

AIDS Awareness Week: Do we still need it?

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HIV/AIDS is still confronting to many people. Newly diagnosed HIV-positive people who are shown around the Positive Living Centre in Melbourne for the first time are often taken aback by the glass shards hanging from the ceiling of the dining room with the names of members who have died etched on them.

They have been called “the death shards” and the “Sword of Damocles” hanging over people’s heads because they bring the subject of death into the room. I don’t share these concerns, believing that it is important that we remember people who have gone before us, to allow friends and relatives to see that they are not forgotten with time. I am comforted to see my friend’s names up there – in the same way as I keep photos of the close loved ones I have lost around me in my home – but then again, I have had to deal with a lot of grief and loss during the early years of HIV and to learn to live with it my life.

It is perhaps not surprising that newly diagnosed people don’t want to be confronted by death in an era when HIV treatments are keeping most people well and there is no great likelihood that they will be facing life-threatening situations in the near future or for many years to come. Even more experienced HIV-positive people speak of moving on, re-engaging with society and the workplace, using better HIV care and treatment as a reason to give previous health concerns a back seat. In the HIV sector (AIDS Councils and [PLWHA](#) [1]Person (or People) Living with HIV/AIDS. organisations, in particular) there is talk of positive gay men reclaiming their gay identity and supposedly, leaving their HIV-positive identity (if they ever had one) behind.

I’ve never been sure that an HIV-positive identity really existed for me, or my friends, but I have needed and felt a strong peer affinity with other HIV-positive people since the beginning of the epidemic in the eighties. It has been a helpful support when not everyone understood the feelings of stigma and isolation that having a sensationalised [virus](#) [2]A small infective organism which is incapable of reproducing outside a host cell. like HIV produced in you, because of a seemingly hostile society.

If people are more accepting and understanding of HIV-positive people today, which I feel they generally are, then the need for this peer support is not quite so intense. But I challenge even the most disengaged HIV-positive person, who wants to have nothing to do with HIV organisations, service providers or even, sometimes, other HIV-positive people to deny that being HIV-positive does bring complications into your life. You invariably think about it when you are having regular blood checks or scoffing down pills every day, dealing with treatment side effects and when you have to disclose – to sex partners, to dentists, doctors, friends and eventually, to family and maybe employers.

Changing the climate of fear about HIV/AIDS and the people who have it has involved putting a human face to the virus so that society at large can see that it affects ordinary human beings, who could be their brother, sister, father, mother, neighbour and so on. It has involved keeping a level of visibility and awareness about the virus before a society that for the most part still has little understanding of it or its impact.

Keeping a high level of awareness of HIV is an essential part of preventing others from contracting it. It seems likely to me that one of the causes of the recent rises in HIV infections is that prevention campaigns, in some states, have not been as prevalent or as well-funded as they were earlier in the epidemic.

If gay men, for instance, are making the assumption that having HIV is no longer a death sentence and doesn’t really bring complications into your life, then HIV-positive people should be a part of campaigns to tell others the truth about living with the virus – that, despite the best prognosis given by doctors, there are few of us who live without uncertainty about what it may do to our health, how fast it will introduce a myriad side-effects and complications or change our lives when details of our status are revealed against our will.

Without an awareness of the virus and its impact, governments will cease to put funding into care and support services as well as HIV prevention. HIV is still a complex, medicalised condition even for someone who is newly diagnosed. HIV-positive people require highly skilled doctors and when complications arise, experienced hospital specialists to intervene. Your average GP is not going to be able or want to take on the complexities of prescribing medications and providing care to HIV-positive people if HIV was to be treated as just another chronic illness akin

to asthma or [diabetes](#) [3][[Diabetes mellitus] A disorder in which sugars in the diet cannot be metabolised into energy due to a lack of the enzyme insulin. Late-onset diabetes mellitus may be a long-term side effect of some anti-HIV drugs..

A number of state governments have started to realise lately that they need to put extra resources into assisting high caseload GPs with the complexities of HIV care and to consider ways that these experienced practitioners can help doctors with less experience in say, rural and regional areas. They have also started to plan for the specific care needs of an ageing HIV-population, issues for those needing supports in the home or in nursing homes and to look at better communication between limited numbers of community service providers.

For all the above reasons I think we still need the broader community to focus on HIV/AIDS for one week or at least, for one day of the year. If it's buying a red ribbon or seeing an HIV related story in the media then it's still registering its presence on your radar. For those of us more closely connected, who either have the virus or have lost friends and loved ones to it, ceremonies and rituals that remember those people still have their place, in my opinion.

I have heard a number of HIV-positive people recoil at the thought of attending a World AIDS Day service. People like me are too preoccupied with death and grief, they say: I need to get a life, come down and enjoy myself at one of the numerous parties that a seemingly indifferent commercial gay scene is running in Melbourne and Sydney on World AIDS Day this year.

I know my involvement in such ceremonies is not about a preoccupation with my possible death from AIDS. It is about respect for the memory of those who I have lost. I know it is maybe too long a bow to draw to compare the AIDS epidemic with a war, but for those of us who lived through the eighties and nineties, it felt like a war with hundreds of our friends being cut down by a seemingly relentless enemy every year. If the RSL can bring out thousands of young people to remember lost relatives from wars that happened seventy or more years ago, maybe we can continue to provide a space for those in our community who have lost their loved ones ten or twenty years ago.

People organising World AIDS Day events tend to combine it with the Candlelight Vigil ceremony and the AIDS Memorial Quilt presentations these days. Formerly the Vigil was held in May and often involved a street procession to a venue where remembrance quilts were presented by partners or family members. It has made sense to combine the two but this adds the mention of death into the World AIDS Day proceedings – which some more recently diagnosed HIV-positive people find hard to cope with. Maybe this won't change and maybe AIDS Awareness Week will become less relevant as the years go on in Australia.

I hope there will still be a time when people come together to remember for a few more years. When I think of the HIV/AIDS epidemic raging in so many other countries around the world it will still be a critical global issue for a long time to come.

- [grief and loss](#)
- [World AIDS Day](#)

Links:

[1] <http://www.napwa.org.au/glossary/term/119>

[2] <http://www.napwa.org.au/glossary/term/125>

[3] <http://www.napwa.org.au/glossary/term/95>