

PositiveLiving

A MAGAZINE FOR PEOPLE LIVING WITH HIV ■ JUNE 2010



To the future

Now that it's more of a **manageable** condition, people with HIV are living much longer. And that's worth celebrating. But as research emerges on the ageing effects of the virus as well as all the comorbidities we are more susceptible to, it's also time we seriously started to plan for the **future**. MORE PAGE 6

THE FLU SEASON IS UPON US AND THE CALL FOR PEOPLE WITH HIV TO BE VACCINATED HAS BEEN ISSUED. BUT WHAT OF THE OTHER BUGS ABOUT AND HOW DO WE DEAL WITH THEM? NEIL MCKELLAR-STEWART INVESTIGATES.

Last year there was concern that the H1N1 (swine flu) virus would have a major impact on the health of PLHIV. Fortunately this was not the case, with most people experiencing only mild to moderate symptoms, which then resolved within a fortnight.

This year's combined vaccine offers protection against three flu strains: two types of seasonal flu that are expected to recur this season, plus the H1N1. This 'trivalent' vaccine is available free to PLHIV under the government's national immunisation program.

If you have already been vaccinated with the 2009 H1N1 vaccine you can choose to receive only the 2010 seasonal flu vaccine. But either way, consider getting vaccinated as soon as possible to ensure you have protection against all three flu strains that are expected to circulate this winter.

PNEUMONIA IS A COMMON, SERIOUS CONSEQUENCE OF FLU. THIS SHOULD BE ENOUGH INCENTIVE FOR ALL PLHIV TO GET VACCINATED.

Pneumonia is still seen in higher incidence amongst people with HIV. One Danish study, which included 3516 PLHIV looked at the incidence of hospital admissions for pneumonia over the period 1995-2007. They found that even as late as 2007 the risk of first-time hospitalisation for pneumonia remained six times higher for those with HIV than for the general population. This increased risk was observed in those with normal CD4+ cell counts (>500) and was even higher in those with lower counts.

The researchers found that the biggest risk



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factors were: a low current CD4+ cell count; injecting drug use as the mode of HIV transmission; and, among treatment-naïve patients, a high current viral load. Smoking is also a significant known risk factor for pneumonia but one on which the Danish study did not have data.

While it is true that antiretroviral treatment has helped reduce the incidence of pneumonia (by more than 60% since it first became available in Denmark in 1995), PLHIV still remain more susceptible to contracting pneumonia.

THE SUPER BUGS

In early 2008 there was an almost hysterical media reporting of an increase in the incidence of multi-drug resistant staph infections in men who have sex with men (MSM) in San Francisco and Boston. What was touted as 'the new AIDS' was actually a case of ill-informed reporting.

Staphylococcal species (Staph) typically lives on most people's skin and in their nasal passages and only becomes dangerous when it penetrates the skin. It's not confined at all to gay men or MSM.

One US study has shown that MSM are at a

significantly increased risk (around 13 times) of having Community-associated Methicillin-resistant Staphylococcus Aureus (CA-MRSA). This is a significant staph infection which is acquired not in a hospital or healthcare setting but in the community. The bug is resistant to antibiotics which can normally treat it.

CA-MRSA can cause significant disease including: skin and soft tissue infections (including abscesses, cellulitis, ulceration and wound infections); sepsis (sometimes called blood poisoning); and pneumonia.

Since this study was published there have been several others which add further evidence that CA-MRSA is a significant issue for MSM, particularly those who are living with HIV.

In April, a study of PLHIV treated for staph-related skin and soft tissue infections in Chicago hospitals found that the incidence of these kinds of infections was six times higher in PLHIV compared to the general community and that the incidence is increasing (four-fold from 2003 to 2007).

Another study in San

Diego of around 500 PLHIV found that, over a seven-year period, around 7% acquired MRSA skin and soft tissue infections. Of these, almost half had a recurrence of their staph infection.

The strain of MRSA which was most often identified is associated with some severe soft tissue infections. There was evidence that PLHIV who were 'doing it tough' (e.g., those in crisis accommodation) were at a higher risk.

PLHIV who had viral loads greater than 1000 copies were much more likely to have recurrences of their infections.

The healthcare-associated form of MRSA has been rife in hospitals for more than a half century, generally infecting people with weakened immune systems.

In Australia, cases of CA-MRSA have escalated in recent years. While it is not being seen in huge amounts, the risk to PLHIV is significant and therefore people should be aware of the risks and symptoms.

THE BOTTOM LINE

All these studies point to an increased risk for PLHIV of reasonably

unpleasant if not dangerous bacterial infections. It all sounds like a real bug-bear! However, you can take some very simple steps to reduce this risk.

FOR THE FLU

- Get vaccinated
- Wash your hands often using soap and hot water or a liquid hand sanitiser
- Avoid touching your eyes, nose and mouth and wash your hands after blowing your nose or sneezing
- Keep warm (stay out of the cold and wear warm clothes, especially around the head, face and neck)
- Avoid contact with people who have the flu
- Ensure that your eating and drinking gear is clean

FOR PNEUMONIA

- Commit to quitting smoking
- If you do get the flu:
 - Visit your doctor and re-visit if symptoms worsen
 - Rest and stay warm
 - Drink plenty of warm fluids like soups and tea
 - Take paracetamol to reduce fever and aches

FOR CA-MRSA

Staph lives happily in gyms, locker rooms, prisons, needles and sex on premises venues (SOPV). It's acquired through skin-to-skin contact with anyone, including sexual partners (especially if it's hot and sweaty). It's even found on pets. Staph becomes dangerous if it gets under the skin through routes such as cuts or abrasions.

DON'T GIVE THIS ONE A CHANCE!

- Wash your hands with soap frequently, and shower regularly
- Moisturise to avoid dry and cracked skin - an easy entry for the bug
- Treat all wounds with an iodine-based antibacterial rub (e.g., *Betadine*) and keep covered
- At saunas and other SOPVs and the gym, sit on your towel, wear protective footwear and shower frequently
- Don't share towels and razors
- Don't try to drain your own abscesses
- Only take antibiotics when absolutely necessary and then as prescribed:

complete the course
 ● Use condoms, and if sero-sorting with other PLHIV recognise that there is a risk of CA-MRSA in every encounter (see below for tell-tale symptoms).

HOW TO RECOGNISE IT

Staph infections often begin as a red lesion or bump resembling a spider bite. It can be itchy or painful and grow quickly. It might come to a head like a pimple, but with more pain and pressure.

WHAT TO DO

- Head straight to your doctor to have the sore or abscess examined – regardless of where it is – and drained if necessary. Don't imagine it will go away because it won't.
- Your doctor can start you on antibiotics while the lab checks to confirm what kind of bug you have. Since many staph infections are now MRSA, the best course of treatment is an immediate prescription of antibiotics capable of overcoming resistant cases.
- Make sure you finish your course of antibiotics. As we've seen above: CA-MRSA can recur.

