

# PositiveLiving

a magazine for people living with hiv/aids ■ july 2008

16 PAGE  
COLOUR  
SPECIAL



## SIX PERSONAL STORIES

*Tips to improve your health and get balance in your life*

Ask us a  
question  
that's been  
on your  
mind

# 1800 817 713

Treatment infoline for people living with HIV  
[www.treataware.info](http://www.treataware.info)

MONDAY  
TO FRIDAY

2-7PM

EASTERN STANDARD TIME

 **treataware**  
A PROJECT OF **napwa**  
NATIONAL ASSOCIATION OF PEOPLE LIVING WITH HIV/AIDS

# AIDS is over (for some): WHO CHIEF

The head of the World Health Organisation (WHO) Kevin de Cock caused some controversy with a recent statement that, apart from African countries, "it is very unlikely there will be a heterosexual epidemic in other countries. Ten years ago a lot of people were saying there would be a generalised epidemic in Asia – this doesn't look likely." An extensive heterosexual spread was also unlikely in Russia, he said.

The statement also noted that, "AIDS still remains the leading infectious disease challenge in public health. It is an acute infection but a chronic disease. It is for the very, very long haul. People are backing off, saying it is taking care of itself. It is not." He also spoke of a crisis in the industrialised world where "transmission among men who have sex with men (msm) is not declining

and in some places has increased." In the developing world too, he said msm transmission had been neglected and was at higher rates than first thought.

His comments were seized on by conservative reporters (including from *The Independent* in the UK) as an admission that the UN and WHO had exaggerated the risk of a heterosexual pandemic and spent vast sums of money

on people who were not at risk of the virus rather than concentrating on high risk groups such as msm, intravenous drug users and sex workers.

Later WHO and UNAIDS issued a clarification to refute what they perceived as misinterpretations, particularly by *The Independent*, on the organisation's position on heterosexual transmission. "Heterosexual transmission continues to drive the

epidemic among sex workers, their clients and their clients' partners. In addition prisoners, injecting drug users, as well as men who have sex with men, may also engage in heterosexual relationships . . . AIDS remains the leading infectious disease challenge in global health. To suggest otherwise is irresponsible and misleading."

[www.independent.co.uk](http://www.independent.co.uk)

## UN BOSS: Stop travel restrictions for HIV+ travellers

UN Secretary General Ban Ki-Moon has called for an end to all discrimination against people with HIV, including restrictions on travel for HIV-positive travellers into some countries.

"It is still shocking that there should still be discrimination against those at high risk, such as men who have sex with men, or stigma attached to individuals living with HIV," said Ban, addressing the UN General Assembly gathering to review the targets on HIV/AIDS set in 2001 held in the first week of June.



Seventy-four countries currently have travel restrictions against people with HIV – including Colombia, Iraq, Omar, Qatar, Yemen, Saudi Arabia, Russia, Solomon Islands, South Korea and the United States.

■ For more information on travel if you are HIV positive check out [www.positive-travel.info](http://www.positive-travel.info) or ask your local HIV organisation for a copy of the resource *Up Up and Away*.

[www.abc.net.au](http://www.abc.net.au)



## NAPWA Treataware project launched

NAPWA's Treataware Project, a phone line, clinical trials website and booklet giving advice on treatments and living well with HIV, was launched by Dr Jonathan Anderson, President of ASHM on May 19 in Sydney.

"The Treataware project is about encouraging people with HIV to be informed, empowered and involved in their health care decision making," said NAPWA Health and Treatments Co-Convenor Bill Whittaker. "It is to help them to know the basics about HIV; to know the issues about when to consider treatment; and to know the best options for maximising their health and wellbeing."

"The project consists of

three components. The *Treataware infoline* is a national, free, and confidential service where trained HIV treatment educators provide information about treatment, health planning and related health issues to people living with HIV.

"The second is the *Clinical Trials Website*. Its purpose is to provide an independent, central information point about HIV clinical trials that positive people can go to.

"There is also a *Checklist Guide* to getting the best health care. This printed booklet takes people step by step through the key issues that they should consider in health planning and decision-making. It covers issues

like when to start treatment, adherence, how often various clinical checks are needed, safe sex and injecting; and steps to support general health and wellbeing."

like when to start treatment, adherence, how often various clinical checks are needed, safe sex and injecting; and steps to support general health and wellbeing."

■ The Treataware infoline 1800 817 713 is available 2pm-7pm EST Monday to Friday.

■ The clinical trials database and the Treataware checklist guide can both be found at [www.treataware.info](http://www.treataware.info). Also see <http://au.youtube.com/user/treataware>

## Nationals MP supports revitalised HIV response

In a welcome intervention to put HIV on the agenda of federal parliament, Nationals MP for Riverina, Kay Hull, moved a private member's bill in the House of Representatives on June 23, asking for bipartisan support for a revitalised response to HIV in Australia.

"We have now seen four strategies. My belief is that we are now heavy on rhetoric and principles but we are most definitely lacking leadership and drive in the delivery of a real HIV Strategy," she said.

Hull's motion was supported by Yvette D'Ath (Labor, Petrie) who ensured the House that, "the Rudd Labor government is committed to reinvigorating the partnerships between governments, researchers, clinicians and affected communities."

## Piot steps down from UNAIDS

Peter Piot, the Executive Director of UNAIDS for the past 13 years, is stepping down at the end of this year. UN Secretary General Ban Ki-Moon described Piot as "a tireless leader who has been in the vanguard of the response to AIDS since the earliest days of the epidemic." A replacement has not been announced.

[www.reuters.com](http://www.reuters.com)

# Why the need for this campaign?

Phillip Keen explains the background to the development of the HIV Balance campaign and the stories on the following pages.

Since 1996, improvements in antiretroviral drugs (ARVs) have meant that most people with HIV in Australia have been leading much longer and healthier lives. In recent years, however, evidence has emerged that people taking ARVs can face increased risks of cardiovascular disease, diabetes, and other conditions. These risks are related to some of the particular side effects of ARVs.

It is now clear that maximising health involves more than taking pills on time and proper monitoring. The risks of developing cardiovascular problems, diabetes and osteoarthritis can be significantly reduced by stopping smoking, maintaining good nutrition, and increasing exercise or activity. Managing alcohol and other drug use, and staying in control of mental health and stress levels are, as always, other important factors affecting wellbeing.

But changing lifestyles and old habits can be pretty challenging. Getting a new cookbook and gym membership are the easy bits. Everyone who sets out to live a healthier lifestyle will have setbacks along the way. Illness, motivation, lack of money, and many other things can become barriers. The temptation to cut loose and party hard with friends can be hard to resist. In the end, the process is about finding a way to balance our goals and strategies about healthier living with a liveable level of fun and indulgence.

In this special edition of *Positive Living*, six people with HIV have shared their stories with us about how they have incorporated healthier lifestyles into their routines, and how they have coped with setbacks. We also spoke to some service providers who specialise in areas like nutrition, exercise, and quitting smoking about their experience working with people with HIV, and the advice they have for people starting or maintaining a health program.

If you're considering making some changes in your lifestyle but feeling a bit daunted, then the good news is that just thinking about making a change is the first step. Once you start, you may be pleasantly surprised at the results; everyone we spoke to had been pleased by how much better they felt after even the smallest changes. Feeling good helped in staying motivated, or setting new goals.

There are loads of programs and resources available to help in working out where you might want to go in developing a healthier lifestyle, and to support you along the way. Some of these are listed at the end of the articles and some can be accessed through your local HIV organisation. We hope that there will be something in these stories that can help all our readers think about making a start towards better balancing HIV and lifestyle.

## SIX PERSONAL STORIES

### Managing HIV. It's about balance.



#### Editor's Note

*"It all comes down to balance. I've made changes and adjustments but it certainly doesn't mean I've become this carrot-eating health freak who is anti-everything."*

This quote from Scott's story in the following pages captures something of the honesty, humour and meaning of the HIV Balance campaign which we are including in this issue. This project, with materials prepared by the AFAO and NAPWA Education Team, presents six personal perspectives on living with HIV in 2008. The stories, I'm sure you will agree, are realistic and insightful accounts of the experiences many people with HIV go through, balancing the needs of their health with the stresses of everyday life.

So many of the health messages we receive from government agencies like "Quit Smoking", "Lose Weight" or "Exercise More" can seem a bit like lecturing and it can be easy to dismiss them as irrelevant or to put them in the "too-hard basket". As Scott implies, people who talk a lot about health can come across as "carrot-eating health freaks" but after putting his body to the test with heavy drinking, smoking and recreational drug use in the past, he decided that the toll on his health required some changes and adjustments. Not to give up everything and deny yourself some pleasures and indulgences but to keep things in a balanced perspective.

The six people featured here give a range of approaches to looking after their physical and mental wellbeing. None of them has pretended that the process has been easy and they all acknowledge that having HIV can make their efforts that little bit harder – but managing the virus is an important motivation in the first place. Antiretrovirals may have done a lot to keep people alive but, with their side-effects and adherence requirements, they have not always improved people's quality of life as we might like.

Personally I felt a strong resonance with Steven's story as he outlined how he coped with surviving several AIDS-defining illnesses and then adjusting to an unexpected extra lease of life post the introduction of HAART. Each story though had a strong effect on me, giving me inspiration and some clues on how to get better balance in my own life. They are also beautifully told, with credit for this going to writer Bill O'Loughlin.

I hope you enjoy reading them and this special colour issue of *Positive Living*. Let us know if you like the look. It is not planned as a permanent change at this stage but all things are possible.

