



# HIV AUSTRALIA

**Mental health and HIV**

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### AFAO's aims are to:

- Advocate on behalf of its members at the Federal level, thereby providing the HIV/AIDS community with a national voice;
- Stop the transmission of HIV by educating the community about HIV/AIDS, especially those whose behaviour may place them at high risk;
- Assist its members to provide material, emotional and social support to people living with HIV/AIDS;
- Develop and formulate policy on HIV/AIDS issues;
- Collect and disseminate information for its members;
- Represent its members at national and international forums; and
- Promote medical, scientific and social research into HIV/AIDS and its effects.

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AFAO is the peak non-government organisation representing Australia's community-based response to the epidemic of HIV/AIDS. AFAO's members are the state and territory AIDS councils, the National Association of People Living with HIV/AIDS, the Australian Injecting and Illicit Drug Users League, Scarlet Alliance and the Anwernekenhe National Alliance.

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Volume 7, No. 4

<b>Australian news</b>	<b>4</b>	<b>Out of sight; out of mind – involuntary admission and treatment of people with mental illness</b>	<b>23</b>
<b>News from the Asia Pacific</b>	<b>5</b>	MÉLANIE ALLARD reports	
<b>International news</b>	<b>6</b>	<b>Stevie’s legacy</b>	<b>25</b>
<b>Migration inquiry: Call for reform</b>	<b>7</b>	ABIGAIL GROVES interviews Stevie Clayton about the last nine years as ACON’s CEO	
LINDA FORBES reports on the inquiry into the migration treatment of disability			
<b>The Counselling Alliance of AIDS Councils (Australia and New Zealand)</b>	<b>8</b>	<b>Reaching out: case study of an HIV Community Health Team</b>	<b>28</b>
SALLY CAMERON provides an update about the recent meeting of AIDS Council Counsellors in Perth		MIKE SMITH showcases the work of a community outreach team	
<b>Mental health reform: more of the same not an option</b>	<b>9</b>	<b>A unique partnership: trial of an HIV/AIDS mental health/drug and alcohol nursing role in a District Nursing Service</b>	<b>30</b>
SEBASTIAN ROSENBERG reflects on the past, present and future of mental health policy in Australia		LIZ CROCK and JUDY FRECKER profile an innovative trial	
<b>Life on the margins: living with mental illness and HIV</b>	<b>12</b>	<b>Traversing through the crisis: key factors affecting an individual’s ability to cope with a positive diagnosis</b>	<b>33</b>
NIKKI WOOLLEY discusses the experience of living with mental illness and HIV		GEORGIA ASH outlines factors that influence coping skills	
<b>HIV/AIDS – mind over matter: a personal account</b>	<b>15</b>	<b>Regional Snapshot: Sri Lanka</b>	<b>36</b>
JAMES MAY recounts his story of dealing with a positive diagnosis		MATTHEW TYNE reports on the response to HIV in Sri Lanka	
<b>Management of HIV and depression in general practice: the Primary Health Care Project on HIV and Depression</b>	<b>18</b>	<b>Review: <i>Pleasure Consuming Medicine: On the Queer Politics of Drugs</i></b>	<b>39</b>
By CHRISTY NEWMAN, LIMIN MAO, SUSAN KIPPAX, DEBORAH SALTMAN and MICHAEL KIDD		JENNIFER POWER reviews Kane Race’s latest book	
<b>What once was old is new again: the re-emergence of HIV-associated dementia</b>	<b>20</b>	<b>Web Watch</b>	<b>40</b>
An examination of HIV-related dementia, and why its occurrence is on the rise		<b>Treatment briefs</b>	<b>41</b>

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# AUSTRALIAN NEWS

## **HIV Futures Six available**

The definitive survey of people living with HIV in Australia is the *HIV Futures* series.

Produced by the Australian Research Centre in Sex, Health and Society at La Trobe University, Melbourne, the *HIV Futures* series provides HIV community organisations, health and funding agencies with detailed information on the experiences of people living with HIV (PLHIV). The *HIV Futures* surveys ask PLHIV about: health issues; use of antiretroviral, complementary and other treatments; issues in accessing information and support services; and housing and financial situations.

The sixth report in the series – *HIV Futures Six* – is out this month, and available at [www.latrobe.edu.au/hiv-futures/](http://www.latrobe.edu.au/hiv-futures/)

## **Suicide prevention – Suicide Prevention Australia report**

Suicide Prevention Australia has released an important new Position Statement in August: *Suicide and self-harm among Gay, Lesbian, Bisexual and Transgender (GLBT) communities*.

The report will be a great resource for policy-makers, researchers and community advocates. Given the current Senate Community Affairs Inquiry into Suicide in Australia ([www.aph.gov.au/Senate/committee/clac\\_ctte/suicide/tor.htm](http://www.aph.gov.au/Senate/committee/clac_ctte/suicide/tor.htm)), the release of this comprehensive report was perfectly timed. The report provides an extensive overview of available research, highlighting the alarmingly high prevalence of severe depression and suicide among GLBT Australians. The report is available at [www.suicidepreventionaust.org](http://www.suicidepreventionaust.org).

## **HIV and gen Y: fact and fiction**

An online survey of young people in NSW indicates that the

recent lack of mainstream community education regarding HIV has allowed myths about transmission of the virus to flourish. ABC Radio's news journalist, Jessica Tapp, reported on 30 November that many survey respondents believed they could acquire HIV by sharing a cup with a positive person or by hugging them. 43 percent believed that the virus can be transmitted by mosquitoes.

Dr Roger Garsia, Chair of the NSW Ministerial Advisory Committee on HIV and STIs, says the Committee is aware that young people are at particular risk. 'The data shows that ... most of the new infections are occurring in people under the age of 40. ... Our job this year's World AIDS Day is to communicate the truth about the real risks of HIV and other STIs to young people,' he said.

## **'HIV is still here': heterosexual awareness-raising**

The Heterosexual HIV/AIDS Service (Pozhet) and Family Planning NSW have together developed a campaign to raise awareness of HIV among young people in the broader community. The campaign includes a video clip on YouTube – 'HIV is still here'. The clip features actors presenting quotes from people of different ages and backgrounds who are living with HIV. The quotes are from *Straightpoz Study: Men and Women living heterosexually with HIV*, a report produced by the National Centre in HIV Epidemiology and Clinical Research.

## **Dementia discussion paper**

Alzheimer's Australia, in association with ACON and the Aged and Community Services Association of NSW and ACT, has produced a discussion paper: *Dementia: Lesbians and Gay Men*. The paper was launched on 19 November by the Hon. Michael Kirby, former Justice of the High Court of Australia.

Glen Rees, CEO of Alzheimer's Australia, says that many GLBT people face additional challenges coupled with the onset of dementia. This includes stigmatisation resulting from estrangement from family, and entrenched social isolation: '... an increased likelihood that gay men and lesbians may experience isolation as they grow older ... in combination with a fear of coming out to service providers, may lead to anxiety and depression,' Mr Rees said.

The discussion paper provides practical advice on the issues faced by lesbians and gay men with dementia and their carers, and will be a valuable resource for policy-makers, researchers, advocates, and health care practitioners. The report is available at [www.alzheimers.org.au](http://www.alzheimers.org.au)

## **Making Links 2009 Conference a success**

'Excellent to meet other community sector colleagues and be inspired. Thanks!' This was just one glowing comment received regarding the 7th annual Making Links conference, held at Melbourne University in November. The conference brings together community sector workers to learn about information and communications technology (ICT).

More than 20 people from AFAO member organisations attended the event, and several AFAO members presented papers on topics including innovative uses of social media and tips for saving time and money. Practical workshops were held on topics including web accessibility and video-blogging. During the event, Making Links ranked as the most popular Twitter topic in Australia. In 2010, Making Links goes west. It will be held 15–17th November at the State Library in Perth.



# NEWS FROM THE ASIA PACIFIC

## Welcome increase to AusAID funding for the Asia Pacific region

The Federal Government has announced that it will provide \$3 million in new funding to curb the transmission of HIV in Indonesia, PNG and Myanmar. The money, to be spent over the next three years on programs focusing on men who have sex with men (MSM), may be modest given the demonstrated need, but the announcement shows that the Australian government is beginning to honour the priority it accorded MSM in the AusAID HIV Strategy launched in April. Given that the authoritative report by the Commission on AIDS in Asia last year indicated that sex between men will contribute to 46 percent of all new infections by 2020, if prevention programs remain unchanged, the announcement is timely.

In welcoming the new funding, AFAO's Executive Director, Don Baxter noted the 'repeated scientific evidence confirming rapidly escalating HIV epidemics among MSM in all the major Asian cities ... Yangon and Bangkok now have more than one in four MSM infected with HIV; Jakarta, Beijing, Ho Chi Minh City have steeply rising rates of infection and AFAO is particularly concerned about Manila and other major cities of the Philippines – with very high rates of risky behaviour creating a time-bomb set to explode.'

## Social networking site for HIV-positive gay men and transgender people living in Asia to be launched in 2010

PositiveVoices.Net, a social networking site for HIV-positive gay men and transgender people in Asia, is set to be launched in mid-2010. The multilingual site is designed to assist positive gay men and MSM to connect with one another and thereby address issues related to isolation. Members will be able to interact and find support. The site is intended to provide a safe haven for HIV-positive gay men and other MSM on the internet.

The initiative, led by Fridae.com – the leading portal for the lesbian, gay, bisexual and transgender people in Asia – will address a need that is largely unmet by existing services. 'The internet gives positive people everywhere a safe way to connect with other like-minded people while maintaining their privacy and anonymity,' explained Dr Stuart Koe, CEO of Fridae.com. 'PositiveVoices.Net has the potential to transform lives simply by allowing positive people to tap into the shared wisdom and communal knowledge on living with HIV. You are no longer alone,' he said.

According to Fridae.com, the number of Asian internet users who are MSM is estimated at around 32 million, with 15 million users in China, over 1 million in Japan and the

Philippines, and 600,000 in Thailand. Given the rising prevalence of HIV across Asia, with gay men and MSM identified as one of populations most at-risk (with rates feared to be much higher for the transgender community), the internet is an ideal tool for prevention and community education programs.

Prevailing stigma and discrimination, coupled with fears of 'losing face,' pose significant barriers for HIV-positive MSM who may otherwise need help. 'HIV care and support is the missing link needed to build better prevention programs as well as better treatment outcomes,' commented Dr Cameron Wolf, Regional HIV/AIDS Technical Advisor, US Agency for International Development (USAID). 'It's so exciting to see the Fridae.com team developing innovative ways to serve the community through PositiveVoices,' he said.

'There is renewed effort to address the needs of gay men, MSM and transgender people in relation to HIV/AIDS throughout the region. PositiveVoices.Net can play a significant role as part of a comprehensive mix of services for this community,' said David Traynor from AFAO's International Program. 'We're hopeful that this will lead to greater self-acceptance and empowerment of PLHIV across the region,' he said.



## Got something to say?

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# INTERNATIONAL NEWS

## Curb rise in injecting drug use: Russia urged

The Eurasian Harm Reduction Network, the International AIDS Society and the International Harm Reduction Association, have called on the Russian Government to expand access to HIV prevention programs for injecting drug users, as a matter of urgency. These programs have averted an estimated 37,000 HIV infections in Russia to date.

Russia has one of the highest rates of per capita injecting drug use in the world – an estimated 1.85 million people (2 percent of the adult population), with around one million people living with HIV, 80 percent of whom are under 30 years. ‘The HIV epidemic amongst drug users in Russia could easily have been avoided’, said Professor Gerry Stimson, Executive Director of the International Harm Reduction Association. ‘Years of government inaction and obstruction have brought us to these staggering numbers. This is nothing short of a public health disgrace,’ he said.

## US to lift HIV travel ban and then host AIDS conference

The United States, currently preparing to lift its travel entry ban on people living with HIV, will host a global AIDS conference for the first time since 1990, in 2012, reports Reuters. ‘The return of the conference to the United States is the result of years of dedicated advocacy to end a misguided policy based on fear, rather than science,’ the International AIDS Society President-elect Elly Katabira said.

US Health and Human Services Secretary Kathleen Sebelius said that the end of the ban was an important shift: ‘It was a policy that tore apart families, kept people from getting tested, forced others to hide their HIV

status and forgo lifesaving medication ... and most of all it didn’t reflect America’s leadership in fighting the disease around the world,’ Ms Sebelius said.

## Alarming levels of stigma in UK

Damning research on the levels of stigma being faced by people with HIV in Britain has led to calls for the government to produce a strategy to tackle discrimination, reports Tracy McVeigh in *The Observer* (29/11/1009).

‘The People Living With HIV Stigma Index’ was the result of a two year research project in the UK. Its findings showed that only 39 percent of people felt confident that their medical records were being kept confidential – with 18 percent saying their HIV status had been revealed without their consent. One in five people with an HIV diagnosis had been harassed or threatened in the past 12 months. Many reported ignorance and prejudice from within the medical profession, particularly from GPs and dentists. One in five reported being denied medical treatment because they had HIV.

On the basis of the research, the UK All-Party Parliamentary Group on HIV and Aids is calling for a cross-departmental government strategy to tackle discrimination. Its chair, David Borrow MP, said: ‘Stigma is rife in Britain ... Discrimination on the grounds of a health condition is totally unacceptable anywhere, but the public sector has a special responsibility to treat everyone it serves with respect.’

## Third of HIV diagnoses in UK still occurring late

A third of new HIV diagnoses in the UK in 2008 were made so late that the people diagnosed had a significant risk of developing an AIDS-defining illness, new figures from the Health Protection Agency (HPA) show, reports Michael Carter at *Aidsmap*.

Overall, there were 7,298 new HIV diagnoses in the UK in 2008, a figure which is comparable to 2007 – with gay men and people of African background continuing to be the focus of the UK’s HIV epidemic. The HPA noted that the high proportion of people who have HIV were diagnosed when their CD4 cell count had already fallen below 200 cells/mm. A total of 2,310 people had a CD4 cell count below this level at the time of their diagnosis in 2008. There were 525 HIV-related deaths in the UK last year, and the cause of these deaths would be late diagnosis of HIV.

## Commonwealth states must repeal discriminatory, anti-gay laws

Civil society groups have called on Commonwealth states to repeal discriminatory legislation left behind from the colonial era, reports Roger Pebody at *Aidsmap*. *The Port of Spain Civil Society Statement*, issued last month, calls on Commonwealth countries to ‘work to actively remove and prevent the establishment of legislation which undermines evidence-based effective HIV prevention, treatment and care ...’. The Statement further calls on member states to ‘legislate anti-discrimination acts in support of people with HIV by 2011.’

