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# POZLITE

The best of 2019

A COMPILATION OF THE YEAR'S  
MOST POPULAR ARTICLES

*Speaking up in plain sight*

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*HIV – the heterosexual context*

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*Women and HIV disclosure*

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It's with pleasure that I present the 2020 edition of *PozLite*, showcasing the 'best of' articles, stories and opinion pieces from 2019.

Today the conversation of HIV remains critical now more than ever, as more of us are living with HIV 'hidden in plain sight' regardless of our age, gender or sexuality. This includes women of all ages, heterosexual men, gay and bisexual men, Aboriginal and Torres Strait Islander people, people from CALD backgrounds, and people born overseas. In this edition, you'll find people living with HIV speaking for ourselves with confidence and dignity.

We are your neighbour, your parent, your brother or sister, your partner or even your priest. We are police officers, CEOs, healthcare professionals, tradespeople, teachers, engineers and entertainers. Those of us living with HIV hidden in plain sight include people from culturally and linguistically diverse (CALD) backgrounds or from minority ethnic communities, people who are sex workers and people who inject drugs. We are not 'emerging' or 'hard to reach' groups of people, instead we have been here all along since the very beginning of the HIV epidemic.

We are not 'emerging' or 'hard to reach', instead we have been here all along since the very beginning of the HIV epidemic.

Today, those of us living with HIV look like anyone else. Sadly, more of us living with HIV are hidden in plain sight for many years without knowing we have contracted HIV and consequently without knowing about the treatment available to ensure our long-term health. We are not colluders in our 'mis-diagnosis' or 'late presentation', instead those of us in this situation are often 'frequent flyers' with multiple doctor visits often ending up in hospital emergency departments. It's time that HIV testing is offered to everyone, free of assumption, including heterosexual people, especially women, refugees, and men from CALD backgrounds who have sex with men.

This edition shares how HIV reaches all areas of our lives, through articles by women living with HIV, the impact of HIV on the lives of heterosexual people, and the impact of HIV for people living at risk of homelessness who struggle to achieve and maintain stable accommodation. These stories consider questions of consent as young adults learn to navigate their social environments in the context of sexually transmitted infections (STIs) including HIV, issues of disclosure in employment and the power of self-acceptance, as well as navigating disclosure in clinical environments such as in the GP consulting room or hospital.

Some of us living with HIV stand in plain sight, unwilling to remain silent and hidden. Others live with HIV in more challenging environments, feeling unsafe and stigmatised, staying silent and travelling under the radar – hidden in plain sight of family and friends. In 2020, people living with HIV, our partners, family and friends live life together within a range of decisions, compromise and choices. No single choice is better or easier than another.

We sincerely hope you enjoy this edition of *PozLite* and thank all the PLHIV who have shared their stories and contributed to this *PozLite* edition.

I look forward to hearing more of your strength and rich diverse lived experience of HIV in 2020, and a year of debate and engagement, as we all work together to benefit the lives of all people living with HIV in NSW.

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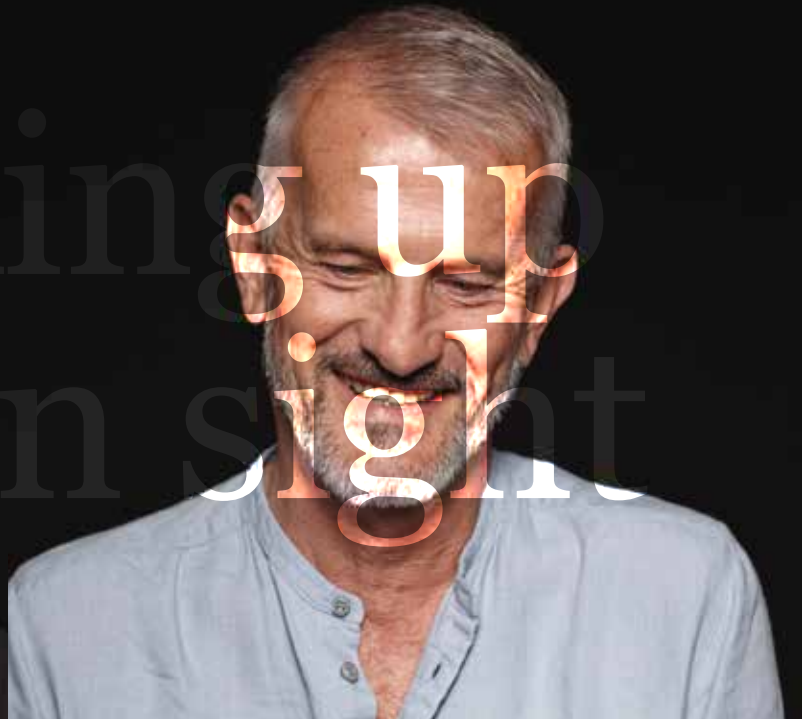
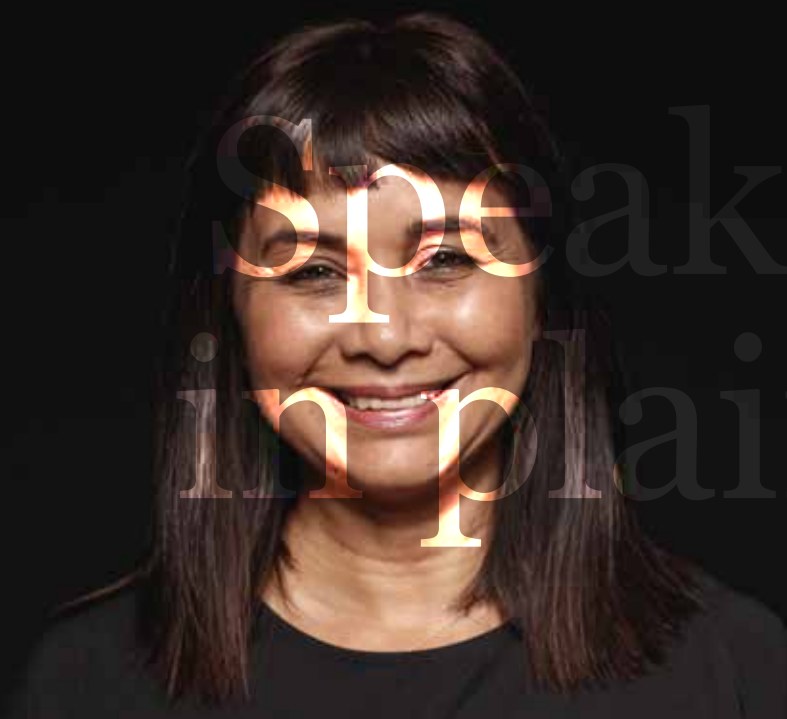
**JANE COSTELLO**

CEO, Positive Life NSW

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# Speaking up in plain sight



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**CRAIG ANDREWS**  
*PSB Coordinator, Positive Life NSW*



Back in 1994, on World AIDS Day, a group of people living with HIV made an unusual choice. Twenty-six years ago, this courageous team chose to stand and speak out about their experiences of living with HIV in a time when a diagnosis of HIV bought Fear and Death as close companions. This was the beginning of the Positive Speakers' Bureau (PSB).

Today many people living with HIV can choose to live 'hidden in plain sight' without revealing their exclusive membership of a health condition that still awakens prejudice and judgement. Each team member of the PSB has come to a personal realisation of their own unique position living with HIV, as they choose to step forward on a regular basis to share what it's like living with HIV to address HIV stigma and ignorance, dispel myths about HIV, and communicate a deeper understanding of what it is like to live with HIV today.

While many people have no choice but to travel with HIV 'hidden in plain sight', all of us along with our partners, family and friends live life together within a range of decisions, compromise and choices. No single option better or easier than another.