David Menadue, Acting Editor (pl@napwa.org.au)

#### CREDITS

INTERVIEWS Bill O'Loughlin ADDITIONAL RESEARCH AND WRITING Paul Kidd PROJECT COORDINATOR Phillip Keen, AFAO

CONTRIBUTORS Deanna, Jorge, Ron, Scott, Steven, Tobin, Jenny McDonald, Dr Caroline Warne, Ian Coutts, Ingrid Cullen and Gold's Gym

PHOTOGRAPHY Cameron Muir, Jamie Dunbar DESIGN Stevie Bee

© 2008 AFAO NAPWA EDUCATION TEAM

Managing HIV. It's about balance.



*Deanna*

**Exercise can  
transform you**

**Eight years ago Deanna was overweight and having trouble with antiretrovirals drugs (ARVs). Becoming pregnant was the impetus for a change in how she approached managing her health. Deanna transformed her body shape and health through exercise. Now she works a personal trainer and runs fitness programs for other people with HIV.**

**D**eanna looks like she should be in gym advertisements. Things weren't always this way; her changes towards healthier living developed over a long period. 'It's been progressive. I was infected and diagnosed with HIV in 1994. I was 26 kilos heavier than now. My lifestyle wasn't good, I was drinking a lot, not watching what I was eating, and I wasn't doing any sport.'

A change came when Deanna fell pregnant. 'When you've got someone relying on you it's essential to look after yourself. I started eating organic food and walking. But I was also wasting a lot.'

Later, side effects from treatments were becoming a problem. 'I was getting abdominal obesity and signs of lipodystrophy, my legs were thinning, my waist was getting heavier. Also, I was in a horrible place mentally. I had no control over what I was doing or the virus.'

'I had a relationship break-up and I felt I needed to completely change my life around. A friend looked fantastic, she's positive as well. I asked 'what are you doing?' and she said 'I've got a personal trainer' and I said 'give me the number'. That's what started the shift in reclaiming my body.'

Deanna believes finding the right trainer made the difference 'I'd done the gym thing before and not succeeded. But I told him what I wanted and he made that happen for me.'

'I started off seeing him once a week, then twice a week. I did a bit of running, cycling and walking, not excessive. And that sort of exercise was enough to make changes in my body. Weight training made me feel strong, my body shape changed. My body image was better. Feeling strong let me feel like I was in control. I went from 700 to 1400 T cells.'

Deanna became passionate about exercise and studied to become a personal trainer. Now she runs fitness programs at the

Melbourne Positive Living Centre.

Finding the motivation to make a start on an exercise program can be hard for some, but Deanna has noticed that once people have started, the small changes they notice become an incentive to go on. 'It's easy to sit at home and use the virus as an excuse to not be bothered. You can blame the virus for lots of things. But, if you are depressed, fatigued, or lethargic, exercise can move you in the right direction. It just means making a start, once you start, you see the changes.'

In 2006, Ian Coutts ran the *Living Positively Project*, which was based at the Melbourne Positive Living Centre. Ian worked as a health coach, providing one-on-one coaching support to people with HIV in relation to exercise, diet, and stopping smoking. Ian says that many participants in the project had experiences like Deanna's, greatly surpassing their initial goals. He said, 'I believe that this is due to the confidence and satisfaction that is felt when someone realises a goal that they set out to achieve. Goal setting can be a great tool to help get you motivated. It enables you to set priorities, gives you a path to follow and it can help you visualise and plan actions to help you achieve what you want. It can provide a positive focus of energy and also help you keep on track. Many of the participants in the project found that setting goals and regularly reviewing and monitoring them resulted in increased self-confidence and provided a sense of achievement.'

If you don't think you want to become a fitness instructor, the good news is that Deanna says a little effort can go a long way. 'If you're with someone who knows what they're doing, a good half-hour session twice a week is all you need. To be a body builder needs more, but if you just want to improve your health, that's enough.'

'One guy has been coming since I started the program. He's

seen big changes. He never wore shorts because his legs were weedy. He's now got beautiful legs, his whole body is proportioned and he swears by the exercise. He's here every week, others come and go around him but he's a work in progress.'

'He's the fittest and healthiest he's been in his whole life. He was diagnosed about eleven years ago and he's 60 and says he never had so much energy in his life.'

Deanna has learnt a lot about food, and although she watches what she eats, she keeps this in balance. 'I feed myself now to fuel my body as opposed to just eat. I'm also human and do enjoy my occasional glass of wine and ice cream and all that. I've got a 19 meals out of 21 rule: if 19 meals in a week are good, then for two I'll cut loose.'

'HIV made me realise I've got to treat my body right. I keep my body in *tip-top* shape because of the HIV. I eat organic foods and take high quality supplementation. It's not cheap.'

Deanna thinks the expense is worth it. 'People will open a bag of chips and smoke a cigarette. That's expensive. I've got two children, you can't put a price on health. I can't afford to be sick.'

Ingrid Cullen is a fitness instructor with many years' experience of working with people with HIV. Many of Ingrid's clients are living on pensions. 'Gyms are bloody dear. So is personal training expertise. That's probably more important, the personal instruction. It's hard to get people that know what they're doing. A lot of gyms don't provide much back-up. And the people that are giving the advice tend to be very inexperienced. There's plenty you can do without a gym. I write articles in *Talkabout* about things you can do at home.'

In Sydney and Melbourne there are programs available that provide specialist advice and support for people with HIV who want to exercise more.

## Exercise

Moderate exercise is beneficial to everyone, regardless of whether they are HIV-positive or negative. Moderate exercise is known to stimulate the immune system and can boost your mood, while keeping fit reduces the risk of a range of illnesses.

Exercise's benefits to the immune system have long been established, with numerous clinical trials finding a positive effect, although the effect typically only lasts a few hours and very intense exercise can actually have a negative effect on immunity. Exercising at moderate intensity for up to an hour can boost the activity of a range of immune system cells including NK cells and macrophages, which should help your body fight infections and could reduce the risk of cancer. Exercise has not, however, been shown to significantly boost CD4 T-cell counts in people with HIV.

Regular aerobic exercise can help reduce levels of blood fats (cholesterol and triglycerides), which are often elevated in people taking anti-HIV treatments. Resistance training can help too – this type of exercise has been shown to increase levels of HDL ('good') cholesterol in people with HIV. Maintaining a healthy level of blood fats is important for people with HIV as it reduces your risk of heart and artery disease and may reduce the risk of lipodystrophy.

## Healthy Life +

ACON's Healthy Life + is an intensive fitness and nutrition program for people living with HIV/AIDS. The program provides a free gym membership for the length of the program, a personal trainer to motivate and support participants in their exercise and nutrition program and seminars related to health, HIV treatment and nutrition. The program was designed and implemented for HIV-positive people who are concerned about weight loss through HIV progression and side effects including lipodystrophy associated with some of the drugs used in ARV combination therapy.

The philosophy of the program is based on the fact that exercise can lead to increased muscle mass, minimising weight loss and slowing or reversing some of the effects of lipodystrophy. Science and research suggests that exercise also helps to build a stronger immune system and overall improved health while also helping to ease depression. In addition, the fellowship of a gym membership can lead to an active re-engagement with community and improved quality of life.

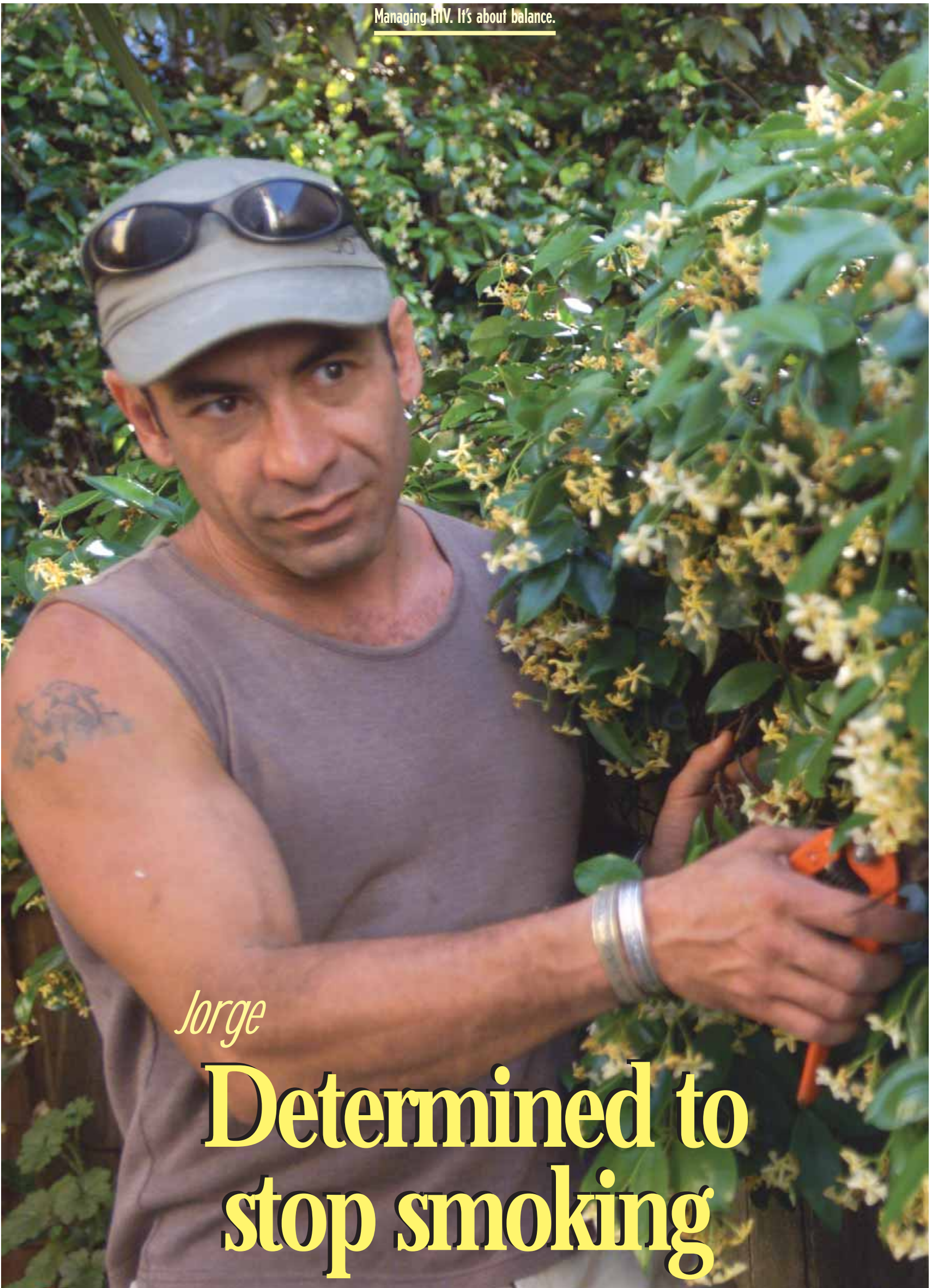
The program includes personal guided training; instruction in training techniques; before and after body measurements; group motivation/peer support; nutritional consultation; and health improvement seminars and discussions.