The majority of Commonwealth states are in Africa and the Caribbean, the two regions with the highest HIV prevalence in the world. Only six of 53 Commonwealth nations have repealed laws that serve to criminalise gay men and other sexual minorities. Stephen Lewis, the former UN Special Envoy on HIV/AIDS in Africa, notes that change is possible, citing India and Latin American countries recent removal of anti-gay legislation as examples of positive legislative change.

In some states, the situation is deteriorating. The Ugandan parliament is reported to be considering an *Anti-Homosexuality Bill* which would impose the death penalty on HIV-positive gay men who continue to have sex, and criminalise homosexual conduct and any public acknowledgement of the existence of homosexuality.

# Migration inquiry: call for reform

By Linda Forbes

Australia's Joint Standing Committee on Migration is inquiring into the Migration Treatment of Disability. Numerous submissions have been made to the Inquiry (available at <http://www.aph.gov.au/house/committee/mig/disability/subs.htm>), and public hearings have been held around the country. The views expressed in this article are based on AFAO's submissions to the Inquiry.

The granting of most Australian visas – permanent and temporary – is conditional on applicants satisfying the 'health requirement' specified in the Migration Regulations. As part of the health requirement, applicants with a 'disease or condition' are assessed on the potential cost and impact on Australian health and community services. An HIV test is compulsory for most visa applicants over 15 years, and for some children under 15 (eg. for adoptive children). Immediate family members of an applicant must also pass the health requirement. If the applicant or their family member fails the health requirement, the visa is refused.

The emphasis on assessing the potential future costs associated with disability means that people with HIV are effectively destined to fail the Health Requirement because of the cost of antiretrovirals. Although the Health Requirement may be waived in some

situations, the decision-making process is complex and potentially costly. This means that the Health Requirement discriminates against people without the means to obtain legal advice and medical evidence to support their case for waiver. Those most disadvantaged are off-shore applicants for refugee and humanitarian visas – who are subject to the Health Requirement but have no access to waiver unless they have an Australian sponsor. This means that people who are deemed to be refugees, and accepted by Australia, are denied entry if they are found to be HIV-positive.

AFAO proposed to the Inquiry that the Health Requirement be withdrawn. In AFAO's view, the Health Requirement policies operate to entrench the stigmatisation of people living with HIV, and are contrary to the Australia's rhetoric regarding international human rights obligations.

We believe that Australia's complex and targeted migration program, with its range of visa sub-classes, constitutes a fair and reasonable means of selecting migrants on the basis of potential economic and social contribution. The Health Requirement represents a clumsy second tier that results in Australia contravening its stated commitments to the rights of people with disability, and undermines our

credibility as a proponent of the human rights of people with disability.

We feel that the Health Requirement should be amended such that it solely consists of the Public Health Criteria, whereby people with conditions posing a risk to public health (such as active TB), are precluded from entering Australia.

If no other reforms emerge from this Inquiry, at the very least refugees should be exempt from any Health Requirement, with HIV testing of off-shore refugees only taking place after a person has been granted Australian residence and has arrived in Australia. It is unacceptable, to put it mildly, that a person can apply for refugee status and be accepted as part of Australia's refugee program, only to be told that they are unacceptable because they or a member of their family live with disability. Whether that disability is due to HIV, a limb amputation, Down syndrome or blindness, this cherry-picking of 'able' refugees is unconscionable.

Linda Forbes is a Policy Analyst at AFAO.



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## The Counselling Alliance of AIDS Councils (Australia and New Zealand)

By Sally Cameron



Intent on strengthening counselling services, the Alliance also aims to better inform health promotion and policy development as a means to impact Australia's HIV response.

The recent meeting of AIDS Council Counsellors in Perth reflects a push to consolidate the emerging Counselling Alliance of AIDS Councils (the Alliance). Intent on strengthening counselling services, the Alliance also aims to better inform health promotion and policy development as a means to impact Australia's HIV response.

The Alliance is a recent incarnation of the National AIDS Counsellors Association, formed at the 1988 National Conference for HIV/AIDS held in Hobart. Since the Association ceased operating in the late 1990s, AIDS council counsellors have been without structured means to communicate across different agencies: Counsellors are rarely delegates to state and national workshops or conferences, which almost uniformly target researchers, managers, educators or policy types.

The Alliance comprises AIDS Council counsellors from each Australian state

and territory and New Zealand, and aims to bring counsellors together twice each year.

Objectives include:

- **The development of models and innovative practices to provide stronger client outcomes**  
Although supported through AIDS Council's internal management structures, counsellors remain relatively isolated. Some work in small teams in larger agencies but in smaller agencies, counselling is often provided by a single person. The Alliance aims to build expertise while working towards standardised counselling policies, training and professional standards across states and territories. It aims to facilitate counsellors' discussion of their work as a means to develop models of best practice, thereby maximising client outcomes. Cross agency/jurisdictional discussion is a means to alert individual counsellors to issues as they arise in different states/territories and the ways different agencies approach these. A strong network will facilitate coordinated and streamlined investigation, distribution and discussion of new information as it arises, such as approaches to the controversial 'Swiss Statement', or changes to treatments or Medicare eligibility.

*continued on page 42*



# Mental health reform: more of the same not an option

By Sebastian Rosenberg

The first National Mental Health Plan came out in 1993.

Seventeen years on, there has been a palpable failure to improve the penetration of services into the community, and this is both startling and disappointing.

The Council of Australian Governments has now released its fourth National Mental Health Plan. It is a good time to review our progress and plot a course to a better future for mental health in Australia.

And let's face it; the journey to this better future seems as long as ever. Usually around now people start howling about how far we have come and how services are different to 20 years ago, at the time asylums closed.

But just how far have we come? This article canvasses some criteria by which we can make some assessment, and suggests key issues for the future.

## Who is accessing care?

In 1997, the Australian Bureau of Statistics (ABS) indicated that only 38 percent of people with a mental illness received care. This was roughly half the service access allocated to other chronic illnesses. In 2007, ABS data revealed that access to care was now 35 percent – meaning that 65 percent of people with a stated need for mental health care in the past twelve months did not receive any care.<sup>1</sup>

The first National Mental Health Plan came out in 1993. Seventeen years on, there has been a palpable failure to improve the penetration of services into the community, and this is both startling and disappointing.

The ABS did not explore the reasons why people didn't seek help, although it did ask a series of questions about the type of help people might like. The overwhelming response received was that people wanted nothing to do with the mental health service sector. What does this say about how welcoming our services are? Why aren't people knocking down the doors to get in when the unmet demand for care is so clear?

## Accountability

For those who do access mental health care, the critical issue is service accountability.

Although the need for robust systems of accountability and evaluation is well understood, the sad fact is that Australia is largely outcome blind when

*continued overleaf*

it comes to mental health services. We know little about who has a mental illness, what treatments they seek and whether those treatments result in good outcomes, such as return to home or return to employment. This is clearly unacceptable and leaves the mental health sector vulnerable.

Billions of dollars are being spent on mental health, mostly on acute hospital based care, and there is little information to reveal the merit of this spending. There have been many reports over the years, including those of the Mental Health Council of Australia<sup>2</sup> and the report of the Senate Inquiry into Mental Health<sup>3</sup> – all of which have demonstrated the inadequacy of mental health services. These reports have drawn heavily on qualitative data collection and the willingness of thousands of Australians to share their stories of despair and frustration. Such surveys provide powerful insights, but the lack of regularly collated and validated data regarding consumers' and carers' experiences of mental health services means that a strong evidence base is missing.

While many services are able to provide some indication of superficial service-level data in relation to client numbers, few are able to deduce whether what they did made a lick of difference to the life of their patient or client. There has never been much investment in this matter. And so we are outcome blind.

### Comorbidities

A further complication with mental illness is the high correlation between it and other chronic illnesses manifesting as comorbidities.

By 2020, depression is expected to be second only to heart disease as a source of the overall mortality and disability burden of disease around the world.<sup>4</sup> Data indicates that only one in four people have depression alone; on average a person with depression has three other chronic conditions.<sup>5</sup> Nearly 50 percent of asthma patients may also suffer from depression, and depression is twice as prevalent among people with diabetes as it is in the general population.<sup>6</sup> People with depression have an approximately 60 percent greater risk of developing heart disease than people without depression<sup>7</sup> and are more than four times more likely to have a heart attack<sup>8</sup>. Similarly, one in three people who have had a heart attack will also suffer major depression.<sup>9</sup> When people with a mental illness die it is often these other illnesses, poorly treated or undiagnosed, which are the main cause of mortality – so the fact that they lived with severe depression is often not accounted for.

Depression is common among people living with HIV. In an extensive 2006 survey of 982 HIV-positive Australians,<sup>10</sup> 43 percent of respondents said that they had been diagnosed with a mental health condition, with most

of those people having been diagnosed with depression and/or anxiety. The research found that living with HIV can either dominate people's sense of who they are, or be a minor facet of their life and self-image.<sup>11</sup> Recognition of this disparity is important when considering how best to deliver mental health services to people living with HIV. For some, mainstream services are the most appropriate and effective, while the needs of others affected by depression and other mental health conditions will only be met by specialist services targeted to people with HIV.

### National Health and Hospital Reform Commission Report

The Rudd Government was elected on a strong health reform platform, which included threatening the states with a federal takeover of the hospital system unless substantive reforms of the health system are achieved. The National Health and Hospital Reform Commission released its report in June 2009. In addition to making a series of important and welcome recommendations, the Commission also outlined a new approach to the governance of the health system, under which the states and territories would basically retain control of everything that occurs in a hospital, while the Federal Government would control the rest. For mental health, where access to community services is negligible, this has significant implications.

The Federal Government is considering actioning the recommendations of the Reform Commission through the establishment of regional Primary Healthcare Organisations (PHOs), which would be charged with managing non-hospital care. This presents a real opportunity to reduce fragmentation and inequity, while establishing a more responsive, consumer-focused suite of health services. This will see valuable, hospital-based resources

While many services are able to provide some indication of superficial service-level data in relation to client numbers, few are able to deduce whether what they did made a lick of difference to the life of their patient or client.

better targeted to meet the needs of those genuinely requiring acute care, while also reducing acute costs and strengthening community-based care, including prevention and targeting of at risk groups.

The proposed PHOs could also be a disaster for mental health services in Australia, exacerbating the exclusionary, crisis-driven, inefficient and ineffectual merry-go-round of responses that characterise the experience of mental health consumers and their carers in many parts of Australia.

### **Collaborative Community Mental Health Care**

International evidence is that the best mental health care is collaborative care – doctors, nurses, allied health professionals and community support workers operating in a coordinated fashion.<sup>12</sup> At the moment, the mental health sector mirrors the general health system's heavy dependence on individualised fee-for-service medicine. There is little incentive for collaboration under existing arrangements. This can be dangerous, particularly when providing services for people suffering a mental illness as well as another chronic illness.

In the 21st century, mental health services should be readily available in the community. Australia lags well behind other countries in investment in community services, with the bulk of health funding still spent on hospital-based acute care. This is the opposite of early intervention and comes at an unsustainable cost, both to individuals and the broader community. Community outreach mental health teams are struggling to survive in Australia, and services rarely have the resources to provide home visits. It is true that the Federal Government has recently invested heavily in primary care mental health services provided by general practitioners and psychologists,

but there is not yet evidence to indicate if this is delivering collaborative care, and it is unclear who is being treated under these new arrangements and to what outcome.

Another key feature of a responsive mental health system is that the individual needs of the person with a mental illness drive the model of care. While there are clearly clinical and other pathways indicating best practice in mental health care, it is consumers and their carers who should determine the shape and nature of the care that is provided. At present, the mental health system is not designed to meet the needs of the consumer. Instead it revolves around the needs of the traditional providers: state/territory governments and private doctors.

### **Accountability as the driver of reform**

What gets measured gets done. With regard to specific accountability for primary mental health care, emphasis needs to be placed on those measures which can assess their connections to the broader health system, together with measures designed to give a picture of the real impact of primary care services on the lives of people with a mental illness and their carers. There is therefore a requirement to assess the performance of primary mental health care using a mix of health, social and system indicators.

A basic indicator of the effectiveness of community mental health care is patient follow up in the community. Too often, patients are lost in the transition following discharge to the community. A responsive system would measure this and put in place appropriate communication, and programs to promote continuity of care across service settings. Australia does not have systems in place currently to report on this indicator.

Similarly, data is not routinely collected on patient experiences or outcomes for services provided in primary care. Without this information, it is not possible to discern whether the investment made has resulted in the key outcomes sought by people with a mental illness, reduction in symptoms, better health, return to study or work, and so on.

*continued on page 43*

... emphasis needs to be placed on those measures which can assess their connections to the broader health system, together with measures designed to give a picture of the real impact of primary care services on the lives of people with a mental illness and their carers.



# Life on the margins: living with mental illness and HIV

By Nikki Woolley

The emotional impact of an ongoing physical illness such as HIV can itself be profound, leading to depression or anxiety. This mental illness can then worsen or complicate living with HIV.

People severely affected by mental illnesses such as schizophrenia and bipolar disorder who experience severe episodic mental illness, have been identified as a high risk group for HIV/AIDS in Australia<sup>1</sup>, and are among the most marginalised people in our community. There is also a high prevalence of psychiatric disorders among people with HIV.<sup>2</sup> Severe mental illness has also been associated with decreased uptake and adherence to antiretroviral therapy, as well as increased viral levels.<sup>3</sup> A Western Australian study found that the rates of hospitalisation for HIV for people affected by mental illness was three times as high as expected, with that rate increasing to nine times as high for people with psychoses.<sup>4</sup>

The emotional impact of an ongoing physical illness such as HIV can itself be profound, leading to depression or anxiety. This mental illness can then worsen or complicate living with HIV.

Mental illness often emerges in late teens or early twenties – interrupting the process of discovering and building

on sexual identity as well as education and working life. Seventy-five percent of mental health disorders emerge before age 25, peaking in later adolescence and early adulthood.<sup>5</sup>

People with mental illness are a diverse group making up around 20 percent of Australia's population in any given year. With a lower than average socioeconomic status, most are in a long-term relationship, employed and have finished high school.<sup>6</sup> However the sub-group of people with more severe mental illness, such as psychosis, comprise 1–2 percent of the population, with most not in a long-term relationship nor employed.<sup>7</sup>

## Mental illness and sexual health

Like many people living with HIV, people with mental illness can find themselves hugely isolated and uncared for. In a recent SANE Australia survey of people severely affected by mental illness, half had no current close relationship (compared to 15 percent of the general community) and 35 percent had had no sexual contact in

the previous 12 months. One in six had not touched or been touched by another person for more than 12 months.

Yet people with mental illness are, of course, sexual beings and sexual health and intimacy also emerged as areas of concern for many SANE study respondents. Approximately 50 percent had not discussed their sexual health with their doctor or health worker, and 46 percent were not receiving routine health checks.<sup>8</sup>

The group with the greatest opportunity to promote the sexual health of people affected by mental illness is ignoring the issue. Recent UK research has revealed that while 80 percent of the sampled mental health professionals agreed that promoting sexual health was an important part of their role, only 30 percent routinely discussed sexual health issues with service users. This may be partially explained, although not excused, by 14 percent feeling uncomfortable discussing sexual health issues, and 13 percent feeling uncomfortable discussing gay and lesbian issues.

