condoms, in addition to antiretrovirals, to further reduce risk and prevent other sexually transmitted infections can then also be promoted.”

Here we are, seven years down the track with a mass of data accumulated from research study after research study (none of which

by the way studied the effect of PrEP with condoms, just PrEP by itself) – iPrEx in 2010, HPTN052 initial findings in 2011 (which provided proof of concept for the Swiss Statement) and on through PROUD, Ipergay, Opposites Attract, Partners, down to the results of the START Study this year – and now it’s an incontrovertible fact. Treatment is Prevention. In fact the release of the START Study findings earlier this year made the ‘Treatment as Prevention’ terminology redundant. Treatment is as effective in halting viral progression as it is in greatly reducing the risk of HIV transmission. NB: whether you use condoms, or whether you don’t.

Let’s absolutely own the fact that condoms do provide partial protection against STI transmission – and gay men will no doubt continue to choose condoms and deploy other prevention strategies such as sero-sorting and strategic positioning to further reduce risk – but, as with all prevention strategies, the operative word is ‘partial.’



because good old anal intercourse is just one way of achieving the skin to skin contact by which STIs can effectively be spread.

In the case of sexual transmission of hepatitis C they're probably next to useless given that the transmission vector is blood to blood – and often via quite microscopic droplets of blood – which can be as easily found on the outside of a condom as anywhere else.

Famously, STIs can also be spread very efficiently by oral sex and no-one is suggesting the use of condoms for oral sex. In fact no-one suggested the use of condoms to counter the effect of the astronomical rates of STIs prevailing among gay men at all until HIV arrived. HIV came as a death sentence. Other STIs did and do not. They're eminently treatable/curable in fact.

In an era when our ability to prevent HIV has reached a new level of effectiveness, repeated calls for gay men to continue to use condoms to prevent eminently treatable STIs are beginning to sound more like slightly desperate moral preaching than considered health promotion advice.

We've never in the history of our HIV epidemic response regarded the STI preventive effect of condoms as other than a secondary 'flow-on' benefit from their primary purpose – preventing HIV transmission. If condoms are no longer central to HIV prevention it seems unlikely that gay men will be persuaded that they're essential for preventing chlamydia. Reliance on condoms alone will never achieve a sustained decline in STI notification rates among gay men. What will achieve that outcome is if

every gay guy – yep, all of us – ensures that we test for STIs in accordance with best practice guidelines. The busier you are, the more tests you should be having – including throat, anal and urethral swabs (use more than one swab obviously) – informing the guys we have sex with if we're diagnosed, taking the treatment as prescribed and not getting back into it until you've finished the treatment and got the all clear.

By the way, when you read about antibiotic-resistant strains of this and that, it doesn't mean that completely untreatable strains of gonorrhoea are amongst us. It means that over time, more patients are presenting with resistance to one or more of the frontline therapies used. So others are used. In Australia, to this point no-one to my knowledge has presented yet with a completely untreatable STI, nor is it likely to be so anytime soon.

An Australian Consensus Statement on STI prevention might well be one way to go, but on current form we'd have solved everything else but the key question by 2022.

An approach to ending STIs, every bit as energised and all-encompassing as the *Ending HIV* approach currently underway could be more effective, and the engagement and mobilisation infrastructure for this is already in place. I think it's important to remember that gay men's sexual practice isn't the issue here. Rather, it's the STIs that are interlinked with that practice. I'd put the focus on constraining the STIs. 

HIV Difference

Why let HIV get in the way of a good relationship?

A magazine highlighting the stories of people who negotiate life and love regardless of living with HIV or not.

To obtain a copy call the PLNSW office on 02 9206 2177 or 1800 245 677.



halc

The HIV AIDS Legal Centre

The HIV AIDS Legal Centre is a not-for-profit, specialist community legal centre, and the only one of its kind in Australia.

We provide free and comprehensive legal assistance (within operational guidelines) to people in NSW with HIV or Hepatitis-related legal matters.

If you have a legal problem please contact us:

p 02 9206 2060 **e** halc@halc.org.au **w** halc.org.au
414 Elizabeth Street, Surry Hills, NSW 2010
10am – 6pm Monday – Friday

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CONDOMS PREVENT HIV

but don't shield you from stigma

Cameron Cox

CEO, Sex Workers Outreach
Project (SWOP)

I am a NSW sex worker who works and lives with HIV. The HIV virus has been in my blood, semen and rectal fluids for over 30 years now, and even though the virus and I are now comfortable with each other, society is neither comfortable with me or the virus.

As a sex worker living with HIV, I occupy a space that is routinely stigmatised. However, as a white cis male, I also occupy an extremely privileged position. The stigma of my HIV infection and of my sex work are concealable stigmas and I have automatic access to all the tools that white male privilege automatically provides.

Despite these privileges, I am subject to a number of perceptions concerning my health and occupation. There is a general, but baseless perception that all or most Australian sex workers carry the HIV virus and are “vectors” of HIV transmission. This baseless perception is counterbalanced by another baseless public perception, that no sex workers in NSW are HIV positive, because there are “laws against such things”.

I am not the only sex worker living with HIV in NSW, nor the only sex worker living with HIV in Australia. Sex workers not only have an excellent record in keeping rates of HIV infection low as part of our work, but we are also members of what is referred to as the ‘general population’; and when we are not at work we tend to behave as members of the general population.

These perceptions feed into stigma against me as a sex worker, and I am also seen as careless, irresponsible

or even evil in ‘allowing’ myself to become HIV positive. The only sex work I offer is protected sex but many people will not even consider having sex with me. Some people believe that if I was ‘careless’ once I will be again and that will put them at risk. Others use the irrational belief that condoms protect during ‘normal or non-commercial’ sex, but not if the sex is paid for!

It took me many years to work comfortably with HIV, not because I was concerned with transmitting the virus to clients. Being 100% condom-compliant, plus employing sex worker safe sex practices which are stricter, more numerous, more complex and effective techniques than used by non-sex workers, would have made that impossible. What was not impossible and in fact likely, was blackmail, police action and life damaging media publicity.

The reality is in Australia, sex workers were the earliest adopters of safe sex practise. Sex workers claim

**Sex workers
have managed to
virtually eliminate
HIV transmission
in our work.**





Stigma is one of the main drivers of HIV transmission rates.

to have started using condoms before gay men and even if this is a slight hyperbole, street based sex workers in the Kings Cross area of Sydney Australia mandated condom use with clients in the misogynistic 1980s. Parlour and brothel workers achieved the same in their workplaces.

So through our own efforts, soon supported by the partnership of government, research and community, sex workers have managed to virtually eliminate HIV transmission in our work to the extent there has been no case of HIV transmission in a sex work setting in NSW ever.

Sounds great doesn't it? Unfortunately, the lived experience is radically different.

While sex work is almost fully decriminalised in NSW, I and my colleagues remain highly stigmatised and we suffer discrimination at almost every turn. The word usually used to describe us is "prostitute".

