
POZLITE

The best of 2017

**A COMPILATION OF THE YEAR'S
MOST POPULAR ARTICLES**

AIDS Silence = Invisibility

Impact of HIV for Women in Australia

Consent and Respect

INTRODUCTION



JANE COSTELLO

President, Positive Life NSW

It's with great pleasure that I present the third edition of Pozlite. While attitudes towards people living with HIV (PLHIV) are constantly changing and evolving and prospects for our health have vastly improved, speaking up about HIV and engaging in the conversation of HIV remains critical now more than ever. The axiom *silence equals death*, is back on the radar of our communities at risk of HIV and for those living with HIV.

In the early years of the epidemic, Silence=Death was a powerful slogan that moved people beyond the taboos of talking about sexuality, health and access to

treatments. It channelled the anger and rage against recalcitrant political administrations during the early 1980s. This lethal silence fuelled fear within people and our communities about HIV and was reinforced by discriminatory treatment which resulted in the premature deaths of many

PLHIV at the time, though suicide, non-disclosure, and refusal of access to health services or medicines.

Today we stand on the shoulders of our loud positive activist elders who spoke out and demanded fast track medication trials, improved HIV test kits, improved medications, quality care from doctors and nurses. Our health outcomes, quality of life and life expectancy are on par with the general community, as long as we know

our status, commence treatments sooner rather than later, and remain engaged in our health and in the health system. Today we can commence treatment immediately on diagnosis, we have returned to the workforce in greater numbers, we travel, study and embrace relationships across the divide of HIV-Difference. We readily take up our role as an integral part of the answer to reducing transmission in the Treatment as Prevention (TasP) space, taking ever closer steps to the end of HIV transmission in NSW.

Even with all the good news about living with HIV today there is a danger of PLHIV invisibility, and the spectre of silence around HIV haunts our communities. The mainstreaming of health services, the increased demand on HIV specialist services due to the increased burden of disease and multi-morbidities in those living longer with HIV, and an assumption that HIV is 'ending' by 2020, casts a tacit and deadly shroud around HIV. With more people living with HIV in NSW than ever before, we all need to be speaking up about HIV more than ever.

While AIDS might not be the killer it once was, silence about HIV fuels stigma and fear which turns PLHIV away from accessing services they need and harms our health or can result in our death. Fear of testing for HIV means people living with undiagnosed HIV or people who are diagnosed with advanced HIV disease (considered to be 'late presenters'), are living longer with damaged immune systems and compromised health outcomes. HIV is moving into the margins and affecting more divergent communities than ever: women of all ages, heterosexual men, Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, and people born overseas. This is no time for silence, it is time to speak up and speak out.

Whenever stigmatising attitudes or discriminatory practices go unchallenged, we disengage with our healthcare providers, avoid social interactions that nourish and build our community and the silent reality of passive suicide emerges. The conversation is made all the more difficult for heterosexual people living with HIV still not specifically named in the National HIV Strategy, and thus not readily considered at risk. How does this help in the fight against HIV, HIV stigma and discrimination and HIV education and support? There are regular and numerous examples of women attending GP clinics with symptoms, and the question 'could it be HIV?', just wasn't asked. More than ever, we need to speak up about HIV and become a vocal and visible presence combating HIV stigma and discrimination with confidence and dignity.

Our elders who fought ignorance, indifference and intolerance, understood silence equals death. Today it is still critical that we re-engage in this powerful adage. For far too many of us even today, the outcome of silence is death.

We must continue to inform and educate, turn apathy and disinterest into action, and challenge each other along with our healthcare providers. Even though the conversations about HIV might be changing, by speaking up and speaking out about HIV we continue to highlight resilience, hope and empowerment for all communities at risk of HIV.

**This is no time
for silence, it is
time to speak up
and speak out.**

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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, our society.

In 2016, the World Health Organisation reported Global Health Observatory data that 1 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 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 how shocking and difficult, 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.

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 July 28 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 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 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 significant number of people at risk of an AIDS-related death, who will struggle to rebuild their immune systems and be at risk of a variety of

So, why are people continuing to die from AIDS in NSW?

serious associated diseases and health conditions. 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 discover 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 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 with 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 PLHIV. Together, I believe we can break through the fear and reduce the number of people each year 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 our community. 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.



"I'm sorry, but your bloods came back with HIV cells present. It shows that you're positive." That cloudy evening on Oxford Street in Sydney, I sat in the a[TEST] clinic stunned and frozen from shock. I was in the process of living my dream, travelling the world with the lightest backpack on my shoulders.