People affected by mental illness generally have much poorer physical health than that of the general population, experiencing heart disease, cancer, diabetes and other conditions at far higher rates. The death rate is two and a half times higher than the general community. This is because of the direct effects of mental illness and its treatment.

During episodes of some mental illnesses, there can be an increased risk of contracting HIV because of impulsivity, high levels of sexual activity and poor skills in negotiating safe sex. Mania during acute phases of bipolar disorder and substance use disorders have been identified as times of greater risk.<sup>9</sup>

The high-risk for HIV infection is established in one 2001 Australian

study of people with chronic mental illness. This study found 20 percent of men and 57 percent of women who had what was described as 'casual sex' in the previous 12 months, never used condoms. The study cited research that people with mental illness were eight times more likely than the general public to have ever injected illicit drugs and had a life-time prevalence of sharing needles of 7.4 percent.<sup>10</sup>

Libido, sexual functioning and relationships more generally can also be greatly affected. People dealing with mental illness and its treatment can experience loss of interest in sex. Women may experience dryness and pain during sex and men may experience difficulty getting or maintaining erections, affecting arousal and orgasm. Emotional withdrawal, decreased confidence and energy levels contribute to sexual health and relationship issues. There may be increased vulnerability to sexual exploitation by others and clients with mental illness may also feel the on-going impact of past sexual, physical or emotional abuse.<sup>11</sup>

When illness and medication may reduce interest in and ability to have sex, there is an inevitable impact on one's sense of self and identity. Weight-gain associated with anti-psychotic medication can lead to a

loss of confidence, which of course makes it harder to meet someone and get into a sexual relationship of some kind. The effect of this on quality of life is significant.

### **Discrimination and social isolation**

Multiple layers of discrimination experienced because of HIV status, sexual identity and mental illness compound the effect on mental and physical health.

Recent research in the UK found that respondents from the general community would find it harder to 'come out' about mental health problems than being gay, having cancer or being bankrupt. It is not hard to understand why as the study also found that respondents were four times more likely to break off a romantic relationship with someone who gets severe depression than with a partner who has a physical disability.

A major effect of discrimination is increased social isolation. Social isolation also contributes to poor physical health outcomes.<sup>12</sup> Social isolation is a known risk factor

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for depression, with rates of other mental and behavioural problems and psychological stress higher among adults who live alone than in those sharing a household with at least one other person.<sup>13</sup>

Research shows that some people affected by mental illness feel discrimination more deeply and internalise the stigma associated with the illness, while others with a strong sense of community can resist the stigma. People who 'self-stigmatise' are more isolated, alienated and socially withdrawn than those who do not internalise the stigma. This social isolation usually involves withdrawal from, and problems with, friendships and family relationships – the potential source of greatest support, as well as social and health services.<sup>14</sup>

### Recommendations

The sexual health of people severely affected by mental illness is all too often ignored. This population has been shown to be at-risk of HIV infection and is worthy of targeted HIV prevention programs. Should this group be prioritised, the best approach will be found through consultation with people with mental illness and mental health professionals. SANE Australia would be interested in assisting with a consultation process such as this.

For those people with severe mental illness and HIV/AIDS, high quality care will sometimes involve intensive access to both mental and physical health services. Psychotropic medications can interfere with the effectiveness of some HIV treatments, so strong relationships across health services must be built to ensure the best possible outcome for the client.<sup>15</sup> The client needs to be part of discussions wherever possible. The importance of good relationships with their GP and

psychiatrist cannot be over-emphasised. A holistic approach to health is highly beneficial and is slowly emerging in the mental health sector through recovery and wellness planning.

Wellness is built on social connectedness, secure sexual and cultural identity, good housing, freedom from violence and meaningful work. Supporting clients with these determinants of health will create a strong foundation for better mental and physical health.

SANE provides information and advice about mental illness to health professionals and the public through our Helpline 1800 18 SANE (7263) and website [www.sane.org](http://www.sane.org). Download free factsheets, research bulletins and podcasts.

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**SANE Australia is a mental health charity working for a better life for people affected by mental illness through education, applied research and campaigning for improved services and attitudes. It runs the only national Freecall Helpline and Helpline Online service about mental illness, which helps thousands of callers every year.**



# HIV/AIDS – mind over matter: a personal account

By James May

Since contracting HIV nine years ago, I have personally found the emotional/psychological impact of the diagnosis the hardest thing to bear ...

While the physical impact of HIV/AIDS is well documented, comparatively little is mentioned about the mental health implications for people living with the virus. Since contracting HIV nine years ago, I have personally found the emotional/psychological impact of the diagnosis the hardest thing to bear, as my physical health has been relatively good, aside from a couple of serious events which I believe were directly related to a mental health collapse, triggered by overwhelming circumstances.

I believe the mental health impact on physical symptoms and disease progression is greatly underestimated, particularly in an ongoing social climate of ignorance and prejudice. An HIV/AIDS diagnosis can be life-altering, a constant source of anxiety and depression – a heavy burden, coupled with the physical and financial complications of living with this condition. There is no quick-fix for these

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deeply entrenched mental health issues which may also stem from childhood trauma, homophobia, poor self image and drug and alcohol abuse.

The diagnosis came as a shock in my mid twenties and was difficult to process at a time when I was emotionally unstable; a heavy drug user with poor self-esteem and very little direction. I was estranged from family and support networks and had few emotional resources to cope with what I saw as a death sentence (I imagine this to be the case for many people diagnosed HIV-positive). At the time, I was living with a partner in inner Sydney and received the news shortly after a major dance party when I fell ill with a seroconversion illness. Still reeling from a cocktail of ecstasy and meth and the subsequent breakdown of the relationship, I found the situation almost impossible to process without sliding into full-blown panic and mental breakdown.

I recall one sleepless night after another, waiting for the illness to dissipate; a debilitating flu with searing chills and relentless night sweats,

grappling with the knowledge I was infected by the partner I lived with. I woke in fear, lost in a black hole, feeling as though the world were closing in, coming to an end. There was no way out, nothing to look forward to. The anxiety and fear were paralysing. I was sure my mind would crack, dealing with the rollercoaster of emotions, crying in the street, walking the city day and night, pleading to wake up from this nightmare, wracked with guilt and shame.

These feelings were reinforced by cynical, unsympathetic physicians tired of handing out HIV diagnoses to young gay men in inner Sydney – tired of trying to get the message out to ‘guys on the party circuit’ – so they interpreted my situation. Coupled with this was the fear and disbelief among friends, judgments and pep-talks. ‘Why weren’t you careful?’, ‘Why did you trust a guy like that?’ Everyone had something to say, barely anything helpful.

I packed up and left Sydney for a whirlwind tour of the States with the words of a friend ringing in my ears; ‘You’ve really blown it this time.’

The next two years were the hardest, mentally and physically. It felt like I had a relentless hangover that wouldn’t go away. Nausea, fatigue, a general feeling of sluggish malaise. Meanwhile, distracting myself with the visual beauty of San Francisco, driving across 27 states to New Orleans in the deep south and New York City in the far east. Running, running, running; trying to forget what happened, see as much of the world as possible before HIV caught up with me.

I returned to Australia to face reality, to have myself checked out and start a new life in another city. I felt mentally and physically wiped out, back where I started, contemplating suicide – something had to give. That’s when I faced a few facts. I was infected with the virus and it wasn’t going away. There was no magic bullet and I couldn’t deal with it on my own. Finally, I began the process of self reflection: what had brought me to this point, what was the best way to move forward, the best way to live with a difficult situation? I engaged with doctors, naturopaths, a variety of healers. I recall one breath worker telling me this was ‘a gift.’ In time, I’d learn to appreciate ‘the lessons it had for me.’ I thought she was out of her mind. I wanted to strangle her, take my money back.

I didn’t leap into medical treatment straight away. My indicators were okay and I wanted to explore the options. After more inner reflection, reading and speaking with various colleagues from all sides of the health spectrum, I decided to begin tackling this healing process – by stabilising my mental health. After a lifetime of upheaval, I was emotionally and

The anxiety and fear were paralysing. I was sure my mind would crack, dealing with the rollercoaster of emotions, crying in the street, walking the city day and night, pleading to wake up from this nightmare, wracked with guilt and shame.

psychologically unwell and realised this had a great deal to do with how poor I felt physically. My body was screaming for me to heal these wounds and a HIV diagnosis was the catalyst I needed.

In my view, the nausea, fatigue and skin conditions that stifled me each day were directly linked to the shame, guilt, anger and fear about living with the virus. The sense of being worthless, unlovable, incensed with friends and family, the gay community – the entire world. Most of the joy had vanished from my existence with the ecstasy and speed and I was a walking ball of toxic emotions.

Those were the early days of my journey with HIV/AIDS – the first time I made the commitment to my health and wellbeing. Tackling mental health issues had a profound impact on my experience in years to follow. Taking responsibility for my emotions improved my quality of life like nothing else. I consciously sought to eradicate any source of negativity, which meant walking away from unhealthy relationships and limiting the use of drugs and alcohol. These changes took monumental effort. I had lived almost thirty years using drugs and alcohol to see me through and every person I knew was a drug user or heavy drinker.

I chose to virtually isolate myself for two years because my life depended on it. I transformed my lifestyle to include a range of therapies, medical and alternative, and sought an array of therapies to resolve toxic emotions, such as natural medicines, yoga and psychotherapy. This became my entire focus for quite a few years, being too drug-affected to work; too afraid,

ashamed and vulnerable to form healthy relations with friends or sexual partners. I felt dead inside until I made the commitment to heal the wounds that made it impossible to connect with anyone or function on any level. At times, the process seemed laborious, overwhelming, futile. I still felt crippled no matter what I did, but my intuition told me to keep going – it had to be done. This challenge had to be faced if I wanted to wipe the slate clean and start again.

Things changed slowly at first. I made a couple of friends, took a short course here and there, some volunteer work. I felt a little more hope each day and this gave me the motivation to push ahead. I felt more clear, calm, confident. My physical health seemed to improve in accordance with my mental health and lifestyle changes, such as better diet and more exercise. The nausea, fatigue, stomach cramps, anxiety and depression dissipated along the way. I showed compassion for myself, for the first time – acknowledging what I'd been through, the obstacles I'd overcome. I gave myself a pat on the back for facing up to HIV/AIDS – a

tremendous challenge that would test the resolve of anyone.

I became a different person with dreams, visions, enthusiasm. I found new ways to enjoy myself, inspire myself, take part in the world. I appreciated life like never before, emerging into another dimension with faith and optimism. The commitment to my mental health brought me to the present where I enjoy a quality of life surpassing that which I had prior to the diagnosis; a diagnosis which I thought would destroy me.

My existence is now more fulfilling and productive on every level – health, work, relationships, creativity. I believe I finally understand the message of HIV/AIDS that my breath worker conveyed all those years ago – to heal myself physically, emotionally and spiritually and make the most of each day.

**James May is a writer of short fiction, theatre and freelance journalism. His work has been published in various magazines and anthologies.**

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# Management of HIV and depression in general practice: the Primary Health Care Project on HIV and Depression

By Christy Newman, Limin Mao, Susan Kippax, Deborah Saltman and Michael Kidd

The data highlights both HIV-positive and HIV-negative homosexually active men as being at high risk of major depression.

## Background

The Primary Health Care Project on HIV and Depression is a study that was conducted over three years to look at issues surrounding HIV and depression in gay men. The study investigated the prevalence, nature, clinical management and self-management of depression among men, particularly homosexually active men, attending high HIV caseload general practice clinics in Sydney, Adelaide and a rural-coastal town in New South Wales.

The study had three broad aims. The first was to describe, measure and compare depression among HIV-positive and HIV-negative gay men. The second was to describe the ways in which depression is managed by general practitioners (GPs) and gay men themselves; and the third was to develop the research capacity and skills of GPs to assess and manage depression among gay men.

The first stage of the study involved conducting interviews with 16 GPs based in three different regions, who

prescribe s100 HIV medications, in order to document their experiences in diagnosing, managing and treating depression, dealing with related issues of HIV, gender, sexuality and drug use, and reflecting on the factors that influence clinical practice.

The second stage involved a combination of patient surveys and GP clinical assessments. 736 men completed surveys while visiting the participating general practices. Over three-quarters self-identified as gay or homosexual and over a third as HIV-positive. At the same visit, their treating GP provided a clinical assessment and treatment history of depression. Data on history of clinical assessment, diagnosis and treatment of depression, as well as HIV management history in the six months prior to the patient survey, were extracted from clinical notes for a selected sub-sample of the men.

Finally, interviews were conducted with 40 self-identified gay men in Sydney and Adelaide who also self-identified as currently experiencing depression when they completed the survey. Of the 40 men, 17 were HIV-positive. These interviews provided first hand accounts of the experience of depression for gay men, including their concepts and beliefs about depression, the precipitating factors and contextual issues that have been associated with depression in their lives, as well as their experiences in the clinical and self-management of depression. In addition, diverse and poignant stories were shared regarding current day experiences in everyday life, gay life and – for some – positive life.

Both the qualitative and quantitative components of the study provide further evidence of the complexity of the associations and linkages between HIV and depression in gay men.

The data highlights both HIV-positive and HIV-negative homosexually active men as being at high risk of major depression. This is likely to be related to

the marginalisation and discrimination routinely experienced by gay men, described in many of the qualitative interviews as ‘not fitting in’.

GPs found that although gay men were willing to talk about sex more openly than heterosexual men that, ‘when it comes to actually looking at how they’re feeling and whether they might be depressed, they’re very blokey, they don’t talk about it’ (SYD-GP4). GPs described characteristics typical of men, both homosexual and heterosexual, such as the use of alcohol and recreational drugs to medicate self depression, and the masking of emotions through excessive time spent working: ‘Sometimes gay men that are high achievers and ... they’ve never had any problems at all in the past ... successful careers, successful relationships and suddenly they hit a brick wall.’ (SYD-GP3)

The patient study validates previous findings that men with HIV are particularly vulnerable to depression. HIV-positive men have the highest rates of major depression in the study, at over 30 percent (compared to 20 percent for non-HIV-positive gay men). However, HIV status is not the sole factor associated with depression.

Rather, socio-economic hardship, interpersonal isolation and personal withdrawal are most significantly and independently associated with major depression in this population of gay men.

It was found that while GPs working in high HIV caseload general practice services in Australia have a heightened awareness for detecting depression in gay men, their capacity to provide ideal levels of clinical support is compromised by an increasing number of complicating factors, such as increasing responsibilities and time pressures, intensive continuing medical education requirements, and co-morbid drug use in their patients.

