

# talkabout

Where we speak for ourselves



#209 | June 2024 | ISSN 1 034 0866 | Positive Life NSW – the voice of all people living with HIV since 1 988

**IN MY  
OWN WORDS**

**THREE  
LITTLE  
WORDS**

**MY  
DISCLOSURE  
DECISIONS**

**LIFE'S  
CURVE-  
BALLS**



# TALKABOUT

WHERE WE SPEAK FOR OURSELVES

## EDITION #209

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Acknowledgement and thanks  
to our eagle-eyed proof readers  
for this edition

Cover artwork: 2024 Sydney Candlelight Memorial  
John McRae Photography

*This June edition of Talkabout offers a range of community reflections and experiences.*

Three community members, share their different approaches and thoughts about HIV disclosure. Phil (page 16) reflects on the benefits and drawbacks about silence in his experience, Kim (page 19) talks about the impact that three little words – “I have HIV” can have on her life, while Maria (page 20) explores the double-edged nature of disclosure against a backdrop of connection and risk.

Positive Life NSW Senior Health Promotion and Peer Navigation Manager, Andrew Heslop shares a very personal series of curve-balls (page 24) he experienced in early 2024. He uses these to illustrate a number of ways to respond to broader unexpected changes in life and stay in control. You’ll find a sampling of photographs from the recent 2024 Sydney Candlelight Memorial across a middle page spread (page 14-15).

We hear from Ava Karusoo-Musumeci, Clinical Trial Coordinator for the UNSW Sydney *Enhanced Advance Care Planning and Life Review Longitudinal Intervention – Community Outreach* (EARLI-comm) Project which is exploring whether life story work in combination with advance care planning can help people to feel better and more clear about their future health care. She discusses the project, the benefits to people living with HIV and invites any members of the community who might be interested or curious about the project to get in touch (page 13).

Long time writer and Talkabout Advisory Group member, Tim Alderman is back to share his perspective on his 40 year journey into (and out of) fear on page 8.

As a member of the Positive Life NSW Elders Group, he was involved in the recent celebration of HIV long-term survivors awareness day (5 June) and offers his reflections on the HIV long-term survival journey (page 26).

Given the recent re-emergence of mpox (monkey-pox), a virus related to smallpox, we have republished an article from *The Conversation* (page 22) authored by Kirby Institute, UNSW Sydney academics and researchers, Professors C Raina MacIntyre and Andrew Grulich, and Dr Mo Hammoud about this virus, who’s at risk, and what preventative measures are available.

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. **I’m on the lookout for the voices of young people living with HIV who can contribute regularly to a column dedicated to younger voices. If you’d like to develop your writing skills as well as contribute to a regular magazine, 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

**EDITION 3 SEPTEMBER 2024 – #210**

**SUBMISSIONS AND ARTWORK: FRIDAY 6 SEPT 2024**  
**DISTRIBUTION: TUESDAY 24 SEPT 2024**

# CONTENTS

## EVERY EDITION

- 04** | BLUE PENCIL
- 06** | IN THE LOOP
- 07** | TALK SHOP
- 12** | 2024 EVENTS CALENDAR



## FEATURES

- 08** | A 40 YEAR JOURNEY INTO (AND OUT OF) FEAR



- 19** | THREE LITTLE WORDS



- 13** | THE EARLI-COMM PROJECT

- 14** | 2024 SYDNEY CANDLELIGHT

- 16** | STARVING SHAME OF SILENCE

- 20** | MY DECISIONS ABOUT DISCLOSURE

- 22** | MPOX IS ON THE RISE IN AUSTRALIA

- 24** | WHAT DO YOU DO WHEN LIFE THROWS CURVEBALLS?

- 25** | A STATIN A DAY CUTS YOUR RISK

- 26** | A LONG-TERM SURVIVOR DIATRIBE

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# IN THE LOOP



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

It has indeed been a busy season for both staff of Positive Life NSW and the community.

The Teen Camp for young people who were born with HIV, which we ran in partnership with Randwick Sydney Children's Hospital at the end of April was a hit with everyone who attended.

Sydney Candlelight Memorial was held on Sunday 19 May which approx. 125 people attended. I was given the opportunity to MC this event and it was a great privilege. The highlight for me was the Memorial address by Australian composer, Lyle Chan. Lyle spoke eloquently about the need to share stories about those community members who we had come to celebrate, lest these be lost. The impact that the epidemic has had on our communities continues to shape our futures today and it is vital that those we have lost continue to be honored and remembered.