Up until that point of my diagnosis; I had been travelling for nearly five months around numerous capitals in America. From working in New York with children with disability to riding horses, cowboy style, in Monument Valley, Utah. Now here in Sydney Australia, being told I was HIV positive, suddenly my light backpack became very heavy with thoughts of stigma, death, denial and that my dream of travelling would have to end abruptly.

Looking back, I am sure that it was while I was in New Orleans, USA, when I contracted HIV. Like most backpackers who get absolutely wasted on alcohol and can only remember small details from the night before, I did recall the guy having deliciously blonde hair and stunning blue eyes. However we had sex without a condom and I never saw him again. I didn't even catch his name.

It wasn't long before I noticed little changes in my body. I developed diarrhoea and the rate at which I was going to the toilet had escalated. I was so tired and I began developing symptoms of HAND (HIV-Associated Neurocognitive Disorder) like losing my concentration really easily.

It was about three months later, when I got to Australia and was attending a Surf Camp at Seven Mile Beach in NSW, that the process of seroconversion really hit. As I lay on my bed nursing a high temperature and the beginning of a chest infection, my friend thought it was a good idea to get laid in the bed opposite me. At least someone was having a good time.

As I sat there in the a[TEST] clinic, paralysed with fear from my diagnosis, I was unable to move. I needed support and luckily a counsellor from ACON managed to lure me out of the room with a hug and a cup of tea (I am English after all). The last thing I was going to do was give up on my dream of travelling. So slowly, I began putting things into place. I decided that I had to tell a friend. To my relief, that friend was understanding and appreciative of my predicament, which allowed them to disclose a few issues about their medical condition. I saw two counsellors on a Monday and I'd booked in for regular check-ups with my doctor over the following six months.

Meanwhile, my HIV symptoms were getting worse. I noticed my memory wasn't so hot, my viral load was far too high and my white cell count had literally hit the floor, it was so low. My doctor suggested that I start medications immediately as he didn't want my brain and memory issues to escalate further.

Luckily I applied for Medicare as I was eligible for reciprocal healthcare with Australia through the UK National Health System.

Starting medications was a massive step for me as it put me on a path to acceptance of HIV. I only need to take a tablet a day for the rest of my life to stay healthy and on top of things. This little pill would become my best friend.

As a backpacker still travelling, attending appointments every two months to collect my prescription was annoying, especially when it came to doing farm work for my second year Working Holiday Visa.

My main problem in rural NSW, was the nearest town was at least 60 kilometres away. I needed the farmer's help to drive me there and I knew he would have to be informed of my status in case anything happened to me on the farm. This raised my fear of stigma and being discrimination against. The farmer was a solid guy who didn't really show emotions and I was nervous talking to him. To my surprise, when I revealed my situation, he began to ask me questions, and showed concern for my well-being and gave me a big bear hug. The following morning, he had organised a truck to pick me up and drive me to the town so that I could collect my meds. It was a beautiful moment.

My journey has been a learning experience. Over the past 17 months since my diagnosis, living with HIV has made my journey as a backpacker more insightful, and allowed me to face new challenges, both mentally and physically.

From dealing with immigration issues to dating guys who were surprisingly accepting of my status. From parachuting out of planes over the Great Barrier Reef in Queensland, to cycling throughout South Australia on a \$99 KMart bike, I want to show people that I am healthy and I still able to make my own choices in how I live my life. My white cell count has risen and my viral load is now undetectable. And as for the weight of that backpack on my shoulder? It now feels light again and I am still travelling!

BACK PACKING *with* HIV

DAVID GRIFFITHS
Community member

Immediate or early. What's the difference?

CRAIG ANDREWS

Communications Officer, Positive Life NSW

We've known for some time that HIV is doing damage from the time you become infected with HIV. Today we also know treatment for HIV is your best course of action to benefit your health in the long run and prevent the onward transmission of HIV to your partners.

For the large majority of people living with HIV (PLHIV), treatment for HIV is a daily single pill with no to minimal side effects. Gone are the days of handfuls of pills, specific timings and gruesome side-effects. The main debate and consideration today is when to start treatment – immediate or early? So, what's the difference between immediate treatment and early treatment?

'Early' treatment is usually defined as starting treatment within six months of diagnosis. The definition of 'immediate' treatment is as soon as you receive a diagnosis.

In December 2016, Positive Life took the position, supported by our members, that 100% of diagnosed people living with HIV in NSW are offered the chance to start treatment the same-day or 'immediately'. This would mean whether diagnosed in a GP setting or a hospital clinic, you would be able to walk into a nearby pharmacist to pick up a free 'starter-pack' of basic HIV medication and immediately gain some sense of control over your health. The diagnosing doctor would offer this option in the understanding that you can choose to 'opt-out' from taking the medication or even delay starting treatment as long as you wish.