The program is open to any HIV-positive person, but due to limited enrolment space, preference is given to those affected by weight loss or lipodystrophy and those with low incomes.

Healthy Life + is a program of the AIDS Council of NSW and is based at the Sydney Positive Living Centre. For more info on the next Healthy Life + and how to enrol, call (02) 9699 8756.

Exercise is just one strategy in relation to lipodystrophy. If you are concerned about lipodystrophy, talk to your doctor about avoiding ARV drug combinations that have been associated with it.

**Feeling strong let me feel like I was in control.  
I went from 700 to 1400 T cells.**



*Jorge*

# Determined to stop smoking

## Having overcome discrimination and isolation after being diagnosed with HIV in his native Columbia, moving to Australia with little English and less money, it isn't surprising that Jorge had the determination to stop smoking by going 'cold-turkey'. Discovering how gardening helps him stay grounded, he decided to set up a landscaping business.

**J**orge has overcome a lot to become as healthy and happy as he is today. He was diagnosed with HIV in his native Columbia where 'you can't talk about it, you feel like a criminal, like you've done something wrong to the society and you have to pay for it.'

'There's a lot of taboo, a lot of discrimination about people with HIV; a lot of stigma. They don't talk about HIV, they talk about AIDS. So a person with HIV, is not "HIV positive", all of them are "AIDS people". I was unable to talk to anyone about it.'

Jorge came to Australia confused about what it meant to have HIV. His English was poor and Australian culture was different. Luckily he found a service with a Spanish interpreter.

'I had an Australian partner who was HIV positive and he took me to the hospital and they offered me medication. I met people from the Multicultural HIV/AIDS and Hepatitis C Service. I had support from them and learned a lot about HIV.'

No longer isolated 'I found other HIV people, we were in working groups, we were chatting together. I had a carer who was giving me emotional support.'

Jorge has remained involved with the Multicultural HIV/AIDS and Hepatitis C Service and he now contributes. 'They offered me a course, so I became a worker. Since last April I've been working with the Spanish speaking community.'

Now he is a peer support worker for others with HIV and does community work. He is proud of this, but it isn't easy.

'A lot of people don't know how to use the services. For most of the community there is a lot of taboo about HIV, they don't want to hear about it. We try to reach them but it's hard because it's a very difficult topic to talk about.'

Meanwhile, Jorge was a heavy smoker of Marlboro Reds. 'In 2000 I was in Arq [a nightclub in

Sydney] dancing, it was Australia Day, and I was smoking a cigarette at five in the morning and I said "no more".'

Quitting smoking was difficult but Jorge was determined. He reflected on his past, 'I had to pass through very difficult moments to be able to cope with the society, with the culture, with the language, so I said to myself, if I can cope with all this and I want to be here and I want to improve my lifestyle, I have to make changes.'

He hasn't smoked since. For Jorge, smoking and socialising had always gone hand-in-hand, but he still wanted to socialise, so he worked hard at finding a balance so that his social life didn't suffer. 'I stopped at 5 in the morning and that night I went out and I had beers and, you know, when you drink you want to smoke. But I didn't.'

Dr Caroline Warne is a Sydney HIV specialist GP who has focused on working with people to support changes towards healthier lifestyles, and disease prevention. She has noticed a change among people with HIV when it comes to talking about smoking. 'People will often come and say "look this is always the way I've been, I've always smoked heavily when I've gone out to dance clubs and parties and when I've used alcohol or other recreational drugs, but I no longer feel that it's okay. This is becoming an increasingly anti-social activity and I'm feeling peer pressure". Peer pressure is encouraging some people to quit now.'

'There can be lots of things that will trigger people to smoke. Going to bars. Using recreational drugs. Having friends that smoke. But I like to think that this is changing, that the culture is changing.'

When asked about how he found the strength to make this life change, Jorge talks like others who've made similar shifts. He describes learning to accept things about himself, facing personal issues, learning better ways to cope with his

problems, worries and anxiety.

'I was upset all the time. The way I was sometimes treating my friends was not good. I realised I had to make changes to live better. I was very upset with society, a lot of things happened to me. I learned to let it go and to heal and to get better.'

He used meditation and personal growth tapes and found the answers within himself. 'I've been making lots of changes to be more understanding with people. I try to not gossip about people's lives or behaviours. I try to respect everybody's behaviour. To improve life every day, and try to be more honest.'

Exercise is important. He visits the gym early mornings, runs on the beach and works as a landscape gardener. He eats lots of fresh fruit and salads and avoids 'bad' fats and oils. Jorge believes in the wisdom of 'healthy body, healthy mind'.

When asked about his most precious times, Jorge speaks of his love for gardens and what happens when he is in them. 'For me, a garden is a place for contemplation, meditation, to be calm. When I get in touch with the garden I forget about the rest of life, about things happening around me.'

Jorge is in great health and other parts of his life are also going well. 'I feel so proud of myself. I came to a new culture with no money, no family, and over six years I have learned a lot. I have my landscape gardening diploma, I'm working for the government, I've got my car, I run my business. I think I am doing very well. I'm going to do much better.'

Some people see HIV as having been an important catalyst to make changes in their lives. For Jorge this experience was life-changing. 'Here I've learned to live with HIV, I've learned to have a better future for me and I learned to be happy. I realise HIV is a great thing that happened to me because I've learned to improve my lifestyle, to be happy and be able to move on.'

## Smoking

Tobacco is a legal and widely-used drug, especially among HIV-positive people. In the *Futures 5* survey, 47.6 percent of respondents had smoked tobacco in the last 12 months, a figure that is significantly higher than the 23 percent of Australians who smoke. Smoking is highly addictive and its negative health impacts have been well established.

Smoking, by itself, does not make HIV infection worse. In clinical studies, people who smoked tobacco did not do any worse (or better!) than those who didn't in terms of HIV disease progression. But smoking has been linked to increased rates of some HIV-related opportunistic infections and HIV-positive people who smoke may be more likely to suffer smoking-related diseases than HIV-negative smokers.

Several studies have shown that the AIDS-related pneumonia PCP is more common among people who smoke, and that the risk of dying from PCP is higher in smokers. Positive smokers are also more likely to develop oral hairy leukoplakia, oral candidiasis and community-acquired bacterial pneumonia, compared to non-smokers.

Compared to HIV-negative smokers, HIV-positive smokers have an increased risk of developing emphysema, a debilitating smoking-related illness which prevents adequate oxygen from entering the bloodstream. There is also increasing evidence that the incidence of lung cancer is higher if you're HIV-positive, regardless of your CD4 count or viral load.

It's well known that smoking is a major cause of heart and artery disease, high blood pressure, and stroke. Living long-term with HIV, and taking some HIV treatments, are also considered risk factors for the development of these diseases, so it's likely that HIV-positive people who smoke will have a significantly increased likelihood of developing them as they get older.

**THE BOTTOM LINE:** Clinical studies have not shown that smoking tobacco worsens HIV directly, but they have shown that positive people who smoke are more likely to develop smoking-related illnesses and some AIDS-related complications. If you're one of the 47 percent of positive people who smoke, giving up the habit could be the most important health decision you can make.

