SIX PERSONAL STORIES
Tips to improve your health and get balance in your life

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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 meat workers, 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, Oman, 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 or ask your local HIV organisation for a copy of the resource Up Up and Away.

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-Convener 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 on people who were not at risk of the virus rather than concentrating on high risk groups such as men, 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

National 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) 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
Why the need for this campaign?

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 daunting, 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 article 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 a 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. 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.

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 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.
Exercise can transform you

Deanna

Managing HIV. It’s about balance.
Eight years ago Deanna was overweight and having trouble with antiretrovirals (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.

Deanna 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 waiting 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 a motivator 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 Couts ran the Living Positively Project, which was based at the Melbourne Positive Living Centre. I 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.

Feeling strong let me feel like I was in control.

I went from 700 to 1400 T cells.
Managing HIV. It's about balance.

Jorge
Determined to stop smoking
In 2000 I was in Aq (a nightclub in Sydney) dancing. It was Australia Day, and I was smoking a cigarette, 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 hadn’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. He 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’.

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 meditation, a form of solace. It’s a place where I can think and relax.”

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 Aq [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”.’
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Scott

Living within boundaries

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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 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 where 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. My weekend mornings were becoming harder.’

‘I ended up in hospital with pneumonia, not HIV related, probably lifestyle pneumonia. It was a wake-up call. ‘This was the impetus for Scott to stop smoking. ‘I 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 a big 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 up 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. 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’s always seemed to be that challenge.’

‘It was difficult for Scott. Putting the brakes on using drugs is the biggest 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. ‘Me, 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 am 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 under 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 losing ground off that scene. Slowly more people are no longer out there every weekend. The other week we just dipped 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. 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.
Being pro-active

Managing HIV. It’s about balance.
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.

Ron was diagnosed with HIV back in the early days of the epidemic. He adopted a different approach to many others. ‘There was a stick in the sand, attitude at the time. It seemed unappealable 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, it’s 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 M P 3, 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 AC ON’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 discipline and focus on themselves.’

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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 point, I do my best to include various forms of exercise in moderation, paying attention to my body as well as just 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.’

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.
It's not about that, it's about giving your full attention to the world around you. People think 'I can't just sit and do nothing for an hour.' But it's possible to do anything, even if it's just sitting and breathing. I've been doing this for years, and it's helped me to manage my stress and improve my overall health. I've even started to incorporate mindfulness into my daily routine, which has been really helpful for managing my mental health.

When I first started doing this, I was worried that I might lose focus or feel bored, but I soon discovered that it's actually the opposite. By focusing on the present moment, I found that I was able to let go of all the stresses and worries of the day. I was able to slow down, reflect and breathe, which was really beneficial for my overall well-being.

I've been doing this for so long that I've become really good at it. I think it's really important to start slowly and gradually build up your practice. By doing this, you'll be able to achieve the benefits of mindfulness and meditation without feeling overwhelmed or burnt out.

I hope that my experience can inspire others to try mindfulness and meditation as well. It's really something that everyone can do, no matter what your background or experience level is. By giving it a try, you might be surprised at how much it can improve your life.
Managing HIV. It's about balance.

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’s sea change has at times been a tricky mix. Tobin has 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.’

HIV was one of the reasons for shifting, but there were other factors – 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?” ’ But said this, go somewhere remote?’ M 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 got 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 earlier, 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 person foxing in 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 people 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 levels 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. 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. Tobin 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. ‘A lot of things are happening 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 this 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.’

Tobin cites examples of how sometimes, one small step can give you the confidence to take another. A quote he likes is: “The greatest thing in the world is not so much where we are, but in what direction we are moving.”

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 budding 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.’

**Stress, depression and mental health**

A significant number of people with HIV suffer from stress, anxiety or depression. In the Futures 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 antidepressives (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, a health coach with a pilot program with the Melbourne Positive Living Centre in 2006.

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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 who have 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 canceled 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.napwa.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, 0.6% 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

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 DUT 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 benefited from treatment with the new drug. Etravirine is currently available in Australia on compassionate access.

www.aidsmap.org

Future flu vaccines may also treat HIV

A New Zealand company is working on an antiviral agent – a micro particle called msi416 – 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

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 or/and neonatal development.

Further information: 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 Miguel 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.pozi.com