

# talkabout

Where we speak for ourselves

A 40 YEAR  
JOURNEY  
PART 3

FINDING  
STRENGTH  
IN THE STORM

IN MY OWN WORDS:  
GARRY  
TROTTER

MANAGING  
SOCIAL  
MEDIA



# TALKABOUT

WHERE WE SPEAK FOR OURSELVES

## EDITION #211

### CONTRIBUTORS

Kim, Maria, Tim Alderman, Roberto Fabbiano,  
Andrew Heslop, Sandra Jones,  
Stephen Lunny, Talkabout Advisory  
Committee, Garry Trotter, Billy Suyapmo

### EDITOR

Craig Andrews |  
[editor@positivelife.org.au](mailto:editor@positivelife.org.au)

### 2024 TALKABOUT ADVISORY GROUP

Kim, Maria, Tim Alderman

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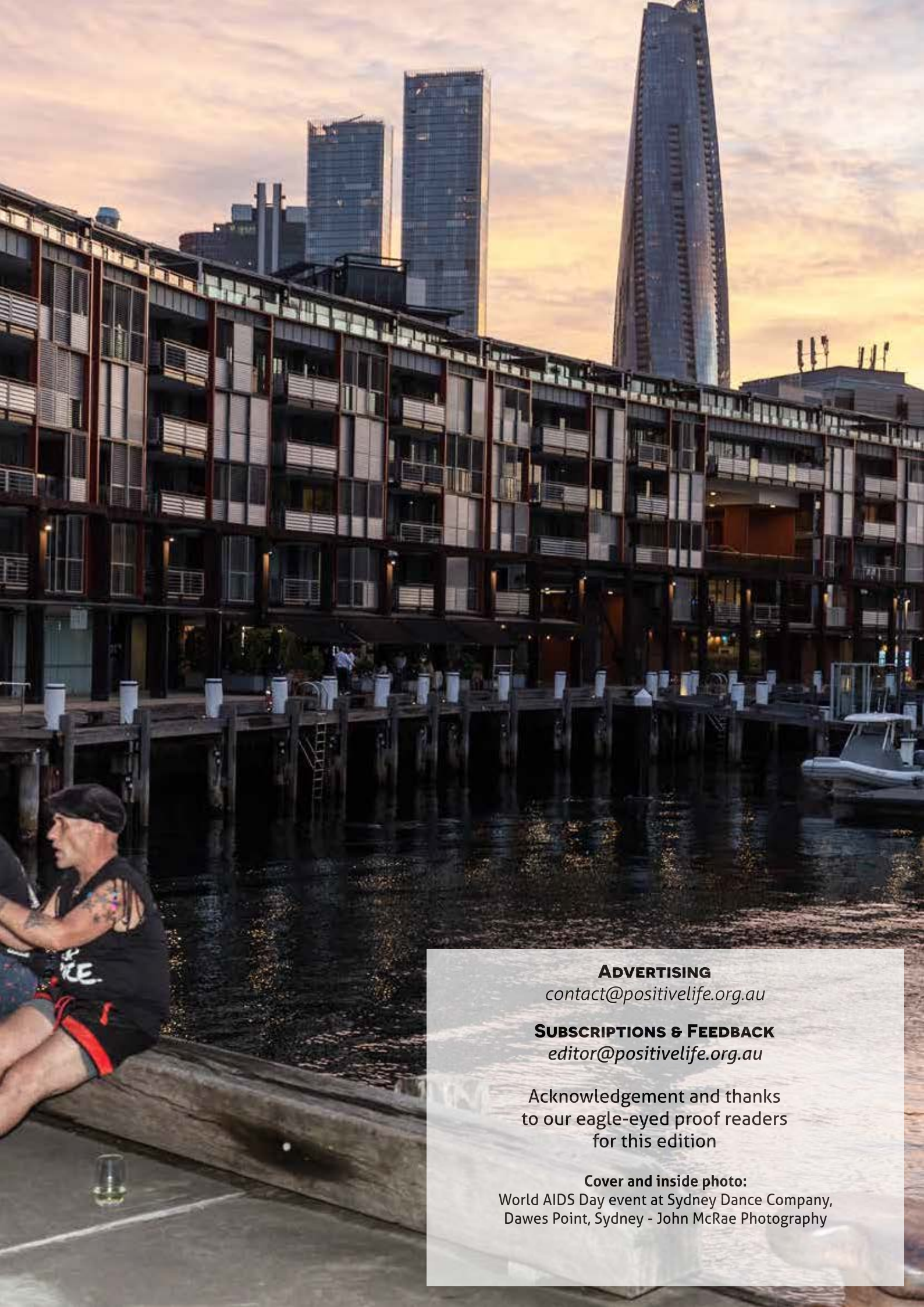
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*contact@positivelife.org.au*

**SUBSCRIPTIONS & FEEDBACK**

*editor@positivelife.org.au*

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to our eagle-eyed proof readers  
for this edition

**Cover and inside photo:**

World AIDS Day event at Sydney Dance Company,  
Dawes Point, Sydney - John McRae Photography

*This (late!) December 2024 edition of Talkabout offers a range of community reflections and experiences.*

In this delayed edition of Talkabout Sandra (not her real name) offers her personal experience at a time in San Francisco, of coming into adulthood, new sexual experiences, alongside HIV/AIDS testing, stigma and fear (page 8); and we hear from Molly, a four-legged ally who invites other four-legged, two-winged, finned or flippered, companions (page 11) to find their voice in Talkabout.

Garry Trotter (page 18) generously shares his thoughts and memories of nursing people living with HIV between 1986 and 2019, while struggling with his own HIV diagnosis, evolving medications, disclosure and finding love.

Long time writer and Talkabout Advisory Group member, Tim Alderman reflects on ageing as a gay man living with HIV and finding himself unexpectedly invisible (page 12), and also continues the third part of his historical commentary, *A 40 year journey into (and out of) fear* (page 24).

Community member and Positive Life NSW Peer Support Officer, Roberto

Fabbiano shares his journey finding strength after his own storm of breakup, illness and job loss (page 16). We also hear from Roberto with some strategies he uses to turn the negative impacts of social media into positive experiences (page 26). Billy Suyapmo highlights some important points about 'under the belt' health (page 22), a common euphemism for genital or sexual health in cultures where these topics and questions are considered taboo.

If you have thoughts or a story to share, or would like to explore how you might be part of Talkabout, please get in touch.

Sharing your story in Talkabout is easy and simple. We can interview you by phone, Zoom or face-to-face as part of 'In My Own Words' to make it easier than ever to get your story in Talkabout.

Call me on (02) 8357-8386 or 1800 245 677 or by email on [contact@positivelife.org.au](mailto:contact@positivelife.org.au). I look forward to hearing from you in the near future.

**CRAIG ANDREWS**  
EDITOR

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*Firstly, I acknowledge the traditional owners of all the lands in NSW.*

Secondly, I would like to congratulate Billy Suyapmo, Positive Life NSW's Peer and Vocational Support Officer on winning the *2024 Young Community Champion Award* at a ceremony held in Melbourne on Friday 22 November 2024. This is a wonderful and well-deserved accomplishment.

