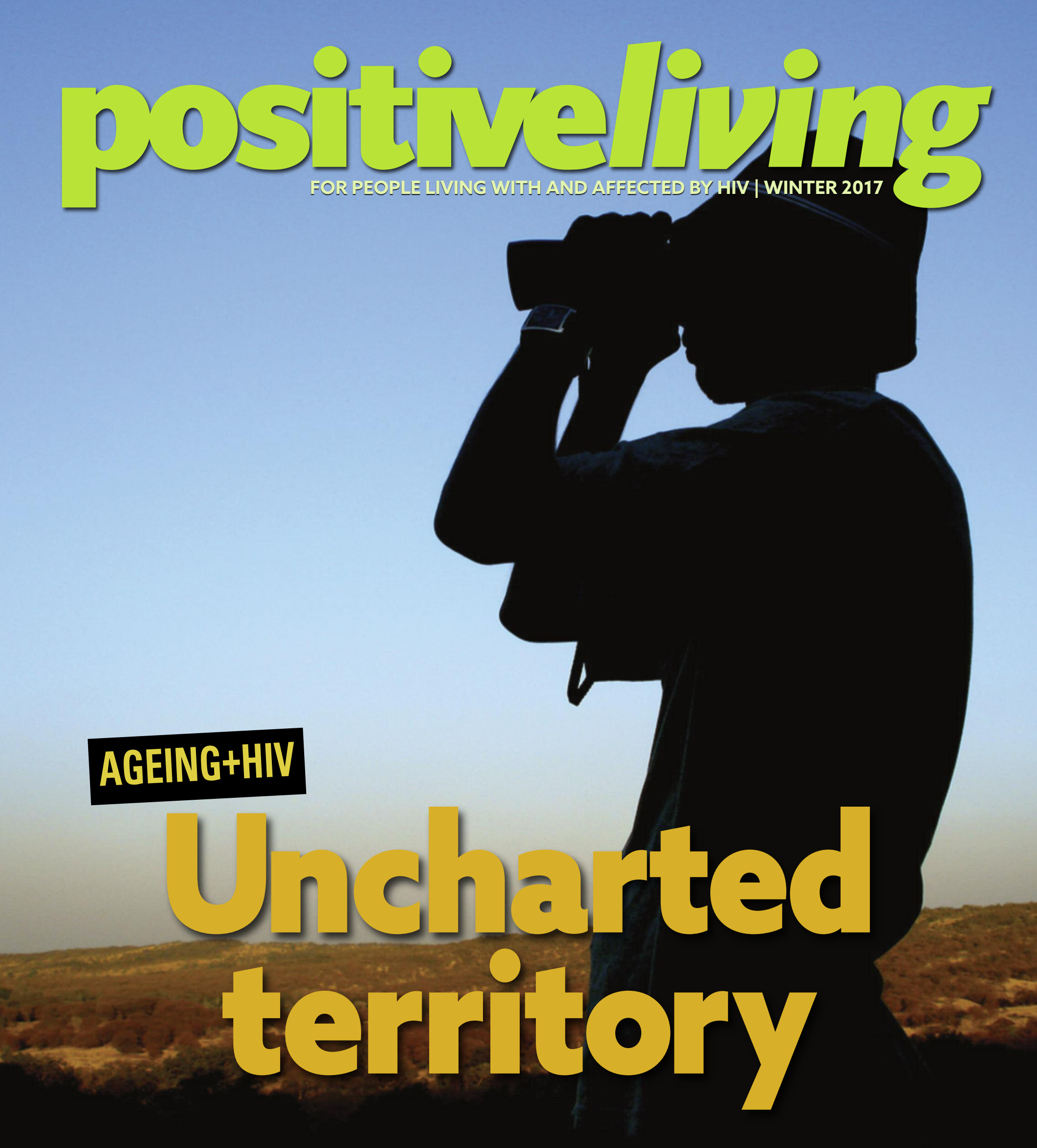


positiveliving

FOR PEOPLE LIVING WITH AND AFFECTED BY HIV | WINTER 2017

AGEING+HIV

Uncharted territory



Even in the midst of this stressful experience of testing positive for HIV, coaching people to feel happy, calm and satisfied appears to influence important health outcomes.

JUDITH MOSKOWITZ, FEINBERG SCHOOL OF MEDICINE
NORTHWESTERN UNIVERSITY OF MEDICINE
SAN FRANCISCO, CALIFORNIA

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The virus is eradicated from every tissue and organ

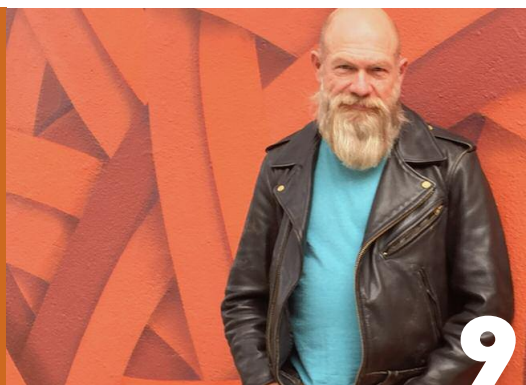
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ISSN 1033-1788

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SUBSCRIPTIONS Free subscriptions are available to HIV-positive people living in Australia who prefer to receive *Positive Living* by mail. To subscribe, visit napwha.org.au or call 1800 259 666. CONTRIBUTIONS Contributions are welcome. In some cases, payment may be available for material we use.

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Positive Living is published four times a year by the National Association of People With HIV Australia and is distributed with assistance from Gilead and ViiV Healthcare. Next edition: September 2017



● *Positive Living* is a magazine for all people living with HIV in Australia. Contributions are welcomed, but inclusion is subject to editorial discretion and is not automatic. The deadline is 21 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.

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from the editor
CHRISTOPHER KELLY

Saluting the survivors

For long-term survivors of HIV — diagnosed before 1996 and the advent of life-saving treatment — the last 20, 30-odd years has been a series of firsts. They were among the first to be diagnosed with an untreatable, often fatal disease; the first to try experimental, often detrimental, drugs; among the first to receive highly active antiretroviral therapy, and to experience the many debilitating side effects. And now, decades on, these same people are the first to grow old with HIV. It is, as the cover says, “Uncharted territory”.

This issue of *Positive Living* salutes the long-term survivors by dedicating much of the content to them. We look at the challenges of ageing with HIV and the community response (page 7). David Menadue (diagnosed 1984) flicks through old copies of *PL* from the pivotal year of 1996 (page 8); Tez Anderson (diagnosed 1986) warns of a multi-pronged crisis affecting the health and wellbeing of older people with HIV (page 9). Neurological disorders are a particular problem for those living long-term with HIV — we report on the symptoms and the solutions (page 10); and — from front-line activists to long-term survivors — we trace the history and achievements of ACT UP (page 11); plus, survivors share haunting memories of the deadly days of the epidemic (page 15).

These days, HIV can all too often be waved away as a manageable disease. Yet, despite the truly miraculous advances, for long-term survivors some scars will never fade. As David Menadue wrote in *PL* more than 20 years ago: “Dealing with the survivors of an epidemic of the proportions we have seen will be no easy task.” As the survivors begin to enter old age, the question is: are we up to the task?

Unwise to speculate on new PrEP diagnosis

In mid-May, news appeared of a Melbourne man testing positive to HIV while participating in a PrEP trial.

This, reportedly, “sparked fears about possible resistance to the medication” despite such an occurrence being extremely rare. Indeed, out of hundreds of thousands of people on PrEP worldwide, there have been only two confirmed cases of a drug-resistant strain of HIV. No such event has occurred in Australia.

Further, study researchers at The Alfred Hospital have yet to conclude reviewing the clinical details of the case, which *PL* understands are complex. “We don’t know how HIV transmission



We don't know how HIV transmission has occurred.

has occurred and it's unwise to speculate,” said Brent Allan, CEO of Living Positive Victoria.

“Speculation leads to gossip and rumour which do nothing more than fuel HIV stigma.”

News of the man’s diagnosis prompted questions as to how the

press got hold of such sensitive information. “Of concern is how this event has come into the public domain and the impact of this on the individual concerned,” said Bill Paterson, Acting Executive Director at NAPWHA. “A seroconversion

event is never a benign experience and NAPWHA trusts that the person involved is receiving the support and care that he requires.”

