

**Reconstructing the public image of HIV 30 years on  
AIDS Council of South Australia  
Annual General Meeting**

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Good afternoon everyone – and thank you for the challenge of this invitation to address you this afternoon.

The topic “reconstructing the public image of HIV, 30 years on”, is a confronting one and thought provoking.

I intend to tackle it wearing two hats – one as the current National President of Alzheimer’s Australia; the other as the former chair of the National Advisory Committee on AIDS – NACAIDS as we were called.

But first let me address two issues in the briefing notes that I received for today.

Firstly that HIV is being increasingly criminalised.

To the best of my knowledge this is incorrect. There have been a handful of cases where people knowingly infected others have been charged. It is hard to disagree with that approach and I certainly don’t. But overall criminal charges are a step of last resort and are quite rare in Australia.

Sex work law reform is being scaled back across the country...

There is a trend towards more regulation of the sex industry and I believe there is some contentious recent legislation under consideration in NSW. But peer-based HIV and STI prevention programs for sex workers remain in place and there are no plans that I am aware of to change this. There would be vigorous opposition if there was.

We can all agree I think that Australia has a good track record as regards to successful education and prevention messages that have resulted in the current low prevalence rates in our country.

But after 30 years it is important to reconstruct and reconsider how to present HIV/AIDS to public opinion and politicians, in Australia and globally.

We have to do this because HIV/AIDS has not gone away. Just the opposite in fact.

New HIV infection rates are rising in Australia – from a low base, to be sure, but still a level of new HIV infections of well over 1000 a year is too high. I believe new figures will be released shortly that will show the caseload has now risen to 1100.

There are currently 22,000 people living with HIV in Australia.

And globally, there are still some 2.3 million new HIV infections, and over 300,000 children each year are born with HIV which could be entirely prevented if their mothers had access to HIV treatments.

Back in 1984, when I was asked to chair NACAIDS I had no idea of the enormity of the task I had taken on. I think few people in the early 80s realised the threat AIDS represented to humankind, even the world health organisation (WHO) admitted that it had underestimated the magnitude of the disease.

In Australia we had to deal with a genuine public health emergency. Bold and radical measures were unavoidable if we were to get on top of the situation.

The times demanded a stark presentation of the realities of HIV/AIDS. What eventually resulted was the Grim Reaper Campaign.

I am aware that is not everyone thinks the 'grim reaper' campaign had positive consequences for societal understanding of HIV and AIDS or the understanding of

gay and bisexual men at the time or indeed afterwards... and even now nearly thirty years on, but you have to remember the situation we were facing when the grim reaper was aired.

In 1986 the head of the AIDS task force David Penington returned from the June AIDS conference in Paris with the news that the risk of AIDS spreading to the heterosexual community had been firmly placed on the international agenda.

He told the federal government that the world medical and scientific opinion was that there was a very real risk of the AIDS virus spreading into the heterosexual community. There was an urgent need for a campaign to shock the Australian public out of their apathy.

We now know a lot more about the HIV virus these days. And that in Australia the homosexual community is most at risk.

But I don't think we would have been as successful as we have been in slowing down the progress of the virus without the grim reaper.

It resulted in substantial funds being allocated to prevention education. Many worthwhile public policy innovations were implemented. Such as needle/syringe exchange programs – in the general community and our prisons...which is why we didn't experience the second wave of the virus into the drug-using community; safe sex programs for sex workers; the lifting on the restrictions of the sales on condoms – for the first time condoms could be advertised and sold at supermarkets; the cooperation of the churches in education programs for children and the general community plus better pastoral care for people living with the virus.

AIDS councils and similar organisations were created and funded ...and most importantly, there was the beginning of a shift in thinking, a more tolerant one, in much of the general community about gay men and women.

Thankfully, as treatments came on line, the atmosphere of crisis dissipated (but the institutions and innovations survived) as things changed, so we had to change the way in which the problem was and is presented to young people. And I will elaborate more on that shortly.

Your challenge in 2012 is:

- To change attitudes to the awareness of the health consequences of HIV.
- To access support of health services for diverse communities that include gay men, lesbians, bisexual, transgender and intersex people.
- To protect the rights of people in these communities.

As I see it, at their best the role of non-government organisations is to be agents of change. Their role is to change attitudes and behaviours so that the quality of life of their stakeholders is improved.

I see my role as president of Alzheimer's Australia in exactly that frame. Our goal is to change the public perception of dementia as a natural part of ageing to one in which people understand that dementia is a chronic disease.

We are determined to lift the stigma of dementia so that individuals are recognised as the person they are and always have been. We don't want people to be defined by their dementia any more than you want individuals identified by HIV and AIDS.

