

It's with pleasure that I present the 2016 edition of PozLite.

More now than ever, I believe that PLHIV need to speak for themselves and remain vibrant and visible. The articles in this edition of PozLite is a perfect example of PLHIV speaking for themselves with confidence and dignity. There are many varied themes and articles which are representative of the rich diversity and PLHIV lived experience.

The following stories by PLHIV were the most popular with our members and are prime examples of issues that PLHIV are faced with in everyday life. Topics reflect culture and age, sexuality and gender; along with relevant HIV related topics, such as HIV testing, cure research and co-infection.

All the more so, our voices and presence is vital when combating stigma and discrimination. The stigma we experience today is very different from that experienced by PLHIV in the 1980s and 1990s. It is nonetheless critical to acknowledge and address stigma in all aspects of our lives. I hope you enjoy this read, as many other PLHIV have.

Looking forward to the year ahead, we are committed to ensuring all PLHIV can commence treatment immediately as well as continuing to advocate for universal access to HIV medication for all PLHIV populations.

CRAIG COOPER

CEO, Positive Life NSW

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FACING AN INCONVENIENT TRUTH

When members of our community are not doing as well as we think

DAVID CRAWFORD

Treatments Officer, Positive Life NSW

Like anyone else, people with HIV grapple with many things in life. For some people these things include judgement, stigma and discrimination. I recently heard that an ambulance officer attending a person who disclosed he was HIV positive, blurted out "how did you get it?" This is not an uncommon question. How anyone becomes HIV positive is no one's business but the person with HIV. Nevertheless, this needless intrusive question comes from those we least expect to pry.

An Aboriginal woman I recently spoke with lives in fear of her community knowing her very painful secret. She is fearful of being stigmatised because of how she caught HIV. As she said, "it's embarrassing but people want to know." I wondered to myself about the burden she was obviously carrying and how unfair that was. If she had cancer there would be a completely different response. Her

level of vigilance and caution has severe impacts on her health, like many other HIV positive people living in rural and regional areas in small communities.

Most HIV transmissions are passed on during sexual intimacy that doesn't always fit within what others see as the 'norm'. Heterosexual, homosexual or bisexual, we lock people into stereotyped boxes of sex and gender. The more we define, the tighter the box gets and the greater the likelihood of treating people as different or 'other'. Along the continuum of sexual orientation, the reality is we are all at risk of being marginalised by another group of people.

Sometimes people will choose to live a lie for fear of being thought of in a stigmatising way. This isn't just HIV causing this. It is misinformed and ignorant people judging other people and discrimination, pure and simple. The worst of this is what I call 'homogeneous discrimination',

or 'like discriminating against like'. For example, gay people against gay people or straight people against other straight people. If you're bisexual or transgender, this experience is a very isolating experience. The truth is there is always someone living with HIV not very far from you. You just won't know.

There is still a perception that having HIV will mean our lives, relationship or career will end, that we will never have sex again, and that we won't be able to have children. These are all myths of living with HIV today and we need to dismantle them.

I have met people who contracted HIV and became the very thing they once discriminated against. Some people feel an added burden of shame contracting HIV. They feel they have let down the dreams and aspirations of loved ones particularly if they are gay and from an Asian culture, or do not provide grandchildren to ageing parents in the traditional sense. Is it any wonder that people with HIV who are living under these pressures and keeping this secret while living with the fear of disclosure, are at increased risk of depression, illheath and even suicide?

I recently listened to a woman's story of domestic violence where HIV became the weapon used in the battle for custody of her children and her freedom. Is it any surprise that we still have people in the community who deny their risk and avoid getting tested? Treatments are so effective today, that in the event of a positive diagnosis, we know if you start medication immediately you have the opportunity for a full and rewarding life.

While we frequently talk about HIV as a chronic manageable condition, and this is the case for 40% of people with HIV in NSW, there is also a small but significant group of older people who have not benefited fully from HIV treatment. Some have stopped work because of illness, live in poverty and social isolation and at times are close to giving up and disengaging in treatment and care. You could call it passive suicide.

Let's acknowledge we have members of our community who are struggling. Increasingly we need to address the emerging problems of age, of multiple health problems, and of poverty and loneliness. We need to stop pretending that everything is going to be okay and face the reality that not all people living with HIV are doing as well as we might want to believe. If you are experiencing any of these thoughts or being treated badly, know that you are not alone and that there is no shame in reaching out.