Having worked alongside Billy on many occasions, this also comes as no surprise. His passion and professionalism in his work shines through, and the support he provides to the many diverse communities we represent is impactful and inspiring.

I would also like to acknowledge Positive Life's Peer and Ageing Support Officer Priscilla Njeri, who has been elected to two influential representative Board roles recently. Priscilla joins the Health Consumers NSW Board as a Director, and has also been appointed to the Central and Eastern Sydney Primary Health Network (CES PHN) Community Council.

This is an incredible achievement and a testament to Priscilla's dedication and expertise. Her selection for these positions is a reflection of the high regard in which she is held within our sector and the outstanding impact she has made through her work at Positive Life NSW.

This follows in the representative tradition of the organisation being the voice of all people living with HIV, and here it would be remiss of me not to mention our Senior Health Promotion and Peer Navigation Manager Andrew Heslop's appointment to the prestigious NSW Ministry of Health's Consumer, Carer and Community Advisory Council in the middle of this year.

Andrew's successful appointment was through a highly competitive EOI process with only 14 community members being chosen from a very large and talented field of applicants. Andrew's exceptional strategic thinking, leadership, and unwavering commitment to integrity, collaboration, and innovation has made him a trusted and

influential figure within the NSW public health sector. It is an honour to see Andrew and our staff take on such influential roles, and please join me in congratulating them all.

We held our Annual General Meeting (AGM) and end-of-year Christmas Party on Tuesday 3 December 2024. The end-of-year Christmas party was well received by the community and many commented that it was the best one that they had attended.

The Positive Life NSW Board welcomes two new Directors to the Board. Phil Quirk and Philippe Smets. Phil Quirk has also taken up the role of Vice President on the Board Executive. Congratulations to you both.

I also wish to thank and say farewell to Robert Agati and Natasha Io who have both stepped down this year. Robert is worthy of further mention as six of the years that he was in the Board he held the position of President. Thank you both for your service and contributions.

At the combined ACON, BGF and Positive Life NSW World AIDS Day event held on Sunday 1 December 2024 at Sydney Dance Company, our CEO Jane Costello delivered a poignant and uplifting speech around stigma and discrimination and how to respond to it. One of the four key responses she mentioned was to practice joy.

I'd like to ask, what is joy and how do we manifest it? There are two types of joy – hedonic joy and eudaimonic joy.

The first is fun but fleeting. We experience hedonic joy when we eat something delicious, watch a beautiful sunset or laugh at a hilarious joke. The Summer season seems a fitting time to find opportunities to practice this kind of Joy.

The second, eudaimonic joy is longer lasting. We can manifest this by practising altruism, by following our passion, and by finding meaning in life. This joy nourishes us and contributes to a lasting sense of contentment. Something to contemplate as we approach another new year.

I hope you all have a joyful and safe summer season and wish you all the best for 2025.

Go well and be kind to each other

**STEPHEN LUNNY**  
**PRESIDENT**

*Positive Life NSW represents and advocates on behalf of our members and the NSW Body Positive in a range of NSW HIV/AIDS sector areas. Below are brief details of topics, events and issues we've carried out that impact the interests of people living with HIV in NSW.*

## **TACKLING STIGMA CONFERENCE**

Positive Life NSW attended the *Tackling Stigma* Conference, coordinated by the Centre for Social Research in Health (CSRH) at the University of New South Wales (UNSW) on Thursday and Friday, 21 to 22 November 2024.

Positive Life NSW staff, Priscilla Njeri and Andrew Heslop had abstracts accepted for the conference. Andrew was part of the keynote lived experience panel on the first day of the conference.

This was an opportunity for Positive Life NSW to collaborate, network, and engage with other health and community professionals from a diverse range of specialties including mental health, women's health, metabolic health, HIV, Hep C, drug users, LGBTQA+ health, sex workers, and health consumers.

Priscilla's presentation detailed the delivery of Positive Life NSW's Body Mapping workshop, which was held in 2023. Body Mapping is a creative process that is useful in exploring physical, emotional and psychological experiences, and this workshop aimed to address diagnosis trauma amongst the heterosexual communities of people living with HIV. Priscilla spoke passionately about the experiences of her community.

Andrew's presentation showcased Positive Life NSW's In-clinic Peer Navigation Program in Greater Western Sydney and highlighted the excellent work carried out by our Peer Navigators, including some of the outcomes of the first year of the program and how it has benefited people who have been diagnosed with HIV in the Greater Western Sydney area.

Our thanks to the CSRH team for a fabulous inaugural Tackling Stigma Conference and we look forward to next year's conference.

## **FROG HOLLOW WORLD AIDS DAY COMMEMORATION**

It was a pleasure to partner with Bobby Goldsmith Foundation (BGF) again this year on Monday 2 December 2024, for the annual World AIDS Day event at Frog Hollow Reserve in Surry Hills, NSW.

This year we were joined by community members, colleagues from the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) and other healthcare professionals. BGF and Positive Life NSW provided morning tea for attendees, and Andrew Heslop delivered a short speech on 'It Starts With Me', which is this year's Australian theme for 2024 World AIDS Day.

Our thanks to BGF for organising this important community commemorative event.

## **ASHM ANAL CANCER SCREENING GUIDELINES FOR PEOPLE LIVING WITH HIV**

Positive Life NSW has been part of the development of the Australasian Society for HIV, Viral Hepatitis Sexual Health Medicine (ASHM) Anal Cancer Screening Guidelines and the testing tool summary for people living with HIV in Australia. Positive Life's CEO Jane Costello is part of the writing group for the guidelines which will be made available on the ASHM website shortly.

Positive Life NSW has a long history of advocating around anal cancer research, care and support for our community and have chaired the Anal Cancer Advisory Group since 2013, which brings together clinicians, researchers and community.

**TALK SHOP**



Services Australia

### **LIVING WITH HIV AND FINDING IT DIFFICULT TO CONNECT WITH SERVICES AUSTRALIA?**

All people living with HIV who are finding it difficult to contact Services Australia (Centrelink, Medicare etc), are invited to get in touch with Positive Life NSW to make a face-to-face appointment with a Services Australia Officer on (02) 835708386 or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)



# THE MESSAGE

It dawned on me what I had done. It was 1996. I was eighteen. I'd slept with someone unprotected. In San Francisco of all places.

I could be pregnant. I could have AIDS. That was my introduction to losing my virginity. AIDS was prevalent there at the time. Thoughts of death flickered in my mind intermittently. I thought of the entropy of my body, my decaying face, my eyes sunken like pits. People would know. They'd know I had HIV. There was no retroviral medications to prolong your life back then. AIDS was pretty much a death sentence. But right now, right at this moment, I was terrified to tell anyone as there was still a lot of prejudice about HIV.

I didn't tell my parents. They were too conservative and judgemental. People thought you were stupid for having unprotected sex. Getting AIDS that way was your fault, not like some poor random housewife or a kid that picked it up from a blood transfusion. So I suffered in silence. The only person who knew was my best friend. We'd both gone after the same guy. I came up trumps. Allegedly.