This is a term defined as a person who puts themselves or their skills to an unworthy or corrupt use for personal or financial gain.

We are seen as immoral, venal and self-interested – not to mention stupid and lazy. Up until recently the law held that we were unable to be raped because we were always on offer and therefore always consenting. We are routinely refused visas to travel and the US refuses us entry point blank. We can be asked to leave rented apartments, hotel and motel rooms, restaurants and bars due to our occupation (even if we aren't practising it in those locations). Just last week the Sex Worker not-for-profit health NGO I work for was refused a bank account by a major bank because our Board are all sex workers.

Being a sex worker living with HIV can be terrifying; blackmail, violence, incarceration and outing by media are constant threats. One of the first sex workers in NSW who publicly admitted she was living with HIV spent the rest of her life, 16 years, detained under a Public Health Order. For many years I always kept my passport up to date and a fair amount of cash handy and a plan on either quickly leaving the country, or going quietly and quickly to the bush if any of those things happened.

Among the extremely small number of sex workers living with HIV that I knew, most had similar plans and strategies in place, and several had a Plan B if their Plan A failed. Plan B was more extreme than a passport and a wad of cash, and that was always suicide.

Even if you do not do sex work, but

live with HIV this may unfortunately sound familiar as perceptions of people living with HIV (PLHIV) in some places and communities is very similar.

People suspected of having or transmitting HIV are demonised in the media and unjustly treated by the courts. Sex workers suspected of having or transmitting HIV are treated as automatically guilty by media and often by the courts.

The ACT has a law that criminalises sex workers just for having HIV and sex working. The last person charged under this law was jailed even though no evidence was presented that he had transmitted the virus to anyone or even that there had been any sexual contact (safe or unsafe) between him and his clients.

Recently I was in court when a West Australian sex worker living with HIV requested bail on an extradition order to face a charge of recklessly infecting someone else with HIV in Western Australia. The sex worker requested 48 hours bail in order to pack her belongings, terminate her lease etc. and fly back to Perth to surrender to the Perth Court. Police opposed bail on the grounds that the public needed to be protected from the sex worker. They believed that in those 48 hours she was likely to “infect innumerable persons with HIV”. The court agreed with the police and bail was refused, even though no evidence was presented that the worker was in fact HIV positive or of any HIV transmission by the worker. In this instance, any regard for the presumption of

innocence, a presumption that is supposedly a cornerstone of our legal system, was ignored.

Sex workers who are not white cis males or sex workers living with HIV who are not white cis males, do not enjoy the privilege that is granted to me almost automatically. For example, female sex workers, intersex, gender diverse, trans sex workers, sex workers of colour, Indigenous sex workers and migrant sex workers, all miss out on the protection of privilege.

We know stigma is one of the main drivers of HIV transmission rates and we have long known that overall stigma creates barriers to access services and quality health outcomes. For most people, stigma and discrimination are just words and intellectual concepts. It is almost impossible to describe an experience of pain by treating pain as an intellectual concept. Pain is a real and visceral experience and cannot be understood without a lived experience of pain.

I firmly believe that it is time we started to not only demand, but to take concrete and effective actions at reducing stigma and discrimination, not only for sex workers and for people living with HIV but for all marginalised and stigmatised communities. 

For more information and support for sex workers

 www.swop.org.au

 02 9206 2166

TAKING MEDS

Some lessons I've learnt

Adrian

Community member

I've been reflecting on the past 20 years of taking my HIV meds. It was fairly simple in the early days – there was just one – an AZT bottle!

Overtime, many more new options came along – sometimes, three, four or more drugs and dozens of actual pills: some to be taken at specific times and others with or without food etc. I used to have the bottles lined up in a row and started to work my way along the line. There were occasions when I lost track – taking the pills so regularly each and every day meant that it was hard

to actually remember which pill I had just that minute swallowed. I also found that it was difficult to keep on top of getting new supplies to prevent the drama of running out of meds.

My saviour was the dosette box! Yes, it was the size of a ream of A4 paper and took up half a shelf in the fridge, but it sure was a great help to me. Once a week I would sit down with all the med bottles and fill up each compartment of the dosette box – this also made it easier to spot when I was running low on meds and acted as a reminder to get the next script filled. However, the best part was that it really kept me on track with taking my meds each day. If I couldn't remember

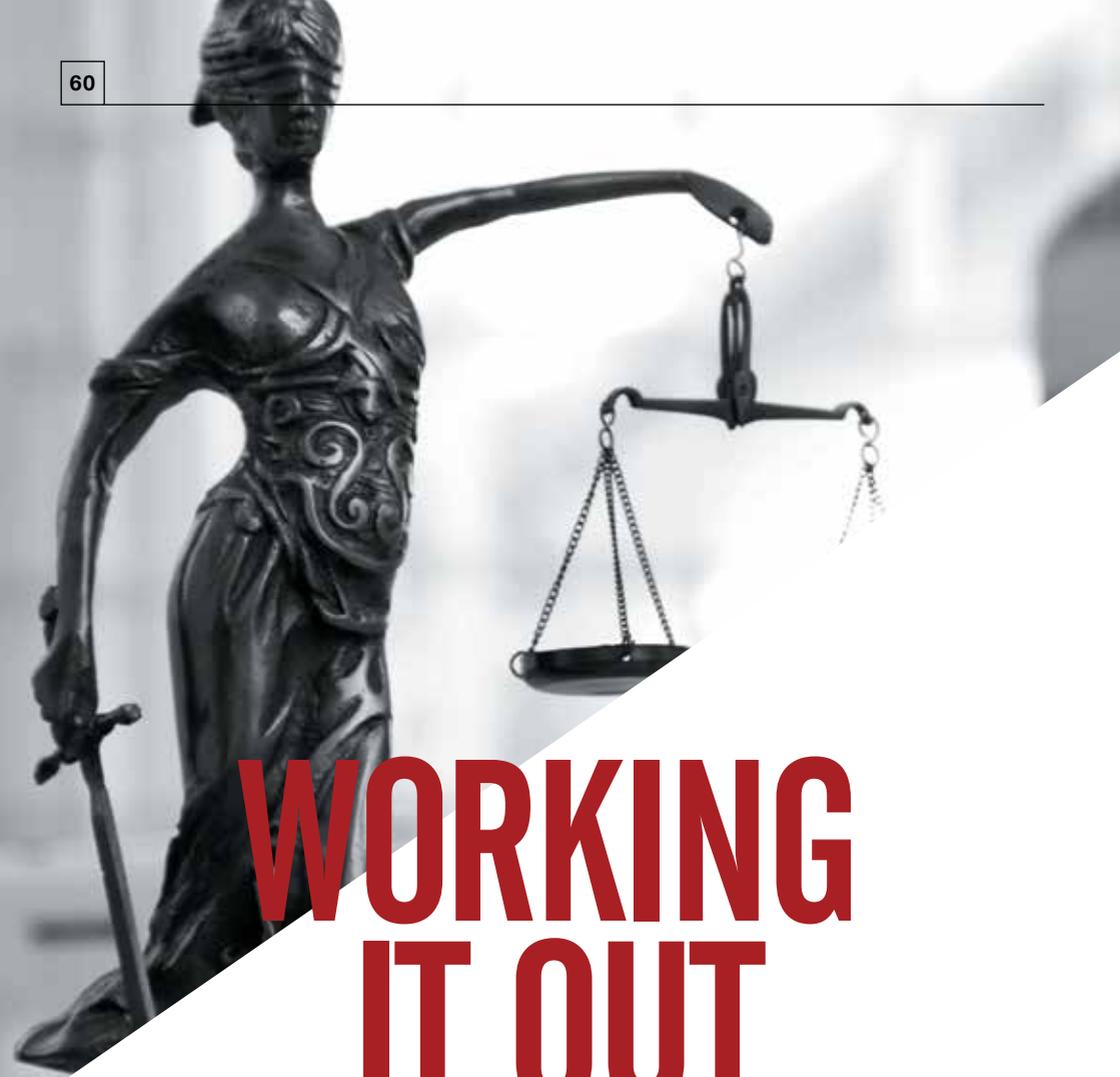
taking the meds on any particular day it didn't matter: if the pills were not in the box, then I had definitely taken them. Conversely, some nights I went to bed only to lay there worrying if I had taken the evening dose. A quick look in the fridge and in the dosette box gave me the answer!