PSB Speakers regularly talk about what it's like to experience stigma and discrimination in the unexpected settings of the emergency ward or the privacy of a GP consultation, in the workplace or up close-and-personal with family and friends. They share how it feels and what it means personally to them, when another person holds out the hand of acceptance without fear or hesitation.

As passionate trained members of a dynamic team, these extraordinary individuals actively put a human face to living with HIV, as they also offer powerful secondary messages of resilience, bullying, and mental health and more. Whether it's living with HIV or the journey of secondary health challenges like depression, Hepatitis C, or cancer, the team members can offer your workforce, students, first responders or training participants the opportunity to hear first-hand the experiences of people who have found themselves challenged in ways most people never expect.

PSB speakers are a diverse team, and come from a range of cultural backgrounds, ages, genders, time diagnosed and HIV life experiences. Besides the key messages of safer sex, harm reduction and HIV prevention woven throughout each speaker's story, team members speak from the heart as they win the respect, understanding and raise awareness across secondary under the NSW Department of

Education Life Ready curriculum and tertiary institutions, youth services, to corporate, clinical and community-based audiences throughout NSW. Increasingly our speakers are complementing the training offered in the health sector at mental health and AOD units (alcohol and other drugs), HIV and sexual health units, accident and emergency units including allied health and aged care.

Today as people live longer and stronger with HIV and as we're more engaged than ever in life, work and love, we seek others who are able and willing to stand up and speak out in plain sight, visible and willing to raise their voices about living with HIV.

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**Today as people live longer and stronger with HIV, more engaged than ever in life, work and love, we are willing to stand up and speak out, visible in plain sight.**

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As HIV warriors, PSB speakers are remunerated for their time by Positive Life, and coached and supported by their PSB peers and the PSB Coordinator to articulate their experiences of resilience and empowerment. The entire team undergoes regular training to upskill their public speaking skills and ensure they keep pace with the ever-changing landscape of HIV information, treatment and prevention.

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To discuss your requirements or to book a speaker, please call the PSB Coordinator on (02) 9206 2177 or visit [www.psb.positivelife.org.au](http://www.psb.positivelife.org.au).

If you live with HIV and are interested in undergoing training to become a PSB Speaker please call the PSB Coordinator on (02) 9206 2177 or email [psb@positivelife.org.au](mailto:psb@positivelife.org.au)

# THE SCAB

Scab: A protective crust that forms over a cut or wound during healing.

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## MAXINE

*Community Member*

I'm a white, educated, healthy, tall, English speaking woman. I have family support. I have sass. I am confident, capable and I manage my life with ease. Paying my way. I've spent so much time and energy trying to appear functional, healthy and well-adjusted. Trying to fit in, trying to manage my life. I've also been working hard to hide the fact I live with HIV. If a confident, articulate person like me has had so much hesitation and struggle around living with HIV, then how must it be for others?

Diagnosed with HIV in my mid-twenties, I was still 'finding myself'. As a normal twenty-something I was working out who I was and where I belonged. It was devastating to be diagnosed at that time in my life and I felt overwhelmed. I was profoundly shocked. Time stood still and my world felt as though it had been turned upside down. What now? My life had always been weird, but this?

At first, I hid my HIV status because it felt important for me to form my identity as a person, separate from HIV. I didn't want to identify too heavily with being HIV positive. I felt vulnerable, confused and fragile. I needed a scab.

It was the 90s. I lived in the straight community. I had no frame of reference for 'coming out'. I didn't know how to do that. There wasn't a community of people living with HIV like me. My family and a close friend knew, but I didn't want everyone to find out. I suddenly felt very different to 'everyone else'. It was foremost in my mind but not anything you could see. It was a headfuck.

I was physically healthy, but my heart was broken, and my confidence took a blow. How would I date again? How would I tell a prospective partner? Would I live long? Would I die and be covered in lesions? I thought of the movie Philadelphia. It seemed tragic. I felt like all my dreams had died. I experienced a lot of grief about perhaps ruining my life.

When you sustain a wound, your body creates a protective scab which forms a barrier so the wound can heal underneath. It's a necessary and

healthy process. I had sustained a psychological wound. I was bruised and weeping inside. I didn't know it then, but I was forming a scab.

I dove into a marriage with a man living with HIV and hid in that relationship as I processed my diagnosis and came to terms with taking medication. I went through therapy and pulled my body and mind together. I prayed. I grounded myself. I went through the stages of grief – denial, anger, sadness, acceptance. It took me ten years. We acted like a 'normal married couple'. Hardly anyone knew our secret. It was safe. A healthy, healing, protective scab.

As I grew stronger the outer scab began to fall off and the marriage developed cracks. We decided to part amicably. I was ready for a new level of interaction. There was another scab underneath though, and it was necessary and important too. I was stronger inside, as well as healthier on the outside, so this scab was softer and more appealing. But it was still there.

I learnt how to live as a single woman again. A woman fresh out of her marriage, ready for fun and freedom, but still with a big, scary

secret. HIV. Most of the time I managed it well. I didn't lie, but I didn't tell the whole truth either.

Why should I tell? Back then, NSW law said I must disclose my HIV before having sex with anyone. When I used the added protection of a condom, I knew I wasn't putting anyone at risk. My sex life was important to me. I felt entitled to explore my sexuality. For me, sex is necessary for my health and wellbeing. I'd also done my homework and I knew by being on effective HIV treatment, I could not pass on HIV to my partners and I was uninfected. HIV had threatened to take that away, now I was claiming it back!

I had a lot of fun. I was popular. Hot. I felt beautiful, sexy and free. All the things people with HIV aren't supposed to be. I was living again! It still felt frightening though. What if someone found out? With casual partners I was always safe (and used condoms properly). I made sure my viral load was undetectable. I took my pills religiously. They were my key to being normal – healthy and sexually viable. I read all I could about the science of transmission.

On the surface I seemed an attractive, fun loving party girl. A big flirt with long legs, who loved men but kept a lot to herself. Ready for fun and freedom, but still with a big, scary secret. HIV.

I practised defence scenarios in case I was found out. How would I argue my case in a court of law? How about in my community of friends and acquaintances? It felt risky, but I was prepared. I was brave.

Whenever it felt like a relationship was developing, I told them (often before we'd had sex, sometimes after) and I had good reactions. I was convincing. I felt empowered because I knew about the science and I understood their concerns. I advocated for myself and for a great sex life. I was sure that I wasn't putting them at risk and that made them feel safe. We were in this together. It was always their decision to stop using condoms, which I supported enthusiastically. The relationships continued and broke up for other reasons - some of which was related to the scab and its remnant fibres.

In the past year or two, I've been thinking about my secret and the impact it was having in my life. I only recently thought of it as a scab. On the surface I seemed an attractive, fun loving party girl. A big flirt with long legs, who loved men but kept a lot to herself. Sometimes I ran away from them. Sometimes I regretted telling them about my HIV status, as the relationship didn't last long. I had to trust they wouldn't tell other people. I grappled with that one and at times it kept me up at night, yet as I grew the scab became softer and I began to care less.

My family and a close friend knew, but I didn't want everyone to find out. I suddenly felt very different to 'everyone else'.

Now, I feel like the scab is starting to peel off. The skin underneath is new but still a bit tender. It's fresh. I've developed wonderful strength, some scar tissue, lots of soft pink cells. I don't really know what's underneath or what the future holds for me. I just don't want the scab anymore. I can't be bothered. I've had enough of it. I don't want the isolation. Keeping it on would mean keeping myself hidden, and I'm too tall to hide!

One thing I do know though is I will be ok on this evolving journey. Maybe there's more freedom coming, who knows. But I'm as ready as I'll ever be.