\*

When I was sixteen, while most girls at this age had lost their virginity, rumours began to swell that I was a weirdo. While some cherished and guarded their chastity, mine was a chain around my neck.

I had grown increasingly unpopular and guys avoided me like the plague. I sometimes heard sniggers in the quadrangle or got funny looks and stares as I trundled off to class. But I wouldn't anymore!

People told me via the grapevine that Dave liked me. He'd been teasing me. When I somehow figured that was to get my attention, I grew to like him. Boy I waited a long time to meet him, though.

Finally, nearly at the end of the period, I made my way down the library stairs to meet Dave, with him and his friends staring at me. They had gone unusually quiet. Dave threw a note near a desk where I was standing. My heart thumped. I picked it up and unravelled it, my fingers almost hyper-coiled with fear. I opened the note but it was nothing of the contents I desired.

Upon realising I succumbed to bring set up, Dave and his friends broke into uproarious laughter, cajoling me and wriggling in their seats until they were teary-eyed and red-faced. Everyone else was going about their business, impervious to what was happening. I wanted to bawl my eyes out but the tears wouldn't come.

Feeling like Sissy Spacek out of 'Carrie', I traversed the library stairs in a daze, realising my virginity again, was a curse and a stain.



\*

Lost in thought, initially the news didn't register.

"You're clear..."

"Sorry?"

"You don't have AIDS," said a female doctor sitting before me.

Suddenly I had an epiphany. I could've ended up with it. It was a close call. I owed it to society that I was still alive. I had to do something with all this insight. I decided to start becoming an HIV/AIDS volunteer.

I didn't care what people had done or how they had contracted HIV. Maybe they did something that put themselves at risk in a moment of impulse and regretted it after. Perhaps, they may not be the hedonists they were considered to be, and did something under duress?

Ultimately, HIV doesn't discriminate and affects anyone at risk of the virus. I was merely there at the time to help alleviate their suffering, offer support and the rest didn't matter.

– Sandra Jones\*

\* Not her real name



# halc

## The HIV AIDS Legal Centre

The HIV/AIDS Legal Centre is a not-for-profit, specialist community legal centre, and the only one of its kind in Australia.

We provide free and comprehensive legal assistance (within operational guidelines) to people in NSW with HIV or hepatitis related legal matters. This includes areas of law as: privacy, discrimination, immigration, end of life planning, insurance, superannuation, social security, criminal, family, housing and more.

For confidential legal assistance please contact us: Phone 02 9492 6540 or email [halc@halc.org.au](mailto:halc@halc.org.au)



**Positive Conversations - a monthly online event for all people living with HIV**  
– Call Positive Life NSW (02) 8357 8386, 1800 245 677 –  
or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

**Want to talk about your HIV and health?**

Contact Positive Life  
02 8357 8386 or 1800 245 677 (freecall)

Positive Life NSW



**Treatments Support for all people living with HIV**  
– Call Positive Life NSW (02) 8357 8386, 1800 245 677 –  
or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

Positive Life NSW

Ageing Support



**Supporting people living with HIV aged over 45, through the maze of aged care, disability, and healthcare services in NSW**

Contact Positive Life NSW on (02) 8357 8386 or 1800 245 677 (freecall)  
[www.positivelife.org.au](http://www.positivelife.org.au)

## JANUARY

- 13 **Positive Life NSW Office reopens**
- 22 **[+CONNECT] Sydney 7pm**  
*For all people living with HIV, our partners, friends and family*



## FEBRUARY

- 7 **Social Club Sydney 6pm**  
*For all heterosexual people living with HIV*
- 16 **Sydney Mardi Gras Fair Day Sydney**
- 18 **Women's Room Online 6pm**  
*For all women living with HIV under 45 years of age*
- 19 **Peer2Peer Sydney 6pm**  
*For gay and bisexual men living with HIV*
- 26 **Digital Mentors Sydney 12.30pm**  
*For all people living with HIV*
- 26 **Positive Conversations Online 6pm**  
*For all people living with HIV*



## MARCH

- 1 **Sydney Mardi Gras Parade Sydney**
- 11 **Men's Room Online 6pm**  
*For all heterosexual men living with HIV*
- 14 **Social Club Sydney 6pm**  
*For all heterosexual people living with HIV*
- 18 **For Women Online 6.30pm**  
*For all women living with HIV over 45 years of age*
- 22 **Community Consultation Forum Sydney**  
*For all people living with HIV*
- 25 **Digital Mentors Sydney 12.30pm**  
*For all people living with HIV*
- 25 **Positive Conversations Online 6pm**  
*For all people living with HIV*



FOR MORE DETAILS:  
Call (02) 8357 8386 or 1800 245 677  
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Details correct at time of printing.





**H**ello everyone, my name's Molly. If you asked Kim what kind of dog I am, she would say that I'm a Maltese Shih tzu puppy. That doesn't mean much to me though, but if we're out and about I'm always on the lookout for cousins.

As long as Kim is close by, you can count on me for adventures. I love our walks (my favourites are bush tracks and the beach), going for drives, and visiting our friends. There's so much to see and smell, and everyone is happy to see me and I get pats and hugs. I'm always trying to think of new ways to make Kim laugh - stealing socks out of the laundry basket and making her chase me is an oldie but it usually works.

I have to say I'm always up for a game with one of my favourite toys! I've heard her call me mischievous but I think she secretly loves my antics. She says that I am often getting into some kind of 'trouble'. I know what she really means though - that I'm curious, playful, clever, creative, and enthusiastic.

Digging up the back yard is my big project. It's such fun and who knows what I'll find! I keep hoping that one day Kim will join in, although so far she hasn't.

She is quite busy though...I really don't like that she goes out finding food without me but she's amazing at hunting! She is sometimes gone for a while but when she comes back it's a big celebration every time, and she never comes home empty handed!

I have other people in my life who shower me with lots of love, but Kim is all of my world. She chose me to live with her, she looks after me so well, and I do everything I can to make her feel special. I love learning new tricks and things that humans call 'manners' and I know that Kim is very proud of me when I do. Sometimes I run out of energy for a while and then I love to snuggle up with her, relaxing and having a snooze.

Kim talks to me all the time, she knows she can tell me anything and she is the cleverest human in the world. I'm still young, but I know when she needs me to give her lots of cuddles.

So now that I've introduced myself, are there any other four-legged friends out there whose humans read Talkabout who would like to write in? Kind of like pen-pals :)

– Molly

PS: A friend of mine wanted me to share these human quotes with you:

"Whoever said you can't buy happiness, forgot about puppies." - Unknown

"If you're uncomfortable around my dog, I'm happy to lock you in the other room when you come over." - Unknown

"No home decor is complete without dog hair." - Unknown

I was lying in bed recently listening to an audiobook, part of a gay series, revolving around the staff in a gay cafe in Cornwall, England. One of the younger waiters had just met, and was having a 'thing' with an older cafe patron, who was in a relationship that was just no longer working. They were having sex in the waiter's home, and the author described their lovemaking in such a realistic, but romantic way that I found myself contemplating my current solo life.