The GPs interviewed for the study were very much in touch with the effects of the HIV epidemic on the lives of individuals and on the gay community as a whole. GPs had a keen sense of the added burden that HIV could add to the many layers of exclusion already experienced by gay men.

GPs reported that many positive gay men had experienced multiple losses which increased their risk of or the severity of their depression, including

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# What once was old is new again: the re-emergence of HIV-associated dementia

... there have been advances in scientific understanding of the processes and causes of HIV-related dementia. There is a growing body of evidence which indicates that HAART fails to provide complete protection from the development of this condition.

In the days before highly active antiretroviral therapy (HAART), HIV-associated dementia (also known as AIDS dementia) was one of the more terrifying and sinister complications of HIV infection. For many people with HIV and their communities, HIV-associated dementia was a highly visible and personally confronting potential consequence of HIV infection.

HIV-associated dementia diagnoses tended to occur primarily in patients with advanced HIV disease and low CD4 cell counts. In addition, HIV encephalopathy (a clinical diagnosis related to HIV-associated dementia) was (and still is) considered to be an AIDS-defining illness.

The advent of HAART changed the landscape considerably. For some people, treatment with HAART managed to stop, and even reverse, the progressive course of the symptoms of HIV-related dementia. In the

broader community the incidence and prevalence of an incredibly debilitating condition decreased. Eventually, new cases of HIV-related dementia were considered rare events, and many cases were considered treatable through the use of supportive care and HAART.

However, recent years have demonstrated an increase in the incidence of HIV-related dementia. In addition, there have been advances in scientific understanding of the processes and causes of HIV-related dementia. There is a growing body of evidence which indicates that HAART fails to provide complete protection from the development of this condition.

## **HIV-associated neurocognitive disorders (HANDs)**

HIV-associated dementia is a disease which sits at one end of a spectrum of related diseases known as the 'HIV-associated neurocognitive disorders (HANDs).<sup>1</sup>

HAND defines three categories of disorders according to standardised measures of dysfunction:

- Asymptomatic neurocognitive impairment
- Mild neurocognitive disorder
- HIV-associated dementia.<sup>2</sup>

### Asymptomatic neurocognitive impairment

The mildest form of HAND is defined to occur when a mild neurocognitive impairment is detected in two or more different cognitive areas. An important facet of this level of HAND is that an assessment of everyday function does not indicate any functional decline. This form of HAND is characterised by very subtle changes in cognitive functioning, which appear not to interfere in the activities of daily living. However, it's important to note that self-report is not sufficient for diagnosis – neuropsychological testing is required. This is particularly important given that other, external variables (such as emotional state and educational level) can interfere with the results of more cursory, less detailed diagnostic tools.

### Mild neurocognitive disorder

Mild neurocognitive disorder exists on the spectrum between Asymptomatic neurocognitive impairment and HIV-associated dementia. It's defined as mild neurocognitive impairment detected in two or more different cognitive areas, as well as disturbances in daily functioning. As with asymptomatic neurocognitive impairment, comprehensive neuropsychological testing is required to assess the level and extent of cognitive impairment and the effects on function.

### HIV-associated dementia

This is the most severe of the HIV-associated neurological disorders. Compared to asymptomatic neurocognitive disorder, a mild neurocognitive disorder, HIV-associated disorder is defined as a marked neurological impairment detected in two or more cognitive areas as well as a

marked disturbance in daily functioning. In addition, dementia must be rigorously diagnosed. To diagnose HIV-associated dementia, the comprehensive neuropsychological tests applied have a greater focus on dementia assessment.

### What are the causes?

Scientists are yet to gain a complete understanding of how exactly HIV interacts with the brain to cause the HANDs to occur. Since the beginning of the AIDS epidemic, neuroinflammation (inflammation of the brain/nervous system) has been found to be common in HIV patients, and was generally termed HIV encephalitis (HIVE). Furthermore, this neuroinflammation usually increased with the progression of HIV infection, from asymptomatic through to AIDS. Because of this, inflammation was considered to be a possible pathologic mechanism.

However, since the advent of HAART, and the distinct change in the presentation and epidemiology of HAND in HIV infected individuals, the situation is not as simple. Although improved treatment (and outcomes) may have been expected to reduce neuroinflammation, some studies have shown the opposite.<sup>3</sup> These studies showed that even in the presence of treatment, there was a comparable amount of neuroinflammation between

treated individuals and comparable individuals in earlier AIDS cases.

However, there were differences between the two groups – differences largely relating to the places in the brain that were affected by this neuroinflammation. The Pre-HAART cases showed strong involvement of the *basal ganglia*. The *basal ganglia* are associated with a variety of functions including motor control, learning, emotions and cognition. Post-HAART cases showed pronounced inflammation in the hippocampus (which plays an important role in long term memory and spatial navigation) and parts of the temporal cortex (important for auditory processing).

### The similarity between HAND, ageing and neurodegenerative disease

Despite HAART, studies have found evidence of persistent HAND and neurodegenerative disease processes. These same studies also suggested that the development of HAND had commonalities with other degenerative diseases (such as Alzheimer's disease and Parkinson's disease). These commonalities are found in the localisation of some neuropathological

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signs (such as oxidative stress and inflammation) and biomarker changes. In addition, HAND appears to share some features with ageing, such as changes in normal physiology and immunology.

Normal aging and HIV infection and HAND share the deterioration of working memory and cognitive ability, as well as several biological processes. And some studies have shown that HIV infection can increase the rate of neurological change due to ageing (ie. HIV 'ages' the brain faster).<sup>4</sup>

### The effect of treatments, and treating HAND

HAART maintains a significant effect on the incidence of HIV-associated dementia in untreated people with HIV. However, as has been discovered and discussed, HAART cannot prevent the progression of neurocognitive impairment (though there are changes in the nature of the neuropathological processes).<sup>5,6,7</sup>

One of the challenges associated with treating HIV in the brain and nervous system is the presence of the 'blood brain barrier'. Simply put, the brain sits in cerebrospinal fluid (CSF) and the blood brain barrier is the separation of circulating blood from this fluid. Some drugs (including drugs used to treat HIV) are better able to cross this barrier than others, and drugs may work differently in the CSF than they do in the rest of the body. This is a new area for the clinical treatment of HIV, and there is a growing body of research looking at this phenomena and how it affects HIV infection.

One paper, published in 2009, examined 22 clinical trials which

looked at the treatment of the neurological complications of HIV infection (including HIV-associated dementia). Of the 22 trials, 16 were completed, three were active and no longer recruiting and three were still recruiting. Unfortunately, none of the trials examined revealed a treatment option that prevents or reverses neurocognitive impairment or HIV-associated dementia.<sup>8</sup>

However, the paper did discuss an investigation into whether HIV drugs which were more able to get to the brain were associated with a lower CSF HIV viral load. (The CSF HIV viral load is the amount of HIV in the cerebrospinal fluid, as opposed to a normal viral load which looks at the amount of virus in blood plasma). The study concluded that lower brain penetration of antiretroviral drugs allowed for continued HIV replication in the central nervous system with consequently higher CSF viral loads and relatively worse cognitive performance.<sup>9</sup>

Therefore a treatment regimen which was designed in order to get access to the brain may further reduce the risk for people with HIV of eventually developing HIV-associated dementia.

Besides the use of antiretroviral agents, there have been studies looking at the effectiveness of other agents (particularly some psychiatric medications such as monoamine oxidase inhibitors and selective serotonin re-uptake inhibitors) in treating HIV-associated cognitive impairment.<sup>10,11</sup> These studies have shown limited or no benefit; however there is more research being done in this area.

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# Out of sight, out of mind: involuntary admission and treatment of people with mental illness

By Mélanie Allard

In developing the national health reform strategies, the Australian Government has demonstrated its commitment to working in partnership with mental health care providers and community advocates to improve community health and service provision. Australia has appropriately adopted a human rights approach in developing policies geared to enhancing the capacity of people with mental illness to fully realise their potential to participate in work and community life.

But what about the human rights of people who have been involuntarily removed from the community because they are deemed to pose a risk to themselves or to others because of cognitive impairment? Are we sufficiently mindful of the human rights of people detained involuntarily in psychiatric institutions?

Under the UN Convention on the Rights of Persons with Disabilities, any deprivation of liberty of a person with a disability must not be arbitrary. As such, it is crucial that procedural safeguards are in place to protect against the overuse and abuse of involuntary admission and treatment.<sup>1</sup> Involuntary admission and treatment should be a last resort.

Mental health legislation in each Australian state/territory seeks to ensure that involuntary admissions are not arbitrary, and are only made where it has been determined that a person requires care but are unable to give informed consent to entering care because of mental incapacity. Involuntary admissions are restricted

to where a person's behaviour is demonstrably and severely disturbed due to a mental disorder, and where their care, treatment and control is deemed necessary for their own protection from serious harm, or for the protection of others from serious harm. Harm can include physical and financial harm, harm to reputation, and neglect.

Involuntary admission can be an issue for people living with HIV.<sup>2</sup> HIV-related brain impairments can cause cognitive impairment, affective disorders, psychosis and dementia.<sup>3</sup> AIDS Dementia Complex (ADC), caused by infection of the central nervous system, is the most common cause of dementia in people under the age of 40.<sup>4</sup> Although ADC normally occurs in the late stages of HIV infection, it can occur within a few years of contracting the virus.<sup>5</sup> ADC can involve severe depression, personality changes, psychosis and, less commonly, intense excitability (mania).<sup>6</sup>

As the life expectancy for people with HIV increases, so too will the incidence of ADC – yet there are no drugs currently available that can penetrate the brain and adequately treat brain infection.<sup>7</sup> The treatment and care of people involuntarily detained for psychiatric care is a significant issue for people living with HIV, and for partners, family, friends and carers. We need to guard against arbitrary involuntary admissions and ensure that the human rights of people in care are respected.

Unfortunately, the rights of people whom society has seen fit to remove from community life due to mental

disability are given only peripheral attention in the national strategies and the National Mental Health Plan. This omission represents a fundamental oversight that must be addressed.

Whatever reforms are made, it is essential that people living with HIV plan for the possible loss of decision-making capacity. In fact, appointing an enduring guardian to make decisions regarding medical care if decision-making capacity is lost, is good advice for everyone – HIV-positive and negative alike.

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# Stevie's legacy

By Abigail Groves

Stevie Clayton, OAM, left ACON in September, after nine years as Chief Executive Officer of Australia's largest GLBT health organisation. In this interview Stevie shares her thoughts on the future of HIV prevention and LGBT health in Australia.

***HIV Australia: You have been CEO of ACON for nine years. What do you see as your main achievements in this time and ACON's main achievements?***

Stevie Clayton: It's really hard to bring nine years down to just a few dot points but I would have to start with ACON's and the NSW response to the increase in HIV infections in 2003/04. This required amazing analytical work, rapid action, reprioritisation of budget allocations and the strength of all our collaborations. All these things helped to turn the increase around. Without this work it could easily have gone the other way, and that would have been disastrous for all of Australia.

I would also have to include the work we have done in constantly redefining our services to keep them relevant for

the greatest number and range of people with HIV, as the lived experience of HIV has changed for many, and the face of the epidemic itself has changed. We did this despite a lot of criticism, and ended up being the single biggest provider of community-based care and health and wellbeing services to people with HIV in Australia.

Obviously, the move to LGBT health has been a huge achievement which was probably poorly understood by many when it was first proposed, but we now see other like organisations in Australia and overseas following suit. Certainly for ACON the proof that it was the right decision has been born out in the

*continued overleaf*

flat HIV data in NSW, and increasing engagement with health issues more generally by our communities.

Over the last few years we have really built up ACON's role in policy and advocacy work. ACON now puts in submissions to virtually every relevant inquiry in Australia for the LGBT community, people with HIV, drug users and sex workers.

Finally, I think that really important into the future will be the work we have done over the last two years with AFAO and the other AIDS Council (or those who used to be called that) on creating national structures for HIV fundraising through the AIDS Trust of Australia and the National LGBT Health Alliance.

**You refer to a 'move to LGBT health'. What prompted this?**

The concept behind this change was about saying, 'In 1996 along came antiretrovirals and suddenly we had gay men who were not so obviously sick and dying anymore'. HIV moved into a different space in gay men's lives, taking a place alongside jobs and relationships, and violence, and worrying about cancer,

body image, and all of these other things. We realised that if we kept a single focus on HIV we would become irrelevant and not be able to get our message about HIV out to gay men anymore. So we needed to look at the way that we presented all our work.

**How did lesbians, bisexuals and transgender people fit into that equation?**

In both our HIV prevention work with gay men, and our health and wellbeing work with gay men with HIV we had already been pushing the margins into gay men's health for a really long time, simply by taking a holistic approach to health. But we exist within a LGBT community. You can't just isolate one quarter of that community and say 'we are only going to do work that focuses on them'. We started talking about doing much broader health work, tackling the social determinants of health and doing work around violence for instance, or ageing and mental health, and doing it in the population-based health way. We looked at all of the health issues and thought, 'What are the major health issues for our community?' Then we asked, 'What are the health

issues that directly impact on HIV and people with HIV?' We found they were the same issues. So by building those broader health programs we get to do better HIV work.

We have built this whole range of programs so people can now choose to come to ACON because they have got problems in their relationships, or they are experiencing violence or depression or a whole range of issues. You do not have to self-select to come here because you want information about HIV. You are going to get that when you get here anyway, because we actually build HIV education messages into everything that we do. The argument is: the more people accessing us results in more people changing their behaviour, meaning less HIV infections and more people with HIV maximising their health.

**This discussion is timely because the new National Strategies around HIV, hepatitis C, hepatitis B, and Indigenous sexual health are all in the process of being written right now. What do you see as the main issues that people will face over the next five years?**

Obviously, there are a lot of complex issues around how to do HIV prevention work with gay men in re-emerging epidemics. We exist in a world now, in Australia, where it's hard to find a gay man who doesn't know that condoms are going to protect them from HIV – they are making choices to have unprotected sex for a whole range of different reasons. Our task is to a) understand what is going on in their heads, b) be able to design programs that can make a difference in that decision-making process and c) secure funding to be able to run programs as widely as we need to, because it is a really huge issue.

HIV moved into a different space in gay men's lives, taking a place alongside jobs, and relationships, and violence, and worrying about cancer, body image, and all of these other things.

In NSW, one of the biggest problems we have is that HIV has been a non-growth budget for ten years and as all the costs of running an organisation increase, the budget for HIV work has been shrinking. At the same time the population has become more and more geographically dispersed and so, ideally, we need to use mass media like television and radio to reach people. But we can simply never afford to do that with our budget. Our budgets are still based around doing most of our campaigns work by buying advertising in community media and putting posters up in venues, but the community we are trying to reach is not necessarily there anymore.