Around 3,000 Victorians have enrolled in the **PrEPX study**, which is one of a number of similar trials around Australia and overseas. In such studies, PrEP has shown, when taken daily, to effectively protect against HIV. “Thousands of people would be HIV-positive today if PrEP had not been available,” said Allan. “We continue to support the research and the PrEPX study in the hope that this medication will be accessible to all Australians in the future.”

Life expectancy near equal

Young people diagnosed with HIV and on the latest batch of treatments can expect near-normal life expectancy.

A UK study, published in *The Lancet*, found that a 20-year-old who began treatment post-2007 — and who recorded a low viral load after the first year of treatment — will live to 78, similar to the general population. In response, Professor Helen

Stokes-Lampard of the Royal College of GPs said: “It’s a tremendous medical achievement that an infection that once had such a terrible prognosis is now so manageable, and that patients with HIV are living significantly longer.”



However, in the UK, as in Australia, an ageing positive population throws up unique challenges. “As it stands, the healthcare, social care and welfare systems simply aren’t

ready to support the increasing numbers of people living with HIV,” said Dr Michael Brady of UK HIV charity the Terrence Higgins Trust. “We need a new model of care to better integrate primary care with HIV specialist services, and we need a major shift in awareness and training around HIV and ageing, so that we’re ready to help older people live well in later life.” (See page 7)



A place to remember
A memorial to those lost to AIDS has opened in Canberra. Located at the National Arboretum, the ‘**AIDS Garden of Reflection**’ was funded by the AIDS Action Council, which raised \$170,000 for the project.

Sunshine state continues to outshine



With the year not yet half through, Queensland has recorded a 16 percent drop in new cases of HIV.

The encouraging news comes as the government announced an expanded \$6 million PrEP trial. Already, more than 12,000 people across 20 sites – from the Gold Coast to Cairns, Mount Isa to Toowoomba – have signed up. Queensland health minister Cameron Dick (pictured) says, “The research shows PrEP can dramatically reduce the risk of contracting HIV. This trial really has the potential to positively impact the lives of Queenslanders at high risk of contracting the virus.”

There are approximately 800 more places up for grabs. To enrol in the trial, head [here](#).

HIV advocate and Mr Gay New Zealand Charlie Tredway has been forced to defend himself after being criticised for practising condomless anal sex.

Tredway, a community outreach staffer for the New Zealand AIDS Foundation (NZAF), came under fire from online news site GayNZ.com when it was discovered he had a profile on a barebacking website. Readers and commentators complained that such an association was inconsistent with Tredway’s work in HIV prevention.

Tredway – who says he always informs sex partners of his status, which is undetectable – hit back: “My whole platform for entering Mr Gay NZ was to bring visibility to issues facing people living with HIV – the stigma, the judgement, the demonisation and outdated thinking that still seems to be so prevalent. First and foremost I am a human being, one with a sex life to navigate consensually just like everyone else in our community.”



Charlie Tredway

When asked by GayNZ.com whether barebacking was a “good look” for a NZAF employee, Tredway responded: “Whether it be condoms, PrEP and, of course, treatment as prevention (TasP) and managing your viral load – all of these tools are

vital and play a part, and I am a firm, outspoken advocate of them all equally.” NZAF stood by Tredway, saying it endorses a variety of measures, other than condoms, to protect against HIV – including TasP. The backlash against Tredway highlights the need to educate people about what constitutes ‘safe sex’ in 2017 and the continual need to call out HIV stigma.

■ Meanwhile, after much lobbying, NZAF has welcomed news that PHARMAC – the government agency that decides which drugs should receive public funding – is considering granting access to treatment to all people with HIV in New Zealand, regardless of CD4 count. At the moment, only those with a count below 500 are eligible. NZAF’s executive director Jason Myers said, “If the proposal goes through, people living with HIV will have access to immediate treatment – we’ll keep our fingers crossed for a positive outcome.”

Two new hubs

Two new online HIV hubs have launched in Australia.

The first – **ATSIHIV** – is designed to be the go-to resource on HIV for the Aboriginal and Torres Strait Islander community. The website provides accessible and relevant information on HIV, including the transmission risks, harm-reduction techniques and news of prevention tools such as PrEP.

The second website is a joint project of ACON and the Victorian AIDS Council (VAC). Called **Emen8**, and aimed at same-sex attracted men, the online platform is designed to make sexual health information more appealing. “The aim is to significantly increase the reach and impact of our collective efforts to provide information to all gay men across Australia about HIV and STI prevention,” said VAC CEO Simon Ruth.

Let gays and bisexuals donate

A grassroots organisation is calling on the Australian Red Cross and the Therapeutic Goods Administration to relax rules restricting blood donations from gay and bisexual men.

At present, there is a 12-month celibacy period in place for men who have sex with men. “The policy is homophobic,” said Remy Pilot, of Let Us Donate. “In essence, any [gay] man who has sex within the last year – regardless of individual circumstance – has lost the right to donate blood within Australia.”

The 12-month deferment is upheld regardless of whether a person is on PrEP or using condoms, or whether sex is confined to a monogamous relationship. Let Us Donate is

campaigning for a shortening of the deferral period to four months, or alternatively, for eligibility to be determined by individual risk assessment. “Put simply, within three months it is possible to determine whether someone has contracted HIV, a fact which makes the current 12-month deferral period discriminatory and outdated,” said Pilot.

A lifetime gay blood ban was introduced in Australia in 1983 along with legislation making it a criminal offence for an individual not to disclose a history of male-to-male sexual contact. By 2000, regulations were relaxed, allowing donations by gay and bisexual men who had not engaged in homosexual activity for 12 months. Despite the Red Cross



recommending in 2014 that the 12-month period be reduced, the TGA rejected the proposal.

Critics of the current policy argue that if women are trusted to make their own assessment and accurate disclosure of their likely HIV risk – why can’t gay and bi men? It is this lack of trust that fuels accusations of homophobia and discrimination. “It is discriminatory to the extent that gay and bisexual men are not trusted to make responsible

decisions about their own, or others’, sexual safety. Nor are they trusted to honestly disclose their likely sexual risk,” said Jennifer Power of the Australian Research Centre in Sex, Health and Society. “This mistrust stems from a long-term cultural association between gay men, hedonism, irresponsibility and deviance.”

Let Us Donate is running an **online fundraising campaign and petition** to effect a change in policy. “The Australian Red Cross states that ‘the underlying principle on which people give blood has to be one of mutual trust’,” said Pilot. “This trust must be extended to the hundreds of thousands of queer persons it excludes from donating blood.”

Physical abuse in PNG now at 70pc

HIV stigma in Papua New Guinea is at an unacceptable level, according to a new report.

Out of 80 people interviewed about their experiences with stigma and discrimination, alarmingly, almost 70 percent said they had been physically assaulted in the previous 12 months because of their HIV status.

The research, carried out in the Western Highlands and Chimbu provinces by Dr John Rule of the National Association of People with HIV Australia (NAPWHA), also found that more than half of those questioned had not attended any social gatherings because of their positive status, while more than a third said they had been excluded from activities



in their communities.

“People living with HIV are experiencing discrimination in family settings, healthcare settings, clans, workplaces and between their peer networks,” said Dr Rule. Fear of stigma and

discrimination often results in people with HIV shunning treatment and care. “And that means that the person does not take their ART,” said Dr Rule. “That is an outcome that we do not want.”

War on drugs: more harm than good

Making drug use a crime negatively impacts HIV prevention efforts, says comprehensive new research.

Criminalisation has not only been unsuccessful in reducing drug use but it has also driven up HIV rates by ignoring the prevention and treatment needs of people who inject drugs.

US researchers systematically reviewed more than 100 studies on drug criminalisation and HIV prevention or treatment among injecting drug users.

“More than 80 percent of the studies demonstrated worse health outcomes among those targeted by these laws and their communities at large,” said Stefan Baral, an Associate Professor at the Johns Hopkins Bloomberg School of Public



Health.

The findings suggest that alternative strategies and policies need to be put in place to limit the harms associated with drug use, including infectious disease. “The current approach is not working,” said Baral. “People have addiction and they have nowhere to turn. They are getting HIV and hepatitis C because they are sharing dirty needles. We are at a turning point and there seems to be no end in sight.”

Get the shot

Flu season is upon us (typically May to October), and health experts are advising people — especially those with impaired immunity — to make sure they protect themselves and get the jab.