BUGS ARE EVERYWHERE: ALL OVER OUR SKIN, AND INTERNALLY. IF WE'RE LIVING WITH HIV WE HAVE TO TRUST OUR IMMUNE SYSTEMS TO DO THEIR JOB. DON'T PANIC! STICK WITH YOUR HIV MEDS (IF YOU ARE ON THEM). AN INTACT IMMUNE SYSTEM IS THE BEST WAY TO AVOID ALL OF THESE OTHERWISE NASTY BUGS.

MORE ON THE FLU

- www.racgp.org.au/Content/NavigationMenu/About/HealthAlerts/201003FluVaccination_FactSheet.pdf.
- Your local AIDS Council or PLHIV organisation will be able to provide more information on other things you can do to avoid being infected with the coming season's flu viruses. The ACON website provides a useful summary: www.acon.org.au/hiv/news/flu-vaccine.

MORE ON CA-MRSA

- www.public.health.wa.gov.au/3/896/3/camrsa.pm

SOURCES FOR FOOTNOTES IN THIS STORY

Available online www.napwa.org.au/pl

Hiding out in bone marrow

Despite all the drug advances to date, the ability for us to completely eradicate HIV from the body remains elusive. This is because reservoirs of infected cells remain resistant to both our immune response and to treatment.

These reservoirs are thought to form soon after

seroconversion and to contain an original form of HIV that only 'reawakens' under certain circumstances.

In a new study, researchers have found reservoirs of this latent HIV in the 'progenitors' (or parents of blood cells) that are found in bone marrow.

These findings have

major implications for understanding HIV bone marrow pathology and the mechanisms by which HIV causes persistent infection.

The research provides a new target for scientists, but it also presents new challenges because killing off bone marrow cells is a dicey proposition.

In 2007, a positive man

in Germany received a complete bone-marrow transplant and experienced no viral rebound. The case raised interest and many discussions in the community which were then dampened by revelations about the high cost and risks associated with the procedure.

Alcohol, other drugs and depression

In partnership with NAPWA, the National Centre in HIV Social Research (NCHSR) recently completed a three-year study into HIV and depression.

The research provided some valuable insights into how different patterns of alcohol and other drug use relate directly to depression in positive men. Problematic levels of crystal methamphetamine use have been identified as a major contributor to the problem in the community.

With funding from beyondblue – the national



PHOTO: ISTOCKPHOTO.COM/TADEJIZUPANCIC

depression initiative – the NCHSR is proceeding with further research.

Outcomes we hope to see include some specialised training for general practitioners and other healthcare providers

who work with positive clients to help them identify and manage drug and alcohol-fuelled depression.

Look out also for articles in the community press on the subject.

Erectile dysfunction linked to cardio risk

Data from two recent studies suggest that erectile dysfunction (ED) is a common manifestation of cardiovascular risk.

What's more, the treatments for cardiovascular disease used by participants in these studies appeared to have no effect on their ability to get and maintain an erection, suggesting that other approaches are necessary.

While this was not an HIV study (it was conducted in older men of a mean age of 65 – many with a history of heart attack) its findings show that ED is best corrected by addressing cardiovascular risks, such as increasing exercise, stopping smoking, lowering of blood fats (if they are high), and managing diabetes (blood sugar disturbances) and hypertension (high blood

pressure) where they exist.

Viagra, and the like, only remove the symptom of ED, but don't address the cause. In many cases there may be multiple causes so addressing them singly may be the simplest method.

Good-quality sleep, a healthy heart diet along with drinking ample water are all excellent personal initiatives that can be assisted by consultation with a doctor or dietician.

Darunavir expanded access

The Pharmaceutical Benefits Scheme (PBS) has extended access to the new protease inhibitor, darunavir, now making it an option for more people.

The approval follows the results of the TITAN study that showed *Prezista* has fewer side effects than other treatments in the same class. These include heart problems, yellowing of the skin, interactions with ulcer and reflux medication and the more serious and debilitating cases of diarrhoea.

'The HIV community is very pleased that it is now more broadly available,' said Jo Watson, Executive Director of NAPWA.

Prezista has also demonstrated effectiveness in other trials looking at once daily dosing, and monotherapy (taking one HIV drug at a time).

Initial results of another trial have shown that if people have been taking a combination containing the drug and have had an undetectable viral load for six months, they may be able to take *Prezista* alone and still maintain an undetectable viral load. The trials continue.

Vale

Stephen Gallagher
 17 July 1955–22 March 2010
 HIV activist and educator

New drug cures hard-to-treat hep C

People who fail current hepatitis C treatment have few other options except trying the same drugs again, but an experimental antiviral drug is poised to change all that.

In the trial, when the drug telaprevir was added to standard treatment with peginterferon alfa and ribavirin, about half of patients who had failed previous treatment with the two drugs cleared the virus.

The patients showed no evidence of HCV infection six months after completing treatment, which is considered a cure.

Telaprevir is one of two highly anticipated drugs in the protease inhibitor class being studied in patients with chronic hepatitis C infection.

Simple guide to HIV treatment and care for non-nationals

In association with the Australasian Society for HIV Medicine (ASHM), NAPWA has developed a simple step-by-step guide for overseas visitors and new residents living with HIV.

This online tool explains how our pharmaceutical system works, who qualifies for subsidised treatment (and the alternatives if you don't), plus guides you to where you can find appropriate and affordable care in Australia.

View the factsheet at <http://napwa.org.au/access>

To celebrate this important new addition, our website has also gone multilingual. Every page on the NAPWA site, including the online versions of *Positive Living*, is now translatable into 53 languages.

So, welcome, bienvenue and 欢迎 - to people living with HIV everywhere!

Herpes and HIV transmission risk

A number of studies have shown that there is a higher risk of HIV transmission if one or both sex partners have genital ulcers.

Ulcers can provide a portal of entry for the virus, and the inflammation associated with them can result in the presence of a large number of CD4 and other immune cells, which are targeted by HIV. In people with HIV, the virus may also be present in the ulcers.

In a recent study of serodiscordant couples, investigators found that the only two factors significantly associated with an increased risk of HIV transmission were viral load and genital ulcers.

HIV was detected in the lesions of almost 50% of HIV positive men with genital ulcer disease, investigators reported in the April 1 edition of *Clinical Infectious Diseases*.

Herpes simplex virus type 2 (HSV-

2) is the leading cause of genital ulcers, and both symptomatic and asymptomatic HSV-2 have been shown to increase HIV shedding in individuals co-infected with both viruses.

This evidence supports the ongoing use of herpes prophylaxis medication, such as *Valtrex*, particularly for sexually active people with HIV.

<http://www.eatg.org>

Sixth National HIV Strategy launched

While welcoming the launch late last month of the new HIV strategy, there is also concern within the sector that without effective implementation, the strategy's goals cannot be achieved.