#### **What about the internet?**

Obviously the internet is a huge area that we all need to be doing more work with. I have some doubts about how useful it is ever going to be for us as a site for interventions – I think that will always be a challenge.

People who are really internet savvy are used to having millions of pop-up advertising screens thrown at them. They know how to filter it, so the risk is that anything that we try to do in that space would quickly become white noise. The question for us is going to be the point of engagement: whether we want to bring the people to us, or whether we are going to go to them.

Rather than trying to force feed people with something they do not want in their space, our energy should be about creating a desire in people to care enough about their health so that they come and seek the information from us.

**It is interesting that you frame health promotion in terms of self-care. I look at gay men and think, who could fetishise their health and style more**

**than gay men? Gay men go to the gym, they shop, and they value their health and wellbeing really highly.**

Do they? I don't know – it's a good question. We do not look at other health issues enough, at other research that's done in the other parts of the health system. And I suspect that if we looked at research about men generally and the way they think about their health we would probably find that gay men are much the same. Men, generally, do not prioritise their health. What often happens in straight relationships is that women look after that stuff. For instance, we have been looking at some research on chlamydia which shows good results when women go in and get checked for chlamydia and then take the treatment home for their husbands, so the husband never has to go in at all. But if you have got two men together, then there is no one who is doing that stuff.

I wonder whether if we paid more attention to that sort of research we would find some clues that it's more about generating a desire for self-care, and getting guys to do more about their health. Yes, there are guys that go out a

lot to particular venues and hang out in gyms, but we also see them taking lots of drugs, taking steroids, taking viagra and crystal and all these things that are actually doing terrible things to their bodies; doing stuff that will maybe make them look good for five years and then age them twice as fast and damage their health in the long term.

**Ageing is an emerging issue, not just for positive men, but for the LGBT community as a whole. What are your thoughts on this, in terms of ACON's work with older people?**

We see ageing as a major area for us in the future. We are planning to do a lot of advocacy work with the State and Federal Governments to try to get them to pay more attention to the needs of our community and to develop some of their own programs around it as well as developing training programs for service providers to try and make mainstream services more welcoming to our communities. All of that is, of

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... we have got a community that has never seen itself as growing old and so hasn't prepared for it ... The larger numbers of people who are going to get there soon will find that a vast majority of the age care providers are not ready for them or do not want them ...



# Reaching out: a case study of an HIV Community Health Team

By Mike Smith

The HIV Community Team is unique for the reason that it can provide comprehensive support for a multiple range of problems. The team has the capability to support clients with complex medical issues and works closely with specialist clinics.

The HIV Community Team is a new and dynamic team set up by the HIV/AIDS and Related Programs (HARP) unit of South Eastern Sydney Illawarra Area Health Service (SESIH).

The team officially began working with people living with HIV/AIDS (PLHIV) from November 2007. The team has been set up with a format that is intended to provide a comprehensive approach to supporting people living with HIV/AIDS in the South Eastern Sydney Illawarra region.

The team is comprised of a Team Manager and Administrator, working alongside two Clinical Nurse Consultants, two Clinical Nurse Specialists, two Social Workers, an Occupational Therapist and a Dietitian. The team has received over 200 referrals to date, and care is classified as short term care, targeted case management, ongoing case management or dietitian clinic.

The HIV Community Team is unique for the reason that it can provide comprehensive support for a multiple range of problems. The team has the capability to support clients with

complex medical issues and works closely with specialist clinics. The specialty clinics include St Vincent's Hospital, Albion St Centre, Sydney Sexual Health, Prince of Wales Hospital, St George Hospital, Port Kembla Sexual Health Clinic and s100 prescribing General Practitioners. The team can provide assistance with medications and complex dressings; assessments and monitoring of physical health; and coordination of care with all involved services. The team will work with inpatient units to facilitate early discharges and the provision of discharge care. This care is primarily lead by the specialist HIV nurses that are employed by the team, and all team members are involved in providing ongoing support with clients' physical health.

In addition to these services, the team has two mental health specialist nurses and has the capacity to provide support with mental health issues. This involves close consultation with mental health agencies and other HIV agencies, as well as private psychiatrists and psychologists. A recovery approach to mental health is negotiated and

encouraged for clients with mental health issues. The team also has the skills and knowledge to provide counselling, drug and alcohol support, dietary assessment and advice and assessments for functioning at home, mobility and other issues.

The team will also advocate for and support clients working with non-government organisations (NGOs) such as The Bobby Goldsmith Foundation and ACON, as well as Centrelink and the Department of Housing.

As a mental health clinician I have always had a strong interest in working with people who are difficult to engage. Clients who present with complex and challenging needs, such as mental health, drug and alcohol homelessness, a criminal history and/or a reluctance to engage with services, present problems for health services. Health care agencies have huge demands on their services and cannot afford time to engage with people who do not keep appointments and have no contact address or phones. Clients such as these often have only minimal contact with a service and will only seek attention when it is absolutely necessary.

The HIV Community Team is 100 percent outreach, and a primary goal has been to identify clients with complex and challenging needs who are HIV-positive. The clinicians on the team work intensively to assess and engage with clients that other health agencies (including HIV clinics and mental health agencies) have difficulty working with.

To work with these clients we have been proactive in developing a profile with both health agencies and non-government agencies. This has resulted in numerous referrals for people who are require antiretroviral treatments, but whose current lifestyle is too chaotic to attempt such treatments. Clients who are referred to us are often socially isolated and physically and mentally unwell. These clients are commonly well known to a variety of

services, but do not engage enough to receive ongoing support and treatment.

As an outreach service, clinicians arrange assessments in an environment and location that is comfortable and convenient for the client. Assessments and appointments are worked out with agencies such as day centres, drop-in centres, housing agencies, the Office of the Protective Commission, etc. With this flexibility it is hoped that a rapport and trust can be established with clients, many of whom are suspicious and untrusting of health services. The choice to work with the team is completely up to the client, so developing this trust is of key importance.

Once a rapport has been established, the difficult task of working towards health and social goals begins. People suffering from a combination of mental health, HIV, drug and alcohol and social issues often find it difficult to make appointments and engage with health care services.

While arrangements not being followed through can be challenging for clinicians on the team, this behaviour is taken into consideration. The team may also have to wait for contact from other agencies or see the client at short notice, generally doing whatever is necessary to engage the client in the most effective way.

I feel strongly that my work as a mental health professional and the work the team is doing has been a success. In the past 18 months the team has been successful with five clients who

health services were finding very difficult to work with. Outcomes have included housing, access to Centrelink entitlements, assessment for and commencement of antiretroviral treatments and assessment and treatment for mental health issues.

These clients have engaged with the HIV Community Team and with other health services and NGOs. The results are encouraging, with marked improvements in physical and mental health, as well as stability in housing and social circumstances. The team is also continuing to work with a number of other clients who require this intensive engagement.

In my role as the Clinical Nurse Consultant with a lead in mental health I am very fortunate to have an opportunity to work with clients that present with such challenging needs. Professionally, the work done with all clients, and the positive outcomes achieved to date, demonstrate the success of the team's current approach. People who are HIV-positive and have complex physical and mental health needs face huge challenges within society. The HIV Community Team will continue to target and work with clients who remain a challenge to all services.

**Mike Smith is a Registered Nurse and Clinical Nurse Consultant for the HIV Community Health Team. He has worked in mental health since 1993.**

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# A unique partnership: trial of an HIV/AIDS mental health/drug and alcohol nursing role in a District Nursing Service

By Liz Crock and Judy Frecker

The RDNS HIV team had long recognised that many PLHIV in their care had mental health issues (including depression, anxiety, bipolar disorder or schizophrenia), cognitive impairment, alcohol/other substance use, and co-infections including hepatitis B/C.

Alcohol and substance use are recognised as the most common co-occurring problems in people with mental illness, and service provision for this group has been characterised by neglect and poor health outcomes.<sup>1</sup> People with dual diagnosis experience multiple barriers in accessing services, including health workers' negative attitudes, systemic and clinical issues.<sup>2</sup> Similar barriers have historically also existed for people living with HIV (PLHIV).<sup>3,4</sup> Consequently, PLHIV who have a mental health problem and/or drug and alcohol issues, face substantial obstacles to quality care.<sup>5</sup>

The Royal District Nursing Service (RDNS) is the largest provider of home nursing and healthcare services in Australia, employing over 1,100 registered nurses and allied health professionals from 21 sites across Melbourne and the Mornington Peninsula. RDNS has had an HIV/AIDS Program since 1986.<sup>6</sup> The HIV team at RDNS consists of three regional-based Clinical Nurse Consultants (CNCs), three

HIV Resource Nurses in areas caring for large numbers of PLHIV and an HIV Liaison Nurse at a public hospital.

The RDNS HIV team had long recognised that many PLHIV in their care had mental health issues (including depression, anxiety, bipolar disorder or schizophrenia), cognitive impairment, alcohol/other substance use, and co-infections including hepatitis B/C. There was therefore a growing need for additional expertise in mental health/drug and alcohol care ('dual diagnosis')\* within the HIV team, to enhance its capacity to provide optimal care for PLHIV in the community.<sup>7</sup>

Problems associated with dual diagnosis include: higher rates of relapse, hospitalisation and use of emergency services; increased cognitive deficits; poorer adherence to treatments; increased criminal offences and likelihood of incarceration; increased anger/violence and increased risk of unemployment, homelessness, suicide and early mortality.<sup>8,9</sup>

These issues are magnified for PLHIV with dual diagnosis, especially those who are homeless and/or isolated. They can have problems accessing and adhering to treatments<sup>10</sup>, leading to further morbidity and higher risk of transmitting HIV if engaged in high risk behaviour. Community nurses are in a position to help PLHIV with dual diagnosis achieve better health outcomes, and engage them in health promotion and prevention activities, but require appropriate professional support, resources and skills to do so effectively. This is recognised in the Victorian Department of Human Services (2007) document *Dual diagnosis: key directions and priorities for service development*<sup>11</sup> and nationally, in the Australian National Comorbidity Initiative<sup>12,13</sup>.

The RDNS HIV/AIDS Program is integrated with the Victorian AIDS Council/Gay Men's Health Centre (VAC/GMHC) HIV Services Program through a Partnership Agreement.<sup>14</sup> This unique partnership entails the RDNS HIV team working with HIV Services at VAC/GMHC in coordinating care for PLHIV within the home and community. The RDNS HIV team also participates in education for VAC/GMHC and this is reciprocated by VAC/GMHC for RDNS.

Prior to the implementation of the HIV/AIDS Mental Health/Drug and Alcohol Nursing Role described here, PLHIV with dual diagnosis cared for by RDNS had limited access to mainstream community-based mental health/drug and alcohol services or hospital outpatient services. The HIV team was often limited to crisis intervention resulting in acute hospital presentations, mainly for assessment. Considering all of the above, in late 2006, the HIV team obtained funding from the Victorian Department of Human Services\*\* for a 12-month project trialling a Mental Health/Drug and Alcohol Clinical Nurse Consultant (MHDA CNC)<sup>†</sup>. The project began in 2007.

Key aims of the HIV MHDA CNC role were:

- To assess clients with a diagnosis of HIV/AIDS and concurrent

mental health and/or drug and alcohol issues. PLHIV without a diagnosed mental health problem were also eligible for the service if RDNS staff or PLHIV themselves identified a need;

- To assist RDNS staff and relevant community workers (such as VAC Community Support Programme [CSP] staff and volunteers) in the areas of mental health, drug and alcohol care and support;
- To deliver education on HIV/AIDS, mental health/drug and alcohol related issues within RDNS and the community;
- To establish better links with community-based mental health and drug and alcohol services;
- To contribute to the evaluation of a model of mental health care at RDNS.

Referrals followed the standard process for the HIV team; that is, self-referral or referral by family, carers, doctors or treating hospitals with the person's consent. All referrals were initially assessed by the HIV team CNCs. This process ensured holistic assessments and appropriate referrals to the MHDA CNC.

### The MHDA CNC role

The MHDA CNC role had three major components, each emphasising capacity-building:

1. Assessment and clinical consultation: Formal mental health/drug and alcohol assessment in the home enhanced RDNS staff's ability to develop holistic care plans and to provide appropriate ongoing community-based care for PLHIV with dual diagnosis. Secondary consultations were conducted for agencies including VAC/GMHC. An outreach service, where the MHDA CNC spent an afternoon each week at the Positive Living Centre (PLC), was commenced. Here clients were reviewed (self-referred or referred by PLC staff), and PLC staff were advised on strategies to help them deal effectively with issues affecting clients' behaviour and interactions with others at the PLC.

2. Education and support: Education was tailored to the needs of RDNS staff caring for PLHIV, and involved formal presentations (as part of the HIV Team's established education programme) and locally-based informal sessions. Support included debriefing, consultation for staff, and joint home visits. The MHDA CNC also provided education to VAC staff and volunteers. Sessions were presented on depression, suicide risk assessment, and general mental health assessment.
3. Developing and maintaining relationships with community-based mental health/drug and alcohol services: The MHDA CNC assisted with referrals to these services. Crisis management plans were developed with specialist mental health/drug and alcohol services to enhance RDNS staff's capacity to work with clients, prevent crises and reduce the need for acute hospital admissions. Primary mental health teams in the community are often unfamiliar with RDNS' role and expertise in HIV/AIDS and fostering closer links and communication pathways aimed to promote more comprehensive care for PLHIV.

An evaluation was carried out by the Research Department at RDNS in collaboration with the HIV team, and results recently published.<sup>15</sup> PLHIV, staff, and external service providers were interviewed about the role and both qualitative and quantitative data analysed. Principal findings included that PLHIV found the service to be effective and empathic; they felt they had enhanced support, relief from feelings of isolation and that the education provided empowered them. Participants commented:

*"It's just made me a little bit more aware that possibly we can be suffering from depression or things like that and not really recognise it as such."*

*continued overleaf*

*“It added to the holistic treatment of someone, of me, it was so important that the mind was also included in all the physical stuff that was actually happening to me”.*<sup>16</sup>

RDNS staff (nurses and social workers) evaluated the role positively, finding the MHDA CNC enhanced their confidence in their own assessment skills, whilst giving them an easily accessible route for consultation or advice.

*“You can actually manage and pre-plan for a lot of the crises if you have all the knowledge and the resources available ...”*<sup>17</sup>

External service providers within the HIV sector felt that the role added value to the existing HIV team at RDNS and collaboration was extremely effective:

*“It’s decreased a lot of the inpatient need for psychiatry and HIV as it’s been dealt with more appropriately in the community.”*

The outreach sessions at the PLC were highly valued:

*“It was through the [MHDA CNCs] input in that situation saying well this is what the client needs and yes it is safe to introduce a volunteer provided it is within these parameters. We can then with confidence put a far less trained person in to assist, because [the MHDA CNC] has made that assessment as to what is appropriate.”*

### Limitations and recommendations

During this 12 month project, the HIV team found that the real value of the MHDA CNC role in clinical practice was underestimated, as data

collection requirements inhibited time available for clinical work. There was also insufficient time to establish links to community services that weren’t already associated with the HIV sector. Since many PLHIV reside far from HIV services, access to local services is crucial.