I had to stop the story for a bit. W...T...F was this all about!

The fact was that while listening to the lovemaking description in the book...in my head I was thinking...“will this ever happen to me again...will I, at this stage of my life, ever have sex with another man again?” and no, I don't think I ever will...and I really miss it... both the sex...and the intimacy!

You see, if I had to write a formula for this stage of my life, it would be: ageing+gay+hiv=invisible!

At 70, I'm probably a bit harsh with my self-assessments! HIV+ (and undetectable)...severely vision-impaired, and with mobility problems stemming from huge doses of AZT in the late 80s/early 90s, mixed in with AIDS in 1996. I no longer have my own teeth, and the proud owner of one prosthetic eye.

I keep myself relatively fit, but have a bit of fat around the middle, brought about by HIV meds, and which I can't seem...despite some pretty intensive attempts...to get rid of.

I live in a world that is ostensibly driven by vanity, an obsession with body image, and if you're male... looks! I can't get away from it!

It follows me around, mocking me. It's on Facebook. It's on Instagram. It's in every magazine I pick up, every television show, movie, advertisement, and gym visit. At my age, I'm supposed to be past all this, but should I be?

I do question the apparent notion that I'm 'past it' and if I want to have an ongoing sex life...(and I laugh hysterically here)...I should be labelling myself as a 'Bear' or a 'Daddy' or a 'Silver Fox'! This is stereotyping at it's very worst, telling me that to be desirable I have to give up being 'me'.

In my experience, ageing is a bit of a convoluted thing. One minute you are desirable...then you get hit by that reality stick whereby you go out, and no one pays attention to you, or approaches you. Guys walk past you like you just don't exist. You sink into the wallpaper and furnishings.

As a gay guy who was active on the scene, I found ageism to be rife, and it was often thrown in your face by younger guys. You were made to feel that you WERE old, and thus no longer desirable. And you were often just in your 40s, so not old at all in the real world. There has always been the joke...that is not a joke on the gay scene...that once you hit 40 you are considered too old to be desirable any more!

Well, trying hitting 50, 60 or 70! I remember being at the bottom bar in The Midnight Shift one night with a guy who had bought me a drink. We were chatting away, and I mentioned I was HIV+. He just stood up and walked out. One of the few times I have ever felt 'unclean'! It is not a nice feeling!

The one thing that drove home to me the real impact of ageism, invisibility, and HIV stigma, was the sex apps...euphemistically referred to as 'dating' apps! When my 16-year partner and I called it quits in 2014, these apps and web sites were new territory for me.

I approached them positively, thinking... foolishly, as it turned out...they would assure me an ongoing sex life. I was totally honest in my profile...both my age (at that time), and my HIV status. Well, maybe if I lied about my age, didn't reveal my HIV status, and uploaded a not-recent flattering profile photo I may have scored a sex life!

If you want to feel degraded and humiliated, these are the places to go! Honesty doesn't reap rewards on these sites! I waited for the messages, for fun times to roll in...and waited. Evidently the appeal of sex with a 60-year old didn't appeal to many, especially someone living with HIV!

As well as not going the way I planned, it was my introduction to the language of stigma...phrases like “are you clean?” and “I want you to breed me!” left me feeling deflated! Were these really gay men interacting with me! Did they not know about HIV! Or just choosing to live in ignorance!

This is not language you would use with non-HIV guys, so what is it that makes HIV+ guys 'unclean'...and have you never heard of an undetectable viral load? Has the entire U=U campaign gone right over your head?! Gay men putting other gay men down is not cool!

So I gave up on the apps, after only one contact. I got tired of guys lining up dates, then just not turning up...not even a message. I don't need things that put me down!



So 10 years later, I'm living alone with my dog. I have a great social life, but I'm 70 now, and a lot of guys have their own assumptions about that.

At this stage, I'm not interested in a relationship... I've had enough of those over my time, on the scene. As mentioned earlier, it's not the sex I miss, so much as the intimacy, the sensations of touch, the security of a cuddle. My vision is pretty bad, as is my mobility...all things I can live with (courtesy of both HIV and AIDS) which brings about certain insecurities in the dating game.

I would not want a stranger knocking on my door for 'fun times' these days. Having disability means I am aware of my vulnerability. If someone attacked me, or tried to take advantage of my situation to, say, rob me, I would have put myself in great danger, and could end up beaten up...or worse! It is a scenario I'm too aware of! Already the odds of meeting people aren't good!

So let's drop the assumptions...I am still sexually active! I don't feel 'old', nor do I look or dress 'old'. I'm pretty well adjusted to modern living.

Yes, my social circle is quite different these days, as tags such as 'gay' and 'HIV+' no longer define who I am. It isn't denial...if anyone asked I'd be quite out about it...it's more that first and foremost these days, it's more about just being a person, an individual! Funny how things that used to be important, become less so as time passes.

However, there are still those moments where to be enveloped in another man's arms, the squeeze, the contact, just the feel and smell of another man would be a nice way to be rocked to sleep. So let's stop defining people by how they look, or stigmatising them because of their age, or their status, or even their sexuality.

We are visible! We are thriving, vibrant, engaging, life-experienced beings, still capable of everything that once made us young and desirable, with a breadth of experience, and life, that suffocates all pre-determined notions of being the person YOU think we are.

Push our boundaries, and expand your own! To finish with a cliché... there is treasure to be found.

– Tim Alderman













In the span of a few months, my life was turned upside down. First, my husband of almost five years left me without warning. The heartbreak was unbearable, and I felt a deep sense of loss and betrayal.

Just as I was trying to pick up the pieces, I was hospitalised for several weeks due to complications from an STI. The physical pain was intense, and the emotional toll was even greater. I felt isolated and ashamed, struggling to come to terms with my diagnosis.

While I was still recovering in the hospital, I received another blow: I lost my job. The company was downsizing, and I was one of the many employees let go. It felt like the universe was conspiring against me, and I couldn't see a way out of the darkness that had enveloped my life.

I was not one to give up easily. I knew I had to find a way to move forward, even if it felt impossible. With no family or friends to lean on, I had to rely entirely on myself.

I began to take small steps towards healing, starting with my health. I followed my doctor's advice diligently, attending follow-up appointments and taking my medication as prescribed.

Once I was discharged from the hospital, I focused on rebuilding my life. I joined a support group for people with similar experiences, where I found comfort in sharing my story and listening to others. This community became a crucial part of my recovery, providing a sense of belonging and understanding.

One of the most significant sources of strength for me was swimming. I found solace in the water,

where I could clear my mind and feel a sense of freedom. Swimming became my sanctuary, a place where I could escape the chaos of my life and focus on my well-being. The rhythmic motion of my strokes and the cool embrace of the water helped me find peace and clarity.

Despite these positive steps, my emotional journey was fraught with challenges. There were days when the weight of my circumstances felt unbearable.

I often found myself lying awake at night, consumed by thoughts of what I had lost and the uncertainty of my future. The silence of my empty apartment was a constant reminder of my loneliness, and I struggled with feelings of worthlessness and despair.