# HIV INSIDE OUT



**SEBASTIAN ZAGARELLA**  
*Positive Life NSW Board Director*

I sero-converted back in 2003 and at the time I was very clear in my own mind, I didn't want to be defined by HIV. I just didn't want to talk about it and I certainly didn't tell a lot of people in my life. So, for the first six years, it was just me dealing with it pretty much on my own.

With a background in Visual Arts, I'd graduated from the Sydney College of the Arts in the early 90s. Over time I began to think about how I could try and visualise what I was feeling about the virus and some of the things I'd experienced as a result of it; and from about 2010 started working on what was to become my installation, *Inside/Out* (2015).

Around 2014, I met Craig Cooper, CEO of Positive Life NSW and Jane Costello who was the President on the Board of Positive Life at the time. As people living with HIV themselves, they were both really supportive of the installation and of me. This was the first time I'd really ever reached out to people in such an open way, and we had some really normalising, open conversations about my work and my status. It helped me normalise things in a way I'd hadn't felt before and I started to realise how important it was to have open dialogue around HIV.

The installation was to become my very public *Coming Out*. It was also my way of letting go of fear and shame and just being okay with it. If it sounds like I had no second thoughts or sleepless 3am pangs of fear that kept me second guessing

myself and wondering 'what if...', far from it! I remember thinking; What's this going to mean for my family? Will my friends look at me differently? What will happen with colleagues? All those feelings rushed to the surface and they were real and scary!

These thoughts crossed my mind up to the opening night of the show. I still had the thoughts; this is too big to handle, I should just pull out, this is no one else's business, why would anyone care? Still, there was an inherent part of me that knew it was important for me to do this. I wanted to reclaim myself, my whole self. I'd been hiding a piece of myself for a very long time and I was done with that.

When I started disclosing to friends and colleagues, I realised very quickly I'd been doing them a disservice by hiding. I'd actually shared less of myself with my friends over the last six years by keeping my diagnosis a huge secret. The one thing my friends felt upset about was that I'd not been truthful with them or trusted them to know 'my secret'.

Once the installation was out there, I was really surprised how many people opened up to me about their own status. I found total strangers revealing their HIV status. I also received emails from people who had been to see the installation to thank me and to let me know they had finally come out to friends and family as a result of meeting me and visiting the installation.



It was so humbling to know my work had been a part in making people own their own experience and feeling empowered, rather than being ashamed or worried about implications of being open about HIV.

I also found the more I spoke about it, the more I normalised it for myself and others. Even people who knew nothing about HIV, seemed really open to just ask questions and we had conversations they would never normally have. I found most people, regardless of their status, connected to the work as a 'life-defining' moment; and with experiences that have been left unspoken.

Nowadays, I make a point of being open and speaking up about what is often left hidden or unspoken. Everyone has their own journey in this process. Now I've been through it, I understand the power and strength that comes from being courageous. It feels very liberating when you can unshackle yourself from your secrets. I guess that's what led me to be on the Positive Life Board.

Being a Board Director has been a weird experience. When I first joined 12 months ago I felt a great sense of responsibility to help make decisions for the wider community of people living with HIV, at least 10,000 of us across the state of NSW but I also wondered how I was going to be useful to Positive Life. Over the past twelve months, I've realised that I have a range of skills gained through my professional and personal lives experiences of HIV that do allow me to contribute in my own way within the wider group that makes up the Board. I have more understanding how I can influence decisions being made about and for people living with HIV; and learning more and more about our community and issues that impact it.

Through interacting with the wider HIV community its only reinforced the importance of the peer-to-peer experience and how vital that is. We hear people talking about HIV all the time but it's usually conversations they have with their doctors or health professionals, and I've come to understand how important it is to be sharing personal stories and allow others to share theirs.

Everyone has a role to play in ridding ourselves of the shame and secrecy of this virus. The only way to do this by talking about it and normalising it.

I guess if anything, my call is to get in the driver's seat of your own life and be open about your experiences. Step up and be yourself without hesitation. I believe everyone has a role to play in ridding ourselves of the shame and secrecy of the virus. The only way to do this by talking about it and normalising it. I still know a lot of people who don't like to talk about it. To them I'd say you'll be surprised at the support and understanding that comes your way.

Finally I guess I'd like to encourage anyone, even with only a passing or remote interest in finding out more about getting involved with the community or being on the Board as a person living with HIV, or just want to understand more about Positive Life, to come and talk to us.



# DOES U EQUAL YOU?

**Treatment as prevention (TasP) is just one of many positive aspects of effective treatment.**

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**NEIL FRASER**

*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 fuck buddies.

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 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

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**Positive Life NSW was the first community organisation in Australia that promoted the science from the Swiss Statement in 2008 that an undetectable viral load means HIV is untransmittable.**

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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

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## The use of the word 'undetectable' risks leaving those with less sexual education or health literacy behind or confused.

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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.





# Are we bringing back BARREBACK?

Well over half of young Australians aged 15–29 years are having sex without condoms.

Secret's out! A recent survey (2018 Debrief Study – CSRH, UNSW) found well over half of young Australians aged 15–29 years (75%!) said that we had sex without a condom at least once during the past year.

While this may sound shocking, as a young person myself, giving condoms a miss doesn't surprise me at all.

Lots of us are on the contraceptive pill and some of my gay and bisexual male friends are on pre-exposure prophylaxis (PrEP), but my female friends haven't even heard about it. When I asked my friends, why we aren't always using condoms, most responded that as long as they're protecting against unwanted pregnancy or HIV, they're not concerned. It also concerned me that my friends

didn't seem to realise HIV is an STI (sexually transmitted infection).

It's no surprise, we're not only at a higher risk of picking up an STI, we're also more likely to have an STI without knowing it. While HIV is an STI, when it comes to other STIs, it seems they're off our radar. The survey also found that over 66% of the young respondents thought they were unlikely to contract an STI even though, more of us are having sex without condoms.

As someone who is in this age bracket and also works in sexual health, I think I get it. I can understand why we give condoms a miss and most of us still think we aren't running any risk around picking up an STI, including HIV.



As young adults, we're often told we're risk takers, unwise, or irresponsible. When it comes to sex, I disagree we're any of those labels. We're a highly educated and passionate generation! We talk about sex a lot, we think through our decisions and most of us avoid harming our health or our lives when we understand the risks.

One of my friends told me she had sex without condoms because she couldn't afford to buy condoms. When she found out where to get free condoms, she quickly changed her mind.



We don't actively talk about STIs because we are scared, careless, risk-takers or reckless. The truth is, we don't talk about STIs because we haven't been educated about STIs.

By and large, our education system is silent on the subject. Sex ed in high school sucks. It does very little to prepare us for adult life, which includes sex and relationships. No one talks about how we can have the kind of sex we enjoy, in ways that we can still stay healthy. Encouraging us to practice abstinence (having no sex at all) is not an answer. Many of us feel uncomfortable to have conversations about sex and sexuality with our families or our friends. Loads of us feel like we have to hide who we are.

This combination of outdated attitudes towards sex along with no quality, empowering sexual health education reinforces the idea that conversations about sex including STIs just aren't for us. Without these conversations and education about sexual health, it is any wonder young people have pretty low risk perceptions around contracting STIs?

Given the studies show more of us are choosing not to use condoms, my concern is my generation aren't aware of other options for looking after our sexual health.

One of my friends told me she was choosing to have sex without condoms because she couldn't afford to buy condoms. When she found out how to get free condoms, she quickly changed her mind about condomless sex, given

the high risk of pregnancy and how STIs could affect her reproductive health. When she had the education that Sexual Health Clinics including Family Planning across NSW will provide free condoms and lube whenever you ask for them, she quickly made the decision to protect her health and that of her partners.

An STI diagnosis is also highly stigmatising among young people. If you're diagnosed with an STI, it's going to be okay and you can do something about it. Looking after your sexual health is important and so is letting your sexual partners know they might also need to get tested.