We owe it to ourselves to ensure that whether diagnosed 35 years ago or diagnosed today, nobody living with HIV is left behind.

While I long to remove the pressures of culture, religion and beliefs that are the perpetrators of the pain of stigma and the drivers of discrimination, in the meantime, let's continue to build the resilience of our community. For our peers who haven't been able to fully benefit from medical and economic progress, we must continue to value them and ensure they live out their lives in a meaningful and inclusive way. We owe it to ourselves to ensure that whether diagnosed 35 years ago or diagnosed today, nobody living with HIV is left behind.





About twenty years ago, I never would have thought

I'd be alive today. I was 32 and a mother when I was

told I was HIV positive at the refugee detention centre.

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

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

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

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

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

I could hardly handle the stress of being in the detention centre as a refugee and being diagnosed with HIV, so I isolated myself. After I was released from the centre, I was in and out of hospital and at the same time I needed to raise my two children, who were both under ten years of age. During this period, I never thought I'd live to this day. My arranged husband passed away about 13 years ago from an AIDS-related illness, yet all of my children, conceived during this marriage, are healthy.

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

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

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

ZAINAB

Community member

FINDING THE CONFIDENCE

Steven's steps to moving forward

STEVEN

Community member

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

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

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

My fears, anxiety, hurt, worries about the unknown or rejection, wondering if hot guys would still want to touch me all haunted me. I wondered what would happen in the future and if everyone would say no to me or never want to meet up. Of course that can happen anyway for many reasons other than being HIV positive. We all get rejected at times - positive or not. Fears about being unloved and being anxious about rejection are common emotional experiences, and I wonder if we use HIV as an excuse? I think maybe we do at times.

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

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

Then there was the online world. Where do you start? Being honest always worked for me, whether in my profile, during a conversation or just before meeting someone. Sometimes an online interaction doesn't give me what I'm looking for, but I remember it's only an online exchange through a computer screen. I do what I can to move things into the real world and meet up with people, go to social groups, meet over coffee, at the gym, in the club or out and about. Sure, there are some people who are still frightened to hear the word HIV but there is no need to beat yourself up over becoming positive. Accept, acknowledge, be aware and move forward.

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



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

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

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

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

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

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

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

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

I was nervous and anxious. I had always put off testing for HIV. I knew that I had taken all of the risks.



JANE COSTELLO

President, Positive Life NSW

Today, about 10 per cent of people living with HIV in Australia are women, yet they continue to be relatively invisible in the HIV prevention message. As a heterosexual woman living with HIV for the past 21 years, I am acutely aware today that the experience of women with HIV is still mired in ignorance and invisibility.

Many in the general community and some health providers still think HIV is not an issue for women. I know of more than one woman whose GP said "oh you don't need that" when she asked for a HIV test. Sadly some of these women were diagnosed HIV positive.

Thankfully, Australia has maintained a strong HIV response for many in our community – gay men, men who have sex with men, sex workers and people who inject drugs. Yet based on new diagnoses of HIV, we have all the signs of a gradual "epidemiological shift."

If we are serious about ending HIV, we need to start talking about the different ways HIV affects and impacts women. Unless we acknowledge this, we risk allowing ignorance, stigma and discrimination to gain the upper hand in the virtual elimination of HIV.

There are gender differences in HIV in Australia. Few women are diagnosed early with their HIV infection. When a woman is diagnosed with HIV, she usually finds 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 an AIDS-defining illness. This woman will have missed out on the benefits of early diagnosis and any immediate advantage that antiretroviral treatment could have given her. She will also experience more complications around her reproductive health which then impacts the health of her family and her own psychological health.

Women are less likely to test for HIV, compared to gay men and men who have sex with men. While well-meaning clinicians challenge women who pro-actively ask for HIV testing and tell them they don't need to be tested, they continue to promote the misguided assumption that HIV is not an issue for women.

Young women and transgender women are conspicuously lacking in public health campaigns designed to educate the community about HIV. We must open up the conversation about HIV and women to reduce the invisibility of women living with HIV.

There are gaps in the HIV research data when it comes to understanding the impact of HIV specifically on the female body.