My self-esteem took a significant hit. I questioned my worth and wondered if I would ever find happiness again. The rejection letters from job applications only added to my sense of failure. Each setback felt like a confirmation of my deepest fears—that I was not good enough, that I was destined to be alone and unsuccessful.

In all these moments of darkness, I found small glimmers of hope. I began to practice mindfulness and meditation, which helped me stay grounded in the present moment. I learned to acknowledge my pain without letting it define me. Slowly, I started to rebuild my confidence, celebrating small victories like completing a swim session.

As I regained my strength, I started looking for a new job. It wasn't easy, but I refused to let rejection letters discourage me. I updated my resume, practiced my interview skills, and eventually, I landed a job as a Peer Navigation Officer with





Positive Life NSW, supporting other people living with HIV. This role allowed me to use my experiences to support people, providing empathy and understanding to others facing similar challenges. It was incredibly fulfilling to be part of a community that valued my skills and experiences.

Through it all, I discovered a resilience I never knew I had. I learned to prioritise my well-being, both physically and mentally. I continued to swim regularly, finding that it not only improved my physical health but also my mental clarity and emotional stability.

My journey was far from easy, but I emerged stronger and more self-assured. I realised that life's challenges, no matter how overwhelming, could be overcome with determination and self-reliance. My story is a testament to the power of resilience and the importance of never giving up, even when the odds seem insurmountable.

In addition to swimming, I took up cooking and journaling as part of my self-care routine. Cooking became a therapeutic activity for me, allowing me to express my creativity and nourish my body. Experimenting with new recipes and preparing meals from scratch gave me a sense of accomplishment and joy. The process of chopping vegetables, stirring sauces, and plating dishes became a form of meditation, helping me stay present and focused.

Journaling allowed me to express my thoughts and emotions freely, providing a therapeutic outlet for my feelings. Writing about my experiences helped me process my emotions and gain clarity. It became a daily ritual that grounded me and offered a safe space to reflect on my journey.

Looking back, I am grateful for the challenges I faced, as they taught me invaluable lessons about resilience, self-reliance, and the importance of self-care.

I learned that it is okay to ask for help and that seeking support is a sign of strength, not weakness. My journey has made me more compassionate and empathetic towards others, and I am now more equipped to handle whatever life throws my way.

Today, I am in a much better place, both emotionally and physically. I have rebuilt my life from the ground up, and I am proud of the person I have become. My story is a testament to the human spirit's incredible capacity to overcome adversity and emerge stronger on the other side.

No matter how dark the times may seem, there is always a light at the end of the tunnel, and with perseverance and determination, we can all find our way to brighter days.

– Roberto Fabbiano

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I started looking after people with HIV in 1986. By the time I retired in 2019, I was the longest continuously working nurse in Australia caring for people living with HIV. Lots of people would come before me, lots of people would come after me but I was continuously caring that whole time.

### Early career and HIV diagnosis

In those early days of HIV, I often found myself looking after both the HIV positive haemophiliacs and the HIV positive gay men – at the time called the ‘innocent’ and the ‘guilty’. I would put the patients altogether in one room. This was difficult for some staff because they felt you shouldn’t put them in together. It was also very difficult for staff because nobody knew much about the disease and a lot of staff were very scared and thought you could get HIV just from being in the same room.

I would come back from a weekend off, or come in of a morning for instance, and the food trays were still in the patient’s room. The food services people wouldn’t go into the room to pick them up. There were people who didn’t necessarily need to be in a single room, and there was a whole lot of isolation that happened, some of which was done by nurses who were scared as well. Some of the nurses’ partners thought they could bring home HIV on their clothing and pass it on that way.

There were discussions about isolation and meetings brought on by nursing administration to ask, *What are we doing? How are we caring for these people?* As an openly gay man, I wanted to care and support my community and make things a bit better for people.

Around the end of 1987, I went to my doctor who was a gay GP in Annandale. I can’t recall the specific reason I went to him. I’d been in a long-term relationship and still he said, “you need to have an HIV test.” So, all right, I stuck my arm out. I didn’t think I was HIV positive.

He called me on a Friday afternoon at four o’clock, on the ward in my office, to tell me I was HIV positive over the phone. I just fell apart. There wasn’t any preparation. He wanted to see me in person, and I have no idea how I got in the car and drove to him.

My immediate thoughts were, *How do I tell my partner? What do I do? How long am I going to live? What professionals am I going to see?* I was working in HIV at Royal Prince Alfred Hospital (RPAH), and I didn’t

want my colleagues to know. *So, who the fuck am I going to see?* I couldn’t go to Albion Street. I couldn’t go to St Vincent’s. *Who in the hell am I going to see that knows anything?* This was really difficult. I ended up seeing Professor John Dwyer, at Prince of Wales Hospital, and I saw him privately for quite a number of years.

By the end of 1988/early 1989, RPAH wanted me to set up the HIV inpatient unit at Ward E10 West. St Vincent’s in Sydney already had a HIV unit running since 1984. They sent me to the International Conference in Montreal, and I visited hospitals in San Francisco and St Vincent’s in New York and the hospice in Vancouver, to see what was going on, what people were doing, and how the staff were working. When I got back I was responsible for commissioning Ward E10 West.

### The RPAH HIV inpatient unit

Quite a number of my friends on staff gave me a great deal of support and basically carte blanche to do things the way that I wanted in setting up the unit. For





example, there was no sign that designated the HIV unit. There were those pushy, plastic doors at the end of the corridor before the ward, and you could tell things were different once you walked through those doors.

I had pink carpet on the floor, and proper curtains on all the windows, so the blinds were pulled up. In the single rooms, they had a pine chest of drawers instead of hospital lockers. I had the beds turned around so they actually looked out of the window. You walked in through the plastic doors, and there was the doctor's offices at the end. There was a photocopier at the end of the corridor. Peter Tully had given me one of the oversized Imelda Marcus shoes made for the Mardi Gras, and I had hung this in the corridor above the photocopier.

I'd been in a group called the *Polly's Social Club* for forever, and they started to donate money to support the unit. For instance, anyone who was HIV positive in the hospital was very socially isolated. They didn't necessarily have money, and hospital TVs were incredibly expensive. So I paid for the hospital TVs so that they had something to do.

People had little appetite, and were very thin, so one of the other things we did to get people to eat, was to set up kitchen volunteers who would come in the evening to make food for people. They would make whatever people wanted to basically encourage people to eat. It was very different to any other ward in the hospital. People were asking, *what the fuck are you doing? How do you get away with all this?*

As I said, people were very socially isolated on the ward, so when it was their birthdays they were not getting a lot of stuff. I used to have a birthday party for them, and organised silly little things to make people happy like stripper grams, or Melbourne Cup day lunches where everyone wore big hats. Since 1988 I organised a Daquiri Christmas party for staff and patients to allow mixing of patients and staff to try to breakdown some of the barriers. For some patients it was the only Christmas function they would have. So, there was all that sort of stuff to try and make people feel better.