If you want to talk to a someone who can support you or brainstorm some ideas how to tell your current or ex-partner, or friends-with-benefits, check out the Rypl website [www.rypl.positivelife.org.au](http://www.rypl.positivelife.org.au) where you can download the Rypl App. The Play Safe website [www.playsafe.health.nsw.gov.au](http://www.playsafe.health.nsw.gov.au) is a site packed with quality info about sexual health especially for young people.

Let's take some new steps to change the culture about being young and knowledgeable about sex. There is no shame in talking about sexual health. It is important we normalise talking about sex and looking after our sexual health, especially talking about STIs and testing. We also need to know that having a test for STIs does not include HIV, and you need to ask for this specifically.

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Other tips and ideas to stay on top of our sexual health are:

- Get tested with every new partner (and every three months if you have multiple partners e.g. three to five a month). Otherwise getting tested every six months is a good rule, even if you are in a relationship. STI tests are anonymous and free for anyone (if you go to a bulk-billed GP or sexual health clinic) you can find STI testing at any sexual health clinic in NSW or these Aboriginal community health services. The only way to prevent STIs is to use a condom.
- Contraception options: Such as the pill, IUD, implant or diaphragm are methods to prevent pregnancy but not STIs. The emergency contraceptive pill will prevent pregnancy if taken shortly after you've had sex without contraception or if the condom broke.
- Like the contraceptive pill, pre-exposure prophylaxis (PrEP) is a daily pill that protects people from contracting HIV.
- If you think you've been exposed to HIV either because a condom broke or you didn't use one, or you've had a needle stick injury, taking post-exposure prophylaxis (PEP) within three days is a way to avoid HIV.

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**BELLA BUSHBY**

*Communications and Policy Officer,  
Positive Life NSW*

# HIV: The Heterosexual context

Why aren't heterosexuals an 'at risk' population for HIV? Doesn't everyone's sexual health matter in an age of ending HIV?

**JANE COSTELLO**  
CEO, Positive Life NSW

The recent release of the new World Health Organisation (WHO) guidelines for the treatment and prevention of HIV heralded a landmark change in the international response to HIV. These guidelines remove all of the previous limitations on eligibility for antiretroviral therapy (ART) making all populations and age groups living with HIV eligible for treatment. In this era of immediate HIV treatments, it is important to recognise and acknowledge all of those who came before and are no longer with us. So many of the achievements and milestones we have reached today as people living with HIV can be directly attributed to their sheer courage and determination in the face of adversity. I was reminded of the importance of history at the last Candlelight Memorial Vigil, and how our shared history informs so much of our common future.

Yet as a heterosexual woman living with HIV for the past 25 years what frustrates me is that heterosexuals are still not named as a 'priority' population in the Australian National HIV strategy. This is despite the notable increases in sexually transmitted infections (STIs) among young people aged 16–29 years in particular. There is a perception in the wider community and even some in our health sector that HIV is simply not an issue in the heterosexual community. This leads to all sorts of assumptions about positive heterosexual men and women. In turn, this feeds into a climate of stigma and discrimination that sadly still pervades much of our national discourse. These assumptions also have major implications for public health policy and service delivery in Australia.

Historically in Australia, HIV transmission has occurred primarily through sexual contact between men who have sex with men (MSM). However in the past five years heterosexually acquired HIV increased by 10%, with a 14% increase between 2016 and 2017.<sup>1</sup> In 2017, 25% of newly diagnosed HIV cases in Australia were attributed to heterosexual sex.<sup>2</sup>

In the United Kingdom (UK) which has a similar HIV transmission pattern to Australia "19% and 22% of

new HIV diagnoses reported were among heterosexual men and women respectively in 2016. HIV continues to disproportionately affect men who have sex with men as well as individuals of black African ethnicity. In 2016, one in seven men who have sex with men living with HIV were black, Asian or from another minority ethnic group. Among heterosexual men and women, one in four were white."<sup>3</sup>

Correspondingly, the transmission of STIs has increased exponentially in Australia over the past decade. Notable in these are the high STI rates in the Aboriginal and/or Torres Strait Islander populations, especially in regional and very remote areas. In 2017 the rates of diagnosis of chlamydia, gonorrhoea and infectious syphilis diagnoses in the Aboriginal and Torres Strait Islander population were over 2.8, 6.6 and 6.6 times higher respectively than the rates in the non-Indigenous population. The rate of HIV notifications increased by 41% in the Aboriginal and Torres Strait Islander population between 2013 and 2016, compared with a 12% decline in Australian-born non-Indigenous people, and in 2017 remains 1.6 times as high as the Australianborn nonIndigenous population.<sup>4</sup>

These figures suggest there is little evidence of protected sex being practiced in the wider community. Results from a 2009 Australian Department of Health and Ageing survey found that only 52% of survey respondents aged 15–29 said they had used a condom the last time they had sex, with over 60% admitting they had never been screened for STIs. Astonishingly, when asked to assess their own likelihood of catching an STI, the majority of these young people perceived themselves as 'unlikely' to do so. The Second Australian Study of Health and Relationships survey of 2012 found that "although most respondents had used a condom at some time in their lives, fewer than half of those who were sexually active in the year before being interviewed had used a condom in that year."<sup>5</sup>

Whilst there is a relatively established culture of HIV testing within the gay community, this is not the case in the heterosexual community. The reluctance

to test would appear to be borne out by anecdotal data which indicates heterosexuals are not perceived to be in an 'at risk' group. Young heterosexuals particularly do not view themselves at risk in terms of their behaviour, and HIV still commonly tends to be viewed as a 'gay male disease.'

A basic internet search of 'HIV and heterosexuals' produces results ranging from the misinformed to the downright homophobic. Unfortunately this lack of knowledge and information also filters through to some in the medical profession. I know of more than one young heterosexual woman who on asking their GP for an HIV test was told "oh you don't need that" or "why?" Sadly several of those women have subsequently been diagnosed HIV positive. Many do not realise that screening for STIs doesn't include a HIV test, unless it is specifically requested. This is assuming that they have even tested for an STI.

In a 2014 study examining young people's perceptions of risk of STIs in regional, rural and remote Australia,

the authors concluded that while "sexually transmitted infections were highly feared... recurring statement in our discussions with young people was that they do not 'happen to people like me'."<sup>6</sup>

Internationally, Australia has long been recognised for its response to the HIV epidemic particularly amongst those regarded in 'at risk' populations – MSM, sex workers and people who inject drugs. Because heterosexuals are not considered an 'at risk' population, almost half of heterosexuals diagnosed with HIV are late presenters often with an AIDS defining illness. "A high proportion of late diagnoses were reported in people with heterosexual sex as an exposure risk (48% overall, 49% in men and 45% in women.)"<sup>7</sup>

Nationally in 2017, among HIV cases attributed to heterosexual sex, high levels of late diagnosis was observed across all categories, reaching >60% among people born in South East Asia and those older than 50 years.<sup>8</sup>

The success of treatment as prevention as exemplified in international multi-site randomised trials such as HPTN052 which demonstrated a 96% efficacy rate in the transmission of HIV amongst sero-discordant heterosexual couples and the 2016 PARTNER study whose final results reported zero HIV transmissions between couples who had sex without condoms where one partner has an undetectable viral load. In the wider heterosexual population, this information is not widely known and will only have application if one is aware of one's HIV status in the first instance.