This year, vaccinations are easier to obtain than ever. For the first time, all pharmacies in Australia will be able to administer the shot. “If you find that you are time poor, and you can’t go to your doctor’s surgery to get your flu shot, go to your local pharmacy and get your flu shot as soon as possible,” said Rich Samimi of the Pharmacy Guild of Australia. The vaccination process takes around 15 minutes.

There are four strains to this year’s vaccine: two influenza A viruses, and two influenza B



viruses. Studies indicate the vaccine to be 70 percent effective. It’s important that people get vaccinated early so as to develop immunity before transmission of influenza is at its highest (between August and September). Already, more than 7,000 people in Australia have been diagnosed with flu this year — 1,000 more than in the same period in 2016.

For more information go to flusmart.org.au

Hong Kong hits record high

The number of HIV cases in Hong Kong has hit a record high.

According to the latest government figures, the first quarter of 2017 saw 202 diagnoses — the highest number since records began in 1984. Overwhelmingly, the majority of new cases (116) were among young men. “Despite our decades-long efforts, HIV infections have continued to rise noticeably among young men who have sex with

men,” said Dr Susan Fan of the Hong Kong Advisory Council on AIDS.

The Council forecasts the number of Hongkongers living with HIV to surge by 35 percent in the coming four years. “Drug abuse, inconsistent condom use, inadequate testing and coverage of treatment, and discrimination against at-risk groups are key factors in this worrying trend,” said Fan.

HIV and your family

Researchers at UNSW Sydney are documenting — for the first time — stories of family life in the context of HIV, hepatitis B and hepatitis C.

The Centre for Social Research in Health is hoping to interview individuals living with these infections, and their (self-defined) family members, in an effort to understand what these health issues mean for everyday



family life and relationships.

Researchers hope the findings will inspire new government and community strategies for involving families more

deliberately in the response to these stigmatised infections. “Collating and communicating these stories helps to challenge the fear attached to blood-borne and sexually transmissible infections,” said Associate Professor Christy Newman.

For more information about the My Health, Our Family study contact c.newman@unsw.edu.au

Twice the suicide risk

HIV-positive men are twice as likely as their negative peers to commit suicide.

The shocking statistic comes from a 15-year study of almost 90,000 people diagnosed with HIV in England and Wales

between 1997 and 2012. Those recently diagnosed are most at risk, with the majority of suicides occurring within the first year of diagnosis. The suicides occurred regardless of whether people were linked to care or not, or whether they were on treatment or not.

Stigma, difficulties adapting to the diagnosis and insufficient mental health provision are thought to be behind the findings. Researcher Sara Croxford said: "They highlight the need for a reduction in the stigma surrounding HIV, improvements

It's urgent that people know that with treatment someone can have a normal life expectancy.

Matthew Hodson



in psychosocial support, and routine screening for depression and drug and alcohol misuse, particularly at the time of diagnosis."

Reacting to the data, executive director of NAM Aidsmap, Matthew Hodson, said: "It's urgent that people know that with treatment someone can have a normal life expectancy. Both people living with HIV and those who are not living with the virus need to know that an undetectable viral load on treatment means you will not pass the infection on to your sexual partners."

Happiness boosts health

Teaching happiness skills to men recently diagnosed HIV-positive helps reduce HIV in the blood.

That's the key finding of what is believed to be the first study of its kind to show how mental health can affect physical health in people with HIV. "Even in the midst of this stressful experience of testing positive for HIV, coaching people to feel happy, calm and satisfied – what we call positive affect – appears to influence important health outcomes," said lead author Judith Moskowitz of the Northwestern University of Medicine in San Francisco.

In the study, 80 participants were taught a set of eight positivity skills; another 79 were not – all were on antiretroviral treatment. Fifteen months later, a greater percentage of the 'happiness group' had a suppressed viral load than the control group (91–76 percent).

While it may take some time for the research team to fully understand why happiness appears to influence viral load, the results were described as "amazing" and "potentially huge for prevention of HIV".



The positivity techniques used in the study included:

- **Recognise a positive event each day**
- **Savour the moment**
- **List a personal strength and note how you used it**
- **Set an attainable goal each day and note your progress**
- **Practise a small act of kindness**
- **Practise mindfulness with a daily 10-minute breathing exercise**

HIVCURE

IN TWO MAJOR BREAKTHROUGHS, THE VIRUS IS ERADICATED FROM EVERY TISSUE AND ORGAN AND A NEW DRUG SIGNIFICANTLY REDUCES THE VIRAL RESERVOIR

Complete elimination achieved

Using gene-editing technology (known as CRISPR), scientists have successfully removed HIV implanted into mice — the first time complete elimination has been achieved in live animals.

The breakthrough study included a 'humanised' model in which mice were transplanted with HIV DNA. These latest findings build on previous research that saw the partial deletion of HIV. This time, following a single treatment, the virus was eradicated from every tissue and organ.

"We have confirmed the data from our previous work and have improved the



efficiency of our gene-editing strategy," said lead researcher Dr Wen Hui of the Lewis Katz School of Medicine (pictured). "We also show the strategy is effective in two additional mouse models: one representing acute infection in mouse cells and the other representing latent infection in human cells." The new study marks another major step forward in the pursuit of a permanent cure for HIV, and paves the way for a human clinical trial of CRISPR.

Reservoir reduced

In another first, a drug has proved successful at reducing the viral reservoir in some people with HIV.

Results from a Phase II trial has shown the therapy – called ABX464 – can target viral DNA that hides within blood cells. Despite the groundbreaking results, Jean-Marc Steens of French biotech company Abivax admits there is still a lot more to do. "We saw an average decrease of 40 percent of the viral reservoir, which is probably not enough."

Also, ABX464 only appeared to work in



50 percent of participants. At this stage, Sheen can only speculate the reasons why: "These could include the length of treatment they were on in the past, whether they were treated early or late in their infection, and what type of medication

they have been receiving in the past." Discovering a way to eradicate the HIV reservoir would be a major breakthrough in cure research. Some HIV cells are able to evade treatment, remaining dormant for years, only to suddenly reactivate and start producing more HIV.

The new frontier

In the 1980s and early '90s, people living with HIV found themselves on a battlefield against a disease for which there was no treatment, let alone a cure. In many cases, it was a fight to the death. Today, the long-term survivors of the epidemic find themselves on a new and unexpected battlefield: ageing with HIV.
Rebecca Benson reports.

Ageing with HIV — such an outcome would have once been unthinkable. Back in the day, people didn't age with HIV, they'd die of AIDS. And yet, here the battle-scarred warriors are: the first generation to live into their golden years and the first generation to face the unique, accompanying challenges associated with ageing with HIV.

Studies suggest many of the conditions linked with ageing — cardiovascular disease, certain cancers, weakened bones, cognitive impairment, liver and kidney disease — appear to occur at higher rates among older people living with HIV than their negative peers. Why this is so, scientists are still busy determining. One study in particular — assessing the incidence of heart attack, kidney disease and non-AIDS cancers among people with HIV — found that, although the rate of these events occurred at similar ages than those without HIV, the likelihood of these three outcomes occurring was significantly higher among people

with HIV than their negative counterparts.

Another detailed study — carried out in Denmark over two decades — found HIV-positive people more likely to have severe forms (and to be at much higher risk) of age-related diseases than HIV-negative people. The findings, say the authors, are relatable to other Western countries with maturing populations, such as Australia, where, in 2010, the proportion of people with HIV over 55 years was 25.7 percent. By 2020, it is expected to be 44.3 percent.

Other studies point to evidence that people with HIV are at an increased risk at an earlier age of adopting symptoms of frailty. Ross Duffin works with the HIV Outreach Team (HOT) run by the South Eastern Sydney Local Health District. HOT looks after HIV-positive people with serious health issues. “Most are living with greater comorbidity than their negative peers,” said Duffin. “As a general observation of people with HIV, those who were diagnosed prior to 1996, when the HAART drugs arrived, have the greatest level of illness

and frailty.”

David, 64, knows this all too well. “Early ageing is real for someone like me. I feel I'm frail before my time and only recently accepted the need to use a walking stick,” he said. “I started to experience non-AIDS-related conditions in my early fifties with the onset of type 2 diabetes — undoubtedly linked to the early HIV drugs. This led to renal problems and the need to see more and more specialists.”