Positive Life ran a campaign for HIV Testing Week (1-7 June) where we called all sexually active individuals regardless of sexual orientation or risk profile, Medicare eligible or not, to ask for a test and challenge the assumptions associated with HIV. It's time to ditch the assumptions about HIV and who's at risk for HIV. The risk is not knowing your HIV status.

We have also run a HIV Long Term Survivors Awareness campaign for HIV Long Term Survivors Awareness Day (5 June) which acknowledges and honours people who have lived with HIV for decades including those who have lived with HIV prior to the era of highly active anti-retroviral treatments in 1996, those who were diagnosed after 1996, and those who acquired HIV while very young.

Mpox (previously monkeypox) is still circulating in the community, with recent diagnoses in Victoria and Queensland. If anyone is planning to travel overseas or just want to protect yourself against Mpox, it's a good idea to get the Mpox vaccine. If you want to discuss who and when to access a Mpox vaccine, you can call Positive Life NSW and speak with the Treatments Officer on (02) 8357 8386, 1800 245 677 (freecall) or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au).

Finally, as the winter season officially kicks in, I encourage all of community to consider both flu and COVID vaccinations should they be in need of either. Keeping ourselves as well as possible helps us to live our best lives.

Go well and go strong,

**STEPHEN LUNNY**  
**PRESIDENT**



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)

*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.*

## **HIV LONG-TERM SURVIVORS AWARENESS DAY**

Positive Life NSW ran a HIV Long Term Survivors Awareness campaign for HIV Long Term Survivors Awareness Day (5 June) which acknowledges and honours people who have lived with HIV for decades, including those who have lived with HIV since before the era of highly active anti-retroviral treatments in 1996, those who were diagnosed after 1996, and those who acquired HIV while very young. This campaign ran from 29 May to 7 June which included an article by Tim Alderman (member of the Talkabout Advisory Committee) published in this edition 'A long term survivors diatribe' (page 26).

## **2024 SYDNEY CANDLELIGHT MEMORIAL**

On Sunday 19 May, Positive Life NSW hosted the Sydney Candlelight Memorial in partnership with ACON at The Eternity Playhouse in Darlinghurst. Attended by 125 community members, this year had over 800 names added to the Candlelight roll. Two extra name readers were added to the lineup of speakers alongside guest speaker, Australian composer Lyle Chan and well-known Scottish performer Mary Kiani. This year it was our privilege to hear from Mr Chan about the creation of the *String Quartet - An AIDS's Activist's Memoir in Music*, as a representation of his activism during the 1990s and as a personal reflection on the HIV epidemic then as well as a short recorded piece. We were also delighted to welcome back to Candlelight, Ms Kiani a mainstay of dance parties and nightclubs for over three decades, to perform *Falling Slowly*.

## **2024 HIV TESTING WEEK CAMPAIGN**

Positive Life ran a campaign for HIV Testing Week (1-7 June) where we called all sexually active individuals regardless of sexual orientation or risk profile, Medicare eligible or not, to ask for a test and challenge the assumptions associated with HIV. It's time to ditch the assumptions about HIV and who's at risk for HIV. The risk is not knowing your HIV status. HIV testing should be routinely offered to all women, men, and gender diverse people who ask for a HIV test or who are diagnosed with another sexually transmissible infection (STI).

## **COUNSELLING SERVICE**

The Positive Life NSW pilot program, *Positive Minds* has been operating to capacity since it began in June 2023. All people living with HIV across NSW are eligible to use this dedicated mental health and counselling service free of charge. *Positive Minds* offers counselling services within a safe, supportive, person-centred approach by two accredited, qualified and trained counsellors, both of whom are either living with HIV or directly affected by HIV.