There may be a correlation between the current increase in STIs and a possible increase in HIV in the future,

despite no current research evidence to substantiate this. In a 2014 article on transmission and prevention of HIV amongst heterosexual populations in Australia, the authors have noted – "in Australia, unlike much of the rest of the world, HIV transmission through heterosexual contact remains a relatively rare occurrence. In consequence, HIV-prevention efforts have been firmly focused on male-to-male sex as the most frequent source of HIV transmission. There are emerging signs that this epidemiological landscape may be shifting, which raises questions about current and future HIV prevention strategies."<sup>9</sup>

Although the report focuses on two key but diverse HIV-positive heterosexual populations; people from minority ethnic backgrounds in New South Wales and men in Western Australia who acquired HIV overseas, the

authors state– "despite their differences, there are significant commonalities across groups at risk of HIV infection through heterosexual contact, which not only provide opportunities for HIV prevention, but also call for a rethink of the

dominant HIV response in Australia."<sup>10</sup>

If Australia is serious about the goal of ending HIV transmission, and if we are to achieve the UNAIDS target that 90% of all people living with HIV will know their HIV status by 2020, we need to include all 'at risk' populations and broaden the definition to include heterosexuals.

I recently attended an Asia Pacific regional HIV conference which included a focus on MSM, transgender persons, sex workers, injecting drug users, youth and women, but no reference was made to heterosexual men. I wondered what the heterosexual man I was sitting next to felt about that omission? Doesn't everyone's sexual health, status and wellbeing matter?

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**In 2017, 25% of newly diagnosed HIV cases in Australia were attributed to heterosexual sex.**

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# 2019 Candlelight Memorial

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**ANDREW HESLOP**

*Positive Life NSW Board Director*

As our 2019 Candlelight Memorial at the Eternity Playhouse in Darlinghurst drew to a close, and the applause and warm appreciation for Paul Capsis' heartfelt contribution and talents died down, I had the opportunity to maintain a silent reflective pause that filled the contemplative space of the Eternity Playhouse at Memorial hosted by Positive Life NSW and ACON.

I found myself contemplating the light of a single candle. How much energy and life is represented in each flickering whisper it makes. I remembered the networks of communities, friends, family, lovers, partners, pets, work colleagues, the whole damn lot of a life, for each one a single life. I thought then of every small flame on stage, the thousands multiplied, whispering and flickering in a dark-quiet theatre.

I remembered the rhythmic, stately procession of syllables that suddenly bought each name into flesh in our memory and glimmered an opportunity to gloriously remind ourselves of familiar friendly faces now gone, but never, never forgotten.

My pause was also a reflection on the words that were spoken by Robert

Agati, President of PLNSW and echoed later in the speech given by Cameron Cox, CEO of the Sex Workers Outreach Project (SWOP). Words that reminded us of the lost lives who don't get their moment by candlelight. Our people, those friends, family, lovers and partners many of whom remain nameless, and who bear forever the unremitting product of shame, fear, stigma and doubt within our greater community.

I was moved as Paul Capsis masterfully delivered a song by Lou Reed, *A Perfect Day*. Lou Reed always strongly resisted the allegory others see in this work and *A Perfect Day* is one of those rare musical intricacies that is simultaneously an orison for the everyday yet also a powerful reminder of how great beauty can be blazingly etched into stark simplicity.

*'Oh, it's such a perfect day  
I'm glad I spent it with you  
Oh, such a perfect day  
You just keep me hanging on...'*

I felt stirred by another kind of simplicity in that moment of beautiful twinkling lights, inviting our love in remembrance of those who we have lost too soon from HIV/AIDS.

I remembered the networks of communities, friends, family, lovers, partners, pets, work colleagues, the lost lives who don't get their moment by candlelight.



# WOMEN AND HIV



About ten 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.

As a heterosexual woman living with HIV (WLHIV) for the past 25 years, I am acutely aware that the lived experience of WLHIV 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 asked “why?” or told “oh you don’t need that”. Sadly several of these women were subsequently diagnosed with HIV.

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.

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.

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.

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 National Day of Women Living with HIV Australia (9 March) 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.

Join Positive Life each year in celebrating the National Day of Women Living with HIV on 9 March.

**JANE COSTELLO**

*CEO, Positive Life NSW*

There's something  
we need to

# TALK ABOUT

Let's talk about a silent STI with no symptoms that 80% of us who are sexually active contract sometime in our lifetime.

Did you know most of us currently have or have previously had HPV? Yep, I found this out myself after my most recent cervical screen came back saying that I have a strain of HPV.

HPV stands for Human Papillomavirus. There's plenty of evidence this common sexually transmitted infection (STI) affects just about anyone who is sexually active – men, women and trans and gender diverse people.

80% of us will get this silent STI at some stage, which has no symptoms. The majority of us won't know we've got it and usually it clears itself without treatment.

So why am I talking about HPV? When HPV doesn't clear itself and hangs on in our bodies, this virus has the risk of causing small cell changes, called precancers, which can go on to develop other types of cancer in the cells of the vulva, vagina, cervix, penis, anus and even the throat. For women and people with a cervix living with HIV, the risk of cervical cancer is roughly five times higher than people who are not living with HIV. Worldwide it's more of a grim picture.

As someone with a cervix, I'm super keen to know what I can do to reduce my risk for cervical cancer, especially since like many people my age I currently have HPV. Thankfully in Australia we have access to a number of different strategies and solutions to prevent and treat this type of cancer.

Since 2007, girls were vaccinated at school when we were thirteen or fourteen as part of the free National Immunisation Program (NIP). This program was extended to include boys in 2013. I was lucky enough to be included in this program, however, if you didn't get the vaccine at school, you can still get it at your GP, community health clinic or local public hospital. Even if you do have the vaccination its important you still get the recommended cervical screens, as not all strains of HPV can be vaccinated against.

Recently Australia started using a more effective Cervical Screening Test which detects HPV and also replaces pap smears. My test detected HPV so now my doctors know what to look for in case it doesn't clear on its own. There are also specific cervical screening guidelines for women and people with a cervix living with HIV or immunocompromised which recommends a screen every three

years instead of the otherwise recommended five years. The good news is, we can prevent and treat cervical cancer with early diagnosis and treatment.

A national survey of 1,000 women in 2019 found almost one third of us put off cervical screening because we felt “embarrassed” or “awkward”. In Australia, 80% of cervical cancers are detected in women who are overdue or have never had a cervical screen or pap smear. This shows more conversations with our GPs about testing and vaccination options could save our lives.

While Australia is on track to effectively eliminate cervical cancer by 2035, women and people with a cervix are still being diagnosed late and dying from cervical cancer that could have been prevented. Some have even used the phrase ‘dying of embarrassment’ to describe someone who finds out they have a cancer diagnosis because they avoided talking about HPV and testing for cervical cancer.

I am lucky to have a good relationship with my female doctor who reminds me, and I also get text reminders. Another option to make cervical screens more comfortable is to see if you’re eligible for the self-testing process that started in 2017.

Last year Positive Life NSW and Femfatales, the Australian national network of women living with HIV, asked women and trans and gender diverse people living with and without HIV about their awareness of HPV-related cancers including cervical cancer. Like other surveys, these results showed that many of us are uncomfortable talking about HPV-related cancers.

We said we would prefer clinician initiated, non-judgmental conversations about HPV and

cancer with female doctors or nurses who were non-dismissive, clear, and made them feel comfortable. We also said we’d like to see more public awareness and discussion about screening guidelines, symptoms, risks and general information about HPV-related cancers. A steering group of clinicians, researchers and HIV sector representatives have formed to start progressing the recommendations from this survey report into the future.

While it’s not my favourite thing to do in the world, in a year I’ll have another cervical screen to check up on my HPV.

I really urge all women and people with a cervix, especially people living with HIV, to check in with your doctor to find out your cervical screening options.

Making our health a priority means we stay in control. When we are informed, we are empowered!

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**BELLA BUSHBY**

*Communications and Policy Officer,  
Positive Life NSW*

While it’s not my favourite thing to do in the world, in a year I’ll have another cervical screen to check up on my HPV.