This lack of information creates misunderstanding about the effects of anti-retroviral treatments for women, the impact of their hormonal differences and the HIV treatments side-effects on women. This doesn't even begin to address the experience of women at the intersection of HIV and poverty, access to good medical care and treatment, rural and regional geography, and mental health factors – all aspects disregarded or overlooked.

Many in the general community and some health providers still think HIV is not an issue for women.

The well-established culture of HIV testing within the gay community must be expanded to include women in our community to normalise the reality of HIV as a virus that impacts women as well as men. Recognising the impact of gender differences in HIV is a task for both men and women in the elimination of HIV today.

DAVID CRAWFORD

Treatments Officer, Positive Life NSW

WHAT'S THE RISK?

Sexually acquired Hepatitis C and living with HIV

Several years ago a friend of mine died from complications arising from HIV and Hepatitis C (HCV) co-infection. He had never injected drugs and I remember how frustrated he felt by not being believed that his HCV was acquired sexually.

Until recently, injecting and sharing injecting equipment was commonly believed to be the way most people picked up HCV. Today, there is emerging and compelling evidence that HCV is also transmitted sexually. HCV is a more robust and infectious virus than HIV and it isn't fully understood just how easy it is to acquire sexually. Nevertheless, I'm sure my friend would feel somewhat vindicated with today's evidence.

The way HCV is usually acquired is blood-to-blood transfer (one person's blood being transferred to another person's blood stream) either through a sharp object like a needle or a break in the skin. The amount of HCV infected blood needed to cause infection only needs to be microscopic. This is why people who inject are advised not to share any injecting equipment at all – water, spoons, swabs, tourniquets and needles – hence the message 'a sterile fit for every hit'. Included in

this not-to-be shared list is straws for snorting, syringe barrels for 'booty bumping' (injecting a drug rectally) and pipes.

These same principles to avoid HCV through injecting practices can also be applied to a similar approach to reduce your risks of contracting HCV sexually. The main way is taking care around any activity which could cause small, micro tears in your skin, which allow the virus to enter your blood stream. Generally, the longer and rougher the sex is, the greater potential for skin tears and, if HCV is present, the greater the risk for an entry point for this virus.

There are a number of effective things to do to reduce your risk of acquiring HCV. Change your gloves and condoms regularly and definitely change these between partners. Ensure toys are not shared and are washed in warm soapy water. Even if a condom has been used on a toy, change the condom between each partner or each session.

HCV is present in semen and can survive outside the body for a long time, so it's really important to wash your hands between changing condoms and gloves. It can be really easy to contaminate cleaned or sterile equipment with unwashed hands. HCV has also been detected on the outside of lube containers so it is important to keep these washed and clean. The other factors that increase risk which include 'chem' or 'wired' sex as these sessions tend to last a lot longer and therefore increase the risk of micro tears. Your pain experience can be altered or pain might be part of the pleasure, so there might be no warning of damage to the skin linings of the arse or cock or other areas from fisting, nipple play or cock and ball torture or if it is blood play.

When you're hooking up for a session with a random fuck or fuck buddy, it's important to check that they have cleaned their gear since their last session. There are reports coming out of London where HCV has been contracted from casual hook ups where the host did not clean their toys from a previous session from several days before. HCV can

last longer in moist, warm and dark environments. A long play session or out partying all night increases the likelihood of becoming dehydrated which makes your skin more susceptible to damage. It is possible that cracked and bleeding lips can increase risks for HCV transmission.

There is an increased risk if you have other STIs as well. According to Hepatitis NSW, of the number of all people living with HIV in Australia, it's estimated that one in eight people are living with both HIV and HCV (co-infection). There is evidence that having HIV increases the risk of acquiring HCV and the reason for this is not exactly clear even with an undetectable viral load. It's been estimated that of the gay men in NSW with HIV 13–20% are living with co-infection.

While there are effective treatments available for HCV and the virus can be cleared, it does not prevent HCV reinfection. It is important to note this study also found evidence that for someone with HIV who has successfully cleared HCV, there is a greater risk of developing liver complications and hepatocellular carcinoma (cancer of the liver).