Despite this clear mandate from the positive community, the timing of treatment commencement is informed by a number of concerns and issues.

Some of these concerns are around the issues of making sure the newly diagnosed PLHIV have made an informed decision about starting treatment. The last thing clinicians want to see are people who have felt 'rail-roaded' into

starting treatment or who haven't had time to think about what it might mean for them to have HIV. Positive Life agrees with this caution and we know the majority of PLHIV at this point of diagnosis who want to take some kind of action around protecting their health and the health of their partners.

Other issues raised are about waiting for the results of blood test results to guide the best treatment options for PLHIV. These will take up to two to four weeks and include results of the viral load, CD4 count, resistance testing for the best drug combination to use. In that window of two to four weeks, many people have told us that at that moment of diagnosis, they want to actively do something about the news now that they're living with HIV. A basic starter-pack can help PLHIV get their head around the diagnosis while providing a sense of control. When the blood test results are back, if the medication needs to be changed that's a straightforward process.

The evidence from the Strategic Timing of Antiretroviral Treatment (START) study is clear and compelling about immediate treatment. Immediate treatment means you reduce your risks of developing other opportunistic infections, you give your immune system as much help as possible to stop the HIV virus from replicating in your body and treatment immediately controls progression of the HIV virus. The sooner you start treatment, the better position you'll also be in to get involved in a cure when this becomes available. With any other infectious disease or STI, treatment is immediate and it's common sense that HIV be treated in a similar way.

To discuss your HIV diagnosis and options for treatment with a peer (someone living with HIV), contact the Treatments Officers at Positive Life NSW by calling (02) 9206-2177.



Workplace HIV discrimination

WORKING IT OUT

DAVID CRAWFORD

Treatments Officer, Positive Life NSW

SUZANNE CASTELLAS

*Lawyer and Centre Coordinator, HIV/AIDS
Legal Centre (HALC)*

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

Here 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, having alterations to their job description or working under restrictions 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

Seek support sooner rather than leaving it to 'work itself out'.

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 on 1800 245 677 or HALC on (02) 9206 2060 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.

Impacts of HIV for women in Australia



From an invited presentation at the launch of Futures 8 on Thursday 17 November 2016, at the Australasian HIV & AIDS Conference, by Jane Costello. Futures is a national survey of people living with HIV which began in 1997 and is repeated every two or three years. This long term study explores the health, wellbeing and life experiences of all people living with HIV in Australia, and aims to improve understanding of the complexity of factors that support or hinder good quality of life for people living with HIV.

I have been asked to provide a woman's perspective on Futures 8, and while I acknowledge that Futures 8 is about the lived experience of all people living with HIV, I would like to focus specifically on women living with HIV – a marginalised population that I believe are missing from much of our national discourse and dialogue around HIV which has major implications for public health policy and service delivery in Australia. Women continue to be largely invisible in our HIV response, and women with HIV are a minority who live with inequality, in silence and secrecy. That inequality, silence and secrecy feeds a climate of stigma and discrimination, as well as an assumption that HIV is simply not an issue for women.

Around 10% of the population of people living with HIV in Australia are women, and Futures 8 does provide a representative sample of women's voices. Of the total number of people who completed the survey (895), just under 10% of these were women. Futures 8 therefore, is a critical piece of research around the health and wellbeing of our community, and gives us evidence and data. This evidence is around testing and treatment, and women's lives more generally.

Additionally, it provides us with a snapshot of the differences within the increasingly diverse community of people living with HIV in Australia. If we don't understand these differences and apply them selectively to the areas of health policy, programs, service delivery and research, we are not going to understand or be able to address

the very particular issues and unmet needs that affect that women face in their everyday lives.

I have said it before, but there are gender differences in HIV in Australia. We are doing better in terms of research data on HIV aggregated by gender to enable us to better understand gender difference, but there is more that could be done, particularly around treatment initiation, engagement and retention in care. I will touch briefly on testing and treatment as these are two of the reports being presented here today. Respondents were asked to state the main reason they took an HIV test the time they were diagnosed with HIV. The most common reasons that women gave for taking a test was that their partner tested positive or they became ill. Most women living with HIV in Australia have been infected as a result of heterosexual sex, and in the 2016 Kirby Institute Annual Surveillance Report 20% of new diagnoses of HIV in Australia were attributed to heterosexual sex. HIV doesn't discriminate.