NAPWA notes that the development of implementation plans is still ongoing, and that frameworks for robust monitoring and evaluation of the activities associated with an Australian HIV response over the next four years are still needed.

NAPWA president, Robert Mitchell, is eager to

see the goals articulated in the national strategy turned into meaningful actions for the government, community, clinical and research sectors that together make up the national HIV partnership.

'We are now focused on ensuring that achievements will match expectations,' he said at the launch late last month.

'It is critical the government partners provide leadership beyond a surveillance and health protection approach,' Mitchell said, 'otherwise



Chair of the ministerial advisory group, Professor Michael Kidd (left), and NAPWA president, Robert Mitchell, hold copies of the strategies at the official launch in Sydney on May 27

PHOTO:JO WATSON

the implementation plans will be narrow in focus, and not take advantage of the valuable innovations which can be secured with broader collaborations based on sound program logic and identified

priorities.'

The HIV strategy is one of five national strategies. The others are on STIs, hepatitis B, hepatitis C and Aboriginal and Torres Strait Islander blood-borne viruses and STIs.

Acne drug fights latent HIV

Johns Hopkins scientists have found that a safe and inexpensive antibiotic used since the 1970s to treat acne effectively targets dormant HIV-infected immune cells and prevents them from reactivating and replicating.

The idea came about when colleagues at Baltimore University learned of research showing that minocycline had anti-inflammatory effects on CD4 cells in people with rheumatoid arthritis and cystic fibrosis. They also drew on research showing how effective the drug was

in monkeys with SIV (the primate version of HIV) particularly in lowering the levels of the disease in their central nervous systems.

The claim that minocycline, as an add-on therapy to HAART, may help keep the virus locked in a dormant state contradicts the work of other researchers hoping to 'cure' the virus completely.

It remains to be seen which approach, if either, will result in the best long-term clinical benefit for those of us infected with HIV.



PHOTO:ISTOCKPHOTO.COM/REDMONKEY8

NSW out of step with national strategies

The federal government's sixth national HIV and STI strategies have been welcomed for their human rights-based approach to HIV and the law and their focus on an 'enabling environment' to bring about positive change.

Sadly, the proposed changes to the NSW Public Health Bill do not reflect this same degree of insight.

The HIV/AIDS Legal Centre (HALC) claims the bill undermines the success NSW has had in limiting new HIV infections and damages the human rights framework developed in the community.

In a statement released last month, HALC outlined how the proposed bill seriously weakens the enabling

environment, which encourages people to get tested, to get treated and to engage with their healthcare providers.

The bill goes backwards in increasing stigma in relation to HIV by increasing penalties for non-disclosure and reducing the protections with respect to making invasive Public Health Orders, HALC claims. The

disclosure law punishes being HIV positive, not risky behaviours.

Unbalanced provisions for Health Orders increase fear and uncertainty among HIV positive persons and the community at large.

HALC strongly believes several sections of the draft bill will have a detrimental effect on the successful and

internationally recognised Australian response to the HIV epidemic.

Submissions regarding the bill closed in April. Contributors are hopeful their recommendations will be grasped by the NSW government to ensure that the successful Australian response to HIV is maintained and enhanced.

www.halc.org.au

New NRTI no more

Melbourne-based biotech Avexa has announced the closure of its lead HIV program for apricitabine after failing to attract a licensing partner for the Phase III drug.

The shelving of apricitabine does not come as a surprise in the competitive HIV sector, in which market growth is increasingly being driven by fixed-dose combinations (FDCs) such as *Atripla* which offer improved patient convenience.

Furthermore, apricitabine's twice-daily administration impedes its potential for combination with other antiretroviral drugs and limits its scope for use in FDCs.

This is reflected in the fact that there are currently no other NRTIs in late-stage development for HIV.

Exercise goes to the dogs

Scientists at the University of Western Australia (UWA) have identified that the decrease in physical activity that occurs when a person loses a dog is significantly greater than the increase that occurs when they get one.

They found that people who obtained a dog walked approximately 31 minutes more each week than they had in the past. However, dog owners who lost their dog decreased their walking by as much as 44 minutes per week.

'Clearly, this research shows that the level of physical activity a person undertakes is adversely affected by the loss of their dog but the reality is



PHOTO: ISTOCK.COM/ELENA THE WISE

that if you have been walking your dog, there is every reason to keep walking,' says A/Prof Hayley Christian from UWA.

Dr Christian also says that taking the dog for a 30-minute walk each day will also mean that you are achieving the recommended level of

physical activity sufficient for good health.

These results do not surprise health and fitness expert Michelle Bridges, who says she knows firsthand the motivation a dog provides for exercise.

'Winter is the perfect time to start a regular walking program, even if you don't have a dog. You

might be able to help a friend or neighbour out by walking their dog, or just join them on their daily walk. By summer, you'll be seeing the benefits,' says Michelle.

Australia is a nation of pet lovers. It is estimated that 63% of Australian households have some type of pet, with 53% of households owning a dog or a cat.

Over many years, Australian and international research has shown that owning pets can help improve a person's mental and physical health, reduce the effects of stress, help children learn about responsibility, facilitate social interaction between people and build a sense of community.

Serodiscordant study

While it has long been acknowledged that successful antiretroviral treatment and an undetectable viral load lowers the risk of passing on HIV, we have little research to support the fact.

That's why, with support from NAPWA, a group of researchers from the National Centre in HIV Epidemiology and Clinical Research want to conduct a three-year study into the role of viral load in HIV transmission.

If you are in a relationship with another man and one of you is positive and the other is not, we'd like to hear your thoughts on the project. Please go to www.couplesandhiv.net and let us know what you think.

New Women+HIV factsheets

A new set of factsheets designed specifically for women with HIV has just been released. Written in plain English, they are particularly appropriate for women who have been recently diagnosed, including those from culturally and linguistically diverse backgrounds.

While the services listed are only applicable to women living with HIV residing in NSW, the rest of the information is relevant for women across the country.

You can download the factsheets from: www.fpnsw.org.au > Health Information > Factsheets.

The factsheets are currently being translated into four priority languages: Thai, Vietnamese, Khmer and Swahili, and will be available for download soon.



I know for a fact

that my life has become more complicated as I've progressed into my fifties. I seem to have an ever-increasing number of comorbidities to contend with. While I may not be spending the time in hospital I did in the nineties, thanks to HAART, I do have just as medicalised a condition now as ever.

Excluding my HIV doctors, I consult six different specialists. They advise me on my diabetes, risk of cardiovascular disease, early stage kidney disease, risk of eye complications (from diabetes), bone and joint problems and most recently, after a diagnosis of gout, I added a rheumatologist to the list. I have no doubt that all these conditions have some link to HIV and/or its treatments.

