

## Older than his years

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I know for a fact that my life has become more complicated as I've progressed into my fifties. I seem to have an everincreasing number of comorbidities to contend with. While I may not be spending the time in hospital I did in the nineties, thanks to [HAART](#) [1]Highly Active AntiRetroviral Therapy ??? aggressive treatment of HIV infection using several different drugs together., I do have just as medicalised a condition now as ever. Excluding my HIV doctors, I consult six different specialists. They advise me on my [diabetes](#) [2][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., risk of cardiovascular disease, early stage kidney disease, risk of eye complications (from diabetes), bone and joint problems and most recently, after a diagnosis of gout, I added a rheumatologist to the list. I have no doubt that all these conditions have some link to HIV and/or its treatments.

With many HIV survivors now aged over 50, we have a situation that is being called a 'mini baby boomer' phenomenon. This older age group now accounts for nearly 30% of the positive population in Australia. When you combine this with the alarming increase in new diagnoses among people over 40 – up almost 70% since 2000 – it all points to a growing vulnerability for those of us growing older with HIV. Some of the research suggests that people in their forties who have lived with HIV for ten years or more have the organ systems of someone in their fifties. This may not present as a particular problem – but if you get into your sixties with advanced ageing and much older organ systems, the potential for life-threatening morbidities and the need for extra medical and even nursing care will likely become a serious issue.

A study presented at this year's CROI conference, for instance, showed that 61% of a [cohort](#) [3]In epidemiology, a group of individuals with some characteristics in common. A cohort study is a special kind of clinical trial which looks at a treatment or treatment strategy in a cohort of people. of HIV positive people over 60 had at least two comorbidities, whereas only 12% of the negative cohort lived with that many conditions.

When I talk about this with my positive peers, many of them point out that we are ageing anyway and should expect some level of extra health complications. Often they will mention someone they know in their sixties who has lived with the virus for twenty years with no complications. Of course many of us are doing well. Why some of us will age more quickly than others is possibly as much to do with genetics as anything else.

### CONFRONTING THE RESEARCH

There is a perception in the community that HIV treatments have 'sorted' HIV or allowed it to be seen as a chronic manageable illness, and that the main toxicities associated with living with it are somehow related to treatments. Research has shown the picture to be much more complicated than that.

Reading the research material on HIV and ageing is quite confronting. For starters, I didn't realise that HIV itself is now widely accepted as an independent predictor of a range of comorbidities.

Here are some of my other research findings:

Even if treatment keeps HIV below the level of detection there are still low levels of virus present. This means that the immune system is always activated. This activation can result in chronic inflammation causing many of the complications associated with ageing.

This has been seen in other autoimmune diseases such as lupus where women with lupus have a high level of [coronary](#) [4]A life-threatening emergency in which the blood supply to the heart is suddenly cut off, causing the heart muscle (myocardium) to die from lack of oxygen. heart disease ([atherosclerosis](#) [5](hardening of the arteries) ??? a disease in which fatty material accumulates on the interior lining of the arteries, causing it to become thicker and less elastic.) caused by chronic inflammation and abnormalities in [cholesterol](#) [6]An essential component of cell membranes and nerve fibre insulation, cholesterol is important for the metabolism and transport of fatty acids and the production of hormones and Vitamin D. Cholesterol is manufactured by the

liver, and is also present in certain foods. High blood cholesterol levels have been linked to heart disease and may be a side effect of some anti-HIV medications. and lipids (as in HIV disease). It will be difficult to find treatments that both boost and suppress immune systems at the same time.<sup>1</sup>

There are four big things that doctors are seeing in positive patients presenting in their practices in the US. These are: cardiovascular disease; non-AIDS malignancies (including cancers such as lung cancer); [liver](#) [7]A large organ, located in the upper right abdomen, which assists in digestion by metabolising carbohydrates, fats and proteins, stores vitamins and minerals, produces amino acids, bile and cholesterol, and removes toxins from the blood. diseases (particularly in those coinfecting with hepatitis C); and kidney disease.

Australian studies show similar trends.

A study at last year's CROI conference showed that the cerebral blood flow in positive people was very similar to that of negative people who were ten to fifteen years older.