## Getting help to stop smoking

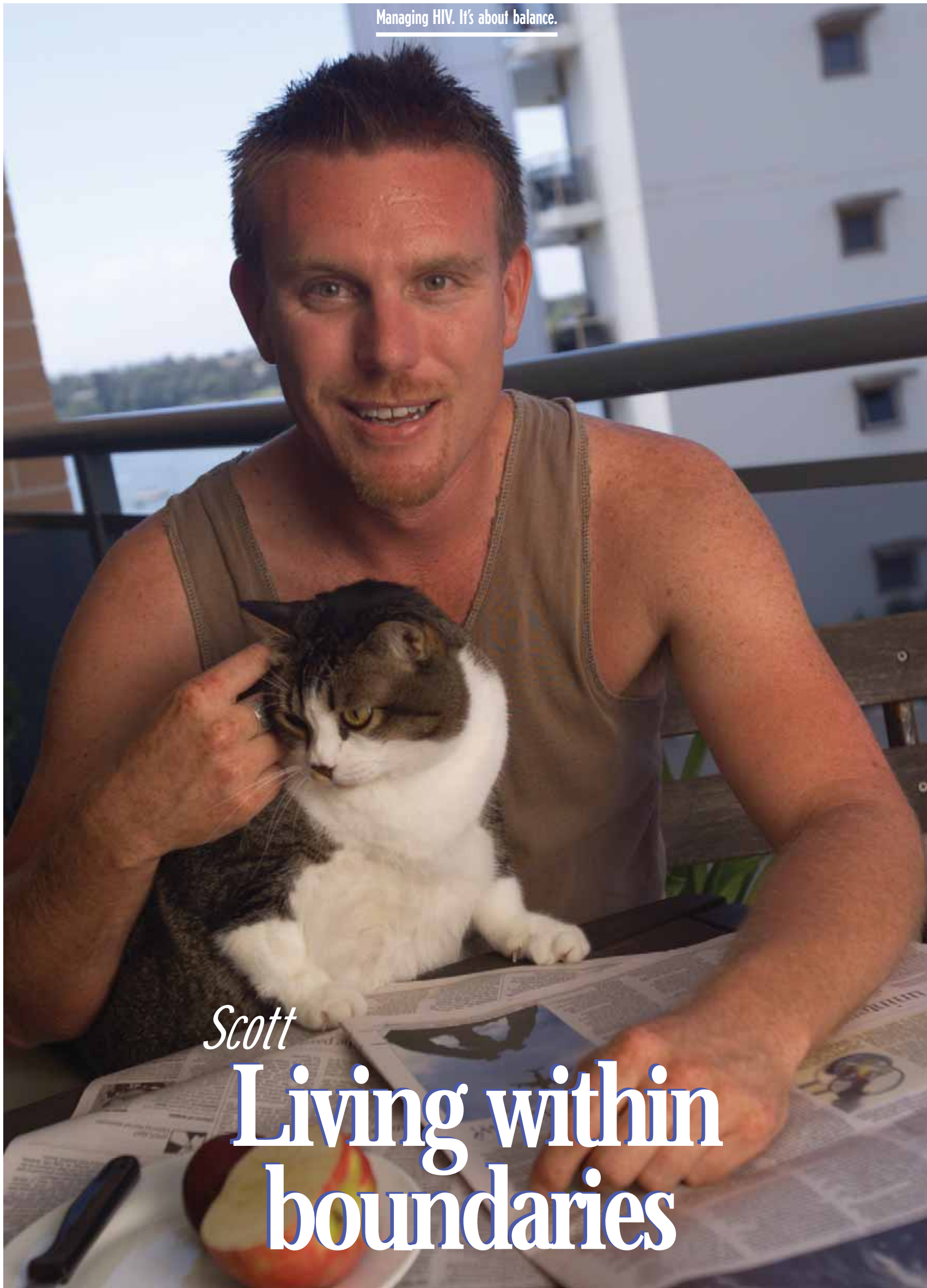
Most people can't just stop smoking as abruptly as Jorge. Different strategies work for different people. For most people, developing a plan for how to quit will improve the chance of success, and help deal with difficulties while quitting.

Your doctor can give advice and support, explain nicotine replacement therapy and other medical options.

Quit organisations in your state or territory have loads of resources available to help you when preparing to quit and can provide support during quitting. Find out more about ways to quit at [www.quit.org.au](http://www.quit.org.au) or call the National Quitline on 131 848 or talk to your doctor or pharmacist. Some PLWHA organisations and AIDS Councils have specific programs, including quitting workshops and one to one support.

**In 2000 I was in Arq (a nightclub in Sydney) dancing, it was Australia Day, and I was smoking a cigarette at five in the morning and I said "no more".**

Managing HIV. It's about balance.



*Scott*

# Living within boundaries



Over the last eighteen months Scott has stopped smoking and cut his drug use. He's had to find different ways to fill the weekends. Doing that without getting bored was a struggle at first, but Scott has now managed to get into a groove.

I wouldn't say I was addicted to anything. But there were situations where I was dependent on my speed, cigarettes or e's. And those were every weekend!

Regular drug use was taking a toll on his relationship. 'My partner of many years, we were worst enemies. It was like two dogs tied to the one chain. It was a period of testing the boundaries of being diagnosed HIV-positive. But, only from hindsight, realising I didn't accept the diagnosis.'

After his diagnosis, Scott had submerged himself into a drug culture. 'It was like daring myself to see how far I could go as a positive person. It was quite strange behaviour, and I've only been able to talk about it in hindsight.'

'To me the whole drug thing was a real destruction, instead of accepting the diagnosis. Not that I've ever been a person going around feeling badly done for by it. I don't at all. My decisions are my decisions and the outcome is something I live with.'

Scott made the scene the centre of his life. 'I feared that if I didn't, then HIV would be the centre of my life.'

The first big change for Scott came when he got bored with his routine around smoking. 'I would have a cigarette and think "I really didn't need that. Why did I have it?" Getting up of a morning and thinking "where's my asthma puffer so I can have my first cigarette because the coffee's ready." And going "this is really silly", and not knowing why. But I would have it. There was this complete blockage in my brain around reason when it came to wanting to give up.'

'I was also tied in with the weekend socialising. God, I look back at that now and laugh at myself, it was getting boring and a waste of money. Monday mornings were becoming harder.'

'I ended up in hospital with pneumonia, not HIV related, probably lifestyle pneumonia. It was a wakeup call.' This was the impetus

for Scott to stop smoking. 'I'd promised I would never stand in front of a hospital with a drip trolley having a cigarette. I kept that promise. It was pretty hard. I had my partner's support, he jumped at the opportunity.'

'I made the stupid mistake of telling everybody. So everybody was watching. They also saw me put on about 15 kilos. So I started thinking "well smoking is an appetite suppressant. If I start smoking again I'll lose the weight." Then the fear of God went into me that I'd end up being a fat smoker. So I thought "I've got to stick this out."'

After six months things started working out. 'I started losing weight and now I'm only two kilos off my original weight.'

'The biggest benefit for me has been the management of my asthma. I don't even have *Ventolin*, my treatment for asthma, in the house now. I still use my preventer once a day. I was using it four times a day before. It's been a huge change for me.'

While smoking causes damage to the lungs and can exacerbate respiratory conditions such as asthma, there is also evidence that demonstrates that people living with HIV who smoke are more likely to get infections and AIDS defining illnesses that affect the chest. For example HIV-positive smokers are more likely to develop PCP pneumonia and oral thrush compared to non-smokers. Also, illnesses such as emphysema occur more commonly in HIV-positive smokers compared to HIV-negative smokers.

Scott's other big change was around drug use. 'Our drug taking phase was in the speed era. I think we hunted down the last batch of speed sold in the gay scene. We made an informed choice that we weren't going to get into crystal. We tried it and there's one thing about being fucked Sunday night, it's another thing not being able to go to sleep 'till Tuesday. That's a whole different boundary to deal with. As crystal came on the scene we

thought "now hang on, time to put the brakes on here."'

The hardest thing was finding ways to fill the time. 'There are only so many games of Scrabble you can play. Saturday night TV is shit. Sundays you can kick around but Saturdays used to be so long.'

'It was hard learning to socialise differently. If you go out for a beer at 11 and you're tired, maybe that's normal - so go home, no race to keep going till 10 the next morning. There always seemed to be that challenge.'

It was difficult for Scott. Putting the brakes on using drugs also meant changes in his social networks. 'You don't want to think that people you used to associate with are bad because they're still doing it, but over time you lose contact with that group of friends.'

'It was quite a discipline. I remember once laughing, if this is what it's like to be straight every weekend, this is really sad.'

Now Scott and his partner have restructured their weekends around other activities. 'More outdoor stuff, a lot more.'

'We live near a 7 km bay walk. I really like getting home and walking. Not saying "I'm really tired because of the day at work."'

'There's certainly a lifestyle and health outcome. Little things, like if you're not tired then you're not irritable around other people. And looking back at moments of psychosis, of paranoia about something, and thinking "that's really weird". Those things don't happen anymore.'

'I always said that I was on top of my diagnosis. I think everybody does until they've lived longer with HIV and understand themselves better. Then they look back. Certainly I've looked back to periods where I had thought "this isn't an issue" and gone "wow, hang on, it really was because where I'm at now proves that."'

'I have more time to give to my health, and friends and family, and work. Giving all that time to activities that give something back to me. I

feel better and more positive. I feel more in control, that's been the better outcome.'

'It all comes down to balance. I've made changes and adjustments but it certainly doesn't mean I've become this carrot eating health freak who is anti-everything.'

'My HIV isn't going to go away but I can do a hell of a lot to make it better. I put that down to acceptance of where I'm at. Realising that there's so much opportunity. It's all about balance at the end of the day. That's what it all comes down to: keeping your head strong, keep it balanced, keep everything around you balanced.'

'I'm at a point now where I'm not looking for those destructions. I'm quite able to talk about being positive and what that means to me. I think getting to that point also means, I'm never going to have a child, but this HIV is the next best thing. I clothe it, I feed it, I look after it, I educate it, and I keep it warm. It's never going to go away, it's always going to be dependent, but the more I look after it the kinder it is to me.'

'I'm fearful of slipping into old habits, but that won't happen. I'd love to take up smoking again. But I'd love to not have asthma as bad again. So I weigh that up and there's no choice.'

'My biggest fear is of being in a bar in six months time trashed with a cigarette in my hand and standing under a picture of me saying "healthy living." That's my biggest fear!'

'The other thing I'm also finding interesting is that, as I'm getting older, even though I'm still quite young, everybody else is getting older. Like I'm dropping off that scene. Slowly more people are no longer out there every weekend. The other week we just slipped up town for a couple of drinks, it's the first time for ages. I might as well have walked into a bar in London. 18 months ago I would have known everybody. And I think that just says that people move on. People change.'