Arguably everyone is at risk, and as a heterosexual women living with HIV for the past 22 years, it frustrates me that heterosexuals are still not named as a priority population in the Australian National HIV Strategy. Unsurprisingly only 2.7% of women completing the Futures 8 survey indicated that it was because they were a member of a risk group, clearly not seeing themselves as part of any of the priority populations.

Around half of the women had never taken a HIV test prior to receiving their HIV diagnosis, and 80.5% of these gave the reason that

Women continue to be largely invisible in our HIV response, and women with HIV are a minority who live with inequality, in silence and secrecy.

they did not think they were at risk, while the remainder who numbered 5, selected 'other' for this question. As a result, very few women in Australia are diagnosed with newly acquired HIV. Women are often late presenters with advanced HIV which has already significantly damaged their immune system and many newly diagnosed women present with an AIDS defining illness.

Whilst there is a relatively well established culture of HIV testing within the gay community, this is not the case in the wider community where HIV is still most commonly perceived as a gay male disease. I truly believe that we should be setting a standard for women's health in this country whereby an HIV test is routinely offered as part of a sexual health check across the board. I would go further to say that for all sexually active women a sexual health check should be a part of a comprehensive health check, and we need to empower women to view this as a way of taking control of their own health and wellbeing.



We need to start advocating for women in a way that is thoughtful and responsive to their specific needs if Australia is serious about health equity.

What continues to be shocking in a developed country such as Australia is the substantially disproportionate rate of HIV diagnosis amongst Aboriginal and Torres Strait Islander women than non-indigenous women, and the high rates of diagnosis amongst women from a CALD background. This was highlighted by James Ward and at the Annual Surveillance Report launch yesterday, and while Australia has long been recognised for its response to HIV particularly amongst gay men and other men who have sex with men, sex workers and people who inject drugs, who are considered the priority populations at greatest risk of infection, we have dropped the ball with our First Nation women and migrant populations.

Futures 8 gives us a clear snapshot of the number of women on treatment and with an undetectable viral load at 94.4% and 86.1% respectively which is fantastic news, but there are still gaps in research into the efficacy of anti-retroviral treatments as well as side-effects that are specific to the female body, and a lack of research into hormonal differences between men and women and the impact that has on women with HIV and treatments. Additionally there is a paucity of research into the reproductive health of women living with HIV, as well as the particular psychological issues for women with HIV in relation to reproduction and family.

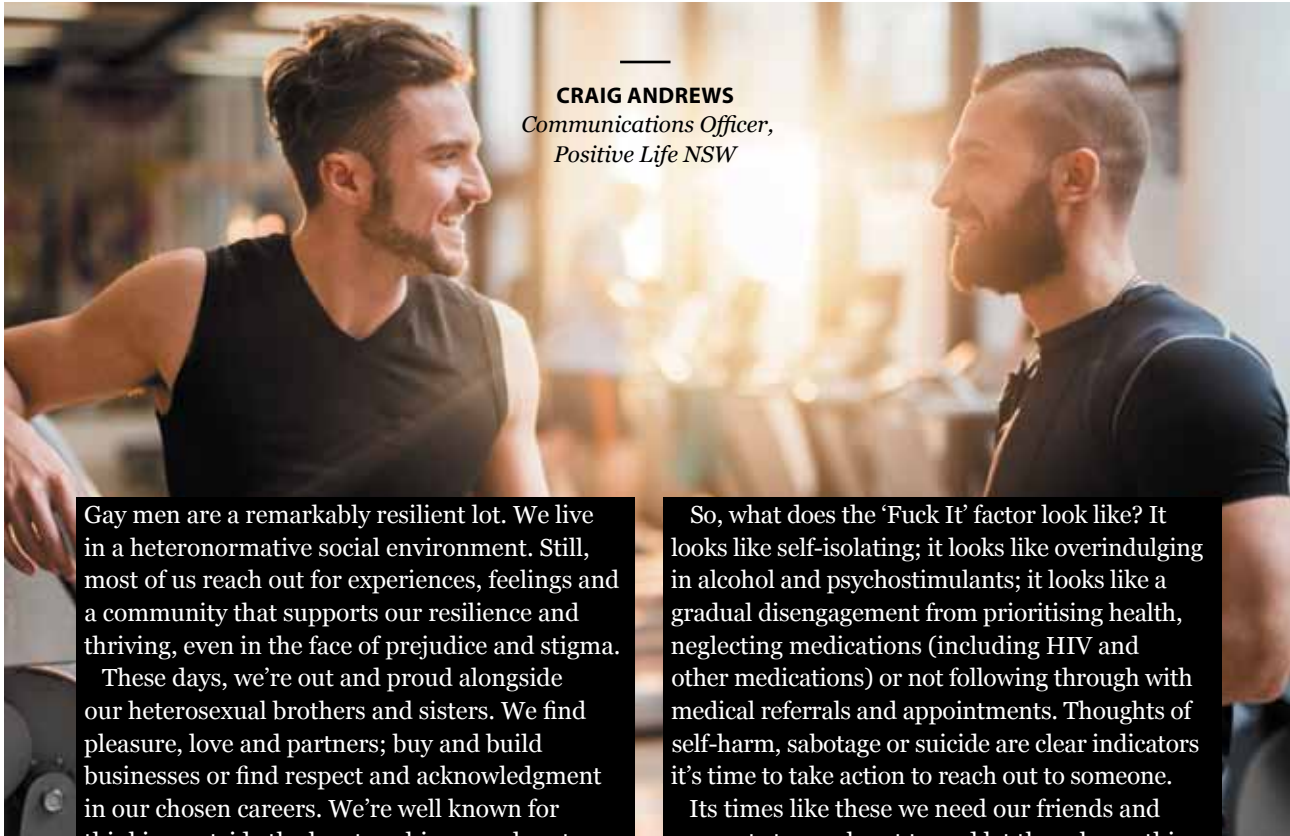
I've discussed the testing and treatment reports, but not really touched on the lived experience of women with HIV. There are particular issues for women living with HIV in relations to disclosure and the negotiation of sexual relationships; reproductive health as I have already mentioned including pregnancy, childbirth, breastfeeding and family life; career paths and coping mechanisms. There is a greater likelihood that women with HIV will live in outer suburban or regional locations and this has an impact on women's access to treatment and care. By comparison with gay men, there is a lack of