There were a lot of difficulties. First of all, when the unit was set up, people didn't come to RPAH because they didn't know about it. St Vincent's was overflowing with people in corridors, and I only had two patients and vacant beds. So, I got the *Star Observer* to do an article to let people know that you could come to Ward E10 West, and it would be alright.

One of the things that the *Polly's* also used to do, was, we would visit the HIV units on three particular occasions. Mardi Gras, *Polly's* birthday and Christmas, where we'd give people presents. We decided to give people teddy bears. Everyone likes teddy bears, whether you're straight, gay, whatever. We did this quietly, with no publicity about it. We didn't make a fuss. Then one of the most amazing things happened at one of the Mardi Gras Parades in one

of the tall buildings on the corner of Williams Street. St Vincent's must have hired a room or something there. A whole lot of people who saw the Pollies in the parade were waving their teddy bears out the windows at us. That was just such a lovely thing to do.

### Personal impact of HIV and disclosure

Another thing that I distinctly remember, was helping a number of my friends in their last days die. These were people who had been my friends for many years. That was very hard, because I knew I was HIV positive and wondered, *was that going to be me? When's that gonna happen to me?* The only way I survived was to tell myself, that's not me in the bed. I had to use that barrier and not see myself as that person, otherwise I wouldn't have survived.

I still hadn't disclosed to anyone about my HIV. I didn't feel comfortable enough for my colleagues to know. That was incredibly difficult. In those early days when I was on medication, some of them would make you disgustingly sick. Some medications you had to have with food. Some you couldn't have with food. For example, there was something called DDI, which you would dissolve in water. You couldn't have it within a couple of hours of food. This medication would make you vomit, it was revolting. I was juggling all of that and I had to go to work and not disclose, still give patients comfort, and try to make them and their relatives feel better.

There were many times where you'd set things up when partners would come in and other times when family would come in because they didn't get on with each other. There was all of that stuff happening at the same time.

While my partner would support me, and I could talk to my doctor, it was very isolating. I had my medical clinician and my partner, and that's it. There was actually no support.

Around 15 maybe 20 years ago, I noticed that I was forgetting some stuff in meetings. You know how sometimes in meetings, if you vague out for a minute and come back, you can normally pick things up again. I was finding that, if I vaged out, I was finding it difficult to come back and pick things up.

This really bothered me. I had also helped set up an HIV dementia service because there were quite a number of people with HIV dementia and advanced HIV disease. I was petrified that was happening to me. So I went to see the expert, Professor Bruce Brew, who I'm still seeing today. I had a neuro psych test, which showed that I had a mild cognitive impairment, which didn't impede my work. In those days, it was called MND, mild neurocognitive disorder.

Eventually when I was feeling braver, I was involved in a doctor education meeting that the drug

companies used to put on. As a nurse who was involved in education, I got up and did a couple of case histories and talked about a patient I had called, Mr M. E. We never used people's real names. So, I did the story of Mr. M. E. and at the end of that, I said, *Actually, this is me. I'm telling you about me*, and there was silence.

The only reason I did that was because my colleagues thought that all this stuff meant you could spot it because people would be gaga and there was no mild disease. I wanted people to recognise what was going on. I wanted to show people that you could still be working and have it. I found lots of positive support from the medical staff.

At that time, there weren't a lot of healthcare professionals who identified as HIV positive. I can certainly recall a number of medical staff who were gay men and who ended up testing positive for HIV, who disappeared. I remember one in particular who endured a real witch hunt and who felt very guilty. He left his particular specialty and went into general practice, and then committed suicide not long after.

### A new experience of ageing

In those early days, there was no concept of ageing and planning for the future. We never thought any of this would happen. Then, there was no treatment or even with early treatment, people just got sick and died. You couldn't stop it. You couldn't prevent it. The medication worked for a little while. It was all progressive, and eventually it was all nasty diseases. It was a lot of brain stuff, a lot of lung stuff, lots of cancers, and that awful KS or *Kaposi sarcoma*, which was purple blotches. You could walk into a room and you would see people back off.

Even though I had worked, I had no concept to plan for the future. I didn't own my own house, I've never been particularly good with money, and I lived from payday to payday. What's the point of planning for the future, when you don't have it? All of a sudden, I realised I had to plan for getting older. That became very different, it was quite an interesting transition.

I'm very lucky in that I've been able to change my habits and plan for a future. In my personal life, I had a long term HIV negative partner, where we were together for 30 years but grew apart and suddenly separated.

Now I had to think about disclosure. What happens? *Do I tell people? When do I tell people? How do I tell people?* I never had to think about any of that. That concept of telling somebody that that you're HIV positive, was extremely difficult. By the time I was ready to disclose it was 'post-the-people-are-gonna-die' stage, it wasn't *fuck off, you're gonna infect me*.

Still it was very difficult to actually say that I was HIV positive. I disclosed to the man who's now my





husband, when he was still in the closet. I've been HIV positive longer than he's been alive! He didn't have a lot of understanding about HIV and comes from a conservative Asian background. When I explained things and said, *anything that we do, I will never put you at risk*, I was very fortunate in that he accepted that without a problem.

### **Reflections on the future of HIV care**

Back in the very early days, if you needed heart surgery, liver transplant or any sort of joint replacement, doctors certainly didn't do anything like that for people who were HIV positive.

Now, I've had a number of major surgeries, and it hasn't been an issue. HIV has never been brought up by anybody, and so seeing that transition in my lifetime has been just amazing. From 'we can't walk into the room', to 'what can we do to fix this?'

Even though I'm still quite concerned about my brain, I know I can still learn. That's reassuring. I've found stuff that I can do. Now at 68, I wonder, is it related to being HIV positive? or is it related to getting old? So, with that word-finding ability for instance, you know what you want to say, but the word or the name of somebody just isn't there. That's incredibly frustrating. I have been worried that it was advancing HIV disease, when in fact I know now, it's about getting older.

I don't want to dismiss the impact of HIV, but in the big scheme of things, it's not such a big issue as it once was. Yeah, it's still there, and the words are still frightening,

but it's not so scary anymore. Clinically speaking, it's not so life changing or life shocking as it was. So yes, it has been terrible but looking at all of these changes that have happened, how marvelous it is that HIV is no longer the number one thing. The fact that you're HIV positive, has become far less significant, and far less an issue for healthcare workers. It is marvelous.

There's also the medical issues that we're seeing in people with HIV at younger ages. Many are aging faster than their chronological age. Now that people have well controlled HIV and undetectable viral loads for most of their life, it'll be interesting over time to see whether that will still be an issue. I suspect it'll be less of an issue. That's just my gut feeling. If HIV is controlled from the day you were diagnosed, it shouldn't have as many longer term health complications as it does for people who didn't have that control.

In some ways, I feel like I worked myself out of a job, if you know what I mean. All of the awful things that HIV positive people experienced, both in health terms and in stigma, weren't around anymore. I retired at the right time.

A lot of the stuff that I was doing was supporting my community at ground zero. Supporting people in these moments, showing them dignity and finding little ways to bring them joy, gave me purpose and a lot of satisfaction. Reflecting back, it was hard, and I'm glad I was there.