How I finally made the decisions to not return to my (now) ex-partner and meth.

# A SAFE PLACE TO LAND

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**'STEVE'**

*Community member*

Life can sure throw some curve balls at you but as the saying goes, what doesn't kill you makes you stronger. That was certainly evident in my case.

Over the past five years, I've been on a real rollercoaster journey of choices and changes that led me through some serious illness, a busted relationship to today where I live with HIV, have stable housing and fairly hopeful employment future.

My usual tendency to gravitate towards relationships that were not necessarily in my best interest was the first warning flag I ignored. Trust (or lack thereof) was a key theme in these relationships and this was absolutely the case with 'Geoff', my last partner.

We met under the influence of methamphetamines. While this gave both of us a lot of confidence which replaced any anxiety or hang-ups about sex, in my experience, substance use has never been a good start to a relationship.

As a sero-discordant relationship, while he was HIV positive and I was HIV negative, we never let our sero-discordance get in the way of a good time! Our relationship and our mutual dependence to meth lasted for the next five years.

Looking back, it seemed like we were both high for the duration of the relationship. We definitely didn't practice safe sex, although from time to time it crossed my mind that I might be positive. It wasn't a thought that hung around for very long. While I was high, I was engrossed in staying there and finding as much pleasure as I could regardless of the realities that were around me.

For the last year of our relationship I was ill. I felt like shit. The sensible thing to do would have been to go see a GP. I did the complete opposite instead and reached for the meth. I wanted the party to keep going and I definitely wasn't ready to come down to earth yet.

Eventually I got so sick I passed out and was taken to hospital via an ambulance. It was there I was diagnosed with both Pneumocystis Pneumonia and HIV.

Again, logic would dictate that I follow my doctor's advice and stay in hospital to get the treatment I needed. Again, I did the complete opposite instead. I discharged myself and ran back to my partner and meth. These decisions continued with more hospital admissions (via ambulance) and more self-discharges.

Eventually, the cold hard slap of reality finally sunk in, when I was faced with the real prospect of death. This time, I stayed in hospital for some much needed rest, recuperation and medical treatment (3rd times the charm, right?).

Around that time, I also finally made the decisions to not return to my (now) ex-partner and meth. The hospital social worker suggested I apply for social housing as a way to get a stable place to start taking care of myself and keep myself healthy.

Once discharged from hospital, I moved in with a family member and trotted off to the local housing office with application for housing assistance. It came as a bit of a shock when they told me I needed to go away and apply online. This was despite standing in a housing office with a completed housing assistance application in my hand! I had no access to the internet and I certainly didn't have a computer. Help!

I contacted my hospital social worker and she suggested I call Positive Life NSW and get in touch with John, their Housing Support Officer.

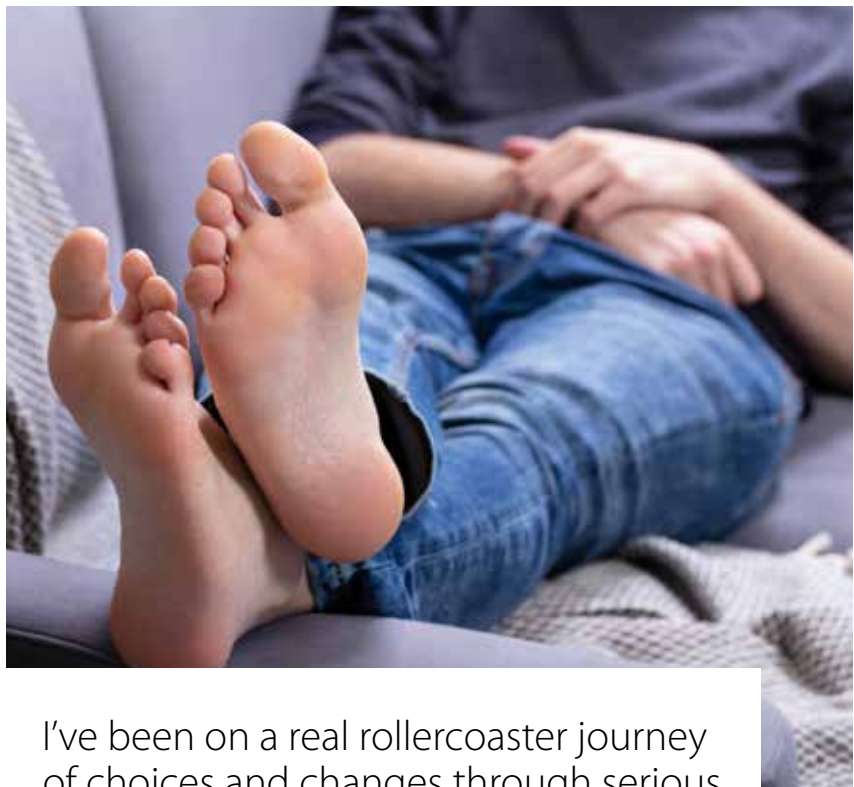
John supported me to complete the application for housing assistance together and we collated the 'truck load' of supporting documents and evidence needed for assessment. He further assisted me by advocating for me to move into transitional accommodation. This is a way I

could access immediate housing. I accepted the transitional offer which completely took the stress out of my precarious couch surfing situation while I waited waiting for FaCS Housing to assess and approve my application for permanent housing.

John came with me when I viewed the transitional property and also when I signed the lease. He also helped to arrange furniture support via one of the local charitable organisations.

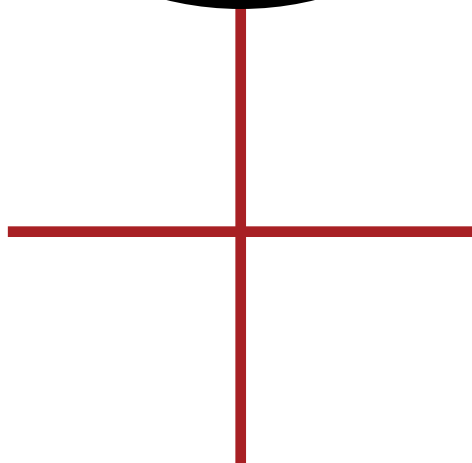
The bureaucratic assessment of my application took many long months and after a few more hurdles, I have been priority approved. I'm just waiting for a suitable offer of social housing.

Today I'm in a place where I can look at other job opportunities and together with my housing security, I am feeling confident for whatever the future may hold.



I've been on a real rollercoaster journey of choices and changes through serious illness, a busted relationship to where I live with HIV, have stable housing and employment.

# Women and HIV disclosure



When I was diagnosed in 1997, I received conflicting messages about HIV and disclosure.

Women living with HIV face unique challenges within the Australian context for a number of reasons. Firstly, we are not seen as a priority group for contracting HIV, so we are not routinely tested and don't receive targeted education for women. Secondly, many of us are unattached to the gay community and our support networks have no awareness or understanding of HIV. Women account for about 10% of people living with HIV in Australia, so our minority status and lack of community attachment makes us particularly vulnerable to isolation. Lastly, disclosure is often a serious concern and a major hurdle for women living with HIV.

When I was diagnosed in 1997, I received conflicting messages about HIV and disclosure. The look on my suburban GP's face who diagnosed me said plenty. "I'm sorry", he stammered. "You don't look like the type." He referred me on and swiftly ushered me out of the appointment. The message to me was clear. If a doctor was so obviously uncomfortable with HIV, how might others react?

Though my parents were very supportive, I was cautious with disclosure. "It could happen to anyone," they said as they hugged me. Others told me not to tell anyone else. Another friend said it might be a quirky thing about me that people might find attractive! I was sceptical. I didn't know how a sexual partner would react. Without any example of disclosing HIV, the first thought on my mind was, what might people think of me as a young woman living with HIV? I was also acutely aware I would be breaking the law if I engaged in any kind of sexual activity without disclosing my HIV status.