support networks, both formal and informal for women.

Futures 8 highlights the alarming numbers of women with HIV living in poverty with over one third of women living in households in which the yearly income was less than \$29,999. In total, only 15% of the women surveyed lived in households in which yearly earnings totalled \$80,000 or more. According to measures defined in Futures 8, 56.1% of women were credit constrained. Women living with HIV are disproportionately affected by family violence and cultural factors are a further multiplier of women's risk of family violence. Approximately 40% of women in Futures 8 also indicated they had a medium to high risk of alcohol related harm, and there are high rates of women with HIV diagnosed with mental health conditions.

Futures 8 therefore continues to be an important and increasingly valuable piece of research providing a critical snapshot of the lives of people living with HIV in Australia. The question is, as researchers, clinicians and community, how do we use its findings and leverage off these to prioritise women's health, and to progress items of work that ensure that the needs of a marginalised group of people living with HIV are met? We need to start advocating for women in a way that is thoughtful and responsive to their specific needs if Australia is serious about health equity and improving the health outcomes for women living with HIV.

Protecting against passive suicide



CRAIG ANDREWS
Communications Officer,
Positive Life NSW

Gay men are a remarkably resilient lot. We live in a heteronormative social environment. Still, most of us reach out for experiences, feelings and a community that supports our resilience and thriving, even in the face of prejudice and stigma.

These days, we're out and proud alongside our heterosexual brothers and sisters. We find pleasure, love and partners; buy and build businesses or find respect and acknowledgment in our chosen careers. We're well known for thinking outside the box to achieve our hearts desires with chosen family structures and relationships. We're at every strata of society and wherever we are, we contribute to the pride and wellbeing of our communities.

A recent Positive Life survey (2015) showed that 40% of our respondents, People living with HIV (PLHIV) had well controlled HIV and no other major health conditions. The remaining 60% lived with between one to eight health conditions, with depression as the most commonly reported secondary condition.

Even for those of us on a decent income, Sydney has become one of the most expensive cities in the world to live. With the demands of living surrounding any of us, an otherwise well-orchestrated life can easily become derailed. Sometimes it's the domino effect of a relationship breakup. For others, the slow-burning fuse of depression can trip over into addiction and spiral out of control. The sudden diagnosis of HIV or any other condition, how unexpected or minor, can tip any of us over the point of what we call the 'Fuck It' factor.

So, what does the 'Fuck It' factor look like? It looks like self-isolating; it looks like overindulging in alcohol and psychostimulants; it looks like a gradual disengagement from prioritising health, neglecting medications (including HIV and other medications) or not following through with medical referrals and appointments. Thoughts of self-harm, sabotage or suicide are clear indicators it's time to take action to reach out to someone.