So here's a check list of important things to include when you're planning your next hot fuck session:

- Take regular breaks to rehydrate with water. Have a snack, fruit or meal and recover;
- Change gloves and condoms between partners and wash your hands after removing a used glove or condom and before putting on a new one;
- Clean equipment, sex toys, and anything that has been touched during sex with soapy water;
- If you're injecting or snorting, ensure you have your own equipment (barrels or straws) and have a 'sterile fit for every hit';
- Check in with random or regular fuck buddies about the cleaning of their gear;
- Let your fuck buddy or partners know what's going on and what you're doing;
- Get tested regularly for sexually transmitted infections and HCV at least yearly.

YOUTH TODAY: SEX, DRUGS & HIV

LIZ SUTHERLAND

Administration Officer, Positive Life NSW

Globally for young people, HIV remains one of the most challenging health issues. Given most of today's youth born in the 90's missed the HIV/AIDs pandemic that spread through the world in the early to mid-1980's, HIV is not high on their radar. Except for sensational reporting by the media and pop culture and brief mentions in sex-ed classes at school, the risk of HIV doesn't seem to apply to most young people.

While the highest risk categories are men who have sex with men and injecting drug users, youth 15-24 years make up 41% of new HIV infections worldwide. In Australia, the dangers of travelling overseas and being naïve about HIV are especially high risk. We recently heard of two young couples fresh out of grade 12 who travelled to Bali celebrating the end of school and the start of their adult lives. Both young men got tattoos while on holiday. Unfortunately the equipment was unsterilised and they contracted HIV. It wasn't long before they'd transmitted HIV to their girlfriends and four young lives were changed forever.

If young people are not informed of their risks of contracting HIV, when they're in unfamiliar surroundings they easily run risks they never expected in Australia. Of the 354 people in NSW diagnosed in 2013, 21% were likely to have been

infected overseas. Usually when people contract HIV in their youth, they might not receive a diagnosis until years later when they start experiencing symptoms. It's estimated that around 60% of all youth with HIV don't know that they're infected. Testing for HIV regularly is faster and easier than ever before, and it's confidential. Identifying when someone has contracted HIV earlier means they can start treatment sooner and reduce their risk of passing on HIV. We need to adapt the messages of Test, Treat and Stay Safe for young people, so this has relevance to them and they know to make HIV/STI testing a regular feature of their routine health screening.

We need to empower ourselves and young people with comprehensive and correct knowledge about HIV through sex education (including same-sex safe sex-ed), affordable health care aimed at the younger demographic, and access to condoms. HIV is not caused by the behaviour of a few reckless individuals. HIV affects us all and we need to start talking about it. We need tvo support each other and start reducing the stigma that is still associated with HIV. Young people need to be informed and empowered, so they know their risk and can do everything possible to look after themselves and their friends.

WHEN ZERO

The benefits of immediate treatment

MEANS ZERO

DAVID CRAWFORD

Treatments Officer, Positive Life NSW

Recently, a guy messaged me with his concerns about a HIV positive friend having sex without condoms. A fairly common situation or scenario you've heard before or might be able to relate to in some way. I pondered his message for some time. What was behind his angst? And, how should I respond?

I ended up sending him a link to the most recent evidence published in the Partners Study which proved Treatment as Prevention (TasP) works. This study is the strongest evidence to date that a HIV positive person on treatment and virally suppressed has no risk of passing on HIV.

Within the Partners Study there were over 58,000 occasions of 'raw' or 'bareback' sex between 548 heterosexual and 340 homosexual couples and not one negative partner contracted HIV from their HIV positive partner who had a UVL. Wait. That means, we're talking about zero HIV transmissions. ZERO.

While eleven of the HIV negative people in the study did acquire HIV, further testing showed these seroconversions came from outside the primary relationship and not

from their regular HIV positive partner. I'm unsure if any of this will give relief to my correspondent, as his concern reflects a broader tension in the community between research and the lived experience. I also suspect there's a level of moral projection within the community about UVL and what this means for people who have regular raw sex.