The sexual double standard that women face rests heavily on the shoulders of women living with HIV. Most women try to avoid being labelled promiscuous, which is not a concern generally shared by men. One comes to see the hypocrisy in society about sex. For women living with HIV, the association with so-called 'bad behaviour' (like sex and drugs) can be frightening

and overwhelming. It takes a lot of strength to maintain confidence and work through issues of judgment, dignity and respect.

In the collective psyche of many cultures, the notion of women as dangerous witches, whores and sirens lingers on, and women are keenly aware of this. No woman wants to be called a slut (unless she has worked through this and embraced it as a positive). Even then she may experience stigma and discrimination. History is full of stories of the Scarlet Woman and the fate she endures. When a woman is diagnosed with HIV these fears can be compounded and many keep their HIV status a secret.

The threat of violence is a reality most women are conscious of. Women grow up aware of their surroundings and their safety, and many have daily strategies to avoid violence and being attacked or raped. When a woman living with HIV contemplates disclosure, the possibility of violence often becomes an issue. I read recently of two reports in the USA where women were killed by men they were romantically involved with, after they disclosed they were living with HIV. Other countries are not much better.

Happily, I have never experienced violence from men after disclosing to them. Yet, it still poses some anxiety for me and I am also prepared for the possibility of an angry or frightened response. I have disclosed many times and I never encountered a heterosexual man who knew the current facts about HIV. Most quote 'the Grim Reaper' as their only memory of HIV and these are university educated, professional men, some with a science background. If I had not been well informed, confident and able to reassure them, the disclosure probably wouldn't have gone well. As women living with HIV, managing to feel sexy and desirable, rather than someone they have to look after emotionally or physically, is an added challenge.

The recent amendment to section 56 of the Public Health Act in 2017 that a person with HIV doesn't

need to disclose provided their viral load is less than 200, they use condoms, or can confirm their partner is on PrEP, relieves some of the pressure to disclose. However, it also has created more confusion and ambiguity. Telling a man

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## When I was diagnosed with HIV, the look on my GP's face said plenty. If a doctor was so obviously uncomfortable with HIV, how might others react?

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after you have had sex with him is undoubtedly a risk. Bearing in mind he is unlikely to have much knowledge about HIV, his reaction could be unpredictable. Telling him before sex may be a preferred option, but this usually means a lengthy education process ensues (if you are able to articulate it and he is willing to hear it), rather than the hot time you were hoping for. When to tell, is often an issue with HIV disclosure.

All these concerns of disclosure, violence, timing, and education can inhibit a budding sexual relationship, and cause women living with HIV to shy away from emotional intimacy or to self-sabotage their relationships. I remember getting close to a guy before disclosing, and the more my feelings developed, the harder it got to tell him I was living with HIV. Eventually he concluded that I didn't like him and the relationship ended with both of us hurt and confused. It was a painful lesson.

The fact that HIV transmission is now proven to have a Zero risk when a person living with HIV is on effective treatment, is an excellent development.

We can now be just like any other woman, except there is just this one thing I need to tell you...

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**MAXINE**

*Community Member*

# UNPACKING

U=U

**Undetectable = Untransmissible**

## **‘Undetectable’ means different things in different jurisdictions.**

The undetectable=untransmissible (U=U) campaign is a popular, wide-spread and fantastic message for all people living with HIV (PLHIV)!

It is a campaign with the message that a person living with HIV who is on antiretroviral treatment, and has been able to maintain viral suppression with an ‘undetectable viral load’ (UVL) for six months, has zero risk of passing HIV onto our sexual partners. This is exciting news for PLHIV and for those we love, bang or fuck.

As a man living with HIV for over 30 years, I know what it’s like to live in a time when we were heavily stigmatised as the ‘vectors of disease’. I know what it’s

like to live in fear of passing on a potentially deadly infection in a time when there were no treatments or treatments with dreadful side effects. In less than half my lifetime, thanks to tireless researchers, HIV is a manageable chronic health condition like diabetes or heart disease, and I am free to love, bang or fuck anyone without fear of passing on HIV. Knowing ‘treatment as prevention’ (TasP) works and there’s zero risk of transmitting HIV to our sexual partners has been profound. The U=U message is liberating and powerful.

However, being undetectable or having a UVL, isn’t universally applicable. ‘Undetectable’ means different things in different jurisdictions.

Back in 2008, doctors in Switzerland noticed that some PLHIV didn’t pass HIV to their HIV negative partners even if they were not using condoms. These doctors were the first to make a statement about their observation also known as the ‘Swiss Statement’ which was that a person taking antiretrovirals maintaining viral suppression could not pass HIV to their sexual partners. At the time, some clinicians thought this was



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## We need powerful messages based on rigorous science that unites the Body Positive without dividing or excluding some of us.

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irresponsible and there was considerable backlash to the statement.

Three very rigorous studies, the Partners Study 1 and 2 and the Opposites Attract Study soon followed, which all supported the Swiss Statement. These three studies used a viral load (VL) test to measure the quantity of HIV in the blood. This test used a sensitivity of measuring the existence of HIV in the blood above 200 copies/mL or more. Based on this test, a person with a VL of less than 200 copies/mL is considered to have an undetectable viral load (U=U).

As the years rolled by, science has refined the sensitivity of VL tests and it's now possible to measure the number of copies of HIV in the blood down to as low as 20 copies/mL, especially in developed countries like Australia or the United States where we can afford this more precise equipment. In some resource-poor jurisdictions, the sensitivity of the testing equipment, if available, remain at 200 copies/mL.

The question that needs to be asked is where do we set the bar for 'undetectable' now there's different availability and standards of VL tests being used around the world? Part of the answer is in the Partners Study 1 & 2 and the Opposites Attract Study.

All three studies used the VL sensitivity of 200 copies/mL. Within these studies it was noted that while all the participants were undetectable below 200 copies/mL, some PLHIV within these studies registered what is known as a 'viral blip' on more sensitive tests e.g. at 20 or 60 copies/mL. Technically, these people were detectable using the more sensitive tests, yet they were under 200 copies/mL and still undetectable by all three studies.

This reality causes a lot of anxiety and confusion for many PLHIV and their partners, when they see a viral blip based on using the more sensitive VL tests. People who are undetectable suddenly see a VL load based on this more sensitive test and U=U no longer seems to hold up for them. Of course, despite this tests sensitivity, these PLHIV are still uninfected.

What does this mean if undetectable tests fall below 10 copies/mL?? As more sensitive tests are developed, many PLHIV who are undetectable reading this right now would be detectable under that kind of testing standard, even though they cannot pass on HIV. This highlights a significant crack in the U=U messaging along with other questions of how U=U relates to other concerns like antiretroviral therapy (ART) interactions with other medications, treatment resistance, ageing, fears of antiretroviral therapy (ART), HIV in breast milk or people who inject substances.

There is very little to explain to the average PLHIV what a viral blip is or what it means. Is the test detecting HIV or a broken inert piece of HIV or even another virus at these more sensitive levels of testing?

In NSW, PLHIV have achieved so much together as a community. As we continue living full lives with HIV, we need powerful messages based on rigorous science that unites the Body Positive without dividing or excluding some of us based on increasingly sensitive tests.

If we talk about U=U, the reality remains that not everyone is undetectable at the more sensitive levels of testing. It would be accurate, and more inclusive of all PLHIV who are maintaining viral suppression, to say you cannot pass on HIV (untransmissible) if you have a U=U below 200 copies/mL. This would also reduce the confusion and anxiety for everyone when we are discussing risk for HIV transmission.

Another question that arises is how high above 200 copies/mL remains 'safe'? We don't have any research to accurately give us a conclusive answer.