PLHIV from culturally and linguistically diverse (CALD) communities were difficult to engage in this project due to the short timeframe and fear and stigma related to mental health issues and drug and alcohol use. Those who did engage generally had well-established trust and strong links with the HIV team. People with cognitive impairment who received assistance from the MHDA CNC as part of clinical care were unable to participate in the study itself and its evaluation, due to ethical requirements of informed consent.

Recommendations of this project included that the role be further developed and established as a permanent element of the HIV team. It was also recommended that the educational role be expanded and resources be provided to enable further investigation into long term outcomes for clients, to appraise the effect of the role on referral systems and care options with external mental health drug and alcohol services, including organisations for people from CALD backgrounds.

In January 2008, the project report was submitted to the Department of Human Services. There is no ongoing funding to date and the role has been discontinued. However, we remain

committed to establishing the MHDA CNC role within the RDNS HIV team and to implementing and building upon the project’s recommendations, with a view to promoting ‘best practice’ care for PLHIV with dual diagnoses.

### Endnotes

- \* The authors recognise that for PLHIV, the term ‘dual diagnosis’ over-simplifies their issues and over-medicalises them. However, it is used throughout this article because it is commonly used within the mental health/drug and alcohol sectors and in the relevant literature.
- \*\* The Victorian Department of Human Services is now known as the Department of Health.
- † Funding was provided through the Victorian Department of Human Services Metropolitan Health and Aged Care Services HIV Community Grants. RDNS provided additional funds for the evaluation.

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... many PLHIV in their care had mental health issues (including depression, anxiety, bipolar disorder or schizophrenia), cognitive impairment, alcohol/other substance use, and co-infections including hepatitis B/C.



# Traversing through the crisis: key factors affecting an individual's ability to cope with a positive diagnosis

By Georgia Ash

... what differentiates a person's ability to cope with a diagnosis of HIV, a chronic disease, which ultimately requires long-term medication and medical management and a definitive change in lifestyle.

Clients often come to therapy in times of crisis. Having never contemplated their life would lead in a particular direction, they are often shocked, numbed, distressed and vulnerable when they enter our rooms. A diagnosis of HIV represents such a crisis for many people. It is often a time of turmoil and uncertainty, however it is clear that not all clients respond to their diagnosis in the same manner. Indeed, the vast majority of people diagnosed with HIV receive only brief pre- and post-test counselling and others none at all. Some people choose the path of substances, alcohol or other self destructive pursuits to cope, or avoid health professionals entirely, remaining in a state of denial and only presenting when their physical health deteriorates. This is the central thesis of this article: what differentiates a person's ability to cope with a diagnosis of HIV, a chronic disease, which ultimately requires long-term medication and medical management and a definitive change in lifestyle.

A considerable amount of research has been conducted on the psychosocial variables associated with adjusting and coping to a diagnosis of a chronic condition such as HIV. A few characteristics known to be associated with a more positive coping style are a good support network, self efficacy in relation to one's own health, acceptance, the use of humour and the attachment we formed with our parents/caregivers in infancy.<sup>1</sup> Conversely, an acopic style of functioning, including the use of denial, avoidance, social isolation, and a history of poor attachment in childhood, has been demonstrated to be indicators of poor adjustment and coping in the face of a chronic stressor.<sup>2</sup> Focusing on the characteristics of what we know anecdotally and empirically to be associated with positive adjustment and living with a diagnosis of HIV,

*continued overleaf*

this article will discuss two pivotal protective factors; attachment style and social support in the lives of HIV-positive people.

Firstly, the influence of social support on a person's ability to adjust and live with a diagnosis of HIV is significant. Indeed, it has been posited that the concept of social support is so influential that the mere perception of support being available can buffer the effects of stress as much as actual social support.<sup>3</sup>

A number of studies have demonstrated that the sense of belonging, acceptance and support people experience, whether to their community, school, work, cultural group, family or social network, places them in good stead to manage and even circumvent the many life stressors they encounter.<sup>4</sup> However, not all social support is useful, and the quality of the social *milieu* that a person participates in is also a determinant of how beneficial and buffering the effects of a social network are. For example, research has demonstrated that social networks associated with substance use and sexual risk taking are deleterious to health and provide support for a continuation of risky behaviour, similar to the effects of an absence of social support.<sup>5</sup>

Generally speaking, social support and secure relations with others assists us by increasing our positive mood

state and, conversely, lessen mood disturbance.<sup>6</sup> This has particular implications for people living with HIV, as studies have indicated that better health outcomes and greater survival rates have been found in individuals who are more connected to others in the context of their illness.<sup>7</sup> Clearly there are many factors that influence our ability to relate to others in an effective meaningful manner. Impediments such as time constraints, mobility, accessibility, environmental factors, personality type and financial considerations all contribute to our socialisation. However after controlling for these variables it remains apparent that another prominent and highly pervasive factor exerts an influence on our ability to connect and form relationships with others. This factor, referred to as attachment, is an important contributing aspect to a person's ability to adjust, to be resilient in the face of stress and to achieve throughout their life.

Attachment refers to a person's early experience of relating to significant others, such as parents and/or primary caregivers during their infancy, and has consistently demonstrated robust links to functionality in later life.<sup>8,9</sup> Essentially, attachment can be conceptualised into two broad categories; secure and insecure, and it is posited that the quality of these attachments formed in infancy, provide the template and working models for

all future relationships throughout our life.

A secure attachment occurs when the primary caregiver/s are emotionally and physically available to cater to the infant's needs. This security fosters the development of, and confidence to, venture forth and explore the world, secure in the knowledge that their caregiver/s will be available on their return. Conversely, an insecure attachment lacks the basic nurturance and consistency in parental responses that an infant requires to develop confidence, trust in themselves and others and a sense of safety and belonging in the world. An insecure attachment style has also been associated with an inflated sense of self or, conversely, an extremely negative view of self. Secure attachment styles are associated with moderate and stable views of self.

Attachment is also a powerful predictor on the coping style a person adopts in later life in response to stressful situations. For example, Mikulincer and Florian<sup>10</sup> reported that following a stressful life event, people with an insecure attachment style experienced increased distress, higher levels of somatisation (physical complaints without any known causative origin), anger and avoidance, than their more securely attached counterparts.

Paradoxically, securely attached people tended to utilise social support as a coping mechanism while their insecurely attached peers used more emotionally focussed and distancing (isolating) strategies. Attachment style has also been shown to influence and regulate mood states, with securely attached individuals able to form positive, proactive perceptions of events and their future, characterised by a healthy self perception and view of others.<sup>11</sup>

However this does not mean that people raised with inconsistent although perhaps loving parents, or

Essentially, attachment can be conceptualised into two broad categories; secure and insecure, and it is posited that the quality of these attachments formed in infancy, provide the template and working models for all future relationships throughout our life.

who experienced emotional, physical or psychological abuse and neglect were doomed to poor adjustment and maladaptive coping in response to stress. Fortunately, the trajectory of our lives invariably requires the consideration of various factors and a 'cause and effect' model is not so linearly applied. Nonetheless, attachment style does undeniably exert a huge influence on a person's ability to form relationships with others, regulate their mood, develop adaptive coping strategies and impact on their overall ability to cope with stress in later life.

Securely attached individuals are more likely to navigate through crises in their life by utilising social support, enabled by proactive coping strategies, positive outlook and self perception and hope for the future. Their more insecurely attached counterparts are likely to avoid, deny, isolate and utilise maladaptive coping styles to manage their crises, often resulting in poorer health outcomes and an exacerbation of other issues in their life.

Armed with this knowledge it is apparent that a comprehensive psychosocial assessment at the time of diagnosis of HIV, commencement of antiretroviral medications, the diagnosis of an AIDS defining condition and at other critical incidents in a person's life is crucial. Additionally, while it is often difficult and even painful to identify and address childhood issues, further exploration of a person's earliest years is sometimes indicated. However, this should only be undertaken with the assistance of a skilled and qualified therapist after a comprehensive clinical psychological assessment, and generally this work would not be undertaken or indicated during times of crisis or extreme stress.

A more practical and tangible means of assisting people is in recognising, reinforcing, and where necessary, facilitating and advocating for the utility and significance of all social

networks. Whether these networks are structured, organised peer support agencies, informal networks of friends or family, or engagement in other social opportunities, all undoubtedly have their validity. Additionally, identification of barriers to socialising, such as financial costs, mobility, accessibility and environmental factors may assist in the formation of greater functionality, self-efficacy and resilience. This in turn may equip HIV-positive people to live more satisfying and rewarding lives, regardless of their past experiences and/or the ongoing challenges they may face in the future.

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A more practical and tangible means of assisting people is in recognising, reinforcing, and where necessary, facilitating and advocating for the utility and significance of all social networks.



# Regional profile: Sri Lanka

By Matthew Tyne

... there are many factors that may yet contribute to HIV epidemics in the country including a large, mobile military within the country and large internal and external migration (both employment and conflict-driven).

In mid May 2009, the main theatre of Sri Lanka's long running civil war closed. The Liberation Tigers of Tamil Eelam's (LTTE) military leadership was dead; people lit fireworks and danced in Colombo's streets to celebrate and nearly 300,000 internally displaced people (IDP) in the country's north and east required resettlement. The country is currently undergoing major socio-political and economic adjustments in this new post-conflict era with a focus on redevelopment of those areas most affected by the war. So what of the country's responses to HIV/AIDS? I worked in the HIV sector in Colombo from 1997–2000, and again from 2005–2007. I returned to Colombo in August 2009.

## HIV situation

Sri Lanka remains one of the few countries in the region with a low level HIV epidemic with the adult HIV prevalence of 0.03 in 2007.<sup>1</sup> The country has, relative to its per capita income, high literacy and reasonable access to health care services, most of which are

free at point-of-care. However, there are many factors that may yet contribute to HIV epidemics in the country including a large, mobile military within the country and large internal and external migration (both employment and conflict-driven). According to the Country Report for the United Nations General Assembly Special Session (UNGASS) 2007, in Sri Lanka 'the spread of HIV is highly dependent on the movement of individuals to and from locations where HIV prevalence is higher.'<sup>2</sup> This may include Sri Lankans who go abroad for employment and visitors to Sri Lanka who have sex with locals. Forty percent of women who have tested positive for HIV are external/out migrants. This data may overstate the significance of this 'group', as workers returning from abroad (often in Western Asia) are mandatorily HIV-tested and, therefore, overrepresented in testing data. It is also not clear how many of these infections were acquired in Sri Lanka or elsewhere.

The first case of HIV was identified in 1987, and the Joint United Nations

Programme on HIV/AIDS (UNAIDS) estimates that at the end of 2007, approximately 3,800 people were living with HIV. By the end of March 2009, reported cumulative HIV cases were 1,099 (642 male and 457 female) with male to female ratio of 1.4:1. There were 37 children living with HIV.<sup>3</sup> The number of reported cumulative AIDS cases was 293 and the cumulative number of AIDS deaths was 189. 58 percent of reported HIV cases are between 20 to 39 years of age while 35 percent of cases are from Colombo District. Transmission is mostly through heterosexual sex (85 percent), with male-male sex accounting for 10 percent of infections. Other transmission modes remain low. Perinatal transmission accounts for 4 percent and blood transfusions and sharing injecting equipment are less than 1 percent, with 0.4 percent and 0.3 percent respectively.<sup>4</sup>

### National response

The Government of Sri Lanka has responded to HIV since the late 1980s. The National AIDS Council, formed in 2006, is the Government's peak governing body responsible for developing a cross-sectoral response to HIV/AIDS. The Sri Lankan President chairs the council with various government ministers, representatives from international donors and non government organisations as members. The National AIDS Committee (NAC) coordinates the national level response to HIV. The Secretary of the Ministry of Health chairs the NAC, whose primary function is to make policy decisions that often deal with operational issues. The NAC comprises several subcommittees including: information, education, communication (IEC) and condom promotion; legal and ethical issues; laboratory services and surveillance; collaboration with NGOs and private sector; collaborations with vulnerable populations, and HIV care and counselling. In 2006, Panos

suggested the highly bureaucratized sub-committees have resulted 'in slow or no progress' on some issues.<sup>5</sup>

### Progress

In late 1997, I attended a meeting of representatives from local non-government organisations working in HIV prevention. Lions Club members dominated the leadership of many of the small organisations present at the meeting, discussing the need to rehabilitate sex workers and the inherent dangers of having sex with foreigners. Towards the end of the meeting Sherman de Rose from Companions on a Journey, which worked with gay men and other men who have sex with men (MSM), spoke. He said members of his organisation and MSM in general were left out of the HIV response. He used the word 'we' rather than 'they' when talking about MSM. The atmosphere in the room changed; participants shifted in their seats, began laughing nervously and appealed to the Chair to close the meeting. The Chair obliged. The usual civil afternoon tea (that so often follows meetings in Sri Lanka) was replaced by banter about 'these perverts'.

One of the criticisms of the country's HIV response is that prevention programs are poorly coordinated and fail to adequately work with people from most at risk populations (MARP).<sup>6</sup> In the last five years, key MARP have been acknowledged. The 2006–2007 *Behavioural Surveillance Survey* yielded

strong evidence to support working more closely with sex workers and MSM.<sup>7</sup> In the 2006 review of the HIV and AIDS Situation and Response Analysis (published by UNAIDS)<sup>8</sup>, MSM together with sex workers were identified as the two groups requiring specially targeted prevention programs. In the current *National HIV/AIDS Strategic Plan 2007–2011* (NSP), 55 percent of the total allocation for HIV prevention is for MARP (MSM 10 percent, sex workers 17 percent and drug users 28 percent).<sup>9</sup> The allocation for drug users is seemingly high, given the very low cases of HIV transmission via injecting.

I asked David Bridger, the UNAIDS Country Representative, what had changed in the past five years in Sri Lanka's response to HIV. The issues we covered were not exhaustive.

### *Mapping MARP and other vulnerable groups*

UNAIDS, in collaboration with the University of Manitoba, is working with Companions on a Journey (COJ) (MSM) and CSDF (sex workers), among others, to estimate the numbers of MSM and sex workers within selected districts. For example, estimates of numbers of sex workers in the country range from 7,000–40,000 (personal communication: David Bridger, UNAIDS). Between three

*continued overleaf*

... participants shifted in their seats, began laughing nervously and appealed to the Chair to close the meeting. The Chair obliged. The usual civil afternoon tea (that so often follows meetings in Sri Lanka) was replaced by banter about 'these perverts'.

and four districts will be covered by the end of 2010, and with future support from Round Nine of the Global Fund, mapping/size estimation of MSM and sex workers can be carried out in a further 12 districts.