As ageing takes its toll, Barry, 63, finds himself in a similar situation. “I have to factor in more doctors' visits than other people my age,” he said. “I am constantly being monitored for toxicity and changes to my liver and kidneys. I have atrial fibrillation. The HIV is also responsible for my high blood pressure. I suffer from chronic peripheral neuropathy and lipodystrophy. Both conditions are very debilitating, causing extreme pain in the case of the former and depression with the latter as it affects self-esteem. Long-term survivors such as me have certainly been wearied by HIV.”

To help people such as David and Barry, Living Positive Victoria

and the Victorian AIDS Council (VAC) are developing self-management courses for older people with HIV. “They aim to help people learn the skills needed to manage an often complex condition like HIV,” said Kent Burgess, manager of HIV services at VAC. “This might involve learning how best to talk to your doctor, how to adhere to your treatments, or learning about good nutrition or advanced aged-care planning.” Other community organisations around the country have begun to develop initiatives to help people with HIV cope with the demands of ageing. Positive Life NSW, for example, has run workshops on how to deal with HIV-associated neurological disorder (see page 10) and better understand the National Disability Insurance Scheme.

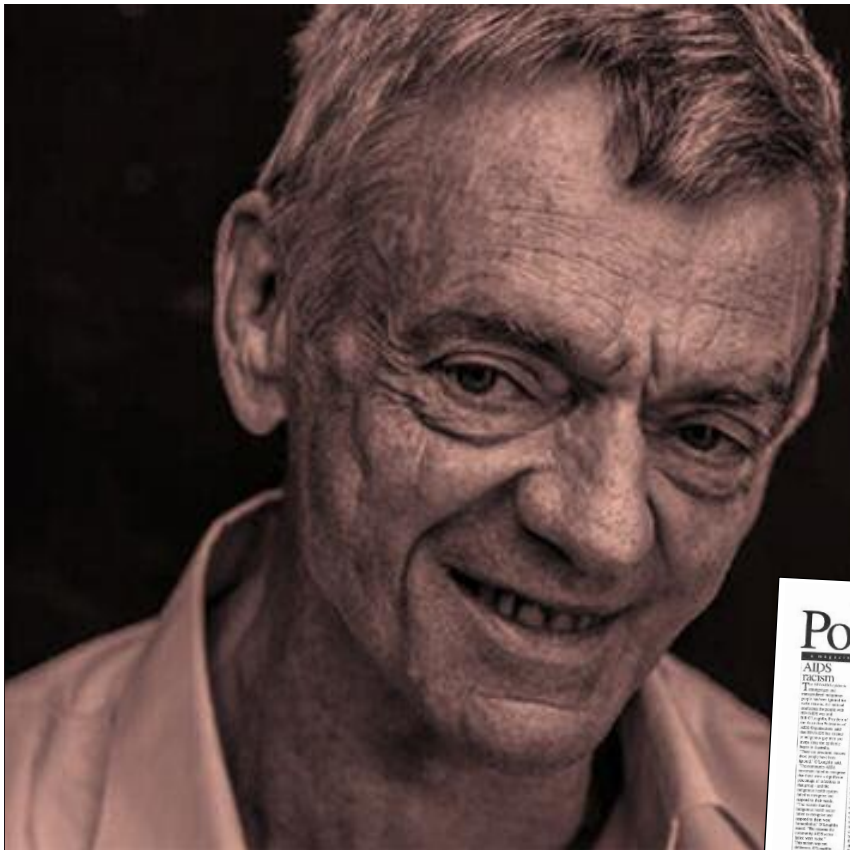
Mainstream healthcare providers will also need to respond to the ageing HIV population. With this in mind, Living Positive Victoria runs the **Senior Voices Project** where positive speakers talk to aged-care workers about the needs of older people with HIV. Similarly, the

Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine has developed an educational guide specifically for the aged-care sector. “It is important we know how values, attitudes and a lack of HIV/AIDS knowledge can lead to discrimination and poor health outcomes for people living with HIV and put measures in place to prevent this,” said Sandy Komen of the Bridgewater Aged-Care Group, which has trialled the guide in WA.

But what about the people ageing with HIV themselves, how can they best ready themselves for the challenges they face? “It's about being prepared and developing resilience in your life,” said Burgess.

Resilience. It's a word often bandied about when the topic of ageing with HIV is discussed. Resilience, in my mind, is not something that can be easily taught. Rather, resilience is something you acquire in the face of adversity. Considering all that they have endured, the long-term survivors will be more than equipped for the uncharted road ahead . . .

The turning point



For long-term survivors, 1996 was a watershed year: with the advent of new treatments, HIV was no longer a death sentence. David Menadue rifles through the PL archives to look back at some of the miracles and challenges of the day.



Jaws drop as AIDS death rates plummet

Positive Living cover Nov. 1996

wasn't trial evidence of such side effects. Well, according to anecdotal evidence, my experience turned out to be quite common in friends who tried efavirenz after me.

Despite their side effects, the new treatments quickly proved effective. 'Jaws drop as AIDS death rates plummet' read November's front-page headline. Thinking it was too early to see such incredible results, Professor John Kaldor from the National Centre for HIV Epidemiology and Clinical Research (now the Kirby

early interview with treatments activist Martin Delaney from San Francisco's **Project Inform** highlighted the difficulties that people were having with the new protease inhibitors saquinavir and ritonavir — both caused awful gastric upsets and, when taken as a liquid gel, ritonavir tasted terrible. "It is a very effective drug for those who can tolerate it," Delaney told *PL*. "But the rate of side effects reported are higher by far than any drug you've ever seen in the epidemic."

Another new treatment causing people problems was efavirenz. While on it, people felt spaced-out for weeks and, when asleep, were assailed by wild, vivid dreams. I wrote about my own experiences with the drug. "I have experienced a pronounced wooziness," I wrote. "I first started to notice it when getting out of bed in the morning and my gait was like I was still drunk from the night before." I reported on this as a warning to others but received a bit of flak from doctors as a result. They said I needed to be careful not to relate my experience as common as there

Institute) postulated on whether the drop in deaths was truly the beginning of a treatment-related decline or some kind of statistical aberration. Fortunately, the former proved to be the case. As the article stated: "There seems to be a consensus among clinicians and people living with HIV/AIDS that people who are taking up combination therapy are faring considerably better."

And so — for the very first time since the epidemic emerged — positive people began to live in hope: those of us who had survived the horrors of the '80s and early '90s were suddenly presented with . . . a future. For years, it was drummed into us that if you had AIDS you'd die. Now, that wasn't necessarily the case. For some, the surprise reprieve was a tough concept to embrace so I wrote about the profound psychological impact that the so-called 'Lazarus effect' was having on AIDS survivors like me.

"Like it or not, [HIV's] presence in our bodies has almost become a part of our identities. There has hardly been a day gone

by when questions of mortality, illness or disability related to the virus have not crossed our minds. To be suddenly given the power to unlock the angst and fear about our futures is actually quite confronting. Curious as it might seem, I think that some people will have difficulty 'giving up' their illness if that is to become a possibility; to start to re-evaluate our lives without the stymie of HIV. Some are toying with the idea of not even taking drugs like protease inhibitors because it interferes with their preconceived view of what life's path is meant to be for them. This might seem like a death wish, but the scars which HIV has etched in our psyches cannot be explained easily."

My piece ended on a sobering note: "With all this promising news, I've had three funerals to attend this month. The epidemic is not over and the grief, loss and angst which AIDS has brought will probably never leave this generation. Dealing with the survivors of an epidemic of the proportions we have seen will be no easy task."

In 1996, along with Bridget Haire, I became co-editor of *Positive Living*. It was an important year for the masthead. Having started out as a Victorian publication, in September, *PL* became a nationally syndicated magazine.

Our first front-page story gave voice to critics of Australia's Third National AIDS Strategy. Many felt it didn't go into enough detail about the role community organisations would need to play in educating people about the merits of taking the new treatments and the importance of adherence. The early drug regimens were complex, often involving a handful of pills taken multiple times a day — some before food, others after. "Without extensive public education in HIV communities, it is believed that only a minority of people living with HIV/AIDS will take up treatment options," read the piece.

From the beginning, treatment developments featured prominently in *Positive Living*. An



LET'S KICK ASS

With more than 4.2 million people aged over 50 living with HIV worldwide, Tez Anderson warns of a multi-pronged crisis affecting the health and wellbeing of older adults with HIV.