This may be one reason we are seeing more people with low-level cognitive impairment.<sup>2</sup>

Another study presented at CROI in 2009 showed that HIV seems to be associated with vascular ageing. The blood vessels in positive people show less ability to dilate which translates to stiffer vessel walls. This is similar to vascular function seen in HIV negative people who were 25 years older and would contribute to higher levels of cardiovascular disease.<sup>3</sup>

People with HIV seem to lose T-cell function faster when they get older. Even if people have reasonably high T-cell counts it seems that they work less well. In one US study, the T-cell patterns of [PLHIV](#) [8]Person (or people) Living with HIV. This term is now preferred over the older PLWHA. with a median age of 56 were consistent with people aged in their late eighties.<sup>4</sup>

People who lived with HIV for about eight to twelve years were fifteen times more likely to be frail under certain measures than their negative contemporaries.

Osteoporosis (including non-traumatic bone fractures) is three times higher in positive people. Inflammation may be the cause as well as some HIV treatments and non HIV related factors such as alcohol use.

What are we to make of these fairly pessimistic findings?

Infectious diseases specialists I spoke with were not completely sure, saying it was too early to make definite claims about the applicability of this research to the broad HIV positive population.

Research is still not clear on what causes the various comorbidities. Is it the virus, treatments, lifestyle factors (such as smoking for some conditions) or a combination of all these? Finding how to prevent or treat these factors is not an easy task.

## ANOTHER KIND OF AIDS CRISIS

Articles have started to appear in the US press referring to 'another kind of AIDS crisis'. Middleaged patients are turning up to practices with ailments that are more typically seen in patients aged 80 or older. And the volume of patients is causing concern, with health planners wondering how the already dysfunctional US health system can cope.

In Australia there is building awareness of the HIV ageing issue, and HIV advocates were able to get the issue included as a priority in the new Sixth National HIV Strategy. How we plan at a government and HIV sector level for the care needs of this 'baby boomer' group is going to be crucial.

Long-time HIV activist Ross Duffin has done a lot of research on this issue, planning for a summit on HIV and ageing to be conducted by NAPWA for the sector in June.

'There is a huge capacity problem particularly facing NSW,' he says. 'HIV patients are already finding it difficult to get in to see their doctors and GP practices specialising in HIV care are closing their books to new clients. HIV GPs are going to be required increasingly to become gerontologists or refer people on, but there is a dearth of such specialists now, particularly those with HIV experience.

'Over the next 15 years the hump of the positive population will be in their fifties and sixties, and increasing numbers will lose their ability to adequately care for themselves and be in need of some sort of in-home care or aged care facility. Who will pay for such services?' he asks.

'Health bureaucrats shrug their shoulders when I have spoken to them, suggesting that people with HIV already have Rolls Royce services in NSW and shouldn't be asking for more.

'These people don't realise that our current services won't be able to cope. When you suggest pilot programs for interventions, we're told to ask the Department of Ageing. They tell us it's the Health Department's AIDS Branch's business,' Ross despairs. 'Passing the buck on funding and planning for the issue won't help anyone,' he says.

## SERVICE GAPS APPEARING

The service providers I talked to around the country seem to be coping with their current workloads but agree that a lot more planning needs to be done to meet future needs.

David Murray from the South Eastern Sydney Illawarra Community Health Team who case manages positive clients in inner Sydney is not currently seeing large numbers of aged clients. He does, however, see the spike that Ross Duffin is talking about coming along the track.

'We try to keep older frail clients in their homes as much as we are able,' he says.

'Of course there may come a time when it is not possible to keep clients with serious physical or mental impairment in their homes. And while there are some HIV specific care facilities in Sydney, such as The Bridge,' he says. 'There is limited capacity.'

David's team can act as advocates to help facilitate access for people to aged care facilities. They consult with nursing home staff around any issues they might have with the management of HIV care needs. The most disadvantaged group would be clients aged 45-65 who require the level of care provided by nursing homes but are too young to meet the age requirements through an ACAT assessment.

'There are exceptions to this for people with disabilities, although aged care facilities are not always the most appropriate option,' he explains.

Many of his older clients are also too young to qualify for government aged care packages to look after them in their homes.

