

Congress of Older People's Voices from the Margins

This story was documented for the #Embolden2023 *Congress of Older People's Voices from the Margins*. A full report on Congress is available at celebrateageing.com/margins

Congress is an initiative of Celebrate Ageing Ltd. Thankyou to our 2023 Congress Principal Partner, Elder Rights Advocacy and our other partners, the Australian Government Department of Health and Aged Care, Older Person's Advocacy Network (OPAN), Australian Association of Gerontology, ADA Australia, The Older Women's Network NSW, QueerSpace Drummond St and Council on the Ageing.

Living with HIV, by David Menadue

My name is David, I'm 70 years old and some days I feel like I am 86. I eat well and I exercise, but at the end of the day my HIV has made me age much quicker than I would have otherwise. We have great treatments for HIV now, but there are still problems with inflammation that cause some of us to age prematurely. We are more susceptible to things like osteoarthritis, heart disease and renal problems. There is a myth that HIV is 'fixed', but we are ageing prematurely, and so we are concerned about aged care.

People living with HIV were isolated in the 80s and 90s. They didn't want to come out because of the stigma and because it wasn't safe. They could lose everything. The stigma is still real. While we have reduced numbers of new HIV infections in Australia greatly because of new treatments to prevent and treat HIV better, there are still around 500 new infections a year and the number of heterosexuals living with HIV is growing.

Imagine the stigma for a heterosexual person who has HIV!! They face significant physical and psychological issues. It's not familiar terrain for a lot of their communities, as relative numbers of infections are still low. They often find it very difficult to find peers for support and can feel quite isolated.

Around ½ the population of people living with HIV are over the age of 50, and this is when most people get comorbidities.

Some people think all gay men are HIV positive, which is very far from the truth. People remember the Grim Reaper public awareness campaign in the 1980s, that scared the hell out of the Australian population and some people are still scared decades later. For some people that advert is all they know about HIV, and we know it's inaccurate information.

The stigma from service providers is a real problem. The *HIV Futures* research showed that for older HIV positive gay men, the greatest predictor of their self-rated wellbeing is whether they experience stigma and discrimination in services. In other words, the knowledge and attitudes of staff makes a real difference to our wellbeing. We need the aged care workforce to be educated.

Some of the HIV orgs are starting programs for people ageing with HIV. We are trying to broaden awareness of the resources they can use and the peer support groups that are running.

I do a peer support group once a month and there are workshops for people ageing with HIV to focus on looking after your health such as the Positive Self-Management program offered by Living Positive Victoria.

I want us to deal with the stigma of HIV so that people feel stronger in their old age. We had the stigma of HIV in the 80s and 90s and now people are worried about the stigma because they are old and fear what might be awaiting them if they need aged care either in their home or in a facility.

We know that some service providers don't understand HIV and are scared. What matters is that there are simpatico carers. We can't have people who are scared of HIV caring for people who are HIV positive. It's not going to work. We feel the stigma very intensely, because we have been there before, we have lived with it for all our lives.

If you think about community responses to Coronavirus and compare it with HIV, you might see what I mean. People fear Coronavirus. When someone gets Coronavirus, they are isolated and then they are over it. Then they are back in the community, and no one throws a hazard sign at them. They are part of the community again. But when someone is diagnosed with HIV – they can face discrimination, ostracization and feel a great sense of internal stigma that seriously affects their mental health.

There is no doubt there are more enlightened attitudes to HIV now, particularly in the gay community when HIV-negative gay men can use drugs called Pre-Exposure Prophylaxis (PrEP) to protect themselves from HIV transmission. HIV positive people on good HIV treatments cannot pass on the virus to others, as scientists confirm. Needless to say, then we cannot pass HIV onto our carers when we have an undetectable viral load either.

One thing that people can do now is get some basic facts about HIV. The Living Positive webpage has great resources, include basic facts, which takes about five mins to read. The webpage also has resources for people ageing with HIV:

- <https://livingpositivevictoria.org.au/living-with-hiv/what-is-hiv/>
- <https://livingpositivevictoria.org.au/programs-and-services/hiv-and-ageing/>
- <https://napwha.org.au/resource/hiv-and-ageing-in-australia-the-new-frontier/>