Of course this doesn't work for everyone – friends of mine have used reminders programmed on their mobile, set alarm clocks, put pills out on a dish by their bedside – whatever works for you, just do it!

Today's HIV meds are a whole lot easier to manage – many people need only take one pill a day. However, the same applies today as has always – the meds are not going to do you any good staying in the bottle. The benefits of getting to undetectable (or close to), are so important to your ongoing health, and we are so fortunate to have access to meds here in Australia, when many of our fellow PLHIV living around the world are denied.

Sure, becoming positive is a real challenge – taking meds each and every day is something that most of us have never faced before (and many people in ordinary life struggle with just completing a short course of antibiotics!). However, the benefits are there in our hands, if we simply use a method that fits our own particular lifestyle, personality or living circumstances etc., to ensure we take our HIV meds every day.

Good luck with you journey. You are not alone. P.S. That dosette box is still in my fridge! ☑



WORKING IT OUT

Workplace HIV discrimination

David Crawford, Treatments Officer Positive Life NSW
with Suzanne Castellanos, HIV/AIDS Legal Centre (HALC)
Lawyer and Centre Coordinator

What can you do if HIV stigma can fuel discrimination in the workplace?

In the early days and months after learning we're living with HIV, some of us feel shame and guilt and retreat into our shells. For some people living with HIV (PLHIV), this experience can leave us feeling isolated and vulnerable. It is usually our friends and connections with other PLHIV where we find support to move through feelings of fear and isolation.

Even after finding our feet, stigma can undermine our self-esteem and impact our newly forming self as we adjust to living with HIV. Stigma is that sense of disapproval about HIV. Stigma can be blatant and unmistakable or something very slight, a look, a step back, a shake of the head, a word, or silence. Stigma can show up unintentionally in the ill-informed words of a friend, relative or a stranger. It can be found in a poorly crafted piece in the media, in the services we access, and even in our place of education or workplace.

The workplace is a significant aspect of many of our lives and a place where stigma can fuel discrimination. When you have worked towards a career or if you are in a job you love, discrimination

Stigma can undermine our self-esteem and impact our newly forming self as we adjust to living with HIV.

based on your HIV causes real fear and anxiety for PLHIV. That said, there are very few professions or workplaces where you are required to disclose your HIV status. There is no need to disclose you're living with HIV and many of us never tell the people we work with. Some of us feel that telling our employer we are HIV positive is the right thing to do and by disclosing, it provides an explanation for the doctor's appointments or gives us extra support without being in fear about our diagnosis. In reality, neither of these are required. A medical certificate is enough to attend to your appointments or short periods of time off.

If you disclose to your employer, the response can vary just like anyone else you've shared this news with and range from being very supportive to unsympathetic. Sometimes an accidental or intentional breach of your confidentiality can happen. Remember, always remain in control of your disclosure and only tell someone you think will treat this information with respect and care, someone you feel you can trust. Regardless of your reason to disclose, your employer's response should always be one of support and understanding. Unfortunately, ignorance and fear of HIV is still around, yet this is no excuse for a poor response. This poor reaction in the workplace can leave you scrambling to make sense of things and to be on your own in this battle can be an isolating and frightening experience.

As we all know, there are many negative effects of stigma, even for those of us who are empowered and resilient, can hold painful moments which cut deep and are lasting. Sometimes it is easier to walk away rather than challenge an assumption, or pick a battle. Sometimes the effort to object to a friend's inadvertent remark is just not worth the drain on our emotional wellbeing. There can be times when stigma turns into unfair

There are many laws to protect us from discriminatory behaviour, or from the disclosure of our HIV status without our consent. These laws give us the power to ensure our basic human rights are protected.

treatment, or discrimination, which often poses real threats to our security or personal safety.

At Positive Life NSW and also the HIV/AIDS Legal Centre (HALC), we often hear from PLHIV who have struggled to manage workplace HIV stigma and discrimination on their own and haven't reached out. Even though we understand your reasons for doing so, PLHIV in this situation can end up being mistreated in the workplace, or having alterations to their job description or working under restriction that are illegal. If you are in this position or just need some advice, seek support sooner rather than leaving it to 'work itself out'.

All workplaces are required to have standard policies and procedures in place to ensure all employees have a safe, protective and secure workplace and ensure everyone within that workplace is protected and treated the same. Employers are required to

make reasonable adjustments for all employees where appropriate. It is unnecessary to adjust an employee's work environment or practices and procedures simply because they are HIV positive, unless they work in one of the very few areas of the workforce where they are required to disclose their diagnosis.

There are severe penalties and sanctions for workplaces that discriminate against employees who are HIV positive. There are many laws to protect us from discriminatory behaviour, or from the disclosure of our HIV status without our consent. These laws give us the power to ensure our basic human rights are protected. As employees we can get support to empower us in ensuring our rights are upheld, especially when it seems the balance of power is in favour of the employer.

If your confidentiality has been breached and your HIV status becomes known within your workplace, or you feel pressured to disclose your HIV status at work, contact either Positive Life NSW immediately for support. We can advise you on your rights and responsibilities helping you and your employer to negotiate what can sometimes seem like a complex path. The outcome is often better when you have the right support and advice to work out what to do and what your options are. 