Its times like these we need our friends and supports to reach out to and let them know things might not be going so well. There is a role for our friends, community, and other HIV-positive men to reach out and make sure that our mates and our fuck buddies don't succumb to despair and the 'Fuck It' factor. Your 'gut feel' for your friend is important to listen to. Other cues could be what the person is saying and doing don't always match. Asking how someone is 'travelling' won't start them thinking about suicide or self-delivery if it isn't already on their mind. If life is so tough at the moment, giving them the opportunity talk about it will often lessen the intensity and lets them know that you care and they're not alone.

When you see someone you know starting to withdraw and isolate; stop taking their medication(s) or go off the rails; reach out and invite them over for a drink, or a meal, or a walk in the park, or whatever. Whether you're a gay guy living with HIV or not, diagnosed 35 years ago or diagnosed today, we need to ensure no gay men are left behind. We all have a role to play to look out for each other. Let's continue to build a strong, unified and resilient community.



OUR CHANGING CONVERSATIONS

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, 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 (PLHIV/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. 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, 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

PETER SCHLOSSER
*Positive Speakers
Bureau*

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 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 and 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 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 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.

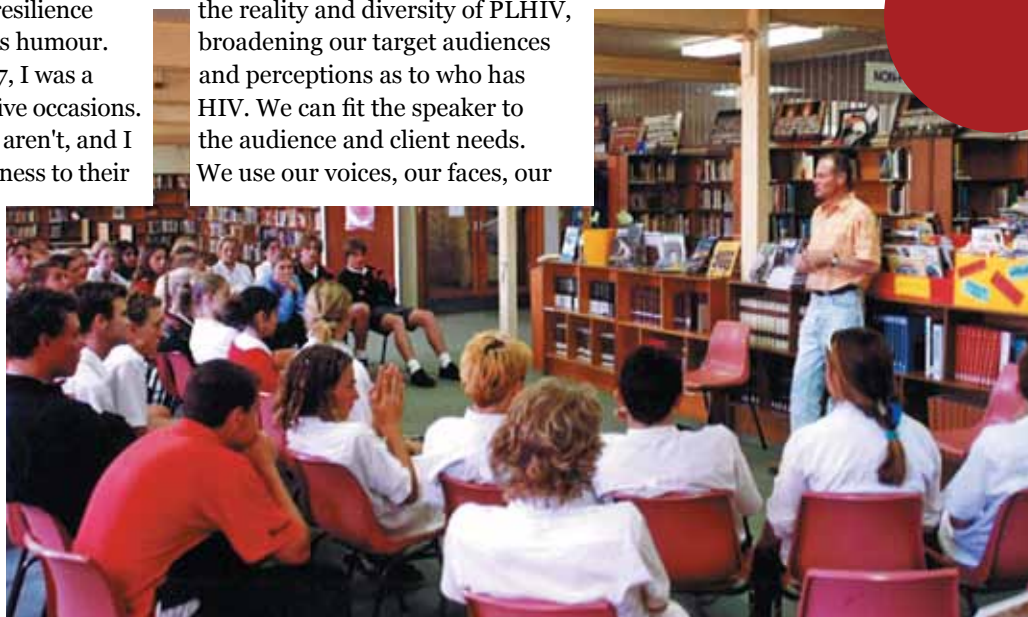
By addressing these in conjunction with HIV, we portray the reality and diversity of PLHIV, broadening our target audiences and perceptions as to who has HIV. We can fit the speaker to the audience and client needs. We use our voices, our faces, our

experience to address stigma, discrimination, our concerns, our needs and in doing so empower ourselves and elicit change.

Through all of this, there has always been a sense of hope and 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 and 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.



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

PLHIV and TasP: What's it mean?

CRAIG ANDREWS

Communications Officer, Positive Life NSW

Since the beginning of the HIV epidemic, from the early-80s to the present day, gay men living with HIV have been at the forefront of embracing the latest changes to HIV health in the 'fight for our lives' to empower ourselves, support and educate each other to take control of HIV. Several crucial shifts in the HIV landscape have been readily embraced by people living with HIV (PLHIV) as activists and mobilisers in advancing that agenda.

Like our peers who found hope and life in anti-retroviral therapies

and championed public access to the medications in the late 80s, we adopted the new combination antiretroviral treatment (cART) in the mid to late 90s rapidly, which improved our life expectancy from months to decades.

In 2011, the evidence which proved the protective effect of

early treatment against HIV for negative partners in the case of serodiscordant couples (where one partner is HIV positive and the other HIV negative), saw positive people support the health and safety of their

loved ones by embracing this early game change.