## Alcohol

In the *Futures 5* study, 77 percent of respondents said they had used alcohol in the previous 12 months. There is no evidence that moderate drinking (1-2 standard drinks per day) has any effect on HIV, and some studies in non-HIV-infected people have shown that an occasional tipple may be beneficial. But there is evidence that heavy drinking can have serious negative effects for people with HIV.

Heavy drinking can affect your immune system and there is some evidence from clinical trials that heavy drinkers have lower CD4 counts.

Alcohol can also affect the way that HIV drugs are processed in your liver, potentially increasing side effects or decreasing the levels of the drug in your bloodstream. Increases in blood fats (cholesterol and triglycerides), which have been linked to some HIV treatments, can be worse in heavy drinkers.

People who have hepatitis B or C as well as HIV should consider stopping drinking altogether or minimising their alcohol intake as both HIV and alcohol consumption are linked to more rapid hepatitis disease progression.

Long-term heavy alcohol consumption affects the liver, the heart and the brain and can lead to significant health problems, regardless of whether you're HIV-positive or negative. People who drink every day are at risk of becoming dependent on alcohol, and may be more likely to develop mental health conditions.

**THE BOTTOM LINE:** For most people with HIV, moderate consumption of alcohol is probably harmless, but if you're drinking more than 1-2 drinks a day or if you also have hepatitis B or C, it makes sense to consider reducing your alcohol intake.

Managing HIV. It's about balance.



*Ron*

**Being pro-active**

After more than 20 years experience of living with HIV, Ron has worked out how to keep his life balanced. He works at remaining self-aware, and he has developed strategies to help manage competing pressures from work, his relationship and HIV, and to stay in control of his physical and mental health.

**R**on was diagnosed with HIV back in the early days of the epidemic. He adopted a different approach to many others. “There was a stick your head in the sand attitude at the time. It seemed unacceptable to me and I just started my own personal research.”

‘I realised very early on that if I was going to be one of the lucky ones, that it was going to be of my own making.’

‘I took a proactive approach. I learned as much as I could about the virus. Where there were no real strategies available at the time, I developed some of my own from a holistic model. I learned about nutrition, anatomy, physiology, and virology and anything that had some kind of a healing component to it.’

Part of Ron’s determination was because there was little treatment available. ‘There was only AZT mono-therapy. I didn’t respond well to that at all. So I started seeing a naturopath, taking vitamin supplements and streamlining my diet. I learned as much as I could about the human body and became a personal fitness trainer. It all worked hand in hand.’

He also had to face personal issues including becoming infected with HIV at the age of 19. ‘I tested positive after having sex with one guy. It was a very unfortunate thing for me. A lot of issues arose from that. Learning to take responsibility from the very beginning and saying “I did know better, I did put myself in that situation, and I am not necessarily to blame but this is my responsibility now.” I think it was very empowering for me, to be able to actually discern between blame and

responsibility.’

Ron also found his HIV diagnosis precipitated a mental health problem. ‘HIV brought it to a head and I overcame a major depressive disorder and I was able to work through that by a combination of treatment as well as psychotherapy.’

Now Ron describes having heightened self-awareness. ‘I pay more attention to my body than ever before. Having 20 years of experience, I understand the nuances better. I know when I’m pushing myself too much and when my body’s run down. I know when it’s more mental or physical. I’m able to discern between what I’m making up and what’s real. My peer network helps me with that. And bouncing those things off of my friends who are also HIV positive.’

Ron is also fortunate to have a wonderful relationship. ‘I have got the most perfect partner I could possibly have. We can talk about anything, and we do. With him I very much feel that as long as one of us is doing well, and as long as one of us is in a good position and has the capacity to make decisions, we’re doing alright.’

These days Ron maintains his health by following routines. ‘My main exercise now is to do the walk from Bondi to Bronte 4 times a week. It takes about 45 minutes, its wonderful as it is paved and beside the ocean.’

‘Half the time I walk alone and the other half with my partner. When I am alone I listen to my MP3, usually uplifting music. It depends on my needs at the time, if I need quiet then I don’t ask my partner to come along.’

‘I follow that up at home with yoga sun salutations and exercise ball work for core stability. It’s also a way of

getting some quiet meditative time in my exercise program.’

‘Because I live and work in a world of HIV, my mind is constantly running on about programs and how to do things better. Taking the walk is an opportunity to shut down and focus on myself.’

Ron works in ACON’s *Healthy Life +* program, which is based at the Sydney Positive Living Centre. He has noticed the relationship between physical and mental health with people involved in the program. ‘With regular exercise people feel improvements in mental health and well-being and describe an increase in confidence and resilience.’

Sometimes the benefits of keeping fit are most apparent when they are reduced. ‘If I take a break, it takes me about a week to get back into it. And I can feel the difference. My capacities diminish, I feel less tolerant and have less stamina. I notice it especially in my relationship with my partner. My tolerance diminishes and I become short and sharp. And he will tell me “you need to take a walk” and I listen when he says that.’

When it comes to his own fitness program, Ron has different motivations now. ‘I still go to the gym and lift weights, but it’s no longer my priority. I have reframed it as I have got older and I am more focused on body movement. It’s about giving my body what it wants, not taking from it what I want. When I say ‘body’ I am talking about the holistic perspective – the body, mind and soul and understanding all of that. It’s about bringing my mind and body to rest.’

Reflecting over the years Ron says, ‘One of the hardest things was to set boundaries for my health care and health management.

Without having to disclose my status, especially early on, it was hard to say, “no I can’t do this, that or the other, because I just can’t, because it’s not good for me.” It took ten years before I was able to really stand behind my ‘yes’s’ and my ‘no’s’. Right or wrong, this is what my body needs’.

After living with HIV for more than 20 years Ron seems to have found his balance. His exercise regime, his outlook on life and the ways in which he chooses to relax all seem to enhance his overall well-being. HIV is a relatively new virus. Living with HIV for 20 years is new territory. We know that ageing naturally increases the risks of cardiovascular disease. However, there is also some evidence to suggest that HIV – as well as the treatments that are used to treat HIV – can contribute to cardiovascular disease. Regular exercise and relaxation can contribute towards reducing cardiovascular problems regardless of the underlying issue.

‘Generally speaking, I have learnt and continue to redefine “balance” in my life. Prior to highly active antiretroviral therapy (HAART), I adopted a very strict, all-or-nothing, approach to healthy living. Twenty years into it I recognise that not just my virus has aged, but so too has my body – so I do my best to listen to what it needs. At this point, I do my best to include various forms of exercise in moderation, paying attention to my body as well as other aspects of my life that will require my energy, like my work. I suppose it’s fair to say that my need for relaxation and having a bit of “reflection” time has become a vital part of establishing that balance.’

## A positive attitude

Living with HIV is never straightforward and lots of people with HIV say it’s essential to keep a ‘positive attitude’ about life with the virus. Maintaining a sense of humour and remaining optimistic haven’t been measured in clinical trials, but most people would agree these are good skills to have for anyone with a serious illness like HIV.

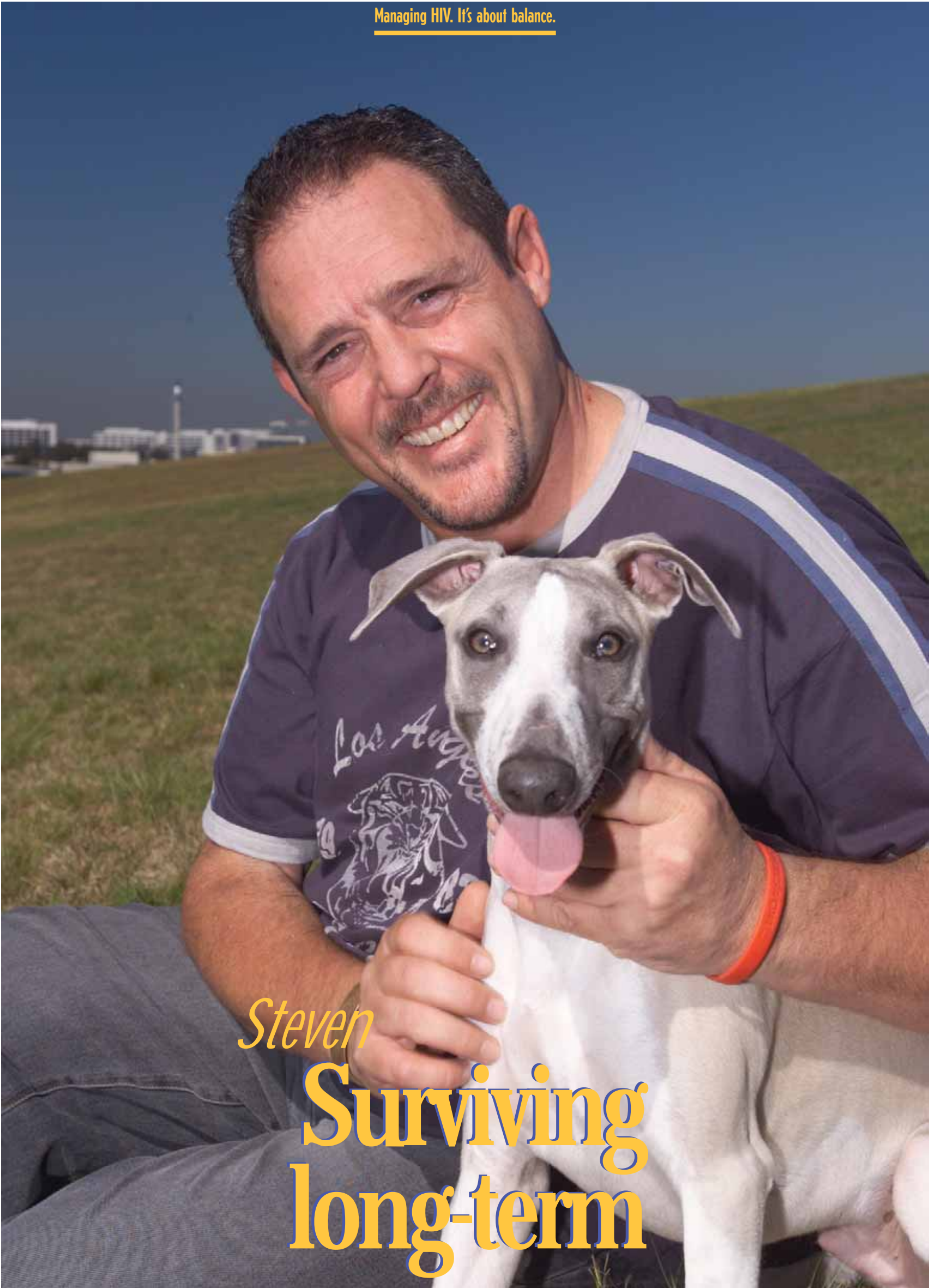
Improvements in HIV treatments over the last decade have reduced the number of people dying from AIDS radically, but these treatments come with a cost in terms of side effects and toxicities. And despite the good news, lots of positive people still struggle with significant physical and mental illnesses. The challenge for all of us is to develop the life skills we need to live well with HIV.