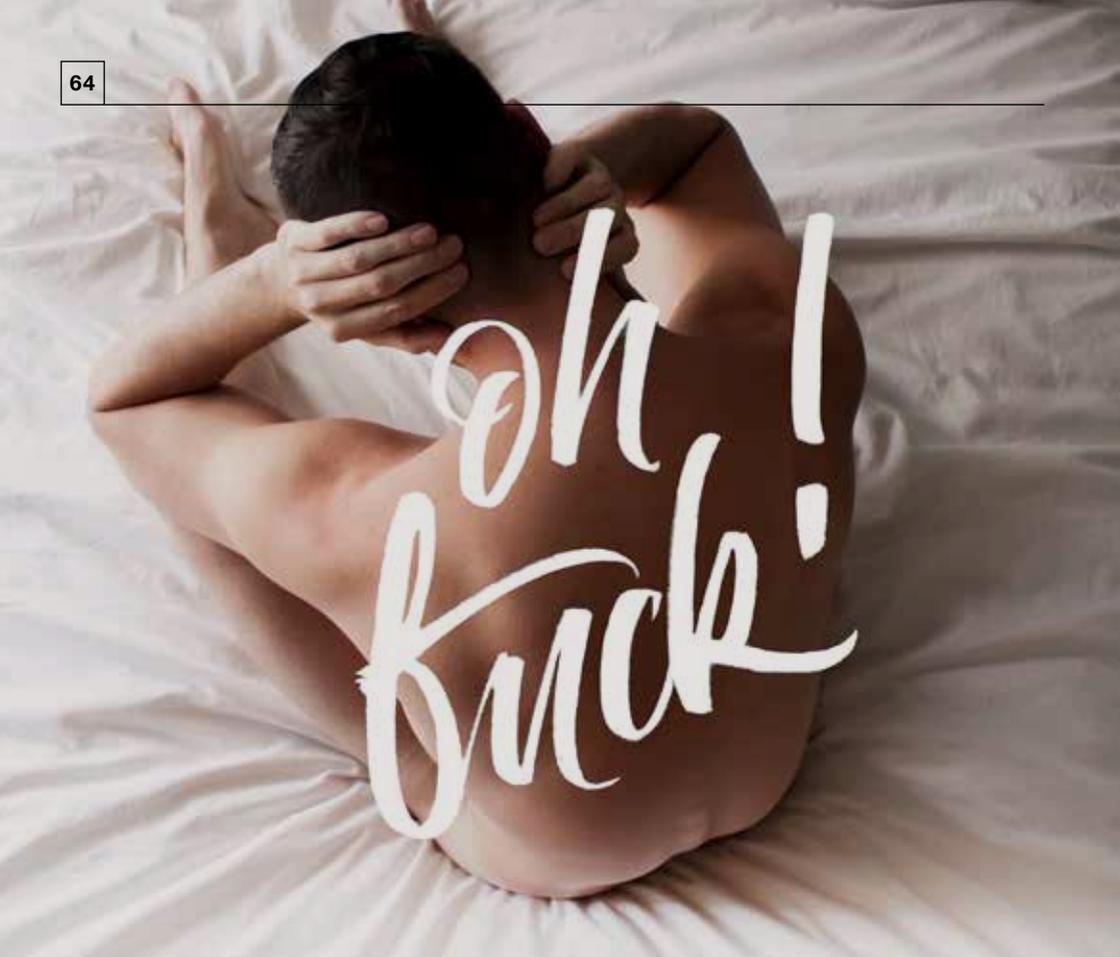
Positive Life NSW

 1800 245 677

HALC

 02 9206 2060





oh fuck!

'Nathan'

Community Member

The sound of my alarm woke me from my sleep. 5:00 am. Time to get up and in the shower. As I lay awake in bed the memories of the weekend rushed through my head. As I slowly woke up, I realised, I was no longer caught in an incredibly hot moment where I was making decisions based on some very hot guys and my urge to fuck them. All that was going through my head now, was the overwhelming sense of “Oh fuck”.

“Oh fuck” because I knew that I

didn't use any condoms. “Oh fuck” because I knew that two of the guys were Poz. “Oh fuck” because I had no idea the HIV status of the other few guys. “Oh fuck” because I never share injecting equipment. But most of all, “oh fuck” because I knew I needed to go and get a HIV test, and I wasn't sure that I didn't already have it.

My first thought was PEP. I needed to get on PEP. I didn't know much about HIV except that

I didn't want it and that there was this thing called PEP that could stop me from getting it if I'd been exposed. The only reason I knew about PEP was a poster on the wall of an SOPV (sex on premises venue). That PEP poster always used to get my attention; it started to make sense that morning why I always looked at that poster regularly. I'd even picked up a brochure about PEP. It was still hidden in my underwear drawer.

I called the hotline number over a coffee and a cigarette. I was nervous and anxious. I had always put off testing for HIV. I knew that I had taken all of the risks. I wasn't just pushing my limits; I didn't really have any limits. I was fucking a lot of strangers raw and enjoying it. I had accepted that just because I wasn't sick, there was nothing to worry about. I had accepted that it wouldn't happen to me. Except now, I was looking down the barrel of cold reality. I realised I'd known the real answer to my HIV status instead of convincing myself that I would be fine.

The rest of that morning played out quickly, and is almost a blur. I remember talking to the nurse on the PEP hotline, I remember her telling me where to go. I remember arriving at the clinic in St Leonards, waiting for them to open. I remember the reception staff being very nice to me (I was clearly shaken up). I remember the doctor asking me some questions, I remember getting the pills. I have no

recollection of the rest of the day.

That week on PEP was tough. I remember being tired. Tired in a way I was never before. And when I did sleep, it was deep and heavy. And I sweated. Every time I woke up there would be a pool of sweat.

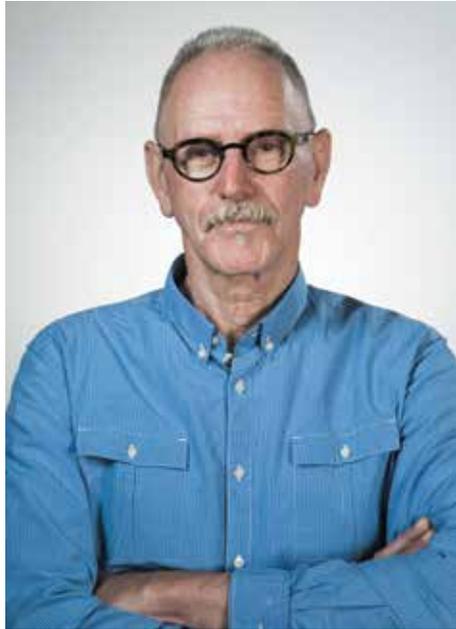
One week later, I had my follow-up appointment. One of two things were going to happen to me that day. I would either be told I was HIV negative and I'd go on with the course of PEP. Or, I was already HIV positive before the weekend that had prompted me to test. That day, I remember little except for the walk from my front door to the bus stop that morning. That walk is very clear in my mind still six years on. I guess there is no prize for guessing which of the earlier two options happened. I was diagnosed HIV Positive on 22 February 2010.