The NSW Health Minister Jillian Skinner MP made an appeal to PLHIV on World AIDS Day 2013 about our choice to take control of HIV when starting treatment. Two short years later with the release of the START study findings and the benefits to the individual and their community around starting treatment earlier than ever, we threw our support behind this latest game changer. Around the same time when improved access to HIV medication in local community pharmacies commenced in NSW, more PLHIV than ever exercised their choice to pick up their HIV medication at a time and place convenient, at no cost.

In late 2016, Positive Life took the position that 100% of people diagnosed with HIV be offered treatment immediately. By adopting an immediate treatment commencement position, which halts disease progression and the onward transmission of, PLHIV step into the driver's seat of our health straight away. We have better long term health outcomes, lower risk of illness and death and contribute to reducing HIV transmission in the broader community. While we talk about 'game-changers' in terms

The rise of one of our latest and strongest tools to prevent the transmission of the virus and offer protection to those we love and the broader community is Treatment as Prevention, or TasP.

of bio-medical or pharmaceutical solutions, the real game changer is the positive person.

Throughout the whole time of the HIV epidemic as positive gay men, we remained sexually active using or inventing a range of responses to sex and HIV educating our peers and protecting the health of our partners and fuck-buddies. HIV positive men are the bower-birds of risk reduction strategies when it comes to having sex. We have always been an integral player in negotiated sex conversations concerning HIV prevention.

Many of us use serosorting or only have unprotected sex with other positive guys to remove the risk of HIV transmission, while others use strategic positioning between partners of mixed sero-status. Many regular or committed partners use disclosure and negotiated safety in relationships. And there's always the mainstay of condoms. Now with PrEP joining PEP in the prevention arsenal, we have a range of HIV prevention strategies to use depending on the circumstance and situation.

The rise of one of our latest and strongest tools to prevent the transmission of the virus and offer protection to those we love and the broader community is Treatment as Prevention, or TasP. This strategy is used by PLHIV who take their HIV treatments as prescribed to prevent HIV transmission or being infectious. When we use TasP to maintain an undetectable viral load (UVL), we are no longer able to transmit the virus.

While not all of us can achieve or maintain an UVL, for those of us who can, it is recognised as a key sexual health strategy by many health promotion NGO's including World Health Organisation, UNAIDS, Positive Life and ACON. Perhaps the strongest evidence of TasP has come out of the 2016 Partners Study. After 58,000 occasions of 'bareback' or condomless sex between 848

sero-discordant couples globally, there were zero instances of HIV transmission. ZERO! Not one negative partner contracted HIV from their HIV positive partner. As community awareness and understanding about TasP grows, the realisation that TasP works not only for positive people but lets HIV negative people know that positive people with an UVL are sexually safe.

The safer sex landscape has definitely changed. We've seen a succession of major HIV game-changes throughout the epidemic. These have been both in the pharmaceutical area as well as in the social interactions between gay men as we navigate our way through sex, pleasure and care to manage our health thoughtfully and responsibly. Today with a range of HIV prevention strategies, the sero-divide in the community is changed. HIV positive or negative, there are new ways for all members of our community to care for each other and share responsibility for informed sexual health choices.

As Mardi Gras for 2017 comes to pass, let's celebrate our sexual pleasures, freedoms and choices in the light of TasP, serosorting, strategic positioning, negotiated safety, PEP and PrEP. Let's continue to encourage and support each other to take control of our sexual health and talk confidently and openly with each other about our sex and pleasure options and choices.



Above: HIV Activists protesting in Castlereagh Street, Sydney NSW (photo: Jamie Dunbar, 1991).

CONSENT + RESPECT



Consent, negotiation and mind-blowing sex.
Let's make it great for all involved!

DAVID GRIFFITHS
Community member

As a community we embrace sex positivity. We talk about sex in its many and varied expressions and experiences with our friends, family, fuck buddies, and partners. We use everything from handkerchiefs to apps to signal to the world how we want to fuck, who we want to fuck, where we want to fuck and when. We have an ever growing list of sexually diverse sub-cultures with their own unspoken gestures to indicate interest in one another. We are increasingly capable and confident discussing what we like, what's hot and what's not.

Yet in the heat of a hot fuck session, there's one major thing that universally matters. That is mind-blowing sex that's mutually consensual, reciprocally negotiated and permissible, and meets all the needs of consent and respect. When consent is negotiated and given, it's

equally important to understand that as fast as it can be given, consent can also be withdrawn.