There’s no magic pill you can take that will give you these skills, but there’s lots you can do to help develop them. Getting good social support by joining a peer group or just spending quality time with close friends. Managing the normal stresses in your life better, by eating well and getting regular exercise.

Avoiding over-consumption of alcohol or drugs. Having a good relationship with your doctor. Taking up a hobby, learning a craft, or taking yourself to places that inspire you and feed your soul. Just taking time to smell the roses.

There may be no clinical data to show that any of these things by itself improves the health of people with HIV, but we can say that they improve the *lives* of people with HIV, and that’s clearly a positive step.

**I realised very early on that if I was going to be one of the lucky ones, that it was going to be of my own making. I took a proactive approach and learned as much as I could about the virus.**



*Steven*  
**Surviving  
long-term**

**Even among long-term survivors, Steven has survived more than most. Steven has been near death a number of times, and has always found the strength to pull through. Despite numerous obstacles, Steven has always been able to find the strength to work out ways to make the best of his situation and develop new strategies to manage his health.**

Over the last 22 years of having HIV I've made lots of changes as part of my journey with HIV. I've had everything: kaposi's sarcoma, PCP, other things, radiotherapy, and chemotherapy, the cancer side of HIV. I've had eight different cancers.'

'It's been ongoing, re-evaluating things, different treatments, and their effects on me. To make those treatments as effective as possible I've had to look at exercise, meditation and other things.'

'I've been at the point of death numerous times. Every time I go see a doctor they say "Oh, oh you're still, oh, so you're well, you look fabulous." And I say, "Yes, well, I have to, I'm a poofter, I'm supposed to look gorgeous all the time."

'Twenty-two years ago we didn't have treatments. When I was diagnosed I said to the doctor "How long have I got?" He looked at his watch. I was just hanging there; my CD4s were going down. I had 160 kaposi's sites on my body from my tear ducts to my legs and hands. I couldn't drive or walk. I had issues about how I looked.'

'I was on the first AZT and other drugs and got sicker. I had early dementia for about four months, I couldn't remember where I lived or my partner's name. It was overwhelming. I still cringe when I think about those days. I could have been depressed about it. But I kicked myself in the arse and got on with it. I saw I needed to own having HIV, to move with it and adjust as quickly as possible to what-ever was going to come at me.'

'A therapist taught me relaxation and meditation – that meditation isn't about stopping thinking, but about slowing down, reflecting back, and focusing on something. You can let your thoughts wander and come back. People think "I can't just sit there doing nothing for an hour." It's not about that, it's about reflection, spending time breathing and listening to yourself and your body, getting in touch with it. It was a big learning curve for me.'

Now Steven finds that meditation and relaxation give him the strength he needs 'I rise at six, take my dog for an hour's walk then meditate. Before the world goes off I just sit and reflect and breathe. And the dog lies next to me and has a little break. It's the best part of the day. I enjoy watching the sun come up. I've made it to another day. It reinforces all of the things that I do. It's been wonderful. It's given me the impetus to go out and share that with other people, and be an activist and play a role in the HIV sector.'

Having a dog helps Steven stay active and motivated. 'After our morning walk we play three or four times during the day. He's an inspiration to me. When I've spent half the evening in the bathroom from diarrhoea and colitis and don't feel like getting involved he jumps up in the morning with the ball ready to go. I'm duty bound to participate. Once I get up and get dressed, it doesn't matter if it's only 3 degrees. When you get out there and start walking you forget about all of that. It's helped me to manage my symptoms a lot better and to have a more positive outlook that I can overcome things. I'm greater than my mind and my body.'

Maintaining a good diet has been an important part of Steven's health management 'Improving nutrition has played a huge part. Convenience was my catch-cry. If I could get it pre-packed ready to go, I was on it. Now I make everything from scratch.'

Like anyone living on a pension, Steven is forced to budget, but he has found ways to turn this into a positive. 'I need to find the best quality for the best price and quantity.'

I go to the markets every weekend. I pick up other people and we make a day of it. We have a coffee or go to a few galleries afterwards. Now I never think "Oh I've got to go fucking shopping." And at the markets \$10 worth of food would cost \$30-\$40 at Woolies.'

Part of Steven's process of taking control of his health

was to stop smoking and to drink less. 'It was a budget issue, but about the side effects too. Smoking caused mouth ulcers and hairy leukoplakia, and between diarrhoea and the vomiting my quality of life was just awful. That discomfort was purely from my diet and excessive use of drugs and alcohol. Now my mouth doesn't have any of that nonsense and stopping drinking reduced the colitis attacks and bowel disorders. I had 6 CD4s, now they're increasing all the time. My viral load is undetectable.'

For Steven, the hardest thing about all his changes is isolation. 'When you're not working and not drinking and smoking you are somewhat isolated and capped by your financial status. You can't spend a third of your pension getting wasted and dancing on tables. I used to do that a lot. People are quite surprised at my huge turnaround, like the QE2 turning around.'

Steven's advice to others is about self-awareness. 'My advice about having HIV is to learn to look and listen to your body and appreciate who you are. Anything is possible. I often say that keeping healthy is 40% because of the medications and the other 60% is the hard work you put in. This is not something that's encouraged. I've nearly died about 11 or 12 times then suddenly I come back. The doctors assume it's because of their treatment. I think it's a lot to do with taking more care about what I put into my body now.'

Steven's advice to others: 'Don't get overwhelmed by major changes. I found that it's the little changes that I can live with. I could live without drinking every second or third day. Then it worked out to being once every couple of weeks. Now I can go for months without a beverage and if I do, two or three is more than enough. I know what my limit is now. So gradually there's a huge change in that whole concept of who you are and how you treat yourself. And you really get to think about 'what is a good time?'

## Diet and nutrition

Eating a balanced, healthy diet is definitely beneficial for people with HIV. Avoiding foods which are too high in saturated fats or processed sugars will help reduce your risk of developing heart disease or diabetes, which are more common in people with HIV. If you eat well, your diet will cover all the important micronutrients (vitamins, minerals and trace elements) which are needed to keep the body strong and healthy, so you shouldn't need any additional fancy supplements, although many people with HIV take a daily multivitamin and mineral pill.

Some studies have shown that people with HIV who are deficient in some micronutrients have more rapid disease progression or respond to treatments less well, however the majority of these studies were done in developing countries, where diets are often very poor and the availability of HIV treatments is limited, so their relevance to positive people in Australia is questionable.

There is a wide range of supplements and herbal remedies that positive people have used over the years either in place of, or in addition to, orthodox medical treatments. While some positive people 'swear by' their particular regimen of supplements, there is very little evidence from clinical trials to support their use, and in some cases these supplements taken in high doses can interfere with anti-HIV medications or can suppress the immune system.

If you're thinking of taking any kind of nutritional supplement, you should always discuss this with your doctor in case there is an interaction between the supplement and your antiretrovirals. If you'd like advice about improving your diet, your doctor should be able to refer you to a dietician with experience in HIV.

