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STRENGTH: WOMEN LIVING WITH HIV

'I had decided very soon after receiving a positive diagnosis that I would live openly with HIV.'

Cath Smith



MY JOURNEY: HIV UPTAKE EXPERIENCE

Cath Smith

I have been living with HIV since being diagnosed in late April 2008. I had decided very soon after receiving a positive diagnosis that I would live openly with HIV. There were the initial “oh god, I’m going to die” thoughts running through my head, while doctors were saying “oh no you’re not going to die because treatments are great now”. But I knew a few people who were on treatments who looked really bad and I didn’t want to end up looking like I had AIDS. I was adamant I was going to be able to control this nasty virus myself through diet and exercise and so on, and there was no way I was going to take medication that would make me look a certain way. So that was my first experience of stigma, and it was an internal one. Ironically, even if I had wanted to start treatment, I would not have been able to do so in 2008 because the national anti-retroviral treatment guidelines stated that a person’s CD4 count had to be less than 500 and mine was still in a higher healthy range. When I eventually made the decision to start treatment in 2012, these restrictions had been lifted.

Post-diagnosis, I also made some other decisions to benefit my health. I asked myself “what makes me happy?” and the answer was very easy – horse riding and snow skiing. I knew I could do that in the Victorian high country because I had grown up holidaying in that area – I had learnt to swim in the rivers around there and my first job had been as a skiing instructor in the area. At that time, I had also been living with depression and was officially diagnosed with major depressive disorder in my early 30s. I was basically seeking a way to improve my holistic health and wellbeing so I made the decision to move.

Shortly after this time, I started experiencing symptoms of cytomegalovirus which is traditionally considered an AIDS defining illness. My eyeballs felt like they were going to explode out of my head! The symptoms had been going on for about 18 months before I finally listened to my ophthalmologist who said it was related to my HIV, while all the time I had refused to believe it because I had a good CD4 cell count and my viral load was not too high. So it seems like my eyes are the weakness in my immune system – that’s where the virus first targeted and was the main indicator of my sero-conversion illness. Eventually my doctor said to me “look your retinas could detach if this goes untreated”, and that was the wake-up call for me.

I decided to start but the irony was that the bloods taken as the benchmark before me commencing treatment came back with a CD4 count just below 500. I would have had to have started anyway. I commenced anti-retrovirals (ARVs) – my first line were Raltegravir and Truvada in late April 2012. My biggest concerns were any possible interactions with the medications I was taking for my depression. Unfortunately there was an oversight made with prescribing this regime and I needed to take vitamin D to counteract a known side-effect of Raltegravir. Six months later,

with all the stress around commencing ARVs and becoming unemployed during this time as well, I developed immune reconstitution inflammation syndrome (IRS). All my childhood allergies, including asthma, came back – all signs that my immune system was under stress and duress. I was completely fatigued and it got to the point where I could not participate in anything I enjoyed or had relocated to do. I was also clinically depressed and checked myself into a mental health clinic, and it turned out my vitamin D level was a quarter of what it should have been.

Shortly afterwards, I started researching the side-effects of my regime as I was determined to find out what was causing this fatigue, especially when I was getting lactic acidosis in the muscles. Let me tell you, shaking is no good when you’re trying to ski!

My HIV doctor at the time, who I started seeing at a women’s health clinic in the outer eastern suburbs of Melbourne, was practicing at the Melbourne Sexual Health Clinic Green Room as well. I had become a client of the Green Room before treatment uptake anyway, and even after having relocated, it was just easier to come down and see her in the city. Despite travel time and cost, it became a pretty simple process of ringing through to my pharmacist a couple of days before coming down, and asking them to dispense the meds for me. I would arrive to see my doctor and give the pharmacy the new script. It required a little bit of pre-organisation – many people who live in rural and regional areas would understand this.

I changed to another HIV specialist after becoming aware that I was not able to claim any reimbursement for travel costs under the Victorian Transport Assistance Scheme because my HIV doctor was only a GP. Under my new specialist, I changed treatment to Eviplera in late April 2015. This change has made all the difference to my muscle fatigue. I also continue to be reimbursed for petrol too.

