

Candlelight Memorial in 2017

By Dr Bridget Haire

This is the text of a speech delivered at Canberra's Candlelight Memorial in 2017, an annual event to remember those lost to HIV.

It is 36 years since the first signs of a devastating new epidemic were noted and reported, but that is only one way of noting when HIV or AIDS, as it was then, began. It probably began on a whole series of different days. The day when someone you love told you they had been diagnosed. The day when you asked for a test, the day when you recognised a symptom. The day you received your diagnosis. Maybe for some, it could even be that day that you attended your first AIDS funeral.

I remember the day it all became real to me as vividly as yesterday. My best friend from the cradle sitting opposite me in Fitz café in Brunswick St in 1993. That sudden lurch, that instant reframing of a cold sore that just would not heal, that recognition that her weight loss had nothing to do with fitting back into her old jeans. Then learning about T-cells, not that she had any to speak of, and the whole new world of opportunistic infections. HIV ceased then to be an abstract social and political problem. It was deeply personal.

Gabrielle died on the last day of July 1995, at age 28, and I went on to have a career in HIV.

But this is not the story I want to tell. One of the things in Australia that we rightly celebrate is the way that our communities were organised well before there was any real evidence that AIDS would happen in Australia. Collectives of gay men met and strategized, with the organisations that were to become AIDS councils forming at the time the very first diagnoses occurred in Australia. Similarly, long before HIV had been identified as the viral agent that caused AIDS, our community media were recommending that gay men use condoms for sex. Faced with this looming threat, the shape and scale of which could not be adequately imagined, our communities were prescient, well informed, and strategic. AIDS councils appeared in every jurisdiction, advocating for condom use and for research, and most importantly providing the care that people living with AIDS needed. Our organisations were funded, it was whispered, because governments recognised the amazingly cost-effective health services they provided by marshalling armies of volunteers from our communities to keep people out of hospital and semi-independent for as long as possible and, of course, to have an option to die at home, if they so choose, with 24-hour care.

But these care and support services, and the adoption of condoms in a population that didn't need contraception, were not the only

remarkable social movements that occurred in the early days of AIDS. I think that we sometimes forget the extraordinary activism conducted by people living with AIDS. Now of course we would say people with HIV. But that term 'people living with AIDS' was ground breaking. It symbolised the refusal to accept a diagnosis of HIV or AIDS as a kind of social death that prefigured literal death. 'Social death' is a chilling concept from medieval times where people with life threatening illness become objects of pity or fear, socially defined by their presumed imminent death.ⁱ In medieval societies, this social death was actualised for people with Hansens' disease (leprosy): the banishment of a person showing symptoms of Hansen's disease to a 'leper colony' was marked with the performance funeral rites and mourning of social death for individuals who were cast out of society from that point.ⁱⁱ

Even in the grim years of the early 80s, prior to any antiretroviral drugs, people with HIV and their communities did not accept that diagnosis equalled death – in fact one of the great slogans from those years was ACT UP's 'Silence = Death', a slogan that placed emphasis on social engagement and speaking out. In 1983 a coalition of people with AIDS produced the Denver principles, a deeply moving manifesto that begins with the statement, "we condemn attempts to label us as 'victims,' a term which implies defeat, and we are only

occasionally 'patients,' a term which implies passivity, helplessness, and dependence upon the care of others. We are 'People With AIDS'.ⁱⁱⁱ

The Denver principles went on to make a series of recommendations which included rejection of and activism against discrimination and stigma, the right of all people to healthcare and to the enjoyment of sex and sexuality, responsibilities to not transmit HIV onwards, to be politically active and to die and most importantly to LIVE with dignity.^{iv}

I wonder whether the extraordinary medical advances made with combination antiretrovirals could have happened without the activism of our communities, collaborating with researchers agitating for change, and sometimes taking the rules of drug development into their own hands in instances where it was felt that promising drugs trials were not equitable enough in the access to experimental therapies that they allowed.