With hindsight and the lessons I've learnt, it's easy to think back and wonder why someone wouldn't want to test to know if they are positive. It is also easy for me to wonder why someone wouldn't reach out to a friend or a doctor to talk about HIV. Then I remember I only understand the fear that comes with testing and I know this fear now because I have been through it.

I'm now a 30 year old Poz guy, with six years lived experience of HIV under my belt. I know more now than I did when I was HIV-negative. While I don't need to test for HIV anymore, I get tested regularly now to make sure I'm on top of my health needs. It's not so hard. 



Lance Feeney, Consultant and Special Representative at Positive Life NSW, writes about the twists and turns of one unlikely lad's journey into HIV advocacy.



I wasn't very interested in politics or activism when I was a young man in the 1970s. I was too busy having lots of sex with lots of men. It was through those men and their diverse lives that I started to work out who I was, and what my place was in the world.

Sydney in the 70s was a cool place to explore your sexuality. After Whitlam came to power, Australia seemed to grow-up and change for the better. The conservatism of the 50s and 60s melted away in a flurry of sex and drug experimentation and a new more liberal morality was the result. I was spending time with a guy I'd met at Sydney University, and we shacked-up together in a run-down semi in East Balmain.

There was lots of dope smoking, music and adventures in beats and gay bars in Kings Cross and on Oxford Street. Guys were experimenting and bisexuality seemed to be everywhere. In a Victorian detached house in Rozelle not far from where we lived, members of a gay bike club met at weekends. These were guys who rode motor bikes, smoked dope, wore leather, and were interested in more than a quick hand-job. I was in heaven, and so were they.

In 1976, my boyfriend and I split. He went to London and I stayed on for a while before flying to Athens and then buying a bike and touring through Italy and France, ending up in London. I remember pushing that bike down the

platform at Victoria Street Station, sun tanned and looking like a million dollars – and thinking, boy am I going to have fun with these pasty-white poms. And I did! London during the late 1970s was going-off – the Coalherne Pub in Earls Court, the leather crowd cruising Hampstead Heath at night, and the London Public Underground toilets, most of which were very busy beats. There was even a Saturday night gay dance party called Heaven for those who preferred dancing before sex.

My best mate worked for the Department of Immigration in Australia House and had an apartment in the West End. Although I was living and studying in Wales, I had a key and weekends were spent in London with him. He loved fisting! Saturday nights were fisting parties for a select group of guys who he'd recruited over the years, and the apartment was transformed

on Friday night for the festivities.

There were lots of drugs, dope, acid and cocaine, and I remember, Crisco, plastic covered furnishings, and dildoes. He was one of those gay men who was sophisticated, educated (spoke five languages fluently) and a total pig. He died of AIDS at his parents' home in Western Sydney in 1983. It was my first exposure to the spectre of AIDS, death and suffering, and it left an indelible imprint on my memory.

I'm not sure where I contracted HIV, whether it was at one of those fisting parties, or on one of the trips to the Mineshaft in New York, or the Argos Bar in Amsterdam. In late 1979 I remember feeling very unwell and struggling to walk up the hill to my lodgings. I consulted a local GP in Swansea who did a range of tests and told me I had an unspecified viral infection. I left the UK in 1980 and returned to Sydney via New York and San Francisco. I got a job as a barman at the Beresford Hotel in Surry Hills. It was fun, the money was OK and there was lots of hot men around. Life was good.

In 1981 I opened my studio in Surry Hills and began to put the education to use. Back in London I'd heard from expats about gay life in Sydney. Sydney was buzzing in the early 80s. Bars like the Signal and Barracks were jumping and some smart gay-dudes who were cashed-up were running private dance/fuck parties in the cattle sheds at the Show Ground in Moore Park. You'd be dancing away off your tits and fall into a concrete piss-trough in the floor. All very novel. Then there were the horse stalls

I wasn't very interested in politics or activism when I was a young man in the 1970s. I was too busy having lots of sex with lots of men.



which were great fun until someone shoved a bottle of amyl nitrate into a horse's face and got bitten and kicked.

I met a guy at the beat at Wentworth Park and we started seeing one another. He was a major in the army reserve and worked in the city by day. He also liked cocaine and we were having a great time together. After a while we drifted apart and the next time I saw him, he wasn't looking well. He had lost weight and the body beautiful was gone. The next I knew he was going to Switzerland for some type of cancer treatment. That was 1982. At about the same time my friend Kevin arrived home from London. He was admitted to St Vincent's Hospital with pneumonia. A bit earlier in 1981/2, Sydney started to hear reports of guys getting sick in New York, San Francisco and London with strange cancers and pneumonias. People speculated that it was caused by lifestyle – too many drugs, sex and amyl nitrite. Now it was happening in Sydney. I remember thinking that if it was infectious that I most likely had it. How could I have not been infected after what I'd been up to!

The reports from San Francisco and London became more worrying. I got a call that Kevin was dying and made the trip out to his parent's home in Western Sydney. I spent about 15 minutes with him. He was close to death and I'd never experienced anything like it before; the laboured breathing, the look of death in his eyes, his abject suffering. His parents were in a dazed haze of disbelief. Shock, I suppose. He died the next day. I don't remember the funeral,

I think I was 'de-gaying' his house in Paddington and also in shock. It was to be the first of many more deaths and funerals!

A week before Sleaze Ball in 1984, I decided to go for a test and find out if I had it. At that time they were measuring CD4 cell counts. A week later I went back to Taylor Square Private Clinic to get the results. All I remember is the doctor telling me I had 210 CD4 cells. When I asked him what that meant, he said "well, we don't know very much about the disease yet, but you've probably got about a 95% chance of contracting a serious life-threatening condition within the next two years". Stunned, I left the surgery and went home to process what I'd been told. My boyfriend at the time wasn't very supportive. His attitude was "you'll be OK, get over it" and that attitude marked a turning point in our relationship. In the meantime, people we both knew were getting sick. Some were hospitalised. I remember sitting on the cliffs at Bondi thinking this might be the last time I did a Sleaze Ball.

We were scared and started cleaning up our acts. I cut down on the party drugs and worked hard at the gym. The Sydney Gay Sports Association and the Sydney Gay Front Runners started up. I joined a gay volleyball team and was playing competitions every Wednesday night. I was trying to stay as healthy as possible. In 1986, our team went to the Gay Games in San Francisco. I stayed with an old friend on 18th Street near the Castro. He'd been a friend since our days working

together as barmen at the Beresford. One of the guys sharing the apartment began to become unwell. He was a big strapping guy from NZ and worked at the local gay gym as a personal trainer. I remember him drinking diluted hydrogen peroxide because some shonk had told him it would help. It didn't! He died some months later.