To discuss your needs and participate in a confidential initial intake process, all people living with HIV across NSW can call Positive Life NSW on (02) 8357 8386, 1800 245 677 (freecall outside metro areas) or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

**TALK SHOP**



## **In My Own Words**

**Tell your story.  
Share your experiences.  
Call and have a chat.**

Phone Craig (02) 8357 8386 or 1800 245 677  
Email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

**I love history. Always have, and excelled at it at school. Not just local and world history in general, but individuals' personal history as well.**

*Though often distorted, edited to fit the times, world history is fixed. There is only one truth to it, no matter what narrators may say. Personal histories are quite a different thing. A hundred people will produce a hundred histories, each distinctly individual, never duplicated by anyone else.*

*I have written much about my experiences with HIV over the last 25 years, most of it via "Talkabout". Though personal, and often intimate, none have really gotten into the nitty-gritty of my personal, lived experience.*

*This reflective piece is to rectify those omissions, giving both a factual and lived insight into a period in gay history that should never be forgotten.*

*The recent COVID-19 experience really drove home to me how HIV, its past, and still present history, was no longer of any consequence. COVID was being spoken about as though it is the only pandemic of recent time. It would be interesting to see where COVID sits in 40 years time.*

*So this is my history with HIV/AIDS. It is more detailed, and more anecdotal than my previous writings...which also means it's much longer. It is, with no strutting involved, a story of survival. If survival is the gauge of one's strength and tenacity, then I have come out at the end of it with flying colours, the glass half full, so to speak.*

Over 40 years have passed since I sero-converted to HIV. I remember it well. I was managing a retail store in Sydney and was due to go on leave in August 1983. My last day before going off on my break was hellish. Temperature, diarrhoea, extreme lethargy, disorientation...I couldn't wait for the day to end. As it turned out, it went on for the fortnight.

I had only been out for three years...a late closet jumper...and I have to admit to being very trashy, making up for lost time as it was. I have wondered over the years, as have many, just who it was that infected me...and where!?

Was it that hot American boy who was staying in The Connaught in Darlinghurst, who picked me up one night just after my return from Melbourne (very likely!). Perhaps it was a Melbourne or Sydney local who had returned from a holiday in the USA, or, like me, gotten off with American boys (the flavour of the month) here! Of course, I'll never know, but the speculation remains!

Since that time, both as a writer, and as a 12-year public speaker with the Positive Speakers Bureau (PSB), I have told of my journey with HIV/AIDS. My story has always had constraints, either in word length with articles, or time restrictions in talks. There is a lot more to the story than I tell in these...often done by rote... sessions.

I have just finished reading Cheryl Wares "HIV Survivors In Sydney - Memories Of The Epidemic" which focused on the years between 1982 and 1996. This was an oral history project that I was part of in 2014, contributing a 2½ hour interview with Cheryl when I lived in Gaythorne, Queensland.

I was disappointed in the book, for as much as Cheryl wanted it to be a story of ordinary gay men surviving HIV/AIDS, and how it affected their lives both then, and now, it really came across as a voice for, and was hijacked by HIV activists, rather than just us bar crawling gays-on-the-Golden-Milers.

I was left feeling that both my contribution, and the contribution of others like me who weren't part of the activist community was largely overlooked, again. I know it sounds like sour grapes, and mine is only one of a thousand survivor stories, but like many others I want there to be some sort of public record of many aspects of the HIV/AIDS survival story that doesn't make it into many articles, or talks.







## IN MY OWN WORDS / TIM

The one thing Cheryl's book did do was to invoke memories of so many personal experiences...and feelings...that made my personal HIV journey...MY journey.

This is not the first time I've contributed to interviews and photo sessions on HIV/AIDS survival, and either been left out in the cold, or had my story overshadowed by activists, or academics. Because this is a personal transcript, I am not putting a word limit on it, so it's going to be long.

I want all this unknown or forgotten information to be in one article. It's not a soul-cleansing, so don't get me wrong. I see it more as an addendum to HIV history. I want it in writing before I either forget it, or confuse it in the fog of ageing. Luckily, I am a bit of a hoarder, so have copies of a lot of the things I will be referencing as the story unfolds. To make sense of it, I guess I need to go back to the beginning.

I have written a lot on my family, the dysfunctionality of my growing up, in my blog (<http://timalderman.com>), so I am not going to rehash already-told stories here.

In a nutshell, I was born in St. George Hospital, in Kogarah, NSW on the 18th January 1954. I had one younger brother Kevin, who was born in 1959. My childhood was pretty uneventful until I was 11, where once my mother deserted the family home, the housekeeper from hell entered our lives.

The death of my brother, at my father's hands, on the cliff top known as The Gap blew it all to shit. My knowledge of 'being different' at age nine, and my eventual coming out are also on my blog, so let's move along.

1980 finds me in Melbourne, where I had just come out as a 26 year-old. A HIV story begins. Little did I know that both my life as a gay man, and my life as a HIV+ man were to walk the same road.