– Garry Trotter



Moving to a new country for education is an exciting adventure, and it also comes with its own set of challenges.

One of these challenges is navigating the healthcare system. [Your questions](#) might be, “What should I do if I’m sick?”, “Who do I need to call?”, or “Which hospital should I go to?” can feel overwhelming.

In many cultures and countries, talking about sexual health is taboo. In NSW, there are [special health clinics](#) that focus on all the health ‘under the belt’ topics. This includes things like pain during urinating or an itchy genital rash.

These health clinics are called [sexual health clinics](#). They are also free for everyone and you don’t need to give your real name.

Often, we only pay attention to our health when [something goes wrong](#). This is very true for sexual health.

Taking care of your sexual health before something goes wrong, means you are taking the best care of your health before something goes wrong. This is called ‘prevention’.

In NSW, your relationship with your doctor is your business only. This relationship is confidential, private and your doctor must treat you with respect. In this country, you’re in charge of your own health, so you can always ask your doctor about everything.

It’s your health, and there’s no such thing as a bad question. This includes asking questions about having sex, pap smears, contraception, STD or STI testing, or any other sexual health concerns.

There are many different services you can use to help you do this. [Nurse Nettie](#) is a free, online website where all young people can ask health questions and get answers confidentially. [ACON](#) is here for all people who are GLBTQ. [Positive Life NSW](#) offers confidential support and advice for all people living with HIV, or people who have questions about HIV.

These services are here to make things easier and offer you the support you need. Your health is in your hands. So be brave, ask questions, and get the care you deserve.

– Billy Suyapmo





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The voice of all people living with HIV

Positive Life NSW

We created our own memorials for the growing list of names of friends, acquaintances, partners, and family members swept away in this new tide, a tide of grief.

I attended my first AIDS Candlelight Rally and Vigil, which was also the first held, in October 1985. My friend Dietmar Hollman was a reporter for 2SER Gaywaves. He reported from the rally and the AIDS Candlelight Vigil organised by Sydney City councillors, Brian McGahen (who died using voluntary euthanasia in 1990) and Craig Johnston.

The recording, which can be found on the National Film & Sound Archive of Australia, includes discussion of the 1985 *Public Health Proclaimed Diseases Amendment Act*, speeches from Brian McGahen, Craig Johnston, Dorothy McRae-McMahon (Dean of the Pitt Street Uniting Church), Dennis Scott, a performance from Judy Glen and vox pops from the crowd, including Robert French, and Mother Inferior (Sisters of Perpetual Indulgence).

The candlelight walk down Oxford Street started in Green Park, had the vigil in Hyde Park and finished with a rally at Parliament house in Castlereagh Street. There weren't many names to read out at that stage, yet as the years rolled by, the list got longer and longer.

Along the way, there was a brief halt to remember Michael Stevens, a young gay man who had been

bashed to death two months earlier, caught up in the tide of gay hate and hysteria brought about by media reports on the HIV/AIDS pandemic at that time. The whole event was solemn, and tearful.

The other equally emotive memorial was the AIDS quilt. The panels were created as part of the Australian AIDS Memorial Quilt Project, which was founded in September 1988 by Andrew Carter OAM (the brother of Don Carter, known as Dodge Traffic) and Richard Johnson in Sydney. It was formally launched on 1 December 1988 World AIDS Day, by Ms Ita Buttrose. Quilt unfolding started in 1988 with 35 panels, now 122 quilt blocks with eight panels per block. This was the most powerful of the AIDS memorials, due to its panels being designed and partially put together by friends and family of the deceased.

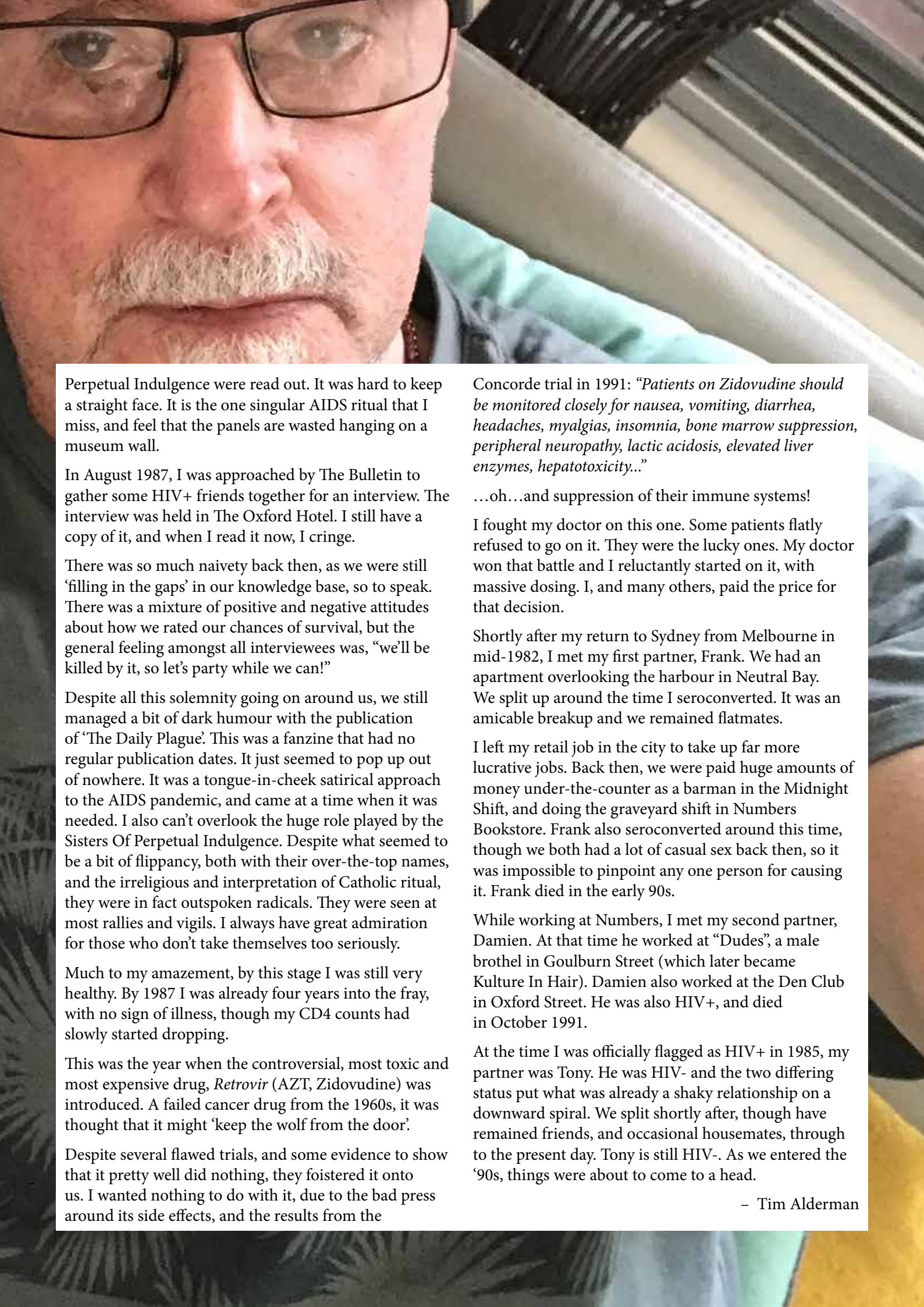
Wandering around the blocks of panels, with conveniently placed boxes of much needed tissues and hearing the names being read out was a truly moving experience. No one left with dry eyes, and all departed the event feeling emotionally drained.