The first 20 years of the HIV/AIDS epidemic were traumatic. It is a testament to the human spirit, to individuals and communities who rolled up their sleeves and refused to accept HIV as a death sentence that we are here now.

We are long-term survivors of the AIDS pandemic — the most devastating health crisis of the modern era. With courage and compassion we survived the darkest days of the plague. Without access to effective treatments, we were forced to rely on each other and ourselves. We exhibited strengths we didn't know we had.

For us, AIDS was more than simply a medical diagnosis or the end-stage of a deadly disease. AIDS shaped our psyches. It also galvanised our communities and gave us a sense of meaning and purpose. AIDS was a cultural, political and social force that changed the course of our lives and killed many of our loved ones. All of that is affecting our lives right now.

AIDS Survivor Syndrome

(ASS) is a phenomenon unique to long-term survivors and their carers who survived the worst decades of HIV/AIDS. It describes the psychological state resulting from living through the AIDS pandemic — especially vulnerable are those who became HIV-positive pre-1996 when HIV was considered a terminal diagnosis.

ASS is not a linear phenomenon; it varies in degrees of intensity and affects long-term survivors differently at different times. Symptoms include depression, suicidality, self-destructive behaviour, social withdrawal, survivor's guilt, loss of ability to enjoy life, a sense of hopelessness, and low self-esteem. In the era of "Ending AIDS", many of us feel forgotten and invisible.

We need to draw attention to the numerous challenges facing our continuing survival, including high levels of multi-morbidity (the co-occurrence of two or more medical or psychiatric conditions), inadequate social supports, barriers to community-based

services, and truncated opportunities for employment and participation in society.

Attention needs to be drawn to some of the changes that need to be made in our communities and in our healthcare system to

ensure older adults with HIV have the tools we need to live productive lives into our older years. We know older adults with HIV face a higher number of comorbidities than adults at the same age without HIV, but we need to better

understand the psychological and biomedical forces at play that are creating this outcome.

Additionally, large numbers of survivors face financial difficulty because they are likely to have been on disability for decades.

Many survivors live on or below the poverty line. This has far-reaching effects that affect access to quality care and affordable housing, ability to engage in the community, and efforts to improve self-esteem and

motivation. Long-term survivors have a wealth of knowledge and a depth of experience that must be tapped in order to better understand how to create communities where our needs — mental, physical and financial —

are met. We urgently need access to care that is culturally sensitive to the experiences of long-term survivors of HIV, and to identify unique and innovative solutions to meet the needs of older adults with HIV.

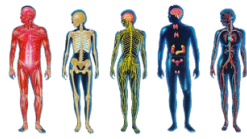
Long-term survivors have a wealth of knowledge and a depth of experience that must be tapped in order to better understand how to create communities where our needs — mental, physical and financial — are met.

Some advocates contend that we have reached a transition point; they reason there is a need to focus on building a more hopeful future for adults with HIV, where they and their providers are able to collectively advance efforts to achieve optimal ageing.

While HIV therapy has created a turning point in the epidemic, some advocates say that healthcare providers, policymakers, caregivers, people working in HIV organisations, and others supporting people living with HIV need to recognise that achieving a longer lifespan is not the end of the battle. In fact, it may be only the beginning of a more protracted struggle to ensure that people living with HIV are able to live healthier lives into their older years. It is time to advance the conversation beyond survivorship and focus on a culture of ageing well with HIV.

The goal is moving beyond merely surviving to thriving.

■ Tez Anderson is a long-term survivor and founder of **Let's Kick Ass**



HIV+THE BODY

EXPLAINING THE EFFECT HIV HAS ON PARTICULAR PARTS OF THE BODY

The grey matters

HIV has many hiding places — or “sanctuary sites” as the scientists like to call them. One of which is the brain.

The virus enters the brain within the early stages of infection — just a matter of a few weeks. Usually, the blood-brain barrier (BBB) acts as a shield to protect against invasion. But HIV is not your usual virus: it employs a Trojan horse-like method to compromise the BBB and gain access to the brain. Once there, the virus can genetically mutate, meaning that treatment may not work as effectively in the central nervous system as it does in other parts of the body. Over time, HIV in the brain can affect movement, memory and concentration — a syndrome known as HIV-associated neurocognitive disorder, or HAND. Those who have lived with HIV for a long period of time and/or are ageing are at particular risk of HAND.

The brain damage seen in people with HIV is similar to the impairment experienced by people with early-stage Parkinson’s or Alzheimer’s disease. (However, no studies have shown that either of these conditions is occurring at greater rates in people with HIV than the general population.) HAND symptoms can range across the spectrum from mild (when they can often go unnoticed) to severe. Tell-tale signs can include: bumping into things, or dropping things; tripping or falling; a reduced ability to recall names or spell words; a lack of concentration; sudden mood swings and increased anxiety levels; becoming forgetful; losing track of a conversation or time. Of course, all of those symptoms could be just a matter of general ageing — so how does a positive individual know if they’re suffering from HAND as opposed to dodderiness?

When diagnosing HAND, neurological specialists are keen to rule out the possibility that



Whether you have memory problems due to HAND (HIV-associated neurocognitive disorder), another co-existing condition, or the normal ageing process, there are things you can do that may help.

problems with memory or thinking are not symptomatic of other, more common causes. Similar symptoms could arise from cardiovascular disease, hepatitis C coinfection, anxiety and depression (both found at higher rates in people with HIV) and heavy use of alcohol or recreational drugs. HAND can also be caused by a number of prescription medications — including antiretroviral drugs, such as efavirenz found in Atripla.

If, however, HAND is suspected, a neurocognitive screening test (a simple Q&A) will be sought. Such a test will involve an individual being asked, for example, whether they’ve noticed changes in memory loss, whether they’ve experienced difficulties in paying attention, or if they’ve felt their reasoning has slowed. If further tests are needed, then an MRI (brain) scan will be carried out.

Detecting HAND — even if a person doesn’t notice any

problems or symptoms (i.e., asymptomatic) — is important. People who are asymptomatic are more likely to develop increased neurocognitive impairment in the future. Also, asymptomatic neurocognitive impairment may interfere with treatment adherence and HIV management.

Since the advent of highly effective antiretroviral treatment in 1996, the number of people diagnosed with HIV-related cognitive impairment has decreased dramatically. In the past, without effective treatment people with HIV would develop a severe form of cognitive impairment called AIDS dementia complex (ADC). This was brought on by high viral loads and immune activation in the cerebrospinal fluid. These days, ADC is only seen in individuals who present extremely late for treatment.

Although antiretroviral treatment can help prevent HAND, people on HIV meds can

still develop cognitive difficulties: a 2010 study found that 52 percent of people with HIV had registered some form of cognitive impairment. By contrast, according to the **CNS HIV Antiretroviral Therapy Effects Research study**, only 10 percent of people in the general population experience such problems.

Whether you have memory problems due to HAND, another co-existing condition, or the normal ageing process, there are things you can do that may help:

- Take time to learn new information — avoid remembering new things when you’re tired or under pressure
- Use the recorder on your phone or a pad and pen to keep notes of things
- Use your phone as an alarm to remind you to take your pills and remember healthcare appointments

- Remembering involves all five senses. Seeing a phone number, repeating it out loud, and writing it down increases the chance of remembering it