So what was it really like in 1982 to be reading snippets in our local gay press about this mysterious illness. KS, or Kaposi Sarcoma was rearing its ugly head in the gay ghettos of America, that seemed to be targeting gay men who frequented the saunas, and quickly killing them.

There was cynicism and disbelief to start with, and the surety that within a short period of time they would find an antibiotic to clear up yet another sexually transmitted infection (STI) or in those days, a sexually transmitted disease (STD).

However, the snippets were to become columns, the columns became pages as the mysterious and deadly virus leapt from the shores of America and found its way into the gay scene here. Originally labelled as GRID (Gay-Related Immune Deficiency), also the Gay plague or the Gay syndrome in 1981, it was followed by human

T-lymphotrophic virus type 3 (HTLV-3) in 1983. The panic and fear began!

Our response was mixed. The first case of AIDS was reported in Sydney in October 1982 by Dr Ronald Penny. In July 1983, the first recorded Australian death from AIDS-related causes occurred in Melbourne.

The most notable death in these early days was Bobby Goldsmith in 1984. We had our usual ratbags who yelled and screamed about "God's vengeance on the evil, sick and perverted gay lifestyle", obviously a different God to the compassionate, all-forgiving one that Christians liked to rant about.

The most vocal and notable being the Rev Fred Nile MLC and his Festival of Light, and Call To Australia affiliations. These advocates of hate and intolerance who demanded quarantine for all infected persons, along with those of the citizenry who either quietly or vocally wished that we would all die or just go away. Mind you, we did have our fun with them.

I vividly recall one early Mardi Gras. Back then, joining the parade was a very informal process. The Festival of Light group was protesting at the Parade's starting point. Myself and some friends, dressed in leather chaps with our bare backsides hanging out of them, deliberately stood in front of them, shaking our booty, much to their horror and disgust.

There is no watering it down...discrimination and stigmatisation was rife. It was frightening!

Thankfully, common sense eventually prevailed and both the government and the grassroots gay community combined to put both AIDS Councils and NGO programs in place. Our quick response was instrumental in Australia always being at the forefront of HIV/AIDS care.

Within two years, every state had an AIDS Council. The formation of various support organisations such as The Bobby Goldsmith Foundation (BGF), Community Support Network (CSN), PLWA (which was to become PLWH/A, eventually Positive Life NSW), ActUp, and Ankali quickly started along with the beginning of NAPWA, the National Association of People with AIDS.

Without these organisations life would have been grim for those who found themselves living with the virus. Some provided financial support, others offered emotional and spiritual support. Many of us had quite suddenly found ourselves with a death sentence hanging over our heads, along with the fear of unemployment and homelessness in the midst of the hysteria going on.

In 1985, HIV testing was introduced. It was a bit of a strange affair in the early days. Due to the hysteria, discrimination, and fears of being dragged off to quarantine, which was a genuine concern. No one wanted

their personal details on a database.

At clinics like The Albion Street Centre, you chose a fictitious name, and the clinic then issued you with a number that then became your ID. Mine was Peter 3080.

When things cooled down, the fictitious name was dropped, and replaced with your real name. You had a blood test, and waited for two to six weeks to get your result. Talk about high anxiety!

At the time of my HIV test, I already suspected that I had sero-converted and was going to come up HIV+. I was right. Counseling? Oh yeah, we had a lot of that back then. "You've got about two years to live." Shrug shoulders. "Okay." And off we went knowing the inevitable was rapidly approaching!

The initial window periods were reasonably long, but got much shorter as time progressed, and the virus mutated. I did not get seriously ill with AIDS until 1996. I'd always put this down to getting infected early in the history of the virus, thus getting a much weaker mutant of the virus than what was to come, though there were other factors in play.

I was in a relationship at that time, and my partner came up HIV-. Already the juxtaposition between positives and negatives had begun.

The strange thing was that I felt no need to hide my status. I turned up at the Oxford Hotel and said to friends... "oh well, I'm positive." Of course, I was far from being the only one.

Then the horror stories started! The disgusting treatment of young Eve Van Grafhorst is something for all Australians to be ashamed of.

Born in 1982, she contracted HIV via a blood transfusion. When her parents attempted to enrol her in a Kincumber pre-school in 1985, other parents threatened to withdraw their children due to the (supposed) risk of infection. The family was literally hunted out of town, and forced to leave the country for New Zealand.