#### *Sensitisation of health workers and police*

One of the barriers to testing and accessing treatments for people from MARP is the lack of sensitivity of some medical and nursing staff. In 2005, one man told me of being asked to stand on a table in the clinic and 'sing like woman' when he informed clinic staff he had sex with men. Community-based organisations such as Companions on a Journey, have delivered sensitisation workshops for medical and nursing staff to explore issues around sexuality and sex work.

Along with clinic staff, the HIV sector has identified police personnel as a necessary partner in HIV prevention and advocacy work. Long standing police practices around sex workers and MSM are an obvious barrier to improving responses to HIV.<sup>10</sup>

#### *People living with HIV (PLHIV) groups*

In June 2009, the United Nations Development Programme (UNDP) assisted Lanka Plus, a PLHIV support and advocacy group, to conduct a review. From the review's recommendations, Lanka Plus appointed a new board of management comprising people from organisations beyond the HIV and health sector to provide better governance and direction. Lanka Plus has more than 130 members comprising both PLHIV and affected families and friends.

#### *Improving treatment in the north and east*

Although the war has ceased, legacies of the conflict remain. Menik Farm is a camp for internally-displaced

persons (IDP) near Vavuniya, about 250km north of Colombo. There are approximately 250,000 people still in the camp.<sup>11</sup> While HIV is not an apparent priority issue within the camp, humanitarian agencies are addressing HIV issues through reproductive health programs.

#### *Improving referral pathways for treatment*

Antiretroviral Therapy (ART) is provided free to people through the Government STI clinic in Colombo. This initiative was initially supported by the World Bank and Round Six of the Global Fund. The Government seeks to expand treatment access to another two clinics, most likely in Kandy (Central Province) and Galle (Southern Province) with support from Round Nine of the Global Fund. UNAIDS, along with local partners, are investigating ways to improve access to treatments in the North now that health services are being reestablished. The referral system for testing, treating and caring for PLHIV needs to be improved dramatically.

#### *Human rights*

Little attention has been paid to a rights-based approach to HIV programming, especially in the care and support of people living with HIV/AIDS. The Centre for Policy Alternatives (CPA) is critical of the 'medical science' approach over a rights-based approach to the country's HIV response. While the current National Strategic Plan addresses some rights and advocacy issues, the Plan remains 'centralised and top-heavy' and almost solely in the ambit of the health sector.<sup>12</sup>

While there have been definite improvements in the response to HIV, the development of a Strategic Plan and identification of MARP and vulnerable groups; the establishment of PLHIV advocacy

and support groups and an emerging evidence base are just a few examples; there remains significant challenges. These include: developing the organisational capacity of community-based organisations to initiate and implement HIV programs; forming and maintaining partnerships between government and non-government agencies; and the development of a human-rights framework to shape the country's response.

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# On the Queer Politics of Drugs

A review of *Pleasure Consuming Medicine: the Queer Politics of Drugs* by Kane Race, Duke University Press, 2009

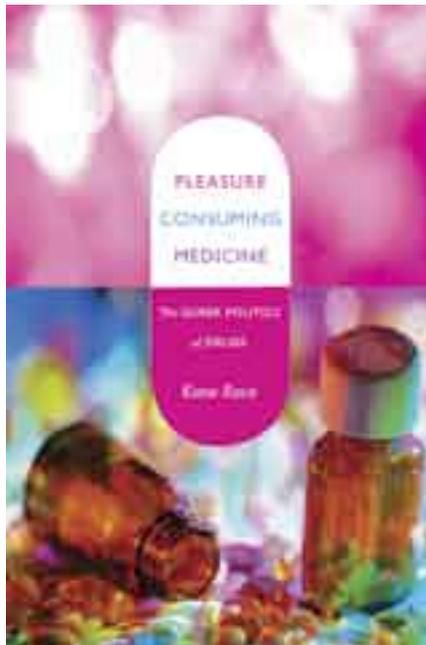
By Jennifer Power

Kane Race is a familiar voice in the HIV sector, having published widely on topics related to HIV/AIDS and safer sex practice. In his latest book, *Pleasure Consuming Medicine*, Race turns his attention to the way in which the personal, cultural and political governance of drug use has implications for HIV prevention.

Race centres his discussion around practices of pleasure. He reiterates a point familiar to community-based HIV educators; that negotiation between pleasure and safety is central to successful HIV prevention.

Yet pleasure holds a complex position in the world of drugs. One the one hand there is an ever expanding legal market in drugs that promote pleasure in one way or another – with Viagra and Prozac being obvious examples. On the other hand, the spectre of ‘drug abuse’ or the use of ‘recreational’ drugs for pleasure becomes a site for legal sanction of, often, marginalised groups in the name of health and safety. (Race cites police arrests made at the 2007 Azure Party – a GLTB event – as an example.)

The perception that taking drugs purely for pleasure is an immoral and dangerous act is reinforced again and again through medico-moral discourse around illegal drug use. The irony of this is that it often doesn’t result in practices



that promote safety. Users are less likely to seek help if they fear arrest, and pathologising drug use is certainly not always appropriate.

Race seeks to move beyond the well-known discourse of ‘harm minimisation’ to explore the implications of a notable absence of pleasure in public health praxis. Rather than seeing the pursuit of pleasure as inherently risky (the antithesis of safety), Race is interested in understanding the way in which practices of self-care and care for others are often a part of the experience of drug use.

Race’s prose is classically academic, however he balances this with discussion of real-life events, popular culture and personal narrative. This makes for fascinating insights into the life of the author, highlighting the constant internal dialogue that emerges for writers when their academic knowledge connects with personal experiences. In the final chapter of the book, Kane invites the reader to reflect with him on an encounter in a Sydney video lounge which, in his words, “haunts this book”:

*We went into a room, and it didn’t take long for me to realise ... this guy was seriously out of it ... I asked him if he was all right; he pulled himself together and we left ... This encounter has stayed with me ... It has forced me to question almost every claim I have made about the possibilities of corporeal responsibility at every scene.*

Kane uses experiences such as this to propose the idea that the pursuit of pleasure through drug use isn’t simply about zoning out, or an effort make oneself feel better when the world sucks, but it is a site in which culture and community is produced. At this site there are multiple ways in which individuals ensure both their personal practices of safety and concern for the safety of others are a part of this culture.

Jennifer Power is a research fellow at LaTrobe University.

# HIV AUSTRALIA

**HIV Australia** reviews books and other publications for readers with an interest in HIV and related issues. We welcome submissions from authors and publishing houses with suggestions of publications to review. If you would like to submit an idea for us to consider, please email [editor@hivaustralia.org.au](mailto:editor@hivaustralia.org.au). Published works can also be mailed to Editor, *HIV Australia*, C/O AFAO, PO BOX 51, Newtown, NSW 2042.

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# WEB WATCH



<http://www.beyondblue.org.au>

The *beyondblue* website is part of a national initiative designed to raise awareness and provide support and resources relating to depression and other mental health conditions in Australia.

*Beyondblue* is well known for its focus on men's health through high profile national campaigns, such as its partnership with the 'Movember' foundation. However, the non-profit organisation also produces campaigns and resources relating to a range of other mental health issues, including post-natal depression, aging, youth and indigenous mental health – all of which are accessible online through the *beyondblue* website.

The *beyondblue* site is a one stop shop for a range of resources aimed at individuals, as well as carers. The homepage includes information for health professionals, providing links for online resource ordering, research and a 'symptoms checklist'. Numerous fact sheets (.pdfs) are available for download and it is pleasing to see that many these are also supplied in audio format, with weblinks to multilingual translations, increasing the site's ability to cater for diversity and special needs.

The site's homepage is continuously updated with stories relating to mental health from around the country. There are links and contact details for external service providers and help/information lines, including services catering for rural areas. A bulletin board and a 'share your story' webpage allow people

experiencing depression and other mental health issues to engage with each other and share their experiences.

*Beyondblue* recently undertook a detailed scoping study about mental health issues relating to gay, lesbian, bisexual, transgender and intersex people, in partnership with the Australian Research Centre in Sex, Health and Society at La Trobe University. The study conducted a large-scale review of International and Australian reports published from 2000 to 2008. Findings from this study outlined on the site include that 'same-sex attracted young people, particularly women, are the group most susceptible to depression' and 'those who identify as bisexual are at higher risk of developing mental health problems than gay or lesbian people'.

The site's homepage also includes a link to a fact sheet on depression and anxiety in gay, lesbian, bisexual, transgender and intersex people entitled 'Tackling depression and suicide in GLBTI people'. While there is little information on the site relating specifically to HIV and mental health, there is a detailed section about chronic illness and mental health issues.

*Beyondblue* is a great online resource for anyone affected by mental health issues who needs support or access to information. If you require information or a referral, you can also call the *beyondblue* Information Line on 1300 22 4636.

# TREATMENT BRIEFS

## US guidelines now favour treatment at CD4 cell counts between 350 and 500; above 500 not ruled out

New US treatment guidelines favour the initiation of HIV treatment by patients with a CD4 cell count between 350 and 500 cells/mm<sup>3</sup>, earlier than current European and British recommendations. The guidelines panel was evenly split on whether to start HIV treatment when a patient's CD4 cell count is above 500 cells/mm<sup>3</sup>.

Issued on World AIDS Day, 1 December, the US Department of Health and Human Services guidelines for the use of antiretroviral drugs include a number of important revisions, most notably about when HIV treatment should be started.

— Michael Carter, *Aidsmap*

## Earlier treatment favoured

Retained in the guidelines is a recommendation that HIV treatment should be started by all patients with an AIDS-defining illness, or a CD4 cell count below 350 cells/mm<sup>3</sup>.

Starting treatment at a CD4 cell count of this level has been shown to reduce the risk of HIV-related illnesses and some other serious diseases such as those of the heart, kidney and liver, as well as some cancers.

There has been debate about the value of starting treatment at higher CD4 cell counts. Some research has shown that this can have benefits, but not all studies have confirmed that there is an additional benefit to starting treatment at a CD4 count above 500.

The guidelines panel was persuaded that therapy should be recommended for patients with a CD4 cell count between 350 and 500 cells/mm<sup>3</sup> but disagreed on the strength of the recommendation. 55 percent of the panel said this should

be a strong recommendation, while the remaining 45 percent supported a 'moderate' recommendation for treatment in this CD4 range.

It's the first time that the US guidelines panel has issued a split recommendation of this sort, and the split verdict indicates the divergent views about the strength of the evidence for earlier treatment.

The panel was evenly split on whether treatment should be started by individuals with a CD4 cell count above 500 cells/mm<sup>3</sup> or whether it should be considered optional. However, certain groups of patients are recommended to start antiretroviral therapy regardless of their CD4 cell count. These include pregnant women, those with HIV-associated nephropathy (kidney disease), and patients co-infected with hepatitis B virus when therapy for hepatitis B is necessary. Also included in the guidelines are recommendations for first-line antiretroviral therapy.

## 'Drug holidays' best predictor of treatment failure, adherence studies find

Failure to take every dose on time is not a good guide to whether patients will fail their therapy, according to studies from several countries presented at the European AIDS Conference. A better guide, and one that correlated with the number of pills taken, was whether patients had taken 'drug holidays' defined as at least two days of missed therapy.

A study from Italy (Ammassari) asked all 584 patients on HAART at a Rome clinic whether they had taken all doses in the last week, been more than two hours late with a dose, had a complete treatment interruption in the last three months, or taken a treatment break of at least two days in the last month.

The proportions answering 'yes' to these questions were:

- Missed dose, last week: 19 percent
- Late dose, last week: 35 percent
- Interruption in last three months: 11 percent
- 'Drug holiday' in last month: 9 percent

A high proportion of patients (63 percent) had some level of poor

adherence by this study's measures, even 60 percent of those with viral loads under 10 copies/ml, indicating that strictly-defined 'poor adherence' may not be a reliable guide to viral control. Women were the best adherers, with injecting drug users twice as likely to report poor adherence and, in this study at least, gay men three times more likely.

There were only two independent predictors of having a viral load over 10 copies per ml in this study. Drug holidays of more than two days in the last month were associated with a fivefold greater risk of detectability (odds ratio 0.18), and an NNRTI-based regimen, as opposed to a protease inhibitor-based one, was associated with twice the likelihood of undetectability (the proportion of patients on boosted PIs was not stated).

'It is likely that for deep HIV replication control, drug holidays, in contrast to other non-adherence behaviours, might determine higher virological rebound with more pronounced impact on virological control,' the authors state.

Another study by the same team, restricted to patients who had taken HAART for more than four years (Trotta), confirmed that although each indicator of poor adherence produced a 60 percent greater likelihood of a detectable viral load (over 50 copies/ml in this study), the only independent predictor of viral load failure was a drug holiday of at least two days in the last month. This was associated with a more than sixfold decline in the chance of virological success (OR 0.16).

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— Gus Cairns, *Aidsmap*

■ **The development of means to better engage with AIDS Councils' health promotion and other campaign based work** Counsellors are well placed to identify emerging issues, particularly given their responsibility to facilitate in-depth discussion with clients. For example, at the recent Alliance meeting counsellors from different jurisdictions identified (among numerous other issues) increased focus on financial issues, same sex domestic violence, intimacy in gay male relationships and access for temporary visa holders. There was also discussion about a shift in focus to support 'long-term survivors': those people who have lived for many years (sometimes for decades) with HIV, and their need to address the cumulative effects of grief and loss and/or to re-engage after putting their life 'on hold' for many years. Notably too, counsellors identified a gradual

increase in the number of clients who are HIV negative, and the intersection of their work with HIV prevention efforts.

■ **The development of means to better inform policy development** AIDS Council based counsellors had approximately six thousand contacts with more than 1000 clients in the 2008/09 year.<sup>1</sup> Those counsellors hold an enormous amount of information on the lived experience of HIV infection and the experience of living within affected communities that should be channelled into the development of effective policy. The Alliance has recognised that counsellors may need training and resources to better engage with policy and campaign work, but is committed to work towards bridging gaps between counselling services and other aspects of AIDS Councils' work through partnerships and greater collaboration. Obviously,

confidentiality provisions are paramount, however, clients' experiences must be de-identified and translated into reports and case studies to inform research, policy development, advocacy, and campaigns. Further, the Alliance is committed to developing a mechanism to collate national counselling data so that the experiences of those with whom they engage is not lost to Australia's HIV policy response.

The Alliance is currently supported by individual AIDS Councils but is working towards securing independent funding to ensure its continuation while minimising the burden on individual agencies.

#### References

- 1 Figures taken from Western Australian AIDS Council, ACON Sydney and Wollongong, VicAIDS, AIDS Action Council of the ACT, South Australian AIDS Council and Rainbow.