In mid 2011 Alzheimer's Australia launched its fight dementia campaign. It was motivated by years of disappointment about the lack of attention to dementia in health reforms and a devastating 2011 budget in which the current government terminated the dementia initiative.

Our campaign is driven by the positive emotions generated by the stories of people with dementia and their family carers.

We know dementia is the most feared disease after cancer. We want people to engage with us and the human face of dementia.

We did not and still don't have funding for a major advertising campaign so we have enlisted the support of our army of stakeholders and used social media to get our messages out. At low cost we have been able to reach on occasions millions of Australians.

And for the first time in my life I have taken part in a protest march – well I led it – I rather enjoyed it too. We marched on Parliament House, Canberra, to raise awareness among politicians about the realities of living with dementia.

I also joined twitter...what an incredible means of communication it is. It is a valuable marketing tool.

Alzheimer's Australia has secured many of the priorities advocated for in the Fight Dementia Campaign – with one exception, research, that I will come to later.

There is no recipe on how to change attitudes and behaviours in the mix of fear, information and positive emotions generated by story telling.

But the common elements are a focused message, unity of purpose among stakeholders and partnering with other organisations.

It seems to me that our respective organisations not only have a wealth of experience to share but also common interests.

I think we could do much more to work together.

The paper that heather birch produced for Alzheimer's Australia in October 2009, *Dementia, Lesbians and Gay Men* was an important turning point for us...I think it might have been for your organisations, too.

It concentrated on the particular issues that gay and lesbian people experience in accessing aged care services. It also illustrated the many social issues such as homophobic attitudes in some sections of the community which many of you would be aware of.

For all the rhetoric around person centred care, the paper showed that a significant population of people in the LGBTI communities, experience discrimination, invisibility and difficulty in accessing appropriate aged care and more specifically dementia support services.

Its publication gave us the opportunity to conduct seminars on these issues around Australia and in doing so to start building some links between Alzheimer's Australia and organisations that support the LGBTI communities.

We recognise the need within the services we provide to include gay and lesbian groups as well as those living with HIV/AIDS in general, in our approach to social inclusion.

Alzheimer's Australia SA has been leading the way within our organisation in working with the AIDS council of South Australia for over three years now – supporting awareness raising activities, developing new programs to support both health professionals and communities and building relationships and links between LGBTI service providers.

Part of this work has included asking the communities what they need to support themselves and those they care for should dementia occur. This has been a true partnership.

Our work has supported the successful implementation of care packages specifically for the LGBTI communities in this state and furthers the important dialogue about both dementia and ageing in the communities.

It was timely this year, that LGBTI communities were listed by federal Mental Health and Ageing Minister, Mark Butler, as a special needs group in regards to funding provided by the Department of Health and Ageing.

We look forward to the outcome of the process that Minister Butler has put in place to produce a report on aged care reforms and access to services for LGBTI communities.

I think I've said enough to support my view that your interests and those of Alzheimer's Australia intersect. We have made a modest start over the last few years in building a relationship.

So if our respective organisations want to be agents of change in promoting changed attitudes and behaviours, what is it that we can do together? And what is it that we can learn from the other?

I suggest the starting point for both working together and changing attitudes is good information – although of course that is not enough alone.

We now know that many younger people living with HIV are at risk of contracting diseases that are more generally associated with ageing.

A Burnet Institute study released in June this year found that diseases such as cardiovascular disease, heart attacks, strokes, dementia, the early onset of cancers, diabetes and high blood pressure, diseases that are normally associated with ageing, are now being associated with younger people living with HIV.

Similarities between ageing and the course of HIV infection such as profound changes in immunity and host defence, suggest that HIV infection compresses the ageing process, perhaps accelerating co-morbidities and frailty.

The consequence is that some people living with HIV are starting to develop these age-related conditions, much earlier than the general community.

A study presented last year at the 16<sup>th</sup> conference on retroviruses and opportunistic infections by American academy of neurology member Dr Beau Ances, who specialises in HIV associated neurocognitive disorders, showed that HIV infection was equivalent to an approximately 15-20 year increase in brain ageing.

Therefore an HIV positive person who is 55 would have brain health and an immune system comparable to a 65-year-old HIV negative person.

The message seems to be that although medical science has made great advances in the life expectancy of people who are HIV positive, they are also at much higher risk of developing these other serious chronic conditions.

HIV is now the most common cause of dementia in people under the age of 40.

Within two decades it's predicted the numbers of long term HIV survivors in Australia that will develop HIV dementia will double.

As with dementia more generally, HIV dementia progresses in stages. It starts from slight impairments in decision making and performance of activities in daily living, to total dependence in all aspects of personal care.