Negotiating sex before a hook-up is fairly common today. With the growing use of apps like Tinder and Grindr, showing interest in someone is as simple as a click or a swipe. When there's mutual attraction and flirting, talking about, then negotiating what sort of a fuck you're interested in, often leads to a meet. Many of us have used this tried and tested method countless times with varying degrees of success. Just because we've negotiated the fuck session before seeing each other, often what ultimately takes place isn't what was agreed. Or the hot fuck happens and you walk away from a session not feeling entirely comfortable with how it played out.

Establishing an understanding of what has been agreed to, not only ensures everyone has a good time, more importantly it ensures that we don't end up doing something that we regret later on. For a party session for example, discussing what happens and who will be involved is important to make sure informed choice occurs before you arrive or as you get into the fuck session.

Whether you're at a sex-on-premises venue or at a private party in someone else's home or your own, just because you're there doesn't mean you automatically have to do what others expect to happen or that this means you've given consent to all that happens. At times, we can feel pressure to do things that we don't feel comfortable doing and coercion can take place. When you can't make an informed choice because you don't know what to expect or you don't have all of the details or facts, you can feel confused.

Sometimes this involves misunderstanding on your part or on the part of others. It could be unintentional and simply assumed understanding or an incomplete description. It could also be deceptive with the intention to deliberately mislead someone.

Just like consenting to what kind of sex you want, disclosing your HIV status to your sexual partners and/or people you're injecting with is an important conversation to have before fucking. This gives your friends and lovers a chance to make their own choice about what type of sex is right for them.

Some people worry that disclosing their HIV status to their partners before sex, will mean rejection and stigma. If partners don't disclose their health status, even after being questioned about it, and then they tell you they have an STI after the fuck session, this can create a great deal of fear. Avoiding or disengaging from a conversation about disclosure or negotiation, also takes away our right to clarify what boundaries are appropriate for us when talking about the type of sex we want, how we want to do it or if we feel comfortable doing it.

For people who enjoy the combined pleasure of fucking and substances, whether it's alcohol or party drugs, then disclosure, negotiation and consent when initiating sex and substance use are key to a hot session. If you're newer to a party scene where other people are used to fucking with substances, while you might feel confident to negotiate and consent to the sex you want, you might not be so familiar with what this means with drugs in the mix. Under these circumstances there's an increased likelihood of feeling peer-pressure, confusion or coercion.

As we all know, a hot fuck happens when there is a connection, respect, chemistry and trust between sexual partners. When you find yourself in an unexpected situation, it can be confronting and challenging to

Just like consenting to what kind of sex you want, disclosing your HIV status to your sexual partners is an important conversation to have before fucking.

manage. When you feel like your boundaries or values are compromised, it can be much harder to manage or respond confidently. At these moments, it's easy for sexual assault to occur and it's important to remember you can always say no, at any time.

Withdrawing your consent or leaving a situation that feels uncomfortable or compromised is okay and also your legal right. If you see someone who looks to be out of their comfort zone or who has said they want to stop, that's a clear sign to stop. Anything that happens from that point of "no" is assault.

If you feel like you might have been assaulted:

- You can contact the 1800RESPECT Helpline for information and support for anyone in Australia experiencing sexual assault or domestic violence, 24/7 on 1800 737 732 or online at www.1800respect.org.au
- You can contact NSW Rape Crisis Centre 24/7 by telephone and online for crisis counselling for anyone in NSW – men and women – who has experienced or is at risk of sexual assault on 1800 424 017 or online at www.nswrapecrisis.com.au
- You can also ask to speak to a GLLO (Gay and Lesbian Liaison Officers) at your nearest police station. If they do not have a GLLO at that station, it is possible for a GLLO from a nearby station or region to be available.

If you seek counselling or support:

- You can contact Mensline, which have a telephone counselling where you can have up to six sessions and make a referral for men. You can call them on 1300 789 978 www.mensline.org.au
- Lifeline National crisis and suicide prevention is a telephone counselling, 24 hours per day, 7 days per week on 13 11 14 or online at www.lifeline.org.au
- Aboriginal Community Controlled Health Services ACCHS, also known as Aboriginal Medical Services/AMS). ACCHS are health services initiated by Aboriginal people, based in a local Aboriginal community, which delivers a holistic and culturally appropriate health service. To find your nearest service visit www.health.nsw.gov.au/aboriginal.

PositiveLifeNSW

the voice of people with HIV since 1988

Positive Speakers Bureau

HIV Work Ready

HIV Health Education

Advocacy + Policy

Peer Education

Talkabout

Housing

Genesis

Positive Life NSW is a non-profit community-based organisation. 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 with HIV, our friends, family and carers in NSW.

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