With many HIV survivors now aged over 50, we have a situation that is being called a 'mini baby boomer' phenomenon. This older age group now accounts for nearly 30% of the positive population in Australia. When you combine this with the alarming increase in new diagnoses among people over 40 – up almost 70% since 2000 – it all points to a growing vulnerability for those of us growing older with HIV.

Some of the research suggests that people in their forties who have lived with HIV for ten years or more have the organ systems of someone in their fifties. This may not present as a particular problem – but if you get into your sixties with advanced ageing and much older organ systems, the potential for life-threatening morbidities and the need for extra medical and even nursing care will likely become a serious issue.

A study presented at this year's CROI conference, for instance, showed that 61% of a cohort of HIV positive people over 60 had at least two comorbidities, whereas only 12% of the negative cohort lived with that many conditions (see Fig. 1, page 8)¹.

When I talk about this with my positive peers, many of them point out



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

CONFRONTING THE RESEARCH

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

than that.

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

Here are some of my other research findings:

- Even if treatment keeps HIV below the level of detection there are still

low levels of virus present. This means that the immune system is always activated. This activation can result in chronic inflammation causing many of the complications associated with ageing. This has been seen in other autoimmune diseases such as lupus where women with lupus have a high level of coronary heart disease (atherosclerosis) caused by chronic inflammation and abnormalities in cholesterol and lipids (as in HIV disease). It will be difficult to find treatments that both boost and suppress immune systems at the same time.²

- There are four big things that doctors are seeing in positive patients presenting in their practices in the US. These are: cardiovascular disease; non-AIDS malignancies (including cancers such as lung cancer); liver diseases (particularly in those co-infected with hepatitis C); and kidney disease. Australian studies show similar trends.

- A study at last year's CROI conference showed that the cerebral blood flow in positive people was very similar to that of negative people who were ten to fifteen years older. This may be one reason we are seeing more people with low-level cognitive impairment.³

- Another study presented at CROI in 2009 showed that HIV seems to be associated with vascular ageing. The blood vessels in positive people show less ability to dilate which translates to stiffer vessel walls. This is similar to vascular function seen in HIV negative people who were 25 years older and would contribute to higher levels of cardiovascular disease.⁴

- People with HIV seem to lose T-cell function faster when they get older. Even if people have reasonably high T-cell counts it seems that they work less well. In one US study, the T-cell patterns of PLHIV with a median age of 56 were consistent with people aged in their late eighties.⁵

- People who lived with

PHOTO: ISTOCKPHOTO.COM/KANGAH

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

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

What are we to make of these fairly pessimistic findings?

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

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

ANOTHER KIND OF AIDS CRISIS

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

In Australia there is building awareness of the HIV ageing issue, and HIV advocates were able to get the issue included as a priority in the new Sixth National HIV Strategy.

How we plan at a government and HIV sector level for the care needs of this 'baby boomer' group is going to be crucial.

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

'There is a huge capacity problem particularly facing NSW,' he says. 'HIV

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

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

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

'These people don't realise that our current services won't be able to cope. When you suggest pilot programs for interventions, we're told to ask the Department of Ageing. They tell us it's the Health Department's AIDS Branch's business,' Ross despairs.

'Passing the buck on funding and planning for the issue won't help anyone,' he says.

SERVICE GAPS APPEARING

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

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

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

'Of course there may come a time when it is not possible to keep clients with serious physical or

mental impairment in their homes. And while there are some HIV specific care facilities in Sydney, such as The Bridge,' he says. 'There is limited capacity.'

David's team can act as advocates to help facilitate access for people to aged care facilities. They consult with nursing home staff around any issues they might have with the management of HIV care needs.

The most disadvantaged group would be clients aged 45-65 who require the level of care provided by nursing homes but are too young to meet the age requirements through an ACAT assessment.

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

Many of his older clients are also too young to qualify for government aged care packages to look after them in their homes. They are managed with a variety of other community supports, such as home care and community care options, which may or may not meet all of their needs.

Similarly, the Victorian HIV Consultancy at the Alfred Hospital deals with people with more complex conditions, including older positive people.

Karen Blyth, Clinical Nurse Consultant with the service, finds she is spending an increasing amount of time negotiating with aged care and supported accommodation facilities on behalf of her frailer clients with HIV. This involves educating about transmission risk and infection control, in addition to the importance of ongoing HIV therapy and any specific cultural needs her clients may have

MAKING AGED CARE HIV-FRIENDLY

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

'Tom (not his real name) and those involved in his care were concerned about how his social needs

as a gay man would be met in a nursing home,' says Karen.

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

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

'I'm only 64 but I'm an old man. The HIV makes me feel old.

I've got no one to talk to because the residents sleep all day and have dementia. My mind is still good but I have no conversation. I talk to Lizzi: she's my Community Support Officer from the Victorian AIDS Council. I talk to her about how much I miss sex, touch and intimacy.'

—Tom, nursing home resident

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

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

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

That we have AIDS Councils who still continue to provide care and support services is also something we must fight to protect. As the demands of an ageing population become more apparent they could act as trainers of mainstream care providers who will need to become involved if

the load on current services is too high. They can also advocate for best practice, ensuring that issues like the cultural acceptability of aged care facilities are dealt with appropriately.

The issue of gay and lesbian ageing is being discussed concurrently in a number of states. Several reports have already produced recommendations for further investigations into possible gay-specific nursing homes or partnerships with aged care providers and the need for training of aged care workers in gay and lesbian sensibilities. These include *Ageing Disgracefully*, ACON's Gay Lesbian Bisexual and Transgender Ageing Strategy, and *My People*, Victoria's Matrix Guild report.^{6,7}

Queensland University recently funded a research study into older lesbian and gay people's care networks to see if they are more isolated from mainstream supports, such as families, and how culturally sensitive age care providers are in that state.

Whether those people who are both gay and HIV positive will benefit from these initiatives is yet to be clear as no government has yet made any funding commitments or even taken up the issue as a priority. Many HIV positive people will not be able to wait for long-term solutions.

PSYCHOSOCIAL SUPPORT

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

Many of these men are no longer part of the gay community and are not looking for sexual contacts. They have lost the networks that come with that. The high cost of rents in inner-Sydney has forced some of them out to the Western suburbs and many are finding the friendships and supports they once had harder to maintain.

When you add poverty into this equation and the loss of an ability to have

much of a social life, the need for peer support groups for these men is evident. It may be about establishing a regular walking group, card nights or subsidised social events. The current drop-in centres are not always the best fit for these people.