The tell-take signs of AIDS were visible all over the Castro. The locals organised fund raising movie nights in the Castro Theatre to help guys who were in need. There were guys begging on the corner of 18th Street and Castro. It was horrible. Some had KS lesions on their face and hands and were painfully thin. They squatted on the pavement with hand scrawled signs saying "please help me". After the Games we tried to party on but it seemed hollow and insensitive. I stayed for a couple of months and then heard that one of my mates had taken a turn for the worst and flew home. I arrived at Sydney Airport early in the morning. The customs officer decided to dismantle and inspect my luggage. She took what seemed like hours to go through the contents. By the time I got home I heard that my friend had just died. He'd hung on waiting to say goodbye, but in the end couldn't hold on any longer. I was distraught! Some of us made the trek to Millthorpe in Central NSW where he'd grown up. The funeral was a joyless affair. Ironically, the year before he'd died he been working as a barman at the Albury Hotel. When the signs of AIDS finally appeared, the

Licensee decided that he was not a good look and bad for business. He was asked to go. I remember sticking pins in an effigy of that owner for some time after.

The period from 1987 to 1991 was a blur. Commissions, commissions and more commissions. I moved to a bigger studio in Leichhardt. Friends and acquaintances continued to weaken, then sicken and die. My best mate committed suicide. On one side of the funeral chapel were the Italian family and on the other side his ungodly and dissolute gay mates. It was a toxic environment. A Queen at the back of the chapel yelled out in a high-pitch and emotionally thin voice "If you don't turn that fucking hideous music off, I'll scream". We huddled in the rain as they carried the coffin to the hearse. Nobody spoke.

About this time, AZT monotherapy came onto the scene, but my sense was that there was limited availability or no benefit. I declined to take it. Increasingly I was being kept alive by prophylaxis drugs. Bactrim for Toxoplasmosis and PCP, Fluconazole for fungal infections, Valtrex for herpes zoster, and fortnightly injections of Decca Derabolin for wasting syndrome. I had a CD4 count of less than 10 and was constantly dealing with CMV in the gut. There were weeks in bed with lung and throat infections. In 1991, I took my doctor's advice, stopped work and went onto the Disability Support Pension. Retreating to my home in suburban Sydney, I spent a lot of time alone gardening and helping others come to terms with the inevitable

course of the disease. I visited friends and watched the inexorable decline in the health of my friends. One of those friends was my mate from 18th Street in San Francisco. By then, all the guys in the house had died of AIDS and he returned to Sydney. He stayed for a while but his health deteriorated and I remember farewelling him when he flew back to the UK. We both knew it would be the last time we spoke to one another. It was a horrible time and now I have difficulty remembering much of that period in any detail. I think I wiped it from my memory in an unconscious attempt to maintain some semblance of sanity.

In 1995/6, the early protease inhibitors became available via compassionate access. My first combo was AZT, 3TC and zidovudine. It worked, but the side-effects were intolerable. They switched the AZT to D4T. Within six months I started to notice tingling and numbness in my feet and hands. Within a year I couldn't run to catch a bus. I hung in there hoping the drugs would improve. In '98 they changed my regime to DDI, hydroxyurea and zalcitabine. On my 50th birthday after weeks of gut problems I was hospitalised with pancreatitis. The treatment was nil by mouth and shots of pethidine and morphine every four hours. When I was discharged from hospital I weighed 54kgs and needed a wheelchair. I had cheated death and it was time for something new.

The road back to health was a slow one. But, within a few months I was working again on a major commission.



I walked away from that chapter in my life knowing that there was nothing more that I wanted to prove. But I did start searching for something more meaningful to do.

It was an act of love and I knew it was the last major commission I'd do. When it was finished I walked away from that chapter in my life knowing that there was nothing more that I wanted to prove. But I did start searching for something more meaningful to do. I wanted to be with my own tribe, with gay men and with people with HIV. It was about then that I met Geoff Honnor. He encouraged me to find a new doctor and I went back onto salvage therapy. My goal was to go back to work when my CD4 got to 200 and within a couple of years, it did.

In 2001, ACON were looking for someone to baby-sit the Positive Living Centre in Surry Hills while they



Effecting some positive change for people with HIV gave me courage. I felt like I had landed.

recruited a manager. They'd taken over the project after it became dysfunctional and defunded. Many of the HIV-positive men who came to the PLC were much like me. They had stopped work at some point in time due to HIV-related illness and were getting the DSP. Many were angry, disillusioned and depressed about how their lives had turned out, and they were trying to get by as best they could and make sense of the madness. I enjoyed their company and decided to apply for the position of manager. Surprised at the appointment, I turned my energies to making the PLC a safe and welcoming place for all people living with HIV. Those early days were a challenge for clients and staff alike. The police were regularly called to break up fights and help deal with men who were out of control. Eventually though, there was a change for the better. We started

running reskilling courses on how to use computers, in writing, in arts and crafts, in cooking and food preparation, and in skilling-up for administrative jobs. There was a peer weekend workshop for newly diagnosed men called *Genesis*, quarterly social nights and on Fridays a social lunch. 50–60 guys would eat together and catch-up with friends. Visits by the police became rare and more and more people started coming to the PLC.

In 2006 it was time for a new challenge. I started writing HIV-related content for the ACON website and for HIV-related health promotion campaigns. Tony Abbott was the Minister for Health in the Howard Government and before they departed office he announced the roll-out of a new Medicare dental scheme for people with chronic disease. Understanding the potential we encouraged people with HIV to get a referral and start the process of reconstructive dental treatment. That scheme over the next few years changed the lives of many HIV-positive gay men. By restoring mouths and allowing them to reengage in employment and regain new social confidence and prosperity, the scheme was arguably the most beneficial health intervention after combination antiretroviral therapy. Witnessing the transformation in people's lives, made me increasingly aware of the power of public policy to change the lives of people living with HIV for the better.

In 2008, Positive Life NSW created a new systemic advocacy position

and I was appointed. The role was to identify barriers to service access and develop joint strategies to affect better outcomes for people living with HIV. It was a dream job, the only funded role in Australia. I had never written a formal submission or a briefing document, let alone provided evidence to a government inquiry. But there were courses where I could learn the skills and mentors providing advice. Effecting some positive change for people living with HIV gave me courage, I felt like I had landed.

I've been in that role for six years and during this time, it has changed and grown. We've improved access and affordability of HIV medication, changed the way the Department of Forensic Medicine treats the bodies of people infected with HIV and HCV, and gained access to life insurance products for people with living HIV in Australia, something that was denied to them for 15 years. We have helped to improve HIV-positive people's acceptance and understanding of the benefits of modern HIV-treatment and played a role in reducing HIV transmission in NSW, and we've partnered with the HIV/AIDS Legal Centre on a range of projects to help people living with HIV better understand their rights and responsibilities.

There are many more issues that will need to be worked through in the coming years. Appropriate and non-discriminatory services for people who are ageing with HIV, measures to help people with depression and

neurocognitive impairment maintain health and wellbeing, drug and alcohol issues, and assistance for those who are living in poverty and struggle to afford the health care and accommodation they need. Over the last decade we've witnessed an increasing move towards a more medical model of HIV management and care. The challenge for people with HIV will be to step-up and remain central and vital in the planning of all future service delivery and public policy. That is if we are to avoid an ongoing disinvestment in the HIV service sector. The danger is that as HIV becomes more normalised, people living with HIV will disengage and become passive recipients of services and the public policies that shape them. That would be a reversal in the involvement of people living with HIV in the Australian epidemic and I have no intention of accepting that reality. Many of my mates may be dead from AIDS, but their impact on me lives on.