## The Nutrition for Life project

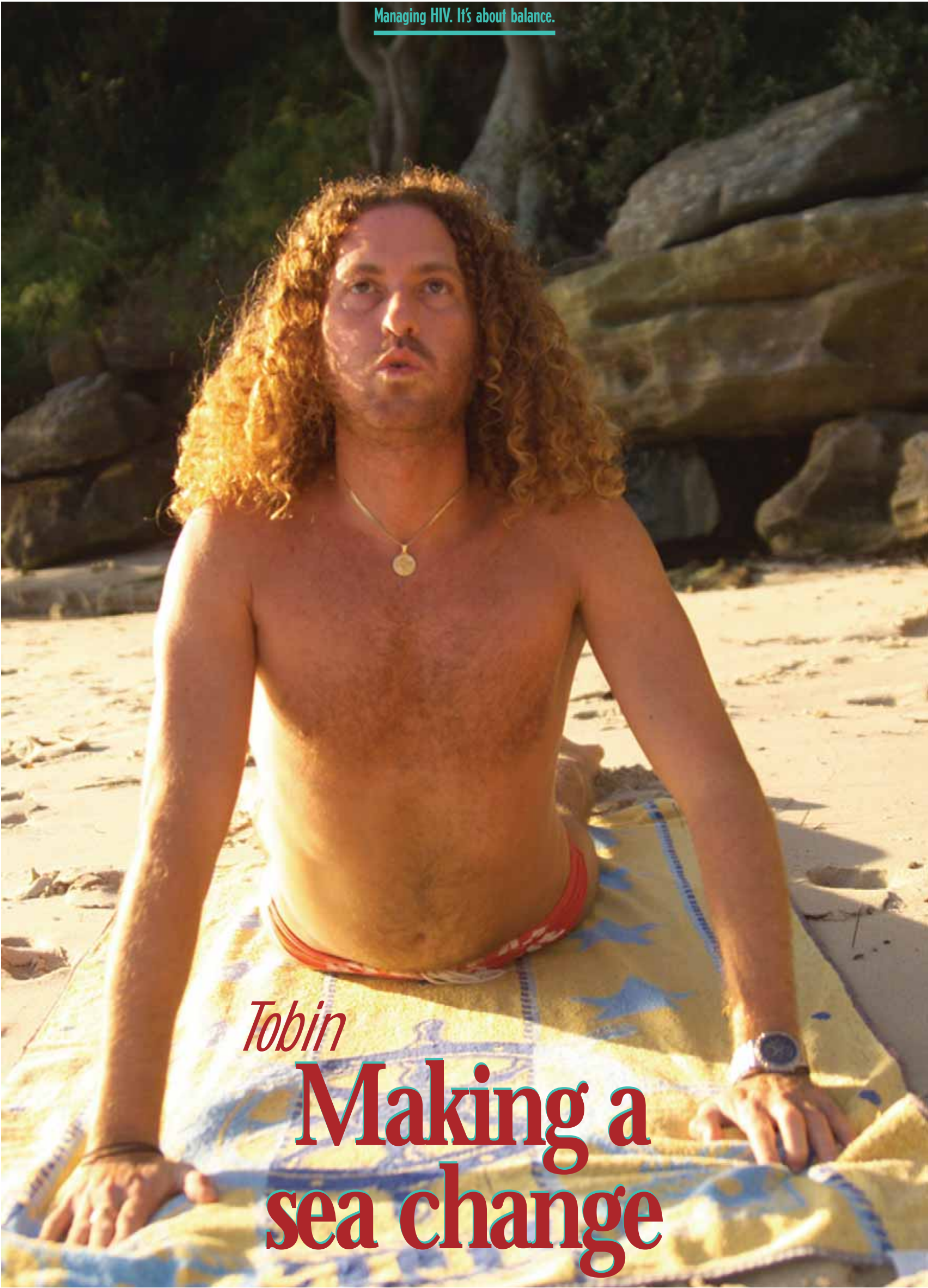
Jenny McDonald is a Melbourne nutritionist who specialises in working with people with HIV. Her work began in 1987, when she was a hospital dietician. Now she does more community-based work through the Melbourne Sexual Health Centre and visiting GPs with HIV caseloads. She runs the *Nutrition for Life* program.

Jenny's work starts with the impact of seroconversion. 'People should see someone when they seroconvert because they go through different processes. They may have lost weight, be eating inadequately or had poor diet before. We check to ensure they're having three meals a day and enough fruit and vegies. Then extra things like protein and vitamin intake, increasing B complex and C vitamins, and antioxidants.'

Countering the potential harm from HIV drugs is now more a part of Jenny's work. 'We're now aware of the potential for ARVs to influence cardiovascular disease. We look at modifying fat intake and better fats, without compromising overall nutrition. Someone with HIV may already be underweight. It's a fine balance.'

Jenny stresses the difference vitamins make. 'People with HIV require more vitamin B complex, which can affect your mood and energy levels. People start on B complex and come back saying they've got more energy, which stimulates more exercise, which stimulates more muscle mass. So their basal metabolic rate may increase and overall sense of wellbeing improves.'

'There's a free *Nutrition for Life* CD I did with Vanessa Wagner. It covers nutrition and HIV, eating well, supplements, diabetes, cholesterol, exercise, common side-effects and maintaining weight, as well as shopping and meal preparation for people on limited budgets. It's available through GPs, AIDS Councils and Treatment Officers'. The *Nutrition for Life* project is in Victoria, Queensland, NSW, Tasmania and ACT. It provides free access to a dietician.



*Tobin*

# Making a sea change

Frocks and footy. Nature and yoga. Cabin fever and isolation. Tobin's sea change has at times been a tricky mix. Tobin had been living in Sydney for years when he decided on his sea change.

As Tobin puts it, 'Things weren't going well. Deep down I wanted to make changes.'

**H**IV was one of the reasons for shifting, but there were other factors – a relationship breakdown, work not coming in, and the stresses of living in a city.

'Ever since I seroconverted, I've had this attitude that HIV will fit my agenda, not make it the centre of my life. That might sound hypocritical because I do work in the HIV area, but I enjoy and learn from that. It's a big part of my life but I don't revolve around it. I try and make it revolve around me.'

'A lot of friends were very encouraging about the move. A small proportion of people were like, "Oh you won't last. How could you – Mr. Socialite – go somewhere remote?" My mum was always very supportive. She's a total rock in my life.'

The move was something Tobin felt driven to do. He knew he'd enjoy nature. 'I get a huge sense of relaxation. It diverts my mind, almost like meditating. Nature seems to answer your questions. It's ever changing so it's really everything that TV wishes it could be. It's really good for my emotional wellbeing and stability. I live by the beach. The sound of the ocean is really meditative. For someone with a fast active mind it's like an enforced form of meditation.'

The move has helped Tobin reduce his stress levels, and he has more time to get to the beach and exercise. 'It's a major change to live by myself with a focused routine. I'm sleeping more, getting up early, buying lots of lovely local fresh fruit and vegetables, planning my week's eating. My diet's improved out of sight because I'm looking after myself.'

Adjusting to life outside a city wasn't easy at first 'I didn't move away to socialise. But I wasn't prepared for being desperate for people. Whether intimate sexual contact, or friends and family, I miss them. For a period I would go to a local pub and drink and gamble just to get out of the house. There are some hidden nasty bits living in a rural area.'

Tobin met a guy from the local footy team at the pub. 'I asked what would they think of a HIV-positive puffer on the team. He said "they don't need to know." So football was one thing I did to change some bad habits, to get out of my comfort zone, force myself to meet people I mightn't feel comfortable with and challenge

some really big things. It was about being with men in a situation that some queens see as some camp fantasy, but to treat it as friendship. It was a big experiment. It worked really well. I got welcomed into the team and my self-image went up enormously. Having these blokes know who I am, what I do, and accept me for it made me realise that a lot of my paranoia is basically just that.'

Perhaps a little surprisingly, football became an important part of staying fit. 'My fitness level went up, and in turn that increased my whole wellbeing. I've always been physical. I studied dance. I've always stretched and done yoga and things like Tai Chi and Kung Fu. I've always felt very connected to my body and felt that these were important things for both my physical and emotional well-being.'

'I stretch at least twice a week. It's essential, I seem to hold a lot of stress in my body. It's like a panacea that deals with almost everything. I find meditating quite difficult because I'm so neurotic. But a stretch routine has a meditative quality. I forget about what's on my mind.'

Tobin incorporates some yoga into his stretch routines. 'The yoga positions are really calming. If I don't stretch, the energy snowballs negatively. If I get a sore back, peripheral neuropathy or little treatments side effects, stretching minimises them dramatically.'

'A lot of HIV-positive people smoke cigarettes and pot, and drink. There seems to be more need and reasons to nullify things that seem overwhelming. Sometimes, no matter how stable you are, you need to just drown it out.'

'I think being homosexual puts us on the outer edge with subconscious negative thoughts in our minds. Then HIV multiplies that isolation and loneliness. For people who are attempting to embark on relationships amidst all this stigma and discrimination and assumptions about positive people – the whole notion of people feeling really toxic and unlovable. This is a source of a lot of problems.'

'Tell them you're positive and they won't want to touch you. But they will go off and fuck someone if nothing is mentioned. Sometimes having to reconcile all that shit makes me really angry. I'd like to just slap some queens in town.'

Part of Tobin's work involves

running forums that deal with some of these issues. 'All these brave positive people inspire me and some find me brave and have gratitude that I do this work.'

For people who are considering making changes in their lives, Tobin has some advice, 'The most important thing is don't set your goal too high. Say if you want to give up smoking. Try it, but if you fall off the wagon, don't make that a reason to start smoking hard again. Or with exercising, start really slowly and don't pressure yourself to try to get stuck into a huge regime quickly because often you get overwhelmed by it. Allow your body to adjust. Especially if you want to lose weight, it can seem overwhelming when you first start. Take it slowly and allow yourself to fall off from time to time without punishing yourself. Look at the bigger longer-term picture. That goes for every change.'

Ian Coutts, a health coach who worked in the *Living Positively* project at the Melbourne Positive Living Centre in 2006 would agree that lapses while pursuing a goal are normal. Ian says that many people he has seen in the project have experienced this situation. 'There can be a number of factors that can cause a loss of momentum, like fluctuating health, stressful life events and also conflicting priorities. Setbacks are a part of life and it is no use to beat yourself up about them. I feel it is much more productive to be forward looking and focus on what can be achieved in the future. I believe that change is a learning process and that each attempt is a step on the path to achieving your goals.' In situations like these, Ian talks with his clients and reviews why they may feel they are losing momentum, helps them to set new goals if required and also to develop new strategies and plans. 'I remind people of what their initial goal was and the strength of their desire to achieve it. Then we set new goals if required and develop new strategies and plans.'