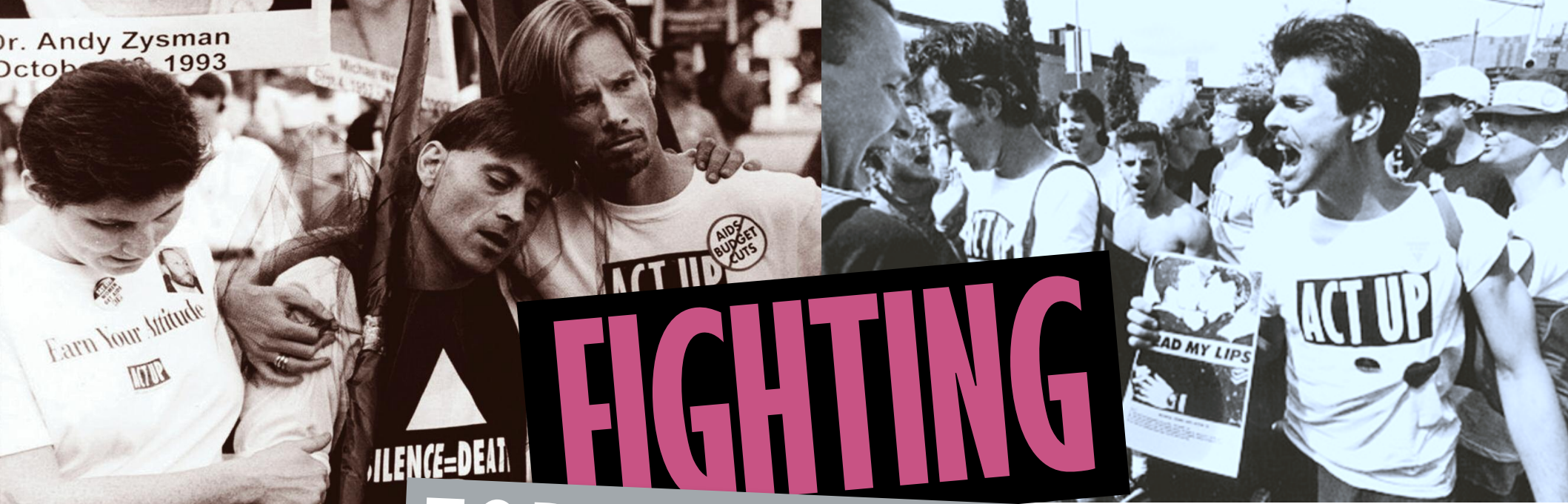
- Break large, difficult tasks into small sections

But by far the most important thing you can do is to ask for help. If you’re worried you may be experiencing symptoms of HAND start a conversation with your healthcare provider. Seeking medical help early on is very important.

There is still much to understand about HAND. It’s not known, for instance, how common the condition is, which people are most vulnerable to it, or how it can be prevented. It will likely take a few more years when older people with HIV can be studied in larger numbers until more is known about HIV-associated neurocognitive disorder. However, there are a number of factors that can significantly reduce the risk of developing symptoms such as:

- Keeping HIV in check with treatment. A study found that people with suppressed viral loads were far less likely to develop HAND, and if they already had symptoms, HAND was less likely to progress
- Treat other causes of cognitive impairment — high blood pressure, high cholesterol and gut fat accumulation can all place stress on the brain, as can hepatitis C and B, and kidney and liver disease
- Get plenty of exercise — studies confirm that regular aerobic activity protects the brain
- Stay socially engaged — social activity helps keep the brain nimble
- Stimulate the mind by learning a new language or playing brain games

Dr. Andy Zysman
October 1993



FIGHTING FOR THEIR LIVES

Do we want to start a new organisation devoted solely to political action?" It was that question and the resounding "Yes!" of an answer that gave birth to a worldwide protest movement — ACT UP (AIDS Coalition to Unleash Power).

The call to arms was initiated by Larry Kramer. He was speaking to a crowd of mainly gay men gathered at a community centre in New York City. Kramer warned them that if they didn't organise and mobilise, two-thirds of them would be dead within five years. "If what you're hearing doesn't rouse you to anger, fury, rage — and action — gay men will have no future here on earth," he said.

It was March 1987. AIDS was ravaging the gay community and the response from the US government was next to nothing. "Larry called us together and asked us to help him take to the streets to sound the alarm," says former activist and long-term survivor Eric Sawyer. And take to the streets they did. Two weeks later, around 250 ACT UP members hit Wall Street to demand access to experimental drugs; 17 people were arrested. Such incendiary tactics were deemed necessary: people were, literally, fighting for their lives.

"The response was triggered by an awareness that we were in danger," says former ACT UP member Loring McAlpin. "Friends, lovers, people we knew, were dying."

By boycotting, marching and demonstrating, ACT UP borrowed from the civil rights movement. "The group operated in a way Martin Luther King, Jr. advocated," says former activist Sarah Schulman: "make a demand that's reasonable and

THIS YEAR MARKS THE 30TH ANNIVERSARY OF ACT UP. AND, AS DOMINIC BROOKES REPORTS, MANY OF TODAY'S LONG-TERM SURVIVORS WERE YESTERDAY'S FRONT-LINE ACTIVISTS.

doable, present that demand to the powers that be who can enact it, and when they refuse, you do civil disobedience until they are forced by pressure to take action."

For many ACT UP members, this was the first time they had become politicised. "Some of them were everything from brokers, to party boys, to quiet men living at home — they didn't know anything about politics," says Schulman. "I've never been

the pharmaceutical industry, the media — all twiddled thumbs while thousands died. As anger grew, so did the size and nature of ACT UP's protests. And in 1989, 4,500 protesters gathered outside New York's St Patrick's Cathedral to demonstrate against the Church's stance on safe-sex education, condom distribution and homosexuality. During the protest a couple of dozen of activists entered the church,

brought the crisis to a point where the government and the media really had to start dealing with it."

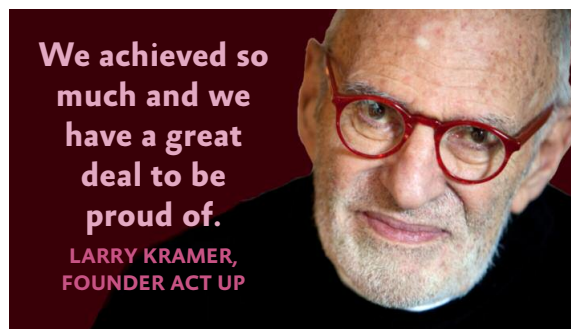
At its height, ACT UP had more than 50 chapters across America, plus satellite organisations around the world — including Australia. ACT UP Sydney was the first Aussie offshoot to form. The group's initial target was the Australian Drug Evaluation Committee, responsible for drug

heard from city blocks away." At the same time, remembers Chan: "We were lobbying to make ddC available on a compassionate basis and we were lobbying governments to expedite approval of this drug."

Other Australian ACT UP chapters soon emerged: in Melbourne, Brisbane, Canberra and Perth. "It was like we were in a war, almost a secret war," says Chan. By 1993, the 'war' had taken its toll on members and emotional exhaustion had set in. Others were incapacitated by ill-health, or had died. But ACT UP in Australia had achieved its main aim: to fast-track access to medication for people living with HIV.

The movement was as equally successful in the States. "There's no doubt [ACT UP] had an enormous effect. We changed the way we make drugs available," says Dr Stephen C. Joseph, a former New York City health commissioner. "We achieved so much and we have a great deal to be proud of. ACT UP created a great amount of energy and got results," says Kramer. "Those people," says Hubbard, "were genuine heroes."

The original chapter of ACT UP still meets at the community centre at 208 West 13th Street New York every Monday evening at 7pm. And with the Trump administration slashing health spending — a move that will see HIV/AIDS funding cut by around US\$300 million — ACT UP still has plenty to rail against. At a recent 30th anniversary event, long-time survivor and ACT UP member Jim Eigo issued the following battle cry: "We have to continue fighting for the very basic protections for the most vulnerable among us because, my god, they are more vulnerable than ever."



We achieved so much and we have a great deal to be proud of.

LARRY KRAMER, FOUNDER ACT UP



It was like we were in a war, almost a secret war.

LYLE CHAN, ACT UP SYDNEY

an aggressive person before I joined ACT UP," says former member Virg Parks. "But I liked the idea of a nonviolent organisation that still said we're going to be strong and powerful and angry, and let them know that we are pissed off."

And there was much to be pissed off about. Not least of all, the indifference shown to the plight of the afflicted. Government, health authorities,

disrupting mass. This time, more than 100 activists were arrested.

Another memorable protest occurred in Washington DC, at 1600 Pennsylvania Avenue. "People had ashes of their fathers, their boyfriends, their friends, and threw the ashes on the lawn of the White House," recalls Schulman. Such dramatic action, says former activist and long-term survivor Jim Hubbard, helped bring ACT UP to mainstream attention. "It

licensing. It was the first of many protests designed to draw attention to delays in the approval process of potentially life-saving drugs.

"The public demonstrations were loud and furious," says Lyle Chan, co-founder of ACT UP Sydney. "We used whistles as we marched down the streets to sound bigger than we were, so a few hundred people can sound like thousands and could be

Immediate or early: what's the difference?

We've known for some time that HIV causes damage from the moment you become infected with the virus.

Today, there's no doubt treatment for HIV is your best course of action to benefit your health in the long run and to prevent the onward transmission of HIV to your partners.