My message for other women living with HIV (WHIV) who have not commenced ARVs is “Just Do It!”

Unfortunately, there is no single message as all WHIV are diverse and it’s an individual decision. It’s about a conversation you need to have with your HIV doctor, and they will recommend medications for you to take based on any medical conditions for which you are receiving treatment. Everyone has the ability to do a little bit of research for themselves. We’ve got some great resources out there like ‘the body.com’ and AFAO’s new resource for women, and do a ‘pros’ and ‘cons’ list of known side-effects and that sort of stuff so you are able to contribute to the decision of what treatments you’re going to commence taking.



CATH SMITH

I am ENUF ambassador, board member of Positive Women Victoria, member of Living Positive Victoria and the Positive Speakers Bureau.

INTERNATIONAL WOMEN'S DAY

Autumn Pierce

On International Women's Day (IWD), we commemorate the achievements of all women around the world. The day is historically celebratory in nature and infused with tones of optimism. Each year there is a 'call to action' around a chosen theme. The theme of this year's IWD is 'Pledge for Parity,' a concept that deserves careful consideration.

As an organisation that advocates for the rights of women living with HIV (WHIV), parity – or equality – is at the core of our work. Since Positive Women Victoria's inception in 1988, women have been fighting the good fight by challenging stigma and discrimination loudly and publically.

On IWD we honour not just the courage of the women of the HIV epidemic; we recognise the opportunities their past achievements afford us today. Because of their efforts, we are now well positioned to address the disparities between the lived HIV experiences of women and men at a systemic level. By applying a gendered lens to identify and analyse the similarities and differences in needs and priorities between women and men, we can give them equal weight. But when you start looking at HIV in the broader context of gender equality, the elusiveness of 'parity' suggests the fight is far from over.

In 2014 the World Economic Forum predicted it would take until 2095 to achieve global gender equality, but just one year later, they re-estimated that a slowdown in the already 'glacial pace' of progress meant the gender gap wouldn't close entirely until 2133.¹ Gender equality is a complex systemic issue, but the fact that parity appears to have done an about-face is even more disturbing.

The manifestations of structural inequalities that disadvantage and disenfranchise women and create a gendered social disparity are evident in Australia. Intimate partner violence is the leading contributor to death, disability and ill-health in Australian women aged 15–44. Attitudes towards women are just as startling. One in five young people surveyed by VicHealth believed women often say "no" when they mean "yes," and 21% of the 1,923 people surveyed were prepared to excuse violence against women.² Over 12 months, on average, that translates to the murder of one woman every week by an intimate partner. In addition, one in three women over 15 years of age has experienced physical violence and one in five has experienced sexual violence.³

Even more sobering than these statistics is the fact that it adds to the ever growing body of evidence that suggests the already amended 2133 parity target is overly ambitious.

The key social determinant underpinning the violation of women's rights is gender inequality and we must recognise that the factors contributing to this are interconnected. Violence, discrimination and harassment impact women's ability to engage in paid work.⁴

Earning almost 18% less than men and engaging in casual and part-time work results in less superannuation for women. Violence and financial instability make women more susceptible to homelessness. These factors cannot be addressed in isolation. Doing so ignores the complexity and gravity of gender inequality in the same way the theme 'parity' glosses over the fact that right now we are in crisis.

For WHIV, their status is superimposed on existing disadvantages women experience as a result of their engagement with a gendered social system. The stigma and discrimination that women from Aboriginal, refugee and other culturally and linguistically diverse (CALD) backgrounds experience because of their race is further compounded by their HIV status.

Yet despite all of this – despite existing within a societal framework that systemically disempowers women and even further devalues women with a highly stigmatised virus – WHIV are not identified as a priority population in Australia's 7th National HIV Strategy.

As the national strategy informs research and data collection priorities, the absence of a gender-based focus inevitably results in gaps in our knowledge of women's experiences of living with HIV. It is upon this partially obscured body of knowledge that policies and strategies are based and priority populations are identified, thus perpetuating the cycle.