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

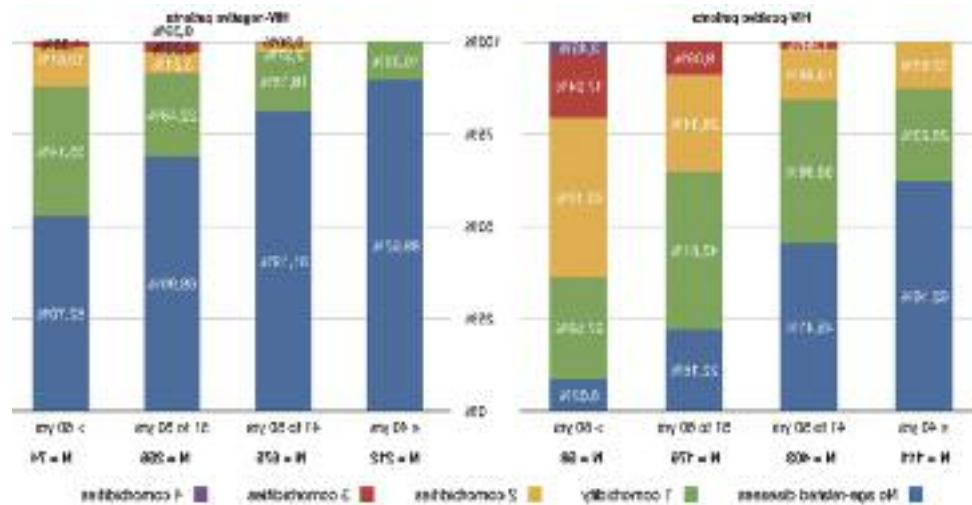
'They are very afraid of the HIV-unfriendly environment they may be forced to live in, that their lifestyles and sexuality will not be accepted. Some even said they would prefer to take their own lives rather than have to endure it.'

Jo Watson, Executive Director of NAPWA, agrees with Ross that specialist training of workers will be a necessary component of preparing the aged care sector for the coming HIV positive caseload. But she also stresses that aged care is just one of the options that should be available for positive people.

She proposes we trial a new model of supported accommodation for positive people. Funded by the Federal government, the model needs to demonstrate the best way to meet the care needs of this group.

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

Fig. 1 Multiple comorbidities: HIV versus controls



Comorbidities analysed: hypertension, Type 2 Diabetes Mellitus, Cardiovascular disease and osteoporosis

Guaraldi G et al. CROI 2010. Abstract 727

This graph, presented at CROI this year, shows a much higher percentage of positive people with comorbidities compared with HIV-negative controls at any age. The comorbidities that were chosen were hypertension, diabetes, cardiovascular disease and osteoporosis.

IN CONCLUSION

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

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

- The need for a strategy

developed between the HIV sector and federal and state governments that recognises premature ageing in people with HIV as an issue which requires attention and resources. Getting the issue on the recently approved National HIV Strategy is a start, but the Implementation Plan that goes with the strategy needs to include specific initiatives – and pilot programs – to plan for the future.

- Advocacy needs to take place so that older people with HIV and advanced care needs can access aged care packages before the

current eligibility of 65 years of age. This is to recognise the earlier onset of ageing and morbidity in this group.

- Attention should be given to developing Model of Care guidelines for all older people with HIV (say, after age 50) to allow for yearly neurocognitive screening, DEXA scans for bone-thinning and other signs of ageing morbidities.

- Training packages for staff in aged care facilities need to be developed to sensitise them to the needs of people with HIV as a client group.

● **If you're concerned about the personal implications of ageing, we recommend a new resource from AFAO and NAPWA called *Ahead of Time – a practical guide to growing older with HIV*. The booklet gives commonsense perspectives on coping with the physical and mental changes involved with ageing and some useful tips to try to prevent its early onset. It is available from AIDS Councils and PLHIV groups nationally. You can also download a copy from the NAPWA website <http://napwa.org.au/living-with-hiv>**

● HIV sector agencies should develop specific interventions to help reduce isolation and provide psychosocial support for older PLHIV.

REFERENCES

1. Guaraldi, G. et al "Prevalence of Poly-pathology is More Common in HIV-infected Patients than in HIV-negative Controls in any Age Strata", CROI 2010 Abstract 727
 2. O'Neal, R. "Aging and HIV: A Conversation with Dr Malcolm John", *BETA*, Summer/Fall 2009, pp37-39
 3. Ances, B. et al "Additive effects of aging and HIV serostatus on cerebral blood flow", 16th Conference on Retroviruses and Opportunistic Infections, Montreal, February 2009, Abstract 157
 4. Van Guilder, G. et al. "HIV-1 infection is associated with accelerated vascular aging", 16th CROI, Abstract 731
 5. Op cit O'Neal, p38
 6. Barrett, C. "My People", a project exploring the experiences of Gay, Lesbian, Transgender and Intersex Seniors in aged care services, Matrix Guild in conjunction with Vintage Men Inc, June 2008.
 7. Berry, S. "Ageing Disgracefully", *acon's healthy gbt ageing strategy 2006-2009*, 2006.
- Thanks to Jennifer Stewart from the Education and Resource Centre (HIV Hepatitis C and STIs) and Professor Jennifer Hoy at the Alfred Hospital, Melbourne for help with this article.

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Good cardio health is becoming more and more important for people with HIV. Sean Slavin explains why and the steps we can take to improve our prospects.

The life expectancy of people with HIV living in developed countries is fast approaching general population norms. We know this is a result of better treatments. But this optimism is tempered by a range of other conditions that are appearing as PLHIV get older and live longer.

One issue that is getting a lot of attention these days is cardiovascular disease (CVD). Several large international studies have shown that PLHIV are one and a half to two times more at risk of getting CVD than HIV negative people.

While trying to understand what might be driving this elevated risk, researchers have reached a number of conclusions.

Firstly, certain HIV treatments are associated with an immediate elevated risk of CVD. This risk has been well studied and doctors are now able to keep patients off these drugs if necessary.

Secondly, many of the risks associated with CVD in the general population – such as smoking, elevated cholesterol or hypertension – are widespread among PLHIV.

Thirdly, HIV itself seems to play a role in elevating cardiovascular risk. It is clear from studies that compare PLHIV on treatment with those who are not, that uncontrolled virus is a significant risk factor for heart disease. But even among people taking treatment the risk is still elevated. The reasons for this are not entirely clear but some researchers have speculated that even very low levels of viral activity, below what is detected by the viral load test, may induce an inflammatory immune response that, over many years, can exacerbate such conditions as hardening of the arteries.

Setting HIV aside for the moment, what are the major risks for cardio-



vascular disease? They fall into two main categories: those we can't control and those we can.

The three uncontrollable risks are age (risk increases as we get older), male sex and family history or genetics.

The risks that we can influence are abdominal obesity, elevated cholesterol, hypertension (high blood pressure), diabetes, smoking and depression. This seems like a daunting list, especially when we consider that modern life seems to drive so much of it, but the fact we can act to reduce the risk is part of the good news and making a few simple changes can have an impact on multiple risk factors.

Let's look at each risk in more detail.

ABDOMINAL OBESITY (carrying extra weight around the gut) is more of a risk for CVD than carrying it elsewhere. Unfortunately, this is a particular problem for men, who typically put on abdominal weight as they age leading to the common potbelly. It's

recommended that men try to keep their waist circumference below 94cm and women below 80cm. Another way to think about weight is using the Body Mass Index (BMI) which should be between 18 and 25. You calculate your BMI using the following formula: weight (kgs)/height (m)².