Myself and a group of friends assisted with the beautiful, quiet unfolding of the panels at both the Royal Hall of Industries Pavilion (in the old Sydney Showgrounds) and the Convention Centre in Darling Harbour. I was also a Name Reader, and despite the solemnity of the occasion, there was the occasional lapse into humour when the names of the Sisters of



Peter McCarthy, Peter Gilmore (deceased), Bevan (deceased), Steve Thompson and myself at an AIDS Quilt unfolding (we were unfolders) at the Royal Hall of Industries Pavilion (Sydney Showgrounds) circa 1992. The tee-shirts bear the Quilts Insignia, and "Remember Their Names".





Perpetual Indulgence were read out. It was hard to keep a straight face. It is the one singular AIDS ritual that I miss, and feel that the panels are wasted hanging on a museum wall.

In August 1987, I was approached by The Bulletin to gather some HIV+ friends together for an interview. The interview was held in The Oxford Hotel. I still have a copy of it, and when I read it now, I cringe.

There was so much naivety back then, as we were still 'filling in the gaps' in our knowledge base, so to speak. There was a mixture of positive and negative attitudes about how we rated our chances of survival, but the general feeling amongst all interviewees was, "we'll be killed by it, so let's party while we can!"

Despite all this solemnity going on around us, we still managed a bit of dark humour with the publication of 'The Daily Plague'. This was a fanzine that had no regular publication dates. It just seemed to pop up out of nowhere. It was a tongue-in-cheek satirical approach to the AIDS pandemic, and came at a time when it was needed. I also can't overlook the huge role played by the Sisters Of Perpetual Indulgence. Despite what seemed to be a bit of flippancy, both with their over-the-top names, and the irreverent and interpretation of Catholic ritual, they were in fact outspoken radicals. They were seen at most rallies and vigils. I always have great admiration for those who don't take themselves too seriously.

Much to my amazement, by this stage I was still very healthy. By 1987 I was already four years into the fray, with no sign of illness, though my CD4 counts had slowly started dropping.

This was the year when the controversial, most toxic and most expensive drug, *Retrovir* (AZT, Zidovudine) was introduced. A failed cancer drug from the 1960s, it was thought that it might 'keep the wolf from the door'.

Despite several flawed trials, and some evidence to show that it pretty well did nothing, they foisted it onto us. I wanted nothing to do with it, due to the bad press around its side effects, and the results from the

Concorde trial in 1991: "*Patients on Zidovudine should be monitored closely for nausea, vomiting, diarrhea, headaches, myalgias, insomnia, bone marrow suppression, peripheral neuropathy, lactic acidosis, elevated liver enzymes, hepatotoxicity...*"

...oh...and suppression of their immune systems!

I fought my doctor on this one. Some patients flatly refused to go on it. They were the lucky ones. My doctor won that battle and I reluctantly started on it, with massive dosing. I, and many others, paid the price for that decision.

Shortly after my return to Sydney from Melbourne in mid-1982, I met my first partner, Frank. We had an apartment overlooking the harbour in Neutral Bay. We split up around the time I seroconverted. It was an amicable breakup and we remained flatmates.

I left my retail job in the city to take up far more lucrative jobs. Back then, we were paid huge amounts of money under-the-counter as a barman in the Midnight Shift, and doing the graveyard shift in Numbers Bookstore. Frank also seroconverted around this time, though we both had a lot of casual sex back then, so it was impossible to pinpoint any one person for causing it. Frank died in the early 90s.

While working at Numbers, I met my second partner, Damien. At that time he worked at "Dudes", a male brothel in Goulburn Street (which later became *Kulture In Hair*). Damien also worked at the Den Club in Oxford Street. He was also HIV+, and died in October 1991.

At the time I was officially flagged as HIV+ in 1985, my partner was Tony. He was HIV- and the two differing status put what was already a shaky relationship on a downward spiral. We split shortly after, though we remained friends, and occasional housemates, through to the present day. Tony is still HIV-. As we entered the '90s, things were about to come to a head.

- Tim Alderman



In today's digital age, social media has become an integral part of our lives, offering a platform for connection, information, and support.

However, for some of us, the experience of scrolling through social media can be a double-edged sword. While it can provide a sense of community and access to vital information, it can also exacerbate feelings of isolation, anxiety, and stigma.

Social media platforms can offer a lifeline where communities may be less visible or accessible. Online groups and forums provide a space to share experiences, seek advice, and find emotional support from others who understand their unique challenges. For those of us living with HIV in regional areas, these platforms can be particularly valuable, offering a sense of belonging and understanding that might be hard to find locally.

However, the constant exposure to curated images and success stories can lead to feelings of inadequacy and anxiety. For those already dealing with the challenges of living with HIV, this can exacerbate mental health issues such as depression and anxiety. The pressure to present a perfect life online can be overwhelming, leading to a disconnect between one's online persona and real-life experiences.

The mental health implications of social media use are significant. Studies have shown that excessive social media use can lead to increased feelings of loneliness, depression, and anxiety. When we experience HIV stigma or discrimination either online or offline in person, these feelings can be further intensified. The fear of being judged or rejected can lead to social withdrawal and a reluctance to seek help.

In NSW regional and remote areas, those of us living with HIV often face unique challenges in managing our health. Limited access to healthcare services, stigma, and social isolation can exacerbate the difficulties.

To mitigate the negative effects of social media scrolling, several strategies can be adopted:

Curate your feed by accounts and join groups that promote positivity, accurate information, and supportive communities.

Unfollow or mute accounts that contribute to negative feelings or spread misinformation. This can help create a more positive and supportive online environment.

Set boundaries by limiting the time spent on social media to avoid becoming overwhelmed. Designate



specific times for checking social media and stick to them. This can help prevent the negative impact of constant exposure to potentially distressing content.

Instead of passively scrolling, actively engage with content that resonates with you. Comment, share, and participate in discussions to build a sense of community and support. This can help foster meaningful connections and reduce feelings of isolation.

If social media is negatively impacting your mental health, consider seeking support from a mental health professional. They can provide strategies and support to help manage the impact of social media use.

Use your platforms and accounts to share accurate information and advocate for HIV awareness and

human rights. By contributing to a positive online environment, you can help combat stigma and discrimination for anyone.

In conclusion, while social media can be a powerful tool for connection and information, it is essential for all of us living with HIV to navigate it mindfully.

By curating our feeds, setting boundaries, and seeking support, we can harness the positive aspects of social media while mitigating its potential harms.

If you want to talk about finding some support, get in touch with others living with HIV at Positive Life NSW on (02) 8357 8386, 1800 245 677 (freecall), or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

– Roberto Fabbiano





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