In honour of the women champions that have come before us, we have a responsibility to continue to fight for the rights of WHIV by challenging the HIV sector to consider the socio-economic drivers of HIV in the broader context of gender equality and women's health and wellbeing. This entails acknowledging the biological, gendered and social disparities between the lived experience of men and women with HIV and tailoring support accordingly; funding the active recruitment of a representative sample of women, including women from CALD backgrounds, for national and international HIV clinical trials and research; aggregating by sex and gender every piece of HIV data and making it available to the wider sector; and ensuring that every stage of HIV policy development makes appropriate considerations for the unique and individual needs of women.

Creating an enabling environment – now wouldn't that be something to celebrate this International Women's Day?



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MODERN HIV PREVENTION: WHAT'S NEXT FOR WOMEN?

At the recent Conference on Retroviruses and Opportunistic Infections (CROI), “what’s next for women?” was the question on the minds of researchers and scientists, after results were released from two trials that looked at one of the most promising new HIV prevention tools of recent time; the long-acting dapivirine vaginal ring, a female-controlled HIV prevention method that could potentially protect women for up to a month at a time. Both the ASPIRE (MTN 020) and the Ring Study (IPM 027) looked at the safety and effectiveness of these women-controlled devices with encouraging and potentially far-reaching results.

Trial results found the ring to be effective in preventing HIV infection among women (27% and 31% protection overall among the roughly 4,500 women enrolled in these two studies). Importantly, adherence to the ring was shown to be a critical element for protection; when excluding two sites with low adherence, protection in ASPIRE increased to 37%. Age was shown to have an important effect on adherence, and consequently protection. For women aged 18-21, ASPIRE demonstrated no protection, while the Ring Study showed only 15% protection. Conversely, for women older than 21 years old, protection increased to 56% for ASPIRE and 38% for the Ring Study.

The vaginal ring is another addition to an existing and varied range of anti-retroviral-based biomedical options in new HIV prevention interventions, including Pre Exposure Prophylaxis (PrEP), vaginal microbicides and male and female condoms. This is a major advance in the field of HIV prevention, especially for women. Offering a variety of effective prevention approaches to suit the needs of diverse populations at different times in their lives is the key to controlling the epidemic. Interventions that address gender-based violence and the socioeconomic needs of young women must also be part of this comprehensive response.

Our focus needs to remain inclusive, involving community mobilisation and leadership at all levels. It must also be broad, encompassing the biomedical, behavioural, and structural components of combination prevention while respecting, protecting, and promoting sexual reproductive health and rights.

It is imperative now that national regulatory bodies such as the Therapeutic Goods Administration (TGA) in Australia move quickly to recognise the opportunity that currently proven PrEP and microbicide vaginal rings offer to reduce HIV infections among women. People will need to understand why PrEP and microbicides are important and how they can help. Practitioners will also need training in prescribing these interventions and supporting patients to ensure effective use. We all have a responsibility to expand access to these life-saving prevention options. It is important to emphasise, however, that neither PrEP nor the microbicide vaginal ring offers protection against Sexually Transmissible Infections (STIs), and they are not contraceptives. At the moment, studies that are looking at multipurpose technologies for women, combining HIV prevention with STI prevention and/or contraception, hold significant promise. With the positive results from ASPIRE and the Ring Study, dual protection vaginal rings might soon become a reality, adding to the only two dual protection methods currently available – male and female condoms.

It is essential to also remember that treatment is prevention. Efforts to help women and men learn their HIV status are essential; once a person knows their status, they can receive treatment if they are infected, or can explore and adopt an effective HIV prevention strategy if they are not. People on treatment are able to control their virus, suppressing their viral load to such a point that their risk of transmission is nearly eliminated.

We must continue to remain vigilant to ensure that effective prevention tools are put in the hands of women, and that leadership actively supports the scale-up and roll-out of combination prevention tools for women. In achieving this, it is vital that women are supported and endorsed as champions of our shared efforts towards a world free of HIV and AIDS.

To read the full article, please visit <http://www.iasociety.org/The-latest/Blog/ArticleID/65/Modern-HIV-prevention-What%E2%80%99s-next-for-women>

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