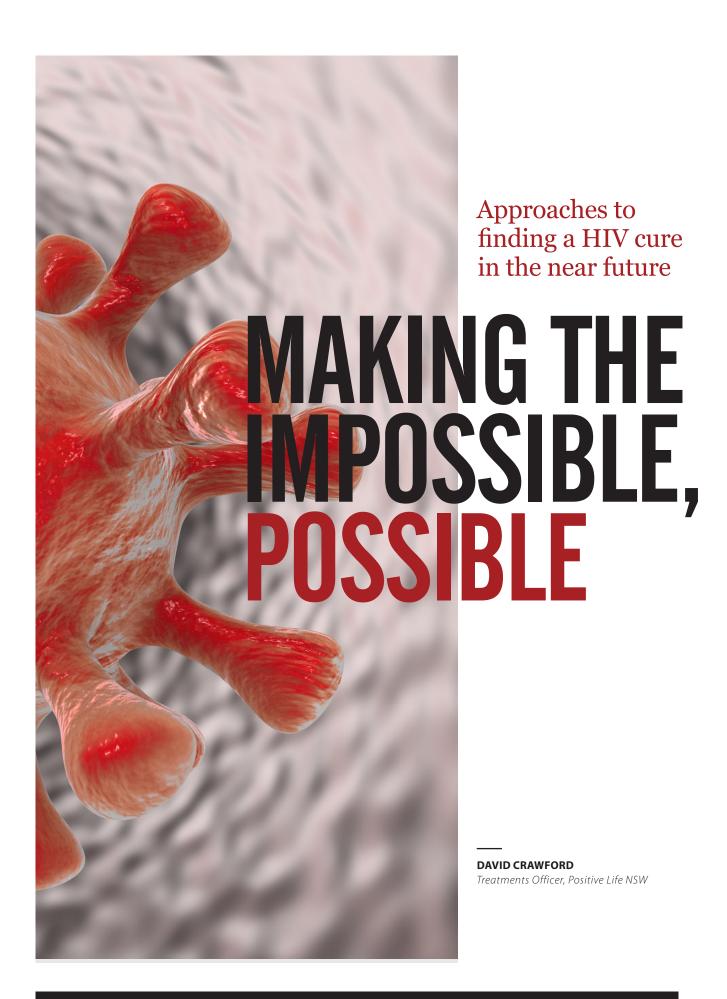
An artefact of statistics is we cannot state zero. Statistics and science is based on probability so despite the evidence of zero, researchers still say they need more evidence. These results challenge those of us who are HIV positive because none of us want to put our partners at risk of HIV. However, as reality and the evidence shows, HIV positive people on treatment with an UVL are not a HIV transmission risk. People living with HIV are doing everything we can to end the transmission of HIV. Condom use, testing and treating for HIV, combined with a number of new tools within the prevention space - pre-exposure prophylaxis (PrEP), post exposure prophylaxis (PEP) and TasP gives us a range of options to end HIV transmission.

When I consider the new freedoms offered by PrEP, we see similar concerns which are somewhat shaped by shame and stigma. Based on the

same science and similar outcomes of the Partners Study, PrEP has been heralded with open arms, yet morality continues to feed similar sex positive hang-ups. Where this becomes different is the law and the criminalisation of people living with HIV. I was hearing my friend (a HIV negative guy) tell a story about sucking the cock of his new sexual interest. The guy told him he was positive with an UVL status, after sex. He said, "he should have told me before he let me suck his cock. It's the law." "True," I responded. "But if you were so concerned about catching HIV from sucking cock why not ask him first?" This example highlights the importance of shared responsibility in this space for both partners; HIV positive and HIV negative.

Even with the new freedoms of TasP and PrEP, sexually transmitted infections (STIs) are still around. As a community we need to be aware the sexual transmission of hepatitis C (HCV) is happening like any other STI. And like any other STI, today's HCV medication means the Hep C virus can be cleared or cured. It's possible to still have sex the way you like, have fun and reduce your risks of getting or passing on HCV or other STIs, and our factsheet 'Sex, drugs and Hep C' offers some practical tips and suggestions how to do this (link below). Of course, it's still possible to pick up Hep C or an STI again after treatment, so getting tested regularly and talking with fuck buddies about your shared risk means we take care of each other.

While living with HIV is far less of a challenge than it used to be, knowing where you stand is more important than ever. The START study proves the sooner people start treatment the better their health in the long run. Everyone benefits, including our partners and fuck buddies. When a 'functional cure' is discovered, and that might not be far off, starting treatment early is a huge boost to anyone living with HIV. The ways we talk about sex and risk with our partners and fuck buddies weighs on all of us equally, regardless of HIV status.