For most people living with HIV (PLHIV), treatment consists of a daily single pill with little-to-no side effects. Gone are the days of handfuls of pills, specific timings and gruesome side effects. The main debate today is when to start treatment — immediate or early?

So, what's the difference between early treatment and immediate treatment? Early treatment is usually defined as starting antiretroviral therapy within six months of diagnosis; the definition of immediate treatment is as soon as possible after diagnosis.

In December 2016, Positive Life took the position — supported by its members — that 100 percent of people diagnosed with HIV in NSW are

offered the chance to start treatment the same day or soon after. This would mean, whether diagnosed in a GP setting or a hospital clinic, you would be able to walk into a nearby pharmacist to pick up a free 'starter-pack' of basic HIV medication.

The diagnosing doctor would offer this option in the understanding that you can choose to opt out of taking the medication or even delay starting treatment for as long as you wish.

Despite this clear mandate from the positive community, a number of concerns and issues remain around the timing of treatment. Some of these concerns are about making sure



the newly diagnosed make an informed decision and don't feel railroaded into starting treatment. Positive Life agrees with this caution. We also hear from PLHIV at the point of diagnosis who want to take some kind of action around protecting their health, and the health of their partners and family.

Other issues are about waiting for blood-test results to guide the best treatment options for PLHIV. These will take up to two to four weeks and include viral load results, CD4 count, and resistance testing. A basic starter-pack can help a person get their head around the diagnosis while providing a sense of protection and control. When

the test results come back, if the medication needs to be changed, then it's a straightforward process.

The evidence from the Strategic Timing of Antiretroviral Treatment (START) study is clear and compelling about immediate treatment: it reduces the risk of people developing other opportunistic infections, while also stopping HIV from replicating in the body. Immediate treatment also controls progression of the virus. The sooner a newly diagnosed person starts treatment, the better position they could be in to be part of a cure when such an option becomes available. With any other infectious disease or STI, treatment is immediate and it's common sense that HIV be treated in a similar way.

● To discuss your HIV diagnosis and options for treatment with a peer (someone living with HIV), contact the treatments officers at Positive Life NSW on (02) 9206 2177.

Peer 2 Peer
for gay men with HIV

Thursday 22 June 2017
6pm till 8.30pm

More information:
call (02) 9206 2177 or
email davidc@positivelife.org.au



PositiveLifeNSW
the voice of people with HIV since 1988

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Capturing resilience

During the month of May, all Australians living with HIV were invited to send in a photograph that represents their strength and resilience against stigma for a chance to win \$1,000 through the ENUF Images ENUF Voices Photographic Prize.

ENUF campaign coordinator Brenton Geyer is passionate about working with artists and arts practitioners to explore new and different ways to deliver messages around HIV stigma and

resilience. "I believe that the creative process is an effective and valuable way to change ways of thinking and draw out feelings and emotions that can easily translate through art," said Geyer. "Through this competition I hope that the ENUF campaign is offering just one more way for people living with HIV to draw upon their experiences of stigma and resilience and



enter into visual conversations with themselves and others about those experiences."

Entries will be judged by a panel of ENUF Ambassadors and will be exhibited at The Atrium in Federation Square, Melbourne from 20-24 June 2017. Winners will be announced on 20 June at the exhibition launch. The launch is open to the

general public in the hope that the images will reach people who may not be part of the HIV community. "There's a whole untapped audience out there who don't pick up leaflets, don't take any notice of posters or read magazine articles but do go to the theatre, visit art galleries and exhibitions," said Geyer. "Those who enter their photo and story give others the opportunity to understand how stigma affects all those living with HIV."

PEER-LED PROGRAMS: THE W3 PROJECT

Testing the effectiveness

The What Works and Why (known as the W3 project) is a study investigating the role of peer-led programs and the influence these programs have in community, policy and sector systems.

Led by Dr Graham Brown from the Australian Research Centre in Sex, Health and Society (ARCSHS), Living Positive Victoria has signed a three-year agreement as a community partner alongside Harm Reduction Victoria.

The W3 project involves two stages:

- Stage 1 began in 2013 and completed last year. During that time the project worked with ten community and

peer-led organisations to develop a new quality and evaluation framework for peer-led programs.

- During stage 2 (which began in 2016 and completes in 2019) the W3 project is working with Living Positive Victoria and Harm Reduction Victoria to apply the framework at an organisational level. This includes the development of practical tools and approaches to improve the impact and quality of programs as well as share real-



ARCSHS, Harm Reduction Victoria and Living Positive Victoria sign the W3 Project collaboration agreement

time knowledge with the broader sector. "What I'm passionate about is ensuring that affected

communities are equipped to articulate their voices and lead the HIV response," said Brent Allan, Living Positive Victoria CEO. "We're investing in W3 because building our community research capacity is something that will drive the kind of systemic changes that will make this happen in Australia."

The collaborators hope the project will:

- develop a more sophisticated understanding of how peer-based programs work;
- help community and peer-based organisations evaluate what really matters to their work; and
- articulate how peer-based programs add value to HIV

and HCV programs and policy, in addition to their community, policy and sector systems.

"We know that peer-led programs and leadership are the key to maximising community engagement with the HIV response," said Timothy Krulic, Living Positive Victoria's Health Promotion Officer. "That's why we're collaborating with the W3 project: to enhance the work we do, to challenge stigma, to enhance engagement with treatment options, and to make the most of the opportunities working in the HIV sector allows."

- For more information on the W3 project head [here](#).



Dr Graham Brown from the Australian Research Centre in Sex, Health and Society and Positive Speakers Bureau members Christabel and Anth delivered spectacular speeches to hundreds of Melbournians at the 2017 International AIDS Candlelight Memorial

New syphilis campaign

QPP is proud to announce the launch of its new syphilis campaign principally targeting HIV-positive gay and bisexual men.

New syphilis infections have more than doubled in the last five years within Queensland, with one-third (or more) cases among HIV-positive men.

The campaign launched in early May with information available [online](#) and as a fact sheet. The campaign includes a ten-month cycle of Grindr-based advertising comprising three

different messages aimed at raising awareness about syphilis to the positive gay community. The messages address the common asymptomatic nature of syphilis; the fact that syphilis is easily contracted from oral sex and skin-to-skin sexual contact; and that reinfection of syphilis is possible after treatment (i.e. there is no immunity gained from an initial infection).



Meanwhile, poster advertising will occur in southeast Queensland sex-on-premises venues (SOPVs), with posters

also distributed to state sexual health services. (QPP thanks the HIV Foundation Queensland for funding the campaign, and assistance in design and marketing.)

As well, during the initial phase of this new campaign, QPP — in association with The Pharmacy Guild of Australia (Queensland Branch) and Queensland Health — has undertaken a novel method of

alerting HIV-positive men about the syphilis outbreaks and the need for regular testing. QPP has approached 15 community pharmacies in southeast Queensland, requesting they give an educational flyer to positive men when they pick up their meds. Recipients are being asked to consider if the information is relevant to them. This aspect of the campaign is still ongoing and will be evaluated after June 2017, while the main campaign will continue until February next year.

Presenting Peer Navigation

Queensland Positive People was invited to showcase its Peer Navigation program by Health Consumers Queensland at its annual forum in Townsville in April.

Titled 'Power and Passion: culture change through consumer engagement and partnerships', the forum showcased some great examples of consumer and community engagement in Queensland. As well as QPP's Peer Navigation program, presentations highlighted partnerships and models of engagement with consumer groups across Queensland's community and healthcare sector.

The Life+ Peer Navigation presentation was delivered by programs manager Chris Howard and team leader Tiko Istiko and focused on the historical role of positive peers in Australia's HIV response. Through volunteerism, essentially peers were the initial

care providers, advocates and activists during the early days of the epidemic. Peer Navigation has its foundations in this community-driven response to HIV. It is also built upon the principles of GIPA/ MIPA (The Greater/ Meaningful

Involvement of People Living with HIV) in recognising and valuing the importance of the lived experience and valuable role positive peers play in the HIV response.

Today, QPP's Peer Navigators work alongside healthcare professionals to support the newly diagnosed and those re-engaging in care. They provide both peer education and peer support. The program receives formal recognition from funders and researchers alike, including:



Queensland Health, ViiV Health Care, HIV Foundation Queensland and University of Queensland. All these groups recognise the important role peers play in the new era of HIV care, treatment and support.