It's accompanied by changes in behaviours, cognition and movement, including difficulties concentrating and retrieving memories as well as changes in personalities.

While the onset of HIV dementia is varied, the prognosis is poor with systems that struggle to support HIV care and the co-morbidity of dementia presents an additional challenge for many services.

The consequences for the individual, family and friends who support people with HIV and for health care services are dramatic.

For the wider community there are very few services that are age appropriate for younger people with dementia. We know from the report of the Australian Institute of Health and Welfare *Dementia in Australia* released late last month, that there are almost 24,000 people under 65 living with dementia.

As a first step I suggest we might do more to promote the facts and evidence in respect of HIV and dementia with a view to promoting awareness that people with HIV are at risk and there is a need for funded services.

For our part we have committed resources to a publication that highlights HIV and dementia and to promoting the issues it raises through seminars and other means to get the message out that medications alone are not enough.

There are three other ways in which I think we may be able to work constructively together to achieve our respective objectives.

- By exploring the common ground that may exist between us in respect of preventive health strategies.
- By working together in promoting access to age appropriate services for those with younger onset dementia.
- By supporting an increased research effort in respect of dementia.

At Alzheimer's Australia we are working towards a goal of a World Without Dementia, a goal I'm sure you would all support.

Our preventive health strategy is based on the evidence that now exists that lifestyle factors can promote brain health and be protective against dementia.

It reflects the reality, as we see it, that medical interventions to modify the progression of dementia are many years away. The outcome of recent drug trials has been disappointing and we know that the brain is complex and that dementia can result from over 100 causes.

So we want to get the message across that there may be something that people can do to help themselves. There is no guarantee of course that by doing all the right things a person will escape dementia. But what we are suggesting will do no harm and quite likely some good.

We also want to get the message across that dementia develops years before symptoms appear or diagnosis. It is not an older person's problem, it is everybody's problem.

Market research that we commissioned revealed that 50 per cent of Australians are unaware that they maybe able to reduce their risk of dementia. Only a small minority is aware of the link between heart disease and dementia and many fewer still appear to be aware of the links between dementia and diabetes, obesity, alcohol and HIV.

Australia is the first country in the world to have a publicly funded dementia risk reduction program. We launched our new brain health program *your brain matters* late last month as part of dementia awareness week.

We want people, young and old, to embrace this program and take care of their brain just as seriously as they do the rest of their body. It's never too late to begin doing this.

Our brain health messages also apply to other chronic diseases linked with dementia. I must confess that we hadn't thought – until now – through the connections that might be made between promoting brain health and HIV... maybe this is something we could advance together.

Those engaging in unprotected sex need to think not only of the consequences of HIV/AIDS but also realise that while medications may help, there are substantive risks in respect of premature ageing and chronic diseases including dementia.

Let me turn to our common interest in services.

In February 2009 Alzheimer's Australia held a national summit at Parliament House in Canberra with the theme of *not too young for dementia*. We had support at the

summit from the AIDS dementia and HIV psychiatric service in Victoria. And prominent among the presentations was one by a gay couple from Victoria on the issues that they had encountered in the diagnosis of dementia.

The summit communiqué still represents a comprehensive overview of the many issues faced by those with younger onset dementia. But the pressing issue remains, access to age appropriate services.

We remain concerned that the consequence of placing with disability services responsibility for people under 65 will result in poorly funded services for the 24,000 people with dementia under 65.

It remains the case that individuals go to aged care assessment teams for help only to be told to go to disability services for assessment and be referred back again to ACATT by disabilities services.

We are planning meetings next year between younger people with dementia and service providers to present the challenge of developing services for those with younger onset dementia.

I suggest that your stakeholders would also have an interest in those issues. We would be interested in discussing how you might be involved in presenting some of the special issues that confront people with HIV.

We have prioritised dementia research in our advocacy of our Fight Dementia Campaign.

The commitments made by the Federal Government in the 2012 budget to the *Living Longer. Living Better* aged care reform package contained crucial measures to tackle dementia, such as timely diagnosis, making hospitals safer for people with

dementia, the quality of dementia care and linking workers for younger people with dementia.

But there was no commitment to increase dementia research which is grossly underfunded relative to other chronic diseases in terms of its prevalence, disability burden and costs.

We are now seeking \$200m over five years for dementia research in the 2013/14 Federal Budget with the aim of building capacity in dementia research, funding new projects and getting research into practice.

It is investment in research in these ways that has worked for other chronic diseases, such as cancer and heart disease.

But, it is not just up to governments. We all have an interest in a dementia free life. We are hoping to increase community support for the campaign, and I hope that many of you will support us by becoming a dementia champion. If so you can sign up by filling in the cards which are available at the back of the room.