CHOLESTEROL is measured using a blood test. If your cholesterol is high, there are a number of strategies available depending on how high it is and whether you have other risk factors. A healthy diet low in saturated fats is a good start and fish oil capsules have also shown to be a benefit. For some people drugs called statins may be prescribed to lower cholesterol.

BLOOD PRESSURE when elevated places stress on the heart and the arteries that supply blood to the heart. Over time this increases the risk of heart attack. Reducing salt in your diet is a good way to start controlling blood pressure as is maintaining a healthy weight, taking regular exercise and

limiting alcohol consumption. If these things don't lead to a reduction then medications are available.

DIABETES is an intolerance to sugar in the blood and must be diagnosed using a blood test. Diabetes can be improved through various lifestyle measures including healthy eating, weight control and smoking cessation. In more serious cases insulin therapy may be recommended.

SMOKING is a well-understood risk for CVD and can also exacerbate many of the other risk factors already mentioned. The benefits of smoking cessation are widely known and support is available to quit from doctors, AIDS Councils and PLWHIV organisations.

Last but not least, psycho-social factors such as **DEPRESSION** are now recognised as independent risks for CVD. Allowing depression to go untreated can be both emotionally and physically damaging. A combination of counselling and anti-

depressant medication seems to work best for most people with depression. Talk to your doctor about the options.

In looking at these different risks and thinking about how to address them it's important to know one thing. Cardiovascular risks multiply one another, they don't just add to each other. That means that if you have three or more risks your total risk of CVD is exponentially higher than if you only have one. That's the bad news; but the good news is that by addressing one or two risks you get a significant reduction in your total risk.

Given that having HIV is roughly equivalent to the risk of smoking it pays to come to grips with this issue. There are a number of common themes here: diet, exercise and smoking. What's recommended is a diet low in saturated fats, salt and sugar, with plenty of fresh fruits and vegetables and limited processed foods.

Half an hour a day of moderate exercise such as brisk walking will fulfil the exercise recommendations, and more than ever it's time to think about quitting the cigarettes.

What works for most people and tends to be sustainable are small regular steps in the right direction rather than dramatic diets or exercise regimes. Likewise with smoking, using nicotine replacement therapy for several months is more likely to succeed than going cold turkey.

Last but not least, if you are over forty make sure you get an assessment from your doctor that includes family history, blood pressure and cholesterol. Knowing your level of risk is the first step towards reducing it and taking small steps that work for your lifestyle is better than doing nothing.

Don't let the fitness and diet fanatics daunt you. Develop some habits that are achievable and enjoyable and the pay-off in quality of life will be significant.

Sean Slavin is NAPWA's Assistant Director in charge of research programs.

PHOTO: ISTOCKPHOTO.COM/CJP

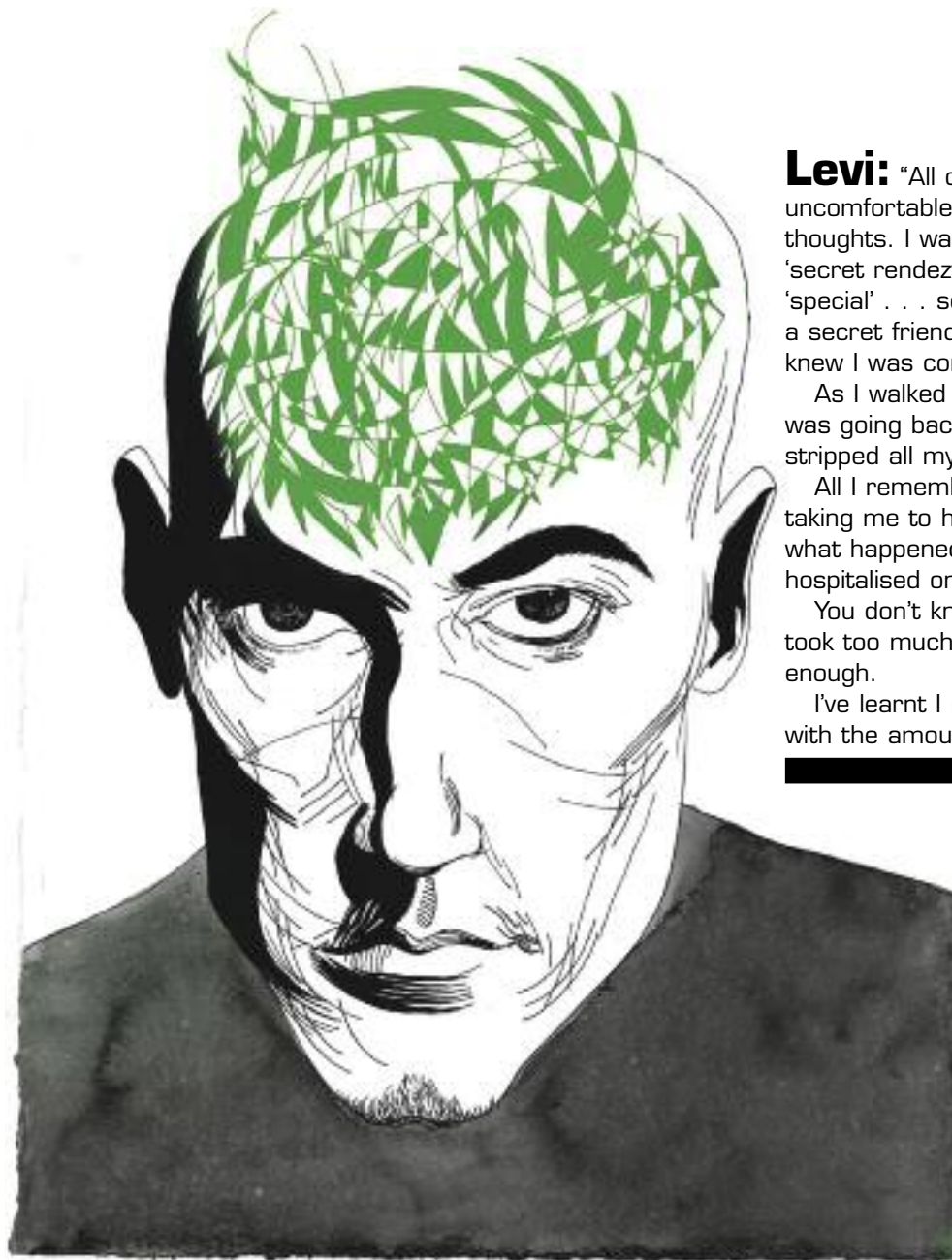
We've all heard about it. Some of us have tried it. A few of us use it regularly. **Dr Fiona Bisshop** reminds us of the dangers.