They are managed with a variety of other community supports, such as home care and community care options, which may or may not meet all of their needs. Similarly, the Victorian HIV Consultancy at the Alfred Hospital deals with people with more complex conditions, including older positive people.

Karen Blyth, [Clinical](#) [9]Pertaining to or founded on observation and [9]treatment of participants, as distinguished from theoretical or basic science. Nurse Consultant with the service, finds she is spending an increasing amount of time negotiating with aged care and supported accommodation facilities on behalf of her frailer clients with HIV. This involves educating about transmission risk and infection control, in addition to the importance of ongoing HIV therapy and any specific cultural needs her clients may have.

## MAKING AGED CARE HIV-FRIENDLY

Along with the Victorian AIDS Council (VAC), the Consultancy was recently involved in placing a 64- year-old positive man in a nursing home in an inner Melbourne suburb.

'Tom (not his real name) and those involved in his care were concerned about how his social needs as a gay man would be met in a nursing home,' says Karen.

'We worked with Tom's social worker and his community worker to develop a care plan which was inclusive of his medical and social needs,' she continues.

The plan they devised included input from community volunteers and respite care staff at his treating hospital. Once a suitable nursing home was located, an education program for staff was delivered by Consultancy team members and this has been followed up with regular reviews of Tom and clinical support for staff at the nursing

home.

'I'm only 64 but I'm an old man. The HIV makes me feel old. I've got no one to talk to because the residents sleep all day and have dementia. My mind is still good but I have no conversation. I talk to Lizzi: she's my Community Support Officer from the Victorian AIDS Council. I talk to her about how much I miss sex, touch and intimacy.' –Tom, nursing home resident

Karen has seen an increase in older gay men presenting with new diagnoses of HIV or frailty and multiple complications of HIV and its therapy. Once treatment has been optimised these men may need months of convalescent care before their health is restored.

'It is important to provide adequate supportive care to these individuals in order to maximise their chance of returning to independent living,' she says.

This level of knowledge is invaluable in the care of people with HIV, and the existence of such services is an advantage that we can be thankful for, at least in some states.

That we have AIDS Councils who still continue to provide care and support services is also something we must fight to protect. As the demands of an ageing population become more apparent they could act as trainers of mainstream care providers who will need to become involved if the load on current services is too high. They can also advocate for best practice, ensuring that issues like the cultural acceptability of aged care facilities are dealt with appropriately.

The issue of gay and lesbian ageing is being discussed concurrently in a number of states. Several reports have already produced recommendations for further investigations into possible gay-specific nursing homes or partnerships with aged care providers and the need for training of aged care workers in gay and lesbian sensibilities. These include Ageing Disgracefully, ACON's Gay Lesbian Bisexual and Transgender Ageing Strategy, and My People, Victoria's Matrix Guild report. [56](#)

Queensland University recently funded a research study into older lesbian and gay people's care networks to see if they are more isolated from mainstream supports, such as families, and how culturally sensitive age care providers are in that state. Whether those people who are both gay and HIV positive will benefit from these initiatives is yet to be clear as no government has yet made any funding commitments or even taken up the issue as a priority. Many HIV positive people will not be able to wait for long-term solutions.

## PSYCHOSOCIAL SUPPORT

The psychosocial support needs of an ageing positive population must also be considered. Ross Duffin conducted ten interviews with positive gay men in their fifties and sixties and found social isolation to be a big issue for many.

Many of these men are no longer part of the gay community and are not looking for sexual contacts. They have lost the networks that come with that. The high cost of rents in inner-Sydney has forced some of them out to the Western suburbs and many are finding the friendships and supports they once had harder to maintain. When you add poverty into this equation and the loss of an ability to have much of a social life, the need for peer support groups for these men is evident. It may be about establishing a regular walking group, card nights or subsidised social events. The current drop-in centres are not always the best fit for these people.

'The biggest fear of these guys is the loss of independence that may come with aged care,' Ross explains.

'They are very afraid of the HIV-unfriendly environment they may be forced to live in, that their lifestyles and sexuality will not be accepted. Some even said they would prefer to take their own lives rather than have to endure it.'