And that's the story of how an unlikely lad from suburban Sydney ended up becoming an advocate for people living with HIV. Maybe not that unlikely after all. Most of us end up putting one step after the other. 

Published as *Effecting Change Gave Me Courage*, in *Through Our Eyes: Thirty Years of People Living with HIV Responding to the HIV and AIDS Epidemics in Australia* (July, 2014) by the National Association of People With HIV Australia (NAPWAH).

The Western Suburbs Haven Inc.



Real people making a real difference

The Western Suburbs Haven Inc is a community organisation in Blacktown providing convalescent/respite care, social support and drop-in services for people living with HIV/AIDS, their partners, families and carers in Greater Western Sydney.

The Haven operates as a drop-in centre and a convalescent/respite care centre.

People Sydney wide affected by HIV access our services. Referrals for respite care are accepted state wide.

We offer a range of services including but not limited to:

- Respite/convalescent care
- Social support and drop-in services
- Drop-in lunches; Friday's are the main drop-in day for lunch, HIV and social support for HIV positive people
- Group activities and social outings
- HIV information, referrals and assistance with accessing other services
- Computer assistance and free internet access
- Pantry Program
- Transport to medical appointments (by arrangement only)
- Pick up and drop off to the Centre from Blacktown station.

Accessing our services

- Services are available to people affected by HIV/AIDS Sydney wide. This includes families and carers of people living with HIV.
- We have two bedrooms available for respite care.
- Drop-in services are open Monday to Friday.
- Referrals mostly come from doctors, nurses, social workers, other HIV specific services and self-referrals from people living with HIV.

How to refer

Respite Care: We have a standard referral form that can be faxed or emailed to the person referring.

Social Support and other services: Referrals from healthcare workers and other service providers are generally by telephone. Formal confirmation of status may be required. Anyone living with HIV/AIDS, their carers or families can refer themselves to access any of our services as long as they accept our checking of their HIV status to confirm eligibility to use services.

We run mostly on volunteer labour. These dedicated volunteers donate many hours caring for our guests and service users and work hard fundraising, cooking, cleaning and driving as well as attending to various other duties to make a difference to the lives of people living with HIV. Enquiries to volunteer are always welcome.

For all enquiries contact The Haven Office

Phone (02) 9672 3600

Email thehavenoffice@bigpond.com



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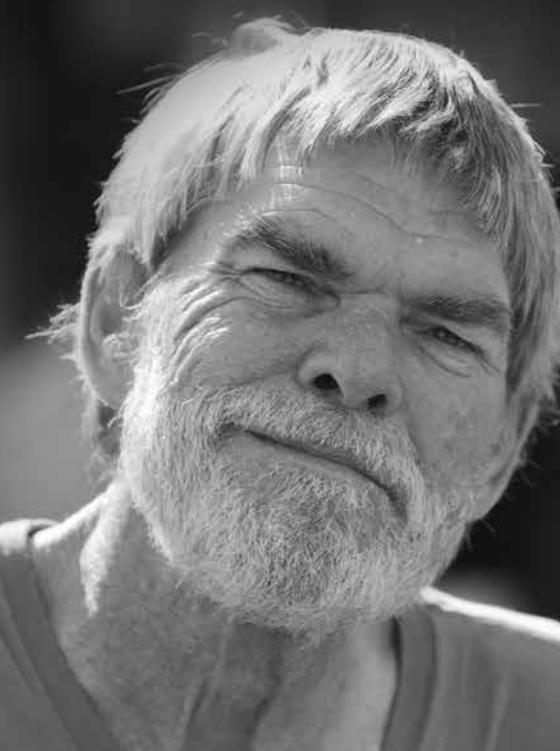
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Returning to work and dealing effectively with Centrelink

Roy Christopher
Community member



I have HIV and a number of other chronic health conditions including living with a mental health diagnosis. Despite taking medications, these conditions still cause a negative impact on my ability to contribute to society and engage as much as I would like to. It has been a constant struggle for me to reach a point in my journey with HIV to be able to say that I feel well enough to give something back to my community. I have experienced discrimination, stigma, live on the poverty line and feel the impact of social isolation due to my health conditions. I receive a welfare payment and reside in government housing. After my rent and bills are paid I am left with barely enough money to feed myself. I am wary of disclosing my HIV status due to the negative attitudes that I have faced in the past, and tend to keep to myself leading to further isolation.

Regular monitoring and effective treatment of my HIV has now given me an undetectable viral load. I take anti-depressants for my depression. I also experience debilitating episodes of anxiety compounded by agoraphobia which I manage by practicing regular breathing and mind focus exercises. Managing these multiple health conditions is hard work. If I wasn't to

take my HIV medications this would open me up to the onslaught of opportunistic infections. Without taking my 'happy' pill I run the risk of sliding back into a severe state of depression and if I don't regularly do my breathing and focus exercises, I am unable to leave my home.

Recently I made the decision to return to casual work after many years of volunteering in the HIV sector. This new position requires me to work for eight hours per week which is a perfect fit for my current state of health. I now get to work with people and change lives in a positive way.

I discovered that people living with HIV are faced with a new burden. What I encountered in returning to work was some staff in positions of authority in commonwealth government agencies apply policies which negatively impacts people like me. These are people with HIV who are living on a disability support payment (DSP) and looking to return to some form of paid or voluntary work. In some cases these people have been on a DSP for longer than ten years and lack the confidence or skills to return successfully to the workforce and are looking for meaningful support to do this.

When I went in to the Centrelink office in Darlinghurst to inform them of my return to casual work I was told that I would have to have my payment reviewed. This was despite that I was not returning to more than eight hours work per week. I raised my objections with the staff member but was bluntly told that my information was incorrect,

it was standard policy to review the payment and to reassess anyone on DSP for a return to work assessment and applies to anyone who enquires about returning to volunteer or paid work, regardless of the hours involved. This process triggered a very stressful and anxious time for me.

For the assessment I was required to have two healthcare providers write support letters to take with me for my review and was faced with an almost two week wait before I would know if I was still eligible to receive a DSP. I approached David Crawford, Treatments Officer, from Positive Life NSW to act as my advocate and attend my review. The Centrelink Workplace Assessment Officer after reading my support letters and on reviewing my file was genuinely puzzled as to why I was asked to participate in this assessment process. We were informed that the information I was given when notifying Centrelink of my intention to return to casual work for eight hours a week was incorrect.

The policy for this type of return to work assessment applies to people on DSP 35 years of age or under and over 14 hours of work per week. She apologised for the inconvenience this process had caused me.