Crystal meth, also known as Tina, Ice and Meth, is basically a super-strong form of amphetamine (or speed). It can be smoked, snorted, swallowed or injected, and is usually sold as clear crystals, white powder or a pill.

Taking crystal makes the user feel hyper-energised, invulnerable, confident, very horny and less likely to feel pain. Crystal raises your blood pressure and your body temperature and can increase the risk of heart attack or stroke. Users can often go days without eating or sleeping, and coming down they can feel exhausted, aggressive and sometimes even paranoid. The come-down can be so hard that sometimes people resort to other drugs such as alcohol, Valium or even heroin.

It is a drug that is often used for energy for non-stop dancing or sex. However, it is harder to get a good erection on crystal, so users will often have to take Viagra at the same time so that they can fuck all night.

People who use crystal are more likely to take part in risky sexual behaviour, and more prolonged sexual encounters, and to injure themselves during sex, which vastly increases the risk of catching a sexually transmitted infection such as HIV or hep C (remember your condom is only likely to last a short time if you're really going for it – put on



Crystal meth and HIV

a new one after 30 minutes of fucking).

Combining crystal with some prescription drugs is dangerous – if you're on an antidepressant you can get a life-threatening reaction from taking crystal. If you

have HIV and you're on a PI (protease inhibitor) you could accidentally OD on crystal. Not to mention the fact that it suppresses your immune system (which you really don't need if you have HIV

already).

It is highly addictive, and tolerance develops rapidly, which means you need more and more of the stuff to get the same effect. Long-term use can lead to serious mental

Levi: "All of a sudden I had uncomfortable and strange sensations and thoughts. I was convinced I had to go to a 'secret rendezvous' to meet someone 'special' . . . someone out of the ordinary, a secret friend, a 'healer' . . . and they knew I was coming, we were connected.

As I walked to find him, I felt the world was going back to its natural state, so I stripped all my clothes off.

All I remember next was the ambulance taking me to hospital. I have no memory of what happened in between. I was hospitalised one week.

You don't know what's in Meth – maybe I took too much, but you don't know what is enough.

I've learnt I need to tread more carefully with the amount of gear I take."

health problems such as psychosis.

Lastly, remember that, as with all street drugs, you never really know what you're getting and how strong it is – plenty of people have come to serious harm or even death through assuming they know how to use a drug like this safely, only to find it's a much stronger batch.

■ If you need more information, try these websites:

- www.rightnow.acon.org.au/crystal_meth
- <http://drugfucked.tht.org.uk/>

Dr Fiona Bisshop specialises in LGBT health at the Central Brunswick Medical Centre in Fortitude Valley, Queensland. This article first appeared in QNews in March 2010.

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What's in my blood?

Sandra from Tasmania

writes: I often wonder why they take so many vials of blood whenever I go to get my counts done. Why do they need so much blood? What do they do with it apart from T-cell and viral load counts?

When my results are in, my doctor generally looks at them and just says 'everything looks fine'. I guess he'd tell me if something was wrong but I feel like I should ask him more questions. Or should I just stop worrying?

Dr Louise replies: That's a good question, Sandra. Those of us in health circles often do things out of routine without always explaining what we are doing.

As you say, the two main things we look at are viral load and CD4 count – and each test requires a separate vial of blood. We usually do a Full Blood Count (FBC) to check your platelets and levels of haemoglobin and other white cells (WBC). HIV and some medications can affect these parameters, so it is important we monitor them regularly.

We often request a Liver Function Test (LFT) because the liver can be affected by medications, infections (such as hepatitis), alcohol and other drugs, and it's important we detect any

what's your PROBLEM?

Doctor Louise answers your questions



PHOTO RICK WALLIS

changes early so we can look into the reasons why.

Syphilis serology is a very simple test which can be done from the same vial as the LFTs. Not everyone with HIV is at risk of syphilis, so we order this test as required. But detecting it early is important because syphilis is often asymptomatic and is easily transmitted. It can also have a window period so even after a negative result we may need to retest for it.

Kidney function is another routine test. And once a year we often add a few extra ones, including fasting bloods for cholesterol, triglycerides and blood sugar and vitamin D levels. A urine test is often done annually to screen for protein, sugar and blood.

All these things are part of a set routine and we generally only let you know if there is something wrong. But don't ever be afraid to ask questions – that's what we're here for.

Repeating on myself

Joe from Sydney writes: Is reflux something to worry about or is it just a discomfort that you put up with? Can it lead to anything else?

I'm a guy in my fifties and get reflux quite badly, particularly after eating and at night. The doctor put me on *Pariet* which does help but I still suffer from it occasionally.

Dr Louise replies: What you are describing is quite a common condition, Joe.

It can be called reflux, indigestion or heartburn but the common medical term is Gastro-oesophageal Reflux Disease (GORD). It is a condition where acid from the stomach enters the oesophagus and causes a burning sensation in the chest. Sometimes you also get the feeling of acid regurgitating up into the throat.

We always ask people to describe their exact symptoms, take a thorough history and do an examination.

Smoking, obesity and some medications such as Non-steroidal Anti-Inflammatory Drugs (NSAIDs) and Aspirin are risk factors for this condition.

Some people find they have symptoms when they have a lot of worry or stress.

In severe cases of immune suppression, Candida (thrush) can cause oesophagitis and present with these type of symptoms.

Sometimes, general measures help. We suggest people reduce their intake of acidic food, pastries, coffee and alcohol (particularly late at night). We look at people's stress levels and if they smoke, we seriously suggest they consider quitting. Some people find that even a small reduction in weight (particularly around the

abdomen) can improve matters.

The initial treatment is usually antacid agents such as 'proton pump inhibitors' for four weeks (*Pariet* is one example). If the symptoms don't improve or if there are other signs such as pain that wakes you at night, loss of appetite, loss of weight or vomiting, we may recommend a gastroscopy. This is an investigation done under light anaesthesia to look inside the oesophagus and stomach for inflammation, ulcers or more serious pathology. Often we look for the bacterium *Helicobacter pylori* at this time too. If this is positive, then a short course of antibiotics along with antacids is prescribed.

It is important to talk to your HIV doctor or pharmacist before taking any antacid preparations as they can interfere with some HIV treatments. Atazanavir is one in particular that can be rendered less effective by some antacid medication.

Keep your questions under 100 words and email them to pl@napwa.org.au.

Dr Louise Owen is Clinical Director of the Centre Clinic in St Kilda. Her advice is not meant to replace or refute any advice given by your own doctor as your individual medical circumstances are best dealt with by your own practitioner.

With a background as a psych nurse, **Jae Condon** also has a good handle on the emotional issues many of us encounter along the way.

Chris came to see him shortly after moving to Sydney.

Only recently diagnosed and new to a big city, Chris was feeling anxious and depressed. He was also drinking heavily. Chris talked to Jae about how much he feared HIV treatments, particularly their side effects and how sick they would make him.