We are cautiously optimistic that community and government funding will provide researchers with the tools they need to reduce the number of people with dementia. If dementia could be delayed by just five years, the number of people with the condition could be reduced by one third by 2050.

This is the objective we have set in working towards a World Without Dementia. I believe it is in all of our interests that dementia research should be prioritised.

The current investment of \$24 million a year through the National Health and Medical Research Council for research is not adequate, and it's certainly not an adequate

investment in relation to the cost to the health system of dementia today of five billion dollars.

The areas for working together that I've identified might perhaps provide a platform for us doing more to help our stakeholders over the coming years.

Acting together in the areas of information, preventive health, services for people with younger onset dementia and research seem to me to be a good foundation to building a closer relationship and I look forward to strengthening our relationship over the coming years.

In our respective areas we have both had successes and failures in promoting changes in attitudes and behaviours.

Alzheimer's Australia's has been effective in changing attitudes through our Fight Dementia Campaign and the strategies we've adopted based on the emotion of empowering people to tell their own stories; this has promoted a better understanding at political and community levels of the issues in dementia.

I do think the public image of HIV, 30 years on, is still benefiting from the pioneering work done all those years ago by NACAIDS and so many other activists to inform the Australian public about HIV and why discrimination is wrong. Not perfect, of course, but the improvements in attitudes continue.

What needs to be done now is communicate the latest scientific advances in HIV prevention and treatment to the general community as well as to most affected communities like gay men.

Australia needs more leadership in that task, particularly from the Commonwealth Government.

Being Sydney based I know that leadership in NSW has been strong, especially from NSW Health Minister Gillian Skinner and from community organisations like ACON.

A new NSW HIV strategy will be released in the next two weeks – I'm told that it's a good document which sets bold, clear targets and timelines for scaling up treatment access and significantly reducing the rate of new HIV infections.

We know how to prevent HIV infection, and how to treat it; to make it a chronic disease rather than a death sentence.

The difference is simply money, and lots of it.

Thanks to anti-retroviral therapy treatments, available from the mid-1990s, in the well-off countries more or less all those who need treatment have access to it. Art has transformed the lives of people living with AIDS.

In the developing world, some six to seven million people are now on HIV treatments but this is only about a third of the number who have HIV and require treatment access.

To increase numbers on treatments more money is needed and money requires political leaders in the developed world to allocate funds that are increasingly hard to come by.

So we need to make this case to our politicians and taxpayers.

And to do this, we have to convey the HIV messages of both hope, and urgent need, in a new way.

In many regions, HIV is still a death sentence if you don't have access to treatments.

The Grim Reaper Campaign worked so well because it was grounded in the then truth and facts of AIDS.

But the truth and facts have changed, at least in Australia so that approach can no longer be credible or believed by young people.

In 1987, we could purchase advertising time on the then three commercial networks (at the same time of the evening) and know we would reach (with editorial support from the ABC) as near as possible every household and viewer in Australia.

In those days, there were few but the big media outlets and they did a great job at getting the message to the market.

Now, the big networks are dinosaurs, newspapers are changing overnight and there is an almost infinite variety of media platforms, blogs, Facebook, Twitter, iPads, smartphones, YouTube and other social networks that young people in particular use to inform themselves about the world.

What worked in 1987 cannot possibly work in 2012...at least in conveying the central messages about HIV.

This multiplicity of media is one of the reasons why the message about HIV has been somewhat lost. We are not talking to those most at risk of HIV infection through the media they consume, or in ways that they believe or respond to.

If they do not hear and see these messages, is it any wonder that HIV rates are rising?

We have to be as subtle and cunning about how we re-present the prevention message as the HIV virus is in infecting young people.

I do not accept the idea that we should "normalise" HIV infection, or simply accept rising rates of HIV infection because treatments are available.

We have gone a long way to reducing stigma and discrimination around HIV/AIDS. More must still be done.

But we must always keep sight of the fact that HIV infection itself brings nothing good – even with treatments, it is a tedious burden for those living with HIV.

To get on top of global HIV, as we can and must, will require tens of billions of dollars and another generation of commitment and sacrifice.

Our goal must not be to adjust to HIV but to eradicate it. But HIV cannot be eradicated if, anywhere in the world including Australia, new infection rates are going up, not down.

If they are properly informed, and given the means to do so, young people generally will do what it takes to prevent themselves from being infected with HIV.

Our challenge is to figure out how to convey these messages for a new generation.

It will take a concerted effort of leadership from both government and the community to do this effectively – but it achievable. I know this from my past experience in tackling HIV/AIDS.

It's time for action.

Thank you.