Whilst I am thankful that my benefit would not be jeopardised by my return to work, I am disappointed that people wanting to enhance their life are placed in a position of experiencing needless anxiety. I am also embarrassed and annoyed that I had to impose this on two very busy healthcare workers to provide the unnecessary documents. 



Oh, you don't need that

'Tom'

Community member

"Oh, you don't need that." This was the reply from my family GP when I asked for a HIV test for the first time. He was our family doctor and someone who had known me for most of my growing up years.

At the time, I was still not completely out to everyone but I recall the feeling as I realised I had to come out to my doctor. The experience of coming out to people was still all quite new to me, and was usually accompanied by an overall rush feeling: increased heart rate, and that 'anxious' feeling.

My doctor's response was remarkable, and immediate: "Which arm do you prefer? Left or right?"

I remember walking away thinking my doctor had also learnt a valuable lesson that day. Our patient-doctor relationship had entered a new chapter: one of absolute honesty enabling a more complete access to health care, appropriate to my life and behaviours.

Today I sit here and think, 'what if I was not on the journey of coming out? What if I did not want people to know I enjoyed having sex with men? What if I did not tell (or want to tell) my doctor I was gay?' I believe I would have walked away that day, without a HIV test. I look back and wonder when (or if) I would have found the confidence to go and ask for a HIV test again, particularly if I was seeing the same doctor.

At the time, I was not connected to the inner city gay life. I was not aware there were medical practices with gay and gay-friendly doctors and nurses. I

I recall the feeling as I realised I had to come out to my doctor.

was living in the suburbs disconnected to the gay community and I was not accessing the information I needed, so it was all a learning curve for me.

The lesson I learnt from this experience is: do not be afraid to ask for a HIV test.

Now I am able to look back and understand my doctor was always bound by confidentiality, so I really had nothing to worry about.

If you don't feel comfortable asking your regular doctor for a HIV test, there are plenty of testing services available, some of which are free, or you can always find yourself a new GP for your sexual health needs. Once you connect in, the whole experience of getting tested becomes surprisingly ordinary in no time at all. 



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the voice of people with HIV since 1988

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Positive Life NSW is the voice of all people living with HIV in NSW. We work to promote a positive image of people living with and affected by HIV with the aim of eliminating prejudice, isolation, stigma and discrimination. We provide information and targeted referrals, and advocate to change systems and practices that discriminate against people living with HIV (PLHIV), our friends, family and carers in NSW.

Phone 02 9206 2177 Freecall 1800 245 677 www.positivelife.org.au

Everyone has a story to tell...



Telling your story of living with HIV can help and encourage other positive people, while educating the community about our lives. If you want to share your story contact the Talkabout editor.

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TALKABOUT



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- Get the latest information on topics such as pregnancy, treatment and living well
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Locations: Coffs Harbour, Hunter,
Northern Rivers, Port Macquarie,
Southern and Far West

Phone: (02) 9206 2000

Email: acon@acon.org.au

Web: www.acon.org.au

ADAHPS

301 Forbes Street, Darlinghurst 2010

Phone: (02) 9382 8600

Email: adahps@health.nsw.gov.au

Albion Centre (The)

150–154 Albion Street, Surry Hills 2010

Phone: (02) 9332 9600

Email: info@thealbioncentre.org.au

Web: www.thealbioncentre.org.au

Ankali Project (The)

150 Albion Street, Surry Hills 2010

Phone: (02) 9332 9742

Email: info@thealbioncentre.org.au

Web: www.thealbioncentre.org.au

Bobby Goldsmith Foundation

111–117 Devonshire Street, Surry Hills 2010

Phone: (02) 9283 8666

Free call: 1800 651 010

Email: bgf@bgf.org.au

Haymarket Foundation (The)

137–139 Regent Street, Chippendale 2008

Phone: (02) 9197 9700 or 1300 029 202

Email: centre@haymarket.org.au

Web: www.haymarket.org.au

HIV/AIDS Legal Centre (HALC)

414 Elizabeth Street, Surry Hills 2010

Phone: (02) 9206 2060

Email: halc@halc.org.au

Web: www.halc.org.au

HIV Outreach team

301 Forbes Street, Darlinghurst 2010

Phone: (02) 9382 8666

Email: SESLHD-HIVCommunityTeam@health.nsw.gov.au

Karumah

1/24 John Hooker Street, Islington 2296

Phone: (02) 4940 8393

Email: admin@karumah.com.au

Web: www.facebook.com/karumahonline

Kirketon Road Clinic

Darlinghurst Road, Darlinghurst 2010

(entrance on Victoria Street)

Phone: (02) 9360 2766

Web: www.seslhd.health.nsw.gov.au/shseh/services/kirketonroad.asp



Have questions about HIV, sexually transmitted infections (STIs) or sexual health? Get confidential, nonjudgmental answers anonymously and free from Sexual Health Info Link.

Call 1800 451 624 Weekdays 9am – 5.30pm

Multicultural HIV and Hepatitis Service (MHAHS)

18 Marsden Street, Camperdown 2050
Phone: (02) 9515 1234
Email: info@mhahs.org.au
Web: www.mhahs.org.au

NSW Sexual Health Infoline

Free call: 1800 451 624
Weekdays 9am – 5.30pm
Web: www.shil.nsw.gov.au

NUAA

Level 5, 414 Elizabeth Street, Surry Hills 2010
Phone: (02) 8354 7300
Free call: 1800 644 413
Email: nuaa@nuaa.org.au
Web: nuaa.org.au

Positive Central

103-105 Redfern Street, Redfern 2016
Phone: (02) 9395 0444

Positive Life NSW

Level 5, 414 Elizabeth Street, Surry Hills 2010
Phone: (02) 9206 2177
Free call: 1800 245 677
Email: contact@positivelife.org.au
Web: www.positivelife.org.au

Pozhet

18 Marsden Street, Camperdown 2050
Phone: 1800 812 404
Email: pozhet@pozhet.org.au
Web: www.pozhet.org.au

Qlife

Phone: 1800 184527
Every day, 3pm – midnight
Web: www.qlife.org.au

SWOP

Level 4, 414 Elizabeth Street, Surry Hills 2010
Phone: (02) 9206 2166
Email: swopconnect@swop.org.au
Web: www.swop.org.au

Tree Of Hope

2C West Street, Lewisham 2049
Phone: 131 819
Email: treeofhope@catholiccare.org
Web: www.catholiccare.org/community-services/social-supportliving-with-hiv/

Western Suburbs Haven (The)

Phone: (02) 9672 3600
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POSITIVE SPEAKERS BUREAU

The Positive Speakers Bureau (PSB) is a program of Positive Life NSW which offers your agency, school, organisation or group the opportunity to hear the first-hand experiences of people living with HIV.

Our trained speakers living with HIV share and educate a range of audiences by delivering key prevention, education, harm reduction and safer sex messages which are woven into each speaker's story.



www.psb.positivelife.org.au

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