In the search for a cure for HIV, three main approaches are being explored. A vaccine to protect against acquiring HIV at the time of exposure, a functional cure likened to putting the virus into remission and a full cure that completely eradicates HIV from the body. Some of these have been achieved in the 'test tube', monkeys, humanised mice or where safe in human trials. These approaches challenge research to its full capacity by relying on the impressive frontiers of science.

Like a Trojan horse, HIV invades the frontline 'cluster of differentiation 4' (CD4) cells that are part of the 'first responders' of your immune system when HIV first enters your body. HIV rapidly inserts its genetic material in the CD4 cell to turn these cells into 'factories' that churn out more HIV. This hijacking of the CD4 cell makes it challenging to find a vaccine. Without combination antiretroviral therapy (cART), eventually your immune system will collapse, no longer able to control other viruses and bacteria that live naturally within your body. In time, these otherwise usually harmless organisms overrun your body to become opportunistic infections leading to acquired immune deficiency syndrome (AIDS).

From the early time of infection, HIV lives and hides in HIV reservoirs. These reservoirs are in places like your brain and nervous system, the immune system, urogenital tract and gut. cART cannot work on HIV when it is hidden or 'sleeping' in these places. When or why sleeping HIV wakes up to come out from these reservoirs is not fully understood. The challenge is getting all these cells to wake up at the same time so they get back into the bloodstream where cART can work on the virus. It is estimated that it would take up to 60 years for all the virus in these reservoirs to wake up naturally.

Scientists are using an approach called 'shock/kick and kill'. That

terminology sounds pretty aggressive and scary. It's what scientists want to do to the HIV virus, not to you! Drugs have been identified to wake up the virus, but it needs to wake all the HIV in the hidden reservoirs at the same time. So far that remains a challenge. The search is on to find better ways to kick or 'wake up' the entire amount of HIV in your body to let cART do its job, which can eventually lead to the eradication of HIV from the body. Another research approach, called 'bind and gag', (think bondage for viruses!), uses genetic engineering to lock down the virus within the reservoirs leaving the virus harmless.

The 'Berlin Patient', Timothy Ray Brown, cured of HIV through a bone marrow transplant, provides another possible avenue of a functional cure. Brown was lucky that the stars aligned for him when he received a bone marrow transplant from someone who was immune to HIV because they had a natural modification of the CD4 cells and other cells of their immune system. Bone marrow transplants have been repeated on PLHIV, specifically to treat their cancer but so far, with no success to curing them of HIV. Bone marrow transplants are extremely risky, complex and life-threatening procedures. Scientists are using a modified bone marrow transplant procedure where immature cells of the immune system, or stem cells, are harvested from the person with HIV. The stem cells are then genetically modified and injected back into the person. This allows the modified specific cells of the immune system to take hold and eventually replace the old immune system with cells resistant to HIV. Similar to remission from cancer, the person remains HIV positive while still controlling the virus without medication. This approach has been approved by the Food and Drug Administration (FDA) in the

USA as a treatment for HIV.

Another approach being explored is full cure. This uses gene splicing technology called 'clustered regularly interspaced short palindromic repeats' (CRISPR) and is intended to eradicate the HIV virus from your body. The process involves genetically 'snipping' the HIV genetic material from infected cells. So far, the virus has been able to find ways around this approach.

The cure for HIV still remains elusive and we are unsure what this means for us in the immediate future.

The cure for HIV still remains elusive and we are unsure what this means for us in the immediate future. Some of us like PLHIV in the US who have had immune system modification treatment, will be the first in line to explore cure options when they become available. Others will be cautious about participating until there is confidence in the science. How a person will eventually be 'cured' is unclear. We think it will involve one or a combination of these approaches and will be heavily reliant on a modification of the immune system and/or a stimulation of it using a vaccine to eventually cure and eradicate the HIV virus.

So far, the most effective approach we have for managing HIV is cART, which maintains a positive person's health and prevents the onward transmission of the virus when viral suppression has been achieved. While a cure will not reverse any damage that has already occurred to the body as a result of HIV, cART can control HIV and keep a HIV positive person in the best possible position until a cure is found.



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.

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