I will never forget the sight of this poor, small, frail girl on her way to the airport. I, like many others, was horrified that this could happen in Australia.

Thankfully, her New Zealand experience was quite the opposite, and she lived a relatively normal life until her death in 1993 at 11 years of age. Her parents received a letter from Lady Di praising her courage.

- Tim Alderman



**WHO IS ELIGIBLE?**  
You can take part if you:

- were diagnosed with HIV in the past 12 months.
- are living in Australia (you don't need to be a permanent resident).
- are aged 18 years or over.

**WHO DO I CONTACT?**  
Call or SMS: Dr Jeanne Ellard on 0400 855 038  
Email: J.Ellard@latrobe.edu.au  
For study website, use the QR code below:



latrobe.edu.au/arcshs/work/newly-positive

**Researchers at La Trobe University are studying the experiences of people who have been diagnosed with HIV in the past 12 months.**

**WHAT IS INVOLVED?**  
Participation involves a confidential audio-recorded interview of between 60-90 minutes. In the interview we will ask you questions about your experiences of: HIV infection; diagnosis, treatment; care and support; sex and relationships; and living with HIV.  
Interviews will be conducted via telephone or video-conferencing platform (such as Zoom).  
You will be compensated for your time with a \$100 retail gift card.

## JULY

- 4 **Tai Chi Sydney 8am**  
*For all people living with HIV*
- 5 **Social Club Sydney 6pm**  
*For all heterosexual people living with HIV*
- 11 **[+Connect] Strathfield 7pm**  
*For all people living with HIV, our partners, friends and family*
- 13 **NAIDOC Event 11am**  
*For all people living with HIV*
- 16 **For Women Online 6.30pm**  
*For all women living with HIV over 45 years of age*
- 18 **Tai Chi Sydney 8am**  
*For all people living with HIV*
- 30 **Digital Mentors Sydney 12.30pm**  
*For all people living with HIV*
- 30 **Positive Conversations Online 6pm**  
*For all people living with HIV*



## AUGUST

- 9 **Social Club Sydney 6pm**  
*For all heterosexual people living with HIV*
- 14 **Peer2Peer Sydney 6pm**  
*For all gay and bisexual men living with HIV*
- 20 **The Women's Room Online 6.30pm**  
*For all women living with HIV under 45 years of age*
- 20 **The Men's Room Online 6.30pm**  
*For all heterosexual men living with HIV*
- 24 **Community Consultation & Engagement Forum Sydney**  
*For all people living with HIV*
- 27 **Digital Mentors Sydney 12.30pm**  
*For all people living with HIV*
- 27 **Positive Conversations Online 6pm**  
*For all people living with HIV*

## SEPTEMBER

- 6 **Social Club Sydney 6pm**  
*For all heterosexual people living with HIV*
- 17 **For Women Online 6.30pm**  
*For all women living with HIV over 45 years of age*
- 24 **Digital Mentors Sydney 12.30pm**  
*For all people living with HIV*
- 24 **Positive Conversations Online 6pm**  
*For all people living with HIV*
- 29 **[+Connect] Liverpool**  
*For all people living with HIV, our partners, friends and family*

FOR MORE DETAILS:  
Call (02) 8357 8386 or 1800 245 677  
or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)  
Details correct at time of printing.



## **Interview with Ava Karusoo-Musumeci about the EARLI-comm Project**

Q: Hi Ava, can you please introduce yourself and let readers know a little about your work?

I'm Ava, the Clinical Trial Coordinator in NSW for The EARLI-comm Project. My role is to work one-on-one with participants in the project. If any of you take part we will most likely get to know each other very well.

Q: What does 'EARLI-comm' mean?

EARLI-comm stands for 'The Enhanced Advance care planning and life Review Longitudinal Intervention – community outreach' Project. I think you can see why we just call it 'EARLI-comm'!

Q: Can you tell us what the EARLI-comm project is about?

Absolutely. EARLI-comm is an exciting project aimed at exploring how engaging in life story work can influence advance care planning decisions.

Our aim is to understand whether helping people to reflect on their past can provide clarity and confidence when it comes to making decisions about future healthcare.

Q: What is advance care planning and why is it important?

Advance care planning is the process of planning for your future healthcare. It involves thinking about, talking about, and documenting your values, beliefs, and preferences for medical care.

Advance care planning is an ongoing conversation which aims to empower individuals to receive the treatment they want, even if they can't speak for themselves. It also helps to provide clarity and guidance to a person's family and medical team.