Sally Cameron is a consultant and former Policy Analyst at AFAO.

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Some of the key markers of primary mental health care accountability would include:

- reduced suicide rates among people discharged from mental health facilities;
- high levels of follow-up in the community for people released from care;
- positive outcomes for general health indicators (regarding, for example, diet, exercise, tobacco, alcohol and other drug use);
- delay in presenting with psychosis;
- positive consumer and carer perceptions of care received;
- high level of rehabilitation program take-up;
- improved employment participation rates; and
- improved levels of stable accommodation.

Without these measures in place there is a very real danger that mental health service provision will continue to be outcome blind, often rewarding

failure, and not responding to the needs of mental health consumers and their carers. A key role for any new primary health care organisation must be to build community confidence in Australia's mental health system. We need to start now because more of the same is not an option.

#### References

- 1 Australian Bureau of Statistics, Canberra. (2008). *Australian Survey of Mental Health and Wellbeing*.
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- 5 *Partnerships for Solutions, Depression: Common Comorbidities*, May 2004, [www.partnershipforsolutions.org/statistics/issue/briefs.html](http://www.partnershipforsolutions.org/statistics/issue/briefs.html).
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- 7 Mancuso C., et al. (2000). Effects of Depressive Symptoms on Health-Related Quality of Life in Asthma Patients. *Journal of General Internal Medicine*, 15(5), 344–345.
- 8 Pratt, L., et al. (1996). Depression, Psychotropic Medication and Risk of Myocardial Infarction. Prospective Data from the Baltimore ECA Follow-Up. *Circulation*, 94(12), 123–129.
- 9 Ziegelstein, R., et al. Patients with Depression are Less Likely to follow Recommendations to reduce Cardiac Risk During Recovery from a Myocardial Infarction, *Archives of Internal Medicine*, 200, 289, 3135–3144.
- 10 Grierson, J., Thorpe, R., and Pitts, M. (2006). *HIV futures five: Life as we know it*. Monograph series number 60. The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia. pp9–10.
- 11 *Ibid*, pp42–45.
- 12 Institute of Medicine, Washington. (2006). *Improving the Quality of Health Care for Mental and Substance-Abuse Conditions*.

**Sebastian Rosenberg is the Deputy CEO of Mental Health Council of Australia and Senior Lecturer at the Brain and Mind Research Institute, University of Sydney.**

**HIV Tests & Treatments**  
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a booklet for HIV  
positive people**

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# HIV Australia Readers Survey results

Thank you to everyone who responded to the *HIV Australia* Readers Survey which was included with the 'Reflections' issue (Vol. 7, No 1). Congratulations to survey respondent K Vesperman in NSW, who received the iPod Shuffle giveaway in September.

We received an overwhelming amount of positive feedback about the magazine, as well as many fantastic constructive comments. These will help guide the development of content covered in the magazine over the next twelve months.

All sections of *HIV Australia* were equally popular with readers. We are pleased to say that each edition of *HIV Australia* is well-read – with almost half of our readership sharing their copy of *HIV Australia* with more than one other person!

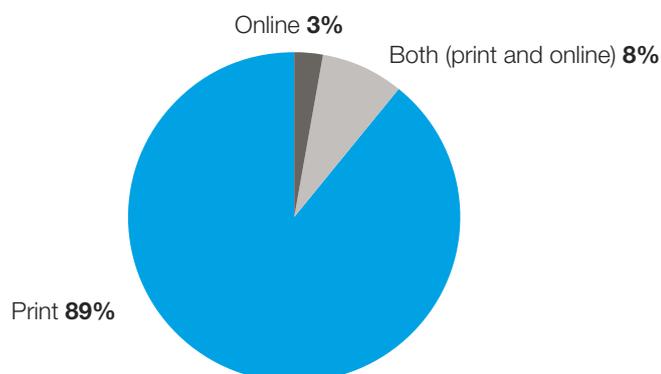
Suggestions for topics that you requested include:

- Policy issues for people living with HIV
- Personal stories and stories of survival
- Information about treatments and managing side effects
- Research
- Immigration issues.

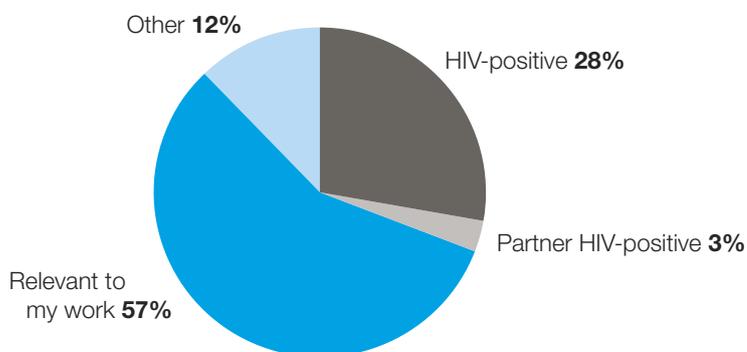
One comment we received from some readers is a request for more personal stories to balance content of a more technical nature. On page 15 of this edition we feature one such personal account, James May's excellent article 'Mind Over Matter'.

A summary of some of the survey findings are represented in the graphs opposite. Thank you for your interest and involvement. We look forward to continuing to serve you in 2010.

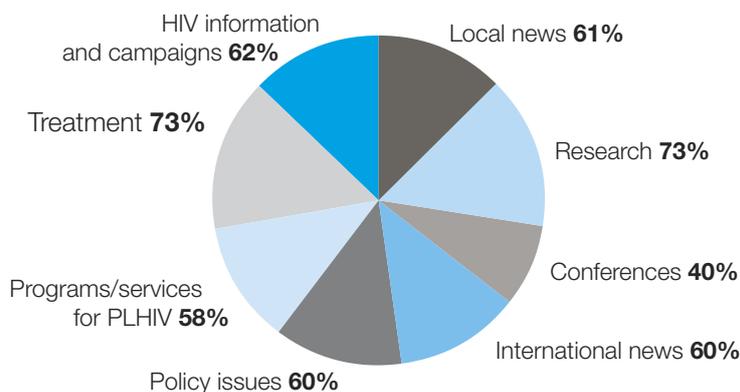
## Print compared to online readership



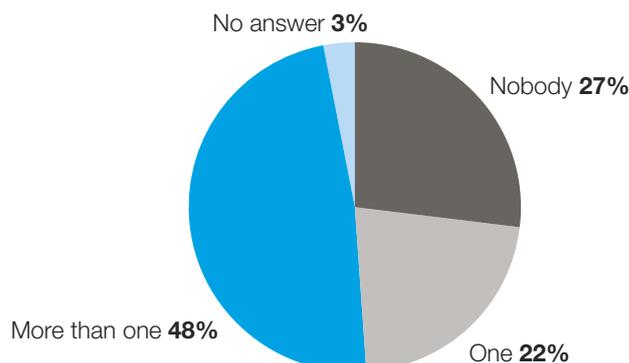
## Reason for subscribing



## Main areas of interest (% of total respondents)



## How many people share your copy of *HIV Australia*?



loss of relationships and social connectedness, career and earning capacity, or their sense of future and longevity. Key events such as a positive diagnosis, the need to start antiretroviral therapy, treatment failure, an AIDS-defining illness, or a friend's AIDS-defining illness were identified by GPs as additional triggers that increased their vigilance and awareness of depression.

This was especially the case for men who have been living with HIV for a long time: '... I was told I was going to die 15 years ago, and I'm still here. And now I'm living in poverty. And I gave up my career because of this. And I've not been able to have a relationship. And I'm quite lonely and isolated.' (ADE-GP1)

Central to the management of depression in HIV positive gay men in general practice settings is maintaining a high frequency of contact with GPs, making use of the specialist multidisciplinary teams who provide additional support services for positive men, and finding ways to alleviate social isolation. However, having the time and capacity to do this effectively may be particularly difficult for GPs with high caseloads and challenging continuing medical education requirements. GPs based in regional areas can find it particularly difficult to manage their HIV positive clients because of the relative lack of services and support outside of urban areas.

Crystal meth use by HIV-positive gay men was identified by several GPs as increasing in urban areas and creating additional challenges for the clinical management of HIV alongside comorbid depression. Particular issues facing the health workforce included GPs feeling unprepared to cope with problematic levels of crystal meth use in their positive patients.

A higher proportion of the HIV-positive gay men (48.4 percent) reported multiple sexual problems than the HIV-negative men (35.1 percent). Factors independently associated with multiple sexual problems among the HIV-positive gay men were adoption of avoidant strategies to cope with daily life stress, sexual risk-taking in casual encounters, and the use of antidepressants.

### Outcomes

A major outcome of this study is the development of a module for the self-management of depression for gay men hosted on the ClimateGP website. The Clinical Research Unit for Anxiety and Depression (CRUfAD), based at St Vincent's Hospital in the School of Psychiatry at UNSW, maintains this website for people with anxiety and depression.

The module for gay men comprises six lessons about overcoming depression, and a fact sheet on managing sexual side effects. While no results as to its efficacy are available, the companion module for heterosexual people has been shown in two trials to produce results similar to face to face therapy. People wanting to take advantage of this module can arrange this with their GP.

GPs can access to the module at <http://www.climategp.tv>. CRUfAD charges \$100 per prescription pad which allows 20 users access to the site, (ie. \$5 per person).

Findings from the study will be used to inform the development or revision of case studies and other materials used in ASHM education and training programs for s100 GP prescribers. This will ensure that GPs are aware of this most recent data on the identification and management of depression and associated psychological issues amongst gay men, including people living with HIV, in Australia.

The study also increases the capacity of community organisations to advise on and participate in social research. For example, The National Association of People Living with HIV/AIDS (NAPWA), completed a six-week internship with the National Centre in HIV Social Research and presented the findings at the Everyday Lives conference in March 2008.

**For further information about this study and its authors, please visit the National Centre in HIV Social Research website at <http://nchr.arts.unsw.edu.au/> or email [nchr@unsw.edu.au](mailto:nchr@unsw.edu.au)**

Key events such as a positive diagnosis, the need to start antiretroviral therapy, treatment failure, an AIDS-defining illness, or a friend's AIDS-defining illness were identified by GPs as additional triggers that increased their vigilance and awareness of depression.

course, relying on getting funding. That is tough because, to date, it's been pretty impossible to get governments to take the issue seriously.

I think part of the problem is that we have got a community that has never seen itself as growing old and so hasn't prepared for it. It's crept up and been a surprise to people who have gotten there already. The larger numbers of people who are going to get there soon will find that a vast majority of the age care providers are not ready for them, or do not want them, because the bulk of aged care services are provided by religious providers.

**Are there other priorities that you see for the new National Strategy?**

I think that whilst the numbers of HIV infections remain low in the Indigenous communities, it is a potential time bomb waiting to take off. It's a miracle that we have not had explosive epidemics amongst Indigenous people. All of the precursors are there – I simply cannot understand why it has not happened. And it is important that the national strategy does not ignore the significant number of infections that are amongst gay men and Sistergirls or the very significant link between hepatitis C and prisons. And that means starting at first principles. We should be adding

to the public health voice to keep Indigenous people out of prison. We have amazingly low rates amongst injecting drug users and sex workers, but particularly our NSP programs are always under threat, so we have to make sure that we keep a focus on maintaining those programs, and not let them slip.

The other thing that we have let ride for way too long is law reform around HIV. Our country led the way at the end of 80s and early 90s. We designed a whole roadmap for reform and then we just let it sit there. It is time for us to set up a new intergovernmental committee where we get the Federal Government together with the people from the States and sit them around the same table to map out all of the laws that need to be changed, and then get serious about fixing those laws. That should be done under these Strategies.

I also think that the changing face of the body positive is a particular challenge for us. Now we have a vast spectrum of people with HIV and it is a huge challenge for us, particularly with community-based organisations, in how we meet the needs of all those people. How we can divide resources to meet the needs of people who are newly diagnosed – and they are the growing majority now – who have very

different needs to those who are living longer term with HIV, right through to people with complex and multiple needs. It is almost like the problem with hospitals: how do you get money out of acute care to put into prevention when you have got hospital waiting lists – even though you know that if you can get money into prevention then you will stop people getting into hospital? And I think that if we can get more money into servicing the newly diagnosed and keeping them healthy longer, then they are not going to end up needing more complex treatments and services. But we want to make sure that we do not leave people who are already sick in the lurch.

We are also starting to find, certainly in NSW, more refugees from Sub-Saharan Africa who are coming in with HIV, particularly women and children. Whilst the numbers are not large, they have limited access to support programs and services. I think it is going to be a challenge for us, we have a particular responsibility to find a way to meet their needs too.

Finally, we have to look seriously at our role in the region. We have a whole range of community-based and other HIV organisations across the country with two decades of experience in delivering successful HIV programs, yet our government tends to employ a handful of consultants, or even fund overseas organisations rather than facilitate their role in the region. There has to be a better way for Australian experience to help in the Asia-Pacific in a respectful way.

**Abigail Groves is the Editor of HIV Australia and Policy Manager at AFAO.**

Now we have got this vast spectrum of people with HIV and it is a huge challenge for us, particularly with community-based organisations, in how we meet the needs of all those people.

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### January 2010

20–22

#### **13th Bangkok International Symposium on HIV Medicine**

Bangkok, Thailand

[www.hivnat.org/bangkoksymposium/index.html](http://www.hivnat.org/bangkoksymposium/index.html)

### February

4–5

#### **Drawing the Line Against AIDS**

The University of Adelaide, Australia

<http://www.hss.adelaide.edu.au/historypolitics/conferences/drawing/>

16–19

#### **CROI: 16th Conference on Retroviruses and Opportunistic Infections**

San Francisco, California, United States

<http://www.retroconference.org/2010/>

### March

9–12

#### **14th International Congress on Infectious Diseases (ICID)**

[www.isid.org/14th\\_icid/](http://www.isid.org/14th_icid/)

24–26

#### **16th International Symposium on HIV and Emerging Infectious Diseases (ISHEID 2010): From Basic Science to Clinical Practice**

Marseille, France

### April

7–9

#### **11th International Workshop on Clinical Pharmacology of HIV Therapy**

Sorrento, Italy

[www.virology-education.com/](http://www.virology-education.com/)

### October

18–20

#### **Australasian Sexual Health Conference**

Sydney, Australia

<http://www.sexualhealthconference.com.au/>

20–22

#### **ASHM Australasian HIV/AIDS Conference 2010 (22nd Annual Conference for the Australasian Society for HIV Medicine)**

Sydney, Australia

<http://www.hivaidsconference.com.au/>

### November

21–22

#### **Ind-International Pediatric AIDS Conference**

Mysore, Karnataka, India

[www.ind-ipac.com](http://www.ind-ipac.com)

29–01 (December)

#### **IAPAC 09**

New Orleans, United States

[www.iapac.org/iapac09](http://www.iapac.org/iapac09)



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