Here today I think we are all familiar with the idea that in 1996 everything changed. That's when we first saw access to life saving combination antiretrovirals though taking these drugs back then could be so complex and demanding that just taking your pills each day was practically a full-time job, let alone managing side effects. In the 20 odd years since then, however, we have seen antiretroviral therapy evolve into a regimen that is as simple as it is effective.

There is less community wide recognition of 2011 as another watershed year in HIV, another year when everything changed, in terms of prevention. In late 2010, early 2011, we saw the first results not only of PrEP trials, but also evidence of the preventative efficacy of treatment as prevention – the now accepted fact that a viral load maintained below the level of detection, prevents onward HIV transmission. We don't yet have a vaccine. However we do have a form of prevention that allows positive people to control their own viral loads and a tool negative people can adopt, PrEP, to

dramatically extend prevention approaches.

The response to the new understanding about the efficacy of treatment-as-prevention in Australia was exemplary. The community HIV sector, including the clinician group ASHM successfully changed the approval processes regarding early access to antiretrovirals to ensure that all barriers were removed to early uptake.

The brave new world of HIV prevention is maybe more challenging than the treatment revolution of the 90s. PrEP and treatment as-prevention has some people worried that gay men are now being 'allowed to have unsafe sex', forgetting that new biomedical prevention options offer effective new forms of 'safe sex'. They will not provide perfect protection – nothing is 100 per cent certain, and we all know someone who knows someone who got pregnant taking the pill – but they are highly effective. Also, the role of the community sector is not to 'tell' anyone what they can and can't do. Our role is to stimulate the conversations, promote awareness and understanding and to help foster sex cultures where people can negotiate the HIV prevention strategies that suit them. For some men this will continue to include condoms, for some not, others are likely to make strategic use of different forms of safe sex depending on relationship status and other lifestyle factors. One size doesn't fit all, and now there is increased freedom for the men who have hated using condoms, and whose sexual expression has been constrained by them, to talk about this and find other options. Those for whom condoms are effective, convenient, and sexually acceptable should be supported to continue their use.

Ending HIV together is the challenge that faces us. This is more than just preventing new infections, it means a commitment to ensuring that HIV becomes as stigma free and easy to treat as other chronic diseases. It means staying aware that people who are socially and economically vulnerable may face greater challenges in practicing safe sex, getting HIV and STI tests, and accessing treatment if that is necessary. The health gap between Aboriginal

Australians and non-indigenous Australians is of particular concern, given increasing rates of HIV in Aboriginal Australians. Addressing this issue needs to be everyone's business.

Australia's disinvestment in HIV in our region is also an issue of great concern. At this time, when we should be building the community and health infrastructures to support HIV treatment and prevention, Australia is withdrawing. But no matter how good our responses to preventing new infections are in this country, we need to pay attention to epidemics on our doorsteps.

Finally, within Australia, we need to be very concerned at the increasing devolution of prevention to individual state jurisdictions, as the result looks like differential access to prevention goods depending on what state or territory you live in - a far cry from an integrated national response to HIV that made Australia a world leader.

We have the tools, we have the knowledge and we have the experience to take on the new challenges of ending HIV. The final question is, does the political will exist? Can we stimulate it? The marshaling of political will is, I think, the final piece of the puzzle.

Tonight, we are here to remember, here to grieve, but also here to energise each other. To remember how well we have done over past decades, and to marshal that strength, that community connection, to do more, to get to the end, to put in that effort to ensure that HIV stays on the political agenda until we have reached those goals.

We can do it together.

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ⁱ Wright, Joe. 2013. "Only Your Calamity: The Beginnings of Activism by and for People With AIDS." *American Journal of Public Health* 103 (10):1788-1798. doi: 10.2105/ajph.2013.301381.

ⁱⁱ Wright, Joe. 2013. "Only Your Calamity: The Beginnings of Activism by and for Centre for Infectious Diseases and Microbiology at Westmead Clinical School

People With AIDS." *American Journal of Public Health* 103 (10):1788-1798. doi: 10.2105/ajph.2013.301381.

ⁱⁱⁱ The Denver Principles viewed at <http://www.actupny.org/documents/Denver.html>

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