Jo Watson, Executive Director of NAPWA, agrees with Ross that specialist training of workers will be a necessary

component of preparing the aged care sector for the coming HIV positive caseload. But she also stresses that aged care is just one of the options that should be available for positive people. She proposes we trial a new model of supported accommodation for positive people. Funded by the Federal government, the model needs to demonstrate the best way to meet the care needs of this group.

'The HIV sector has shown ourselves to be innovative in our approaches in the past and it is time to consider the most appropriate model to meet the emerging need,' says Jo.

## IN CONCLUSION

No one has a comprehensive understanding of HIV and ageing and all its implications. Clearly more research needs to be done in this area. We will be competing with strained resources within the aged care sector in society generally and may struggle to get our issues on the agenda of governments.

Some general conclusions I have drawn out of the conversations I have had researching for this article include:

- The need for a strategy developed between the HIV sector and federal and state governments that recognises premature ageing in people with HIV as an issue which requires attention and resources. Getting the issue on the recently approved National HIV Strategy is a start, but the Implementation Plan that goes with the strategy needs to include specific initiatives – and pilot programs – to plan for the future.
- Advocacy needs to take place so that older people with HIV and advanced care needs can access aged care packages before the current eligibility of 65 years of age. This is to recognise the earlier onset of ageing and morbidity in this group.
- Attention should be given to developing Model of Care guidelines for all older people with HIV (say, after age 50) to allow for yearly neurocognitive screening, DEXA scans for bone-thinning and other signs of ageing morbidities.
- Training packages for staff in aged care facilities need to be developed to sensitise them to the needs of people with HIV as a client group.
- HIV sector agencies should develop specific interventions to help reduce isolation and provide psychosocial support for older PLHIV.

Thanks to Jennifer Stewart from the Education and Resource Centre (HIV Hepatitis C and [STIs](#) [10][Sexually Transmissible (or Transmitted) Infection] Infections spread by the transfer of organisms from person to person during sexual contact. Also called venereal disease (VD) (an older public health term) or sexually transmitted diseases (STDs). ) and Professor Jennifer Hoy at the Alfred Hospital, Melbourne for help with this article.

**If you're concerned about the personal implications of ageing, we recommend the new resource from [AFAO](#) [11]Australian Federation of AIDS Organisations. AFAO is the peak non-government organisation representing Australia's community-based response to HIV/AIDS. AFAO's work includes education, policy, advocacy and international projects.**

It gives commonsense perspectives on coping with the physical and mental changes involved with ageing and some useful tips to try to prevent its early onset. It is available from AIDS Councils and PLHIV groups nationally. You can also read and download it [here](#). [12]

1. [1](#). O'Neal, R. "Aging and HIV: A Conversation with Dr Malcolm John", BETA, Summer/Fall 2009, pp37-39
2. [2](#). Ances, B. et al "Additive effects of aging and HIV serostatus on cerebral blood flow", 16th Conference on Retroviruses and Opportunistic Infections, Montreal, February 2009, Abstract 157
3. [3](#). Van Guilder, G. et al. "HIV-1 infection is associated with accelerated vascular aging", 16th CROI, Abstract 731
4. [4](#). Op cit O'Neal, p38
5. [5](#). Barrett, C. "My People", a project exploring the experiences of Gay, Lesbian, Transgender and Intersex Seniors in aged care services, Matrix Guild in conjunction with Vintage Men Inc, June 2008.

[6](#) Berry, S. "Ageing Disgracefully", acon's healthy glbt ageing strategy 2006- 2009, 2006.

- [ageing with HIV](#)

**Links:**

[1] <http://www.napwa.org.au/glossary/term/96>

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

[3] <http://www.napwa.org.au/glossary/term/477>

[4] <http://www.napwa.org.au/glossary/term/103>

[5] <http://www.napwa.org.au/glossary/term/84>

[6] <http://www.napwa.org.au/glossary/term/88>

[7] <http://www.napwa.org.au/glossary/term/102>

[8] <http://www.napwa.org.au/glossary/term/689>

[9] <http://www.napwa.org.au/glossary/term/475>

[10] <http://www.napwa.org.au/glossary/term/188>

[11] <http://www.napwa.org.au/glossary/term/385>

[12] <http://www.napwa.org.au/resource/ahead-of-time-a-practical-guide-to-growing-older-with-hiv>