Sometimes Tobin misses the support of his many HIV-positive friends in the city, but overall the life changes he has put in place are now yielding other benefits. 'I'm a lot calmer, healthier, and less stressed. I make more informed rational decisions about life. There's more time. I need less to feel happy. I get fewer physical ailments now, so HIV is less in my life.'

## Stress, depression and mental health

A significant number of people with HIV suffer from stress, anxiety or depression. In the *Futures 5* survey, almost one-third of respondents said they had taken antidepressant medications in the previous six months, and one-quarter had been prescribed medication for anxiety.

Getting an HIV diagnosis and living with the threat of serious illness are significant stresses for anybody to live with, so perhaps it's not surprising that mental health problems like stress and depression are more common among people with HIV compared with the general population. Some antiretrovirals (e.g. efavirenz) and changes in the brain chemistry in people with advanced HIV disease can also trigger depression.

Living with these problems adds to the burden of illness that we all have to bear, reduces quality of life and can have a serious impact on treatments adherence, so it is worthwhile doing what you can to respond to stress and depression if it affects you.

There are lots of options for preventing and managing these health problems. Meditation, yoga, peer support, counselling and exercise have all been recommended by positive people as effective strategies to help reduce stress and manage mental health problems, but there's no 'one-size-fits-all' approach, so you have to find what works for you. If you're diagnosed with depression, there are a range of therapies available including psychotherapy, cognitive behavioural therapy and antidepressant medications – your doctor can provide information.

### Stuck in a rut, but don't want to move?

Ian Coutts, was a health coach with a pilot program with the Melbourne Positive Living Centre in 2006. He has some advice for people who want to develop healthier lifestyles, but feel they're in a bit of a rut. 'My advice is to try something different! I believe there is always progress in action and in many cases, one small step can give you the confidence to take another. A quote I like is: "The greatest thing in the world is not so much where we are, but in what direction we are moving."'

Many of the participants in the *Living Positively* project run by Ian have described how they felt they were in a rut prior to starting in the project. 'Having a health coach helped provide them with motivation to make changes and helped them to stick to the changes they wanted to make. It also allowed them to be able to talk over their concerns one-on-one with the coach, and provided them with more confidence, enthusiasm and optimism.'

For people who don't have access to a health coach, Ian suggests buddying up with someone else to exercise together, or to let others know about your goals and seek support. 'Change can be a difficult thing, and building a support network is a good way to get help through the process.'

ACTING EDITOR **David Menadue**  
CONTRIBUTORS **Phillip Keen,**  
**Paul Kidd, Bill O'Loughlin**  
DESIGN **Stevie Bee Design**

Positive Living is a publication of the National Association of People Living with HIV/AIDS.

**napwa**

Positive Living is published four times a year.  
Next edition: September 2008.

Positive Living is distributed with assistance from



#### Subscriptions

Free subscriptions are available to HIV-positive people living in Australia who prefer to receive Positive Living by mail. To subscribe, visit our website or call 1800 259 666.

#### Contributions

Contributions are welcome. In some cases, payment may be available for material we use. Contact the Editor.

ADDRESS CORRESPONDENCE TO:

**Positive Living**  
**PO Box 917 Newtown 2042**  
**TEL: (02) 8588 0300**  
**FREECALL: 1800 259 666**  
**FAX: (02) 9565 4860**  
**EMAIL: pl@napwa.org.au**  
**WEB: www.napwa.org.au**

■ Positive Living is a newspaper for all people living with HIV/AIDS in Australia. Contributions are welcomed, but inclusion is subject to editorial discretion and is not automatic. The deadline is 14 days before publication date. Receipt of manuscripts, letters, photographs or other materials will be understood to be permission to publish, unless the contrary is clearly indicated.

■ Material in Positive Living does not necessarily reflect the opinion of NAPWA except where specifically indicated. Any reference in this publication to any person, corporation or group should not be taken to imply anything about the actual conduct, health status or personality of that person, corporation or group. All material in Positive Living is copy-right and may not be reproduced in any form without the prior permission of the publishers.

■ The content of this publication is not intended as a substitute for professional advice.

## SENATE BLOCKS GOVERNMENT CHANGES

# EPC Dental Access Scheme temporarily opens again

**On Thursday June 19, the Senate successfully blocked the removal of the Enhanced Primary Care (EPC) Dental program by passing a Motion for Disallowance. This means that people with HIV (and other chronic and complex conditions) once again have access to Medicare funded dental care through private dentists.**

It is likely there will be a further vote on this subject when the Senate meets again on August 26,

however the outcome of such a vote will depend on the fine balance of power in the new Senate, and in the meantime the EPC program is currently open to new patients.

People with HIV are now eligible to enrol in the scheme (until a Senate vote might cancel it once again). The previously stated closing date of June 30, 2008 no longer applies. People with HIV are strongly encouraged to see their GP urgently for a referral to a

dentist, and to begin their first dental treatment as soon as possible.

The EPC Plan funds dental care services for people with chronic conditions and complex care needs, including HIV, and uses private dentists not hospitals. This scheme was cancelled in March 2008, but has suddenly and unexpectedly become open again for a period.

It is not clear how long the scheme will now be open for. Accessing the

scheme involves getting a dentist referral from your GP, which can sometimes be time-consuming, so it's important to act quickly. See [www.acon.org.au](http://www.acon.org.au) for further advice on how to commence the procedure to be eligible. It is unclear at this stage what alternative measures the Federal Government are proposing to put in place to assist people with chronic conditions, including HIV, with their dental needs.

## Darunavir and the risk of hepatitis

A warning has been issued by Tibotec, the manufacturers of Prezista (darunavir) regarding the risk of developing drug-induced hepatitis while taking the treatment. Apparently, 0.5% of clinical trial participants who took a combination including darunavir (boosted with ritonavir) developed severe hepatotoxicity. Anyone with a history of liver-related complications such as hepatitis B or C are particularly susceptible, so appropriate tests prior to starting darunavir and regular monitoring while on the drug are vital to avoid developing any hepatotoxic reaction.

[www.ashm.org.au](http://www.ashm.org.au)

## Should positive people get booster hepatitis shots?

The simple answer is 'no' according to Dr Brian Hughes, Infectious Diseases Physician and hepatitis specialist at John Hunter Hospital in Newcastle. Hepatitis A vaccine is highly immunogenic and works just as well for people with HIV. It doesn't lose effectiveness over time so a booster is never needed. Hepatitis B (HBV) vaccination is different and a small proportion of all recipients don't get an adequate antibody response to the vaccine. The lower your CD4 count, the more likely you will not get a response. Therefore, double dosing is initially recommended for people whose CD4 count is



less than 350. Testing for a response is then recommended for those with significant immunosuppression and if no response is recorded a further double dose can be given. If there is still no response then yearly testing for possible HBV infection is recommended.

## Etravirine promising for those with NNRTI resistance

An encouraging outcome of the DUET studies is that etravirine is effective against HIV mutations resistant to existing NNRTIs, efavirenz and nevirapine. Investigators found that 89% who had resistance after treatment with nevirapine were susceptible to etravirine and 91% of patients whose virus was resistant to efavirenz benefitted from treatment with the new drug. Etravirine is currently available in Australia on compassionate access.

[www.aidsmap.org](http://www.aidsmap.org)

## Future flu vaccines may also treat HIV

A New Zealand company is working on an antiviral agent – a micro particle called mis416 – that utilises the immune system to fight flu, hepatitis and HIV. Until they perfect the technology, people with HIV

will just have to make do with the flu vaccines currently available. And at this time of year, that's not a bad idea!

[www.tv3.co.nz](http://www.tv3.co.nz)

## First trial of microbicide in pregnant women

Researchers at the University of Pittsburgh will commence a clinical trial on a vaginal microbicide in pregnant women. Sixteen HIV-negative women, scheduled for caesarean delivery at the University's Women's Hospital, will be enrolled in coming months and given a single dose of tenofovir topical gel applied inside the vagina two hours before giving birth. Researchers hope to understand the extent that pregnancy affects how the body absorbs the active drug in the gel and whether the drug can be transferred to the foetus.

Tenofovir is an effective drug used to treat HIV and researchers wish to know if it could work as a microbicide in the future. The risk of participants in a microbicide trial becoming pregnant has always been of concern to researchers even though trial protocols require the use of contraception. Indeed pregnancy has occurred in 5-10% of participants. Because the risks to the women and their babies are unknown, they

are told to stop using the product immediately.

With this trial researchers hope to learn more about the use and safety of microbicides during pregnancy. Using information from other trials where women have become pregnant while on either a microbicide or an oral antiretroviral drug they are also looking to discover whether using these during pregnancy – a time when women are at even greater risk of acquiring HIV through sexual intercourse – could prevent mother-to-child transmission and if there are any effects on foetal and/or neonatal development.

■ Further information: [www.mtnstophiv.org](http://www.mtnstophiv.org)

## Mediterranean diet lowers diabetes risk

People who adhere closely to a Mediterranean diet – comprising olive oil, grains, fruits, nuts, vegetables and fish and low in meat and dairy – may have a lower risk of developing diabetes according to a recent study by Dr Migel Martinez-Gonzalez and colleagues from the University of Navarra in Pamplona in Spain. This could be important for people with HIV on certain antiretroviral drugs that are more prone to contribute to insulin resistance, the precursor of Type 2 diabetes. The study was published in the British Medical Journal.

[www.poz.com](http://www.poz.com)

Compiled with the assistance of the NAPWA Health, Treatments and Research Unit