This is a conversation to have with our HIV clinicians and discuss results while asking for answers from our doctors and HIV specialists. The clear and undeniable message is that treatment as prevention (TasP) works. PLHIV who maintain viral suppression (below 200 copies/mL), by taking their treatment, antiretroviral medications, as prescribed are at zero risk of passing on HIV to their sexual partners.

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If you want support to explore what the U=U message means for you, call Positive Life on (02) 9206-2177 or 1800 245 677 (freecall).

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**DAVID CRAWFORD**

*Treatments Officer, Positive Life NSW*

# ROUGH SLEEPING

Finding yourself where you have nowhere to stay the night can be a frightening reality for people living with HIV.

JOHN CARR

Housing Support Officer, Positive Life NSW

Recently, SBS aired a social experiment on homelessness called *Filthy Rich and Homeless*. The series followed a group of public figures as they navigated the homeless landscape of Sydney.

It brought terrific awareness to the experience of homelessness and what that feels like, and at the end of the experiment fortunately for the television participants, they returned to their safe, comfortable homes. People living with HIV who are rough sleeping don't have that luxury.

The 2019 February City of Sydney Street Count had an increase in people experiencing homelessness by 13% from last year. This is one major issue that's not going away anytime soon.

There are many reasons why someone finds themselves in this situation. Work falls through, the mortgage or rent get out of control, a partner leaves and takes the second income with them, substance misuse or that perfect storm of misery when several of these happen at the same time.

So what do you do if you find yourself in this situation of nowhere to stay, no food and no money? A good place to start would be to triage or sort the order of your priorities.

If finding somewhere safe to stay is your number one priority, you have a few options. FACS NSW have created a Homelessness Information Line called Link2Home or 1800 152 152. This state-wide, 24/7 telephone service can source temporary accommodation for anyone experiencing homelessness. The temporary accommodation they usually source is often limited to

motel or crisis accommodation.

There are some great crisis accommodation services that can help out, however some PLHIV experience challenges when using in these facilities. Sharing dormitories and facilities with people who are also managing their own crisis can be confronting, however one great benefit is the support you receive. The goal of the staff is to support you to find your own path out of homelessness. This could be in the form of medical referral, linking in with mental health services, assistance with intake into a rehabilitation facility or applying for social housing. Most importantly, these services will provide you with the basics of food and shelter which can help stabilise your current situation.

But say you can't secure a bed for the night. There're no vacancies at the crisis services. None of your friends can offer you a couch for the night. You're literally faced with the only alternative but to sleep rough.

Anyone who has previously slept rough usually has some advice on the best places to bunker down for the night. These can range from parks, beaches, steps of a church or finding a safe nook in that "no man's land" space between city freeways. Weather can play a major obstacle for where you decide as wind and rain can easily sour the best of plans so look for those sheltered options.

Food is probably the next essential necessity. Fortunately for Sydneysiders, there is free food to be found if you know where to look. As well as centre-based food services such as the Wayside Chapel

in Potts Point, St Canice's Church in Rushcutters' Bay and the Station Drop in Centre in the CBD, there are also a host of food vans that pull up to various locations offering either hot meals or sandwiches. These are provided to anyone. No judgment, no questions asked.

There are also laundry and shower facilities. Orange Sky Australia provide a free mobile laundry and shower service around various locations around Sydney. Their volunteers provide a platform for people who are experiencing homelessness to connect through a regular laundry and shower service.

Getting into a routine with your meds can be a challenge. When you're sleeping rough, it can almost be impossible. Taking your daily meds is super vital for keeping your HIV under control. There is no easy answer on how to manage storing your medication. Homeless services may be able to assist. Speak with your GP or pharmacy on some options that may best suit your needs.

Newtown Neighbourhood Centre launched an initiative over the recent winter months called "Newtopian Outreachers". A group of volunteers regularly hit King Street offering rough sleepers with practical assistance such as where to find a meal, organising temporary accommodation and providing phone cards to contact vital services such as FACS or Centrelink.

If rough sleeping is your only option, we hope it's an extremely temporary arrangement for a night or two at most. Sadly, for some PLHIV, rough sleeping can last much, much longer.

Give the Positive Life NSW Housing Officer a call, if you're living with HIV and want a hand with your housing situation whether you're at risk of homelessness or you're already there. Phone 9206-2177 or 1800 245 677 (free call).

# Anna's story

I was diagnosed with HIV after my husband received his AIDS diagnosis. He was so ashamed and felt such guilt that he would not let me tell anyone of our joint diagnoses, and therein followed the longest ten years of my life, a life constructed around secrecy and lies. I created an entirely fabricated world in which we, for all intents and purposes, led a normal life. I wasn't able to tell my family or confide in friends at the time, which I regret to this day. I realise now that these decisions made me put off dealing with my diagnosis, confronting the everyday reality of it, and its long-term implications. I didn't deal with these until years later. I had essentially put my life on hold since my diagnosis. I had been simply existing and not truly living while I waited for my husband in the very late stages with two AIDS-defining illnesses to die. When he didn't die, thanks in part to the advances in HIV medication, I was forced to re-examine my own existence.

'Later' occurred ten years afterward when our marriage ended, when I felt free to tell others of my status. Opening up to good friends was extraordinarily cathartic, but also very difficult as I had effectively lied to them for that period of time. There was also the issue that they would reject me because of the stigma, ignorance and prejudice that unfortunately still exists around HIV and people living with HIV (PLHIV). I am fortunate that family and close friends I disclosed to have been incredibly supportive. I

believe, it is this understanding that led to my gradual acknowledgement and acceptance of HIV in my life, although I would be the first to say while it is a part of me, it certainly doesn't define me.

After having lived a life where I effectively avoided HIV or anything to do with it, I progressively started to become more engaged with the HIV community as a whole. One of the reasons I decided to become involved was the desire to give something back.

I think the writer Isabel Allende sums it up best when she says, "the whole point of being alive is being part of a chain, of a community, and what you do for others is what matters." I realised that my identity as a woman living with HIV (WLHIV) placed me in a unique position as a peer to support and advocate for others. I trained as a positive speaker

I realised that my identity as a woman living with HIV (WLHIV) placed me in a unique position as a peer to support and advocate for others.

because I wanted to raise awareness around the lived experience of HIV in the wider community. In Australia, WLHIV are regarded somewhat as a minority within a minority, so it is important that our perspectives are valued and given due consideration in the HIV response including at the national level in the design and implementation of policies and programmes.

My other reason for becoming more engaged with the HIV community was around the area of human rights. PLHIV are entitled to the same rights as everyone else, and the protection and realisation of these human rights has been recognised to be essential to an effective public health response to HIV. Our HIV-related human rights include our human rights as articulated by the United Nations, as well as encompassing our right to be free of stigma and discrimination. Human rights advocacy impact WLHIV concerns around privacy, gender equity, sexuality, access to

medication and appropriate services, travel and employment restrictions, amongst others, and promote a strong public health response especially for WLHIV.

WLHIV have a right to self-determination and participation in decision-making processes that affect our lives, and a successful rights-based response to HIV prevention requires the involvement of all PLHIV. If Australia is to achieve the goal of eliminating HIV transmission, we must include and respect the voices of all people living with HIV.

As PLHIV, we have led the advances of the past thirty or so years of the HIV epidemic. Our challenge for 2019 and beyond is to continue to build on our achievements and successes, honour and respect the past, and to continue to advocate around issues that affect all people living with HIV including women.

'ANNA'  
Community Member



# PositiveLifeNSW

the voice of people with HIV since 1988

Positive Speakers Bureau

HIV Work Ready

HIV Health Promotion

Advocacy + Policy

Peer Navigation + Support

Talkabout

Housing Support

Genesis

Silver Warriors

Treatments Information

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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**

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