Jae reassured him that most treatment regimens these days have little to no impact on day-to-day life. He lined him up with a compatible HIV doctor and together they encouraged him to seek support for his drinking.

Sober for several months, Chris has now made new friends in Sydney. He has lined up some casual work and feels optimistic about his health and his future.



TALES FROM The network

THERE IS A NETWORK OF WORKERS LOCATED AT AIDS COUNCILS AND PLHIV ORGANISATIONS AROUND AUSTRALASIA WHO UNDERSTAND THE VARIETY OF TREATMENT ISSUES FACED BY POSITIVE PEOPLE. WE CALL THEM THE TREATAWARE OUTREACH NETWORK (TON).

He also remains engaged with ACON's counselling service and has enrolled in their next Genesis workshop for recently diagnosed gay men.

Carol is another one of Jae's clients. Unlike Chris, Carol's HIV had been diagnosed late, and only because she had started to manifest some serious health problems.

When she and Jae first met, Carol had already lost a lot of weight. She was having problems

with her memory and was feeling depressed, particularly about her relationship with one of her adult children.

With Jae's support, Carol found a female HIV doctor with whom she could talk openly about the specific issues that impact on women with HIV. She was prescribed medication for depression and anxiety and now receives regular counselling as well as ongoing support through the ACON Women's and Families

Affected by HIV project.

She also saw a dietician and has started taking dietary supplements.

Jae also helped Carol find temporary accommodation with an HIV-specific housing service and linked her up with the Bobby Goldsmith Foundation (BGF) who are helping her look for training that will lead to paid work.

The last time she saw Jae, Carol said that she was feeling fantastic.

Jae Condon is the Treatments and Client Support Officer at ACON in Sydney. Among other things, he helps people access HIV-friendly and affordable dental care, maintains a vitamin and supplement service and writes news items on developments in HIV for the ACON website.

Jae works out of the Positive Living Centre in Surry Hills. If you have any questions about the services they offer or you'd like to arrange an appointment, call 02 9699 8756.

PHOTO: ISTOCKPHOTO.COM/GLOBALP

As a young man, **John Rule** remembers trawling through bookshops looking for a history, some way to understand the burgeoning of gay life that he was a part of in Sydney at the time.

In 1980 I found Gore Vidal's short story collection *A Thirsty Evil*. Vidal had published this in 1956 and the short story entitled 'Pages from an abandoned journal' gave me license to do my own recording. The story signalled to me that it was okay to pick things up, drop them at will, leave sentences half completed and to write, in my own space and time, what was of importance to me. In other words: to 'abandon' myself. I offer here, a few pages from my abandoned journal.

April 1990

We travelled from the Mountains to Sydney and had a picnic tea on the harbour at Lady Macquarie's Chair. While crazy Japanese weddings went on around us, we watched a full moon rise up over the harbour. A warm evening, a pink sky; the Sydney I love.

After that we went to see *Death in Venice*, a classically gay opera written by Benjamin Britten for his long-time lover, Peter Pears, to play the lead role of Aschenbach. Dark gondoliers ferrying a dying man around Venice – it was a reflection of our living dreams. Graeme Murphy also staged his dance version around this time. In his Venice it was all men in white towels and saunas and death.

Our cultural artefacts are reflecting what's happening. It is Sydney, gay Sydney at the turn of the decade and beautiful young men are dropping like flies.

On the following Monday, after seeing the opera, I attended Brian McGahan's memorial service. Tim died two years ago and Eric will die soon and too many other names to be recalled.

January 1997

I can hear the thumping noise from some factory in East Brunswick. A dog barking somewhere, trams rattling away, occasionally an airplane overhead;

they've all gone to work and I have some time alone.

It seems they have all been reading the book by Eric Rofes, *Reviving the Tribe*, and talking about borrowed time. But I'm nervous of slogans. I'm not sure whether a tribe can be revived – all those dead men can't be danced back into life – and I don't seem able to muster the resources to deal with a concept like 'time'.

Despite myself not wanting to use images of tribes or war, anything I try to write about HIV becomes filled with war imagery. Even the information from a conference in Europe about new HIV drugs I re-write as: There are reports from afar about changes, but lines of communication are hard to keep open when some on the ground still believe that photon machines will preserve their

immune systems.

It's true though. Some are so dazed by this war they really don't know who to believe. (I don't believe in photon machines but the fellow I had sex with yesterday did. Sadly, he believed a photon machine he had in the corner of his flat would protect his declining CD4 counts.)

May 2001

He said he was watching his life flickering on the back of his eyelids – he sounded kind of surprised but not disturbed. The room in which he died faced the mountains. I remembered the way I watched the cloud shadows pass over the mountains and sitting there with dad thinking, yes, this is what life is. The sun is there, the clouds are moving, the mountains are

there and I can watch this shadow play across the mountains. It was a beautiful day, so clear, the sun so strong and the cloud shadows I could see I imagined were similar to the images moving through my father's mind.

From Italo Calvino's *Six memos for the new millennium*: Who are we, who is each one of us, if not a combination of experiences, information, books we have read, things imagined? Each life is an encyclopedia, a library, an inventory of objects, a series of styles, and everything can be constantly shuffled and reordered in every way conceivable.

January 2010

The Black American poet, Essex Hemphill, who died of AIDS, writes of his own

attempts to return to home and community, to return to what was. After all the searching, he says simply: 'I cannot go home as who I am, and that hurts me deeply'.

This year I have been working on a project about HIV-related stigma and discrimination. Often those words have come into my mind about the experience. I cannot go home as who I am, and that hurts me deeply.

My other favourite writer is the ageing lesbian poet, Adrienne Rich. Her recent collection of essays, *The Human Eye*, begins by recounting the way she became friends with and interested in the poetry of Thomas Avena.

Thomas Avena, amongst other things, was the curator of the Smithsonian AIDS history project Face to Face. He was also the editor of a literary magazine which rewarded its contributors with food items, such as smoked salmon, in exchange for poetry.

Adrienne Rich, famous and celebrated poet, was happy to exchange her poetry for smoked salmon. And she was actually more interested in getting to know Avena and his poetry than in having her own work published in his magazine. Having read some of his poetry now, I can understand why.

In his collection, *Dream of order*, are the lines: 'We still crave the body/but we need/its avoidance/and what we want/is impossible.'

This sentiment probably cannot be captured in HIV prevention messages or campaigns. But I think there is something here with explanatory power and, if understood, could help reduce the moralism that exists about HIV and its transmission. We still crave the body but we need its avoidance and what we want is impossible.

Until recently, John Rule held the position of Deputy Director at NAPWA. Rather than us writing a tribute to his many years of service to the organisation, we asked him to contribute something of himself. And he did. We thank him for this and for all the other things he's given us over the years and wish him well for the future.



Pages from an abandoned journal

PHOTO: ISTOCKPHOTO.COM/WHITEMAY