The data presented at the forum also highlighted the success of QPP's Peer Navigation initiative. So far, 76 PLHIV have been 'peer navigated' since the commencement of the program in late 2016 — including ten women, ten people ineligible for Medicare assistance, and ten people from the Aboriginal and Torres Strait Islander community.

If you're recently diagnosed HIV-positive and would like to learn more about the program head [here](#).

QUITTING SMOKING

Could vaping help you give up?

QPP in partnership with the University of Queensland is currently completing a small Brisbane-based clinical trial of nicotine e-cigarettes as a quit smoking aid.

This study is now closed for new participants and QPP looks forward to sharing the results with you later in the year. However, a larger trial — encompassing Queensland, NSW, Victoria and SA — is expected to start in 2018 and will be open to all positive people who smoke and who want to quit. If you would like to be contacted about the study when recruitment starts, please register your details with the UQ team [here](#).

Meantime, for PLHIV in Queensland, QPP continues to reimburse the costs of quitting

therapies, such as nicotine replacement therapy. Also, in light of emerging evidence of the benefits in harm-reduction obtained through electronic cigarettes (being 95 percent less harmful than cigarette tobacco), QPP will also support a 50



percent reimbursement of the hardware items for these products (excluding e-liquid). Conditions apply — contact QPP at the number below for more details and to obtain a reimbursement application form.

SOMEONE DIAGNOSED HIV-POSITIVE TODAY WOULD STRUGGLE TO COMPREHEND WHAT SUCH A DIAGNOSIS MEANT DURING THE YEARS BEFORE EFFECTIVE TREATMENT. HERE, LONG-TERM SURVIVORS SHED LIGHT ON DARK TIMES.

JONATHAN

DIAGNOSED 1984

It's so horrific looking back. I don't look back very often. It's hard to conceive that it was actually all happening. You'd get phone calls to say: "So and so is ill," and it wasn't that they were ill — they were dying. And you would see them dying. Over the course of a couple of years, you would see them wasting away; you'd go to see them in hospital and you'd go to their funerals. And it was one after another. I don't know how we did it. Most of the people I knew, most of my friends, died. I was talking to another friend of mine recently who's also got HIV, and who's also one of us long-term survivors, and he said that although we're well and there are treatments, there isn't a single day that goes by without you having been affected by it.

PHIL

DIAGNOSED 1985

When I was diagnosed, a long-term survivor was someone who lived 12 months, and most people were dead in six months. It was not a question of if you were going to die — it was a question of when you were going to die.

And so there was no expectation that someone would live as long as I have lived.

KIM

DIAGNOSED 1992

When I got the 'confirmation', I felt my life was over. I can remember looking at my cat and wondering what would happen to her when I died. I was contemplating about to whom I should give my possessions. I wondered how I could possibly even be remembered on this planet or leave any type of legacy at all, being unmarried, childless and doomed to stay that way for the remainder of my painful, pitiful days.

BOB

DIAGNOSED 1993

Remember, in those days we're talking about, [HIV] was a death sentence. And since then, we've had to go through this period where, after treatment, suddenly it wasn't a death sentence. That's a — I use the expression 'mind-fuck' for want of a better word. It is! It's a crazy, crazy thing to negotiate. Looking back, you wonder why you were so lucky. It really was just luck. It's just a matter of timing. If I had been

diagnosed, say, in 1990 or 1991, my story would be very different, because treatment would probably come too late.

VICKIE

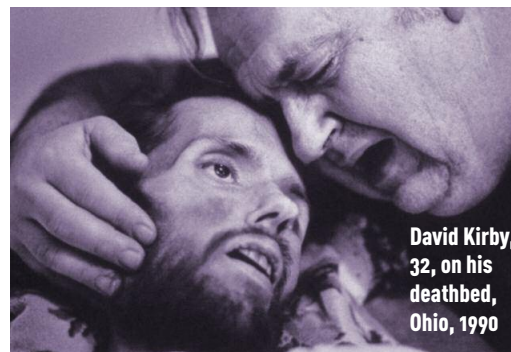
DIAGNOSED 1985

Those living with HIV today can never imagine the horrors many of us had to endure in the early days of this epidemic. I wish I didn't remember; I wish I could forget. Too many died too soon. The pain and fear were unbearable, but we stood as a community — a united front. Always supporting one another — as there were few who dared to support us. We were a group of people who were willing to stand up for ourselves and for others, and face what the world had to offer. There were very few women then who were willing to come forward. And at times, I felt like the only woman in the world who was living with HIV. It was difficult then and is still difficult today.

JONATHAN

DIAGNOSED 1982

The only thing that stopped me committing suicide was that I



David Kirby, 32, on his deathbed, Ohio, 1990

'The Photo That Changed the Face of AIDS'
Life magazine
Nov. 1990

PHOTO
Therese Frare

going to die like all of my friends and that my plans were never going to happen. I had always thought that my health was my most important asset. Now I had a disease

that always ended in death. The impact was so devastating; the fear was so overwhelming that I didn't tell anyone.

STEVE

DIAGNOSED 1987

Back then, they gave us five years at the most. I made it through, but I've got many health problems, mainly due to the medication I took. The damage to my body is nobody's fault — the doctors didn't know what they were dealing with, and the drugs were so strong. You could say I fell out of the side-effect tree and hit every branch on the way down. I've done a lot of grieving, lost a lot of friends and lovers. It's not easy and it's often lonely. I'm still here, though, 30 years on. Am I tough? Not really. I think I've just been lucky.

When I was diagnosed [1985], a long-term survivor was someone who lived twelve months, and most people were dead in six months. It was not a question of if you were going to die — it was a question of when you were going to die.



FOR AGEING WELL

- 1 Keep on the move.** Aim for at least 30 minutes of moderate exercise a day where you're working hard enough to be puffed but can still talk.
- 2 Quit! If you smoke, stop.** Now. A positive person is likely to lose more life years through smoking than through HIV. So quit. Now!
- 3 Go to bingo.** Evidence suggests being socially active stimulates ageing brains, which is good for mental health.
- 4 Eat well.** A good diet helps ward off heart disease, diabetes and some cancers. Keep your food choices healthy, varied and balanced.
- 5 Look on the bright side.** People who view the glass half full are more willing to adapt and seek solutions to problems and difficulties, and are less likely to be stressed and depressed.

HEY MAN!

Native to tropical forests in south-east China, mandarins were apparently named after the Chinese officials who wore orange robes. Smaller in size and with a thinner peel than oranges, mandarins (or tangerines) come packed with antioxidants that help cleanse the system by flushing out toxins. Like their larger cousins, they contain



vitamins A and B and are also rich in minerals like iron, magnesium, potassium and calcium. They're also high in fibre and low in fat.

Mandarins help decrease cholesterol and lower blood pressure. Fittingly for the season, they also help fight off the sniffles by acting as a natural decongestant that relieves cold and flu symptoms. This juicy citrus can be used in salads, jams, cakes, puddings, and smoothies.

Hello sweetie!

Despite consistently being ranked number one for nutrition, the sweet potato (aka kumera) remains a humble veggie. While others, such as kale or sweet beets, preen within the centrefolds of food-porn mags, the sweet potato is happy to remain out of the spotlight where it quietly punches way above its weight. Traditionally a Trump-like bright orange, the sweet potato is one of the oldest vegetables known to man, dating back to prehistoric times. It shares the same familial lineage as squash, parsnips, swede and turnips. So what makes the sweet potato king of the veggies? For starters, it is a source of four essential micronutrients: vitamin C, thiamine, potassium and manganese — which, combined, contain the clout to keep our bodies in tip-top shape. The most prominent nutrient is vitamin C, with one large potato containing more than 70 percent of the recommended daily intake. Among many other things, sweet potatoes are good for the heart, bones, blood pressure, immune system, nervous system and digestive system. Importantly, they also help reduce chronic inflammation. In a word: sweet.



QUOTEUNQUOTE

I found out that I was HIV-positive a few days before the death of Freddie Mercury. I'm very lucky to even be here. Most people of my generation who contracted HIV died in the late '80s or early '90s. I'm just happy to be breathing in and out, to be honest. I think eventually if you do survive storms in your life, you learn to appreciate the simple things that you have and you are grateful for them.

*Singer, and long-term survivor,
Holly Johnson*

GOFIGURE

Out of
37 million
people living with
HIV worldwide,
more than
6 million
are aged **50 years**
or older

UNAIDS