Q: How did EARLI-comm come about, and what inspired its focus on life story work?

EARLI-comm builds upon the groundwork laid by the original EARLI project, which focuses on older adults receiving home care packages.

While advance care planning is known to support person centred care, uptake in Australia is very low. Life story work is another intervention which supports person centred care, and can be a more accessible topic for many people.

Storytelling has the power to illuminate our values, experiences, and preferences in a deeply personal way, all of which are needed when discussing our preferences for future healthcare.

Q: How has the community of people living with HIV been involved in shaping EARLI-comm?

Community involvement has been integral to EARLI-comm from the outset. Before launching the project, we partnered with Positive Life NSW, the Bobby Goldsmith Foundation, and NAPWHA to conduct a community consultation process.

This allowed us to listen to the voices of people directly impacted by HIV and ensure that our approach is both relevant and respectful of their lived experiences. One of the key changes we made to the project from this consultation is the inclusion of Peer Navigators to support people living with HIV take part in the project.

The core research team has also completed training in trauma informed care, and HIV specific training through NAPWHA.

Q: How can people get involved with EARLI-comm?

We welcome anyone aged 45 and over, living with HIV, and residing in metropolitan Sydney, who is interested in exploring how their life story influences their advance care planning decisions.

Whether you're intrigued by life story work or curious about advance care planning, there's a place for you in this project.

You can submit an expression of interest by visiting <https://redcap.link/earli> or by scanning the QR code







## When I was first diagnosed with HIV, I was advised by a social worker to be silent.

To not tell people for fear of the prejudice, discrimination and rejection that was possible. At the time I was shocked. My instinct was that the last thing I needed at that time was social isolation.

Upon reflection, I understood that my priority was to focus on myself and building the strength and security to face other people's potential responses.

After diagnosis it took a few years for me to gradually tell my friends. It would take me eight years before disclosing with my family and 15 years before disclosing at work and even then, only to a very few.

It was not until recently, that I have felt more comfortable to share my status more openly, including participating in this year's Mardi Gras parade – my first time on a float, representing Positive Life NSW. It took many years, therapy and personal growth to learn that silence and shame are bedfellows and that my silence was feeding the shame within me.

### I found myself asking, "who values from my silence"?

Yes, it is true, if no one knows my status I can avoid stigma and discrimination, but I found my own shame eating away inside of me. My silence was hurting me more than it was hurting anyone else.

I am fortunate enough to have a wonderful support network, and today I feel I owe it to myself and the HIV community to be more open about my status. After all, it is a disease and there are many diseases. There is no reason that HIV should be treated like we do with most other diseases... with care, compassion and support. Knowing that I have support through friends, family and my connection in the HIV community has helped to give me the confidence to find my voice in recent years.

We live in a very different time to the early days of the pandemic, and in the age of PrEP, PEP and 'treatment as prevention' (TasP), coupled with the improved quality of life and the life expectancy that many of the HIV community now enjoy, it is tempting to avoid discussing HIV.

Yet, who benefits and who loses from a world where HIV is silenced?

Not everyone enjoys the same support or wellbeing that I might enjoy today and so I feel I also have a responsibility to develop my voice, not just for my benefit, but for the broader community.

The transition from shame to pride in HIV had me asking many questions. How would it feel to be proud of the strength that it takes to receive a diagnosis and navigate the challenges that result for our emotional, physical and social wellbeing?

What would my late father say if he saw the son who faced his diagnosis alone but was able to pick himself up, show resilience and become a better person through the process? What is the worst thing that can happen if I tell this person? And does their opinion of me matter more than the opinion of those I love or the opinion I have of myself?

Everyone deserves love and belonging, and whilst HIV does not define me, it is part my story and who I am ... and I want to be loved for who I am - not loved for how I might try to fit in.

That is what has given me the strength to start being more open about my status and I have found it liberating and rewarding to starve my shame of the silence that it so badly craves.

– Phil







# 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)

I have HIV.

These three little words can have such a big impact.

They can never be unsaid and they can change someone's perception of me forever. For this reason, I am cautious before I tell others about my status; these days I only tell people close to me who I have known for some time.

At this point in my life, I've decided to keep my status private from people in my daily life, acquaintances, work colleagues and the like. I keep my HIV status private for my own self-care and, because I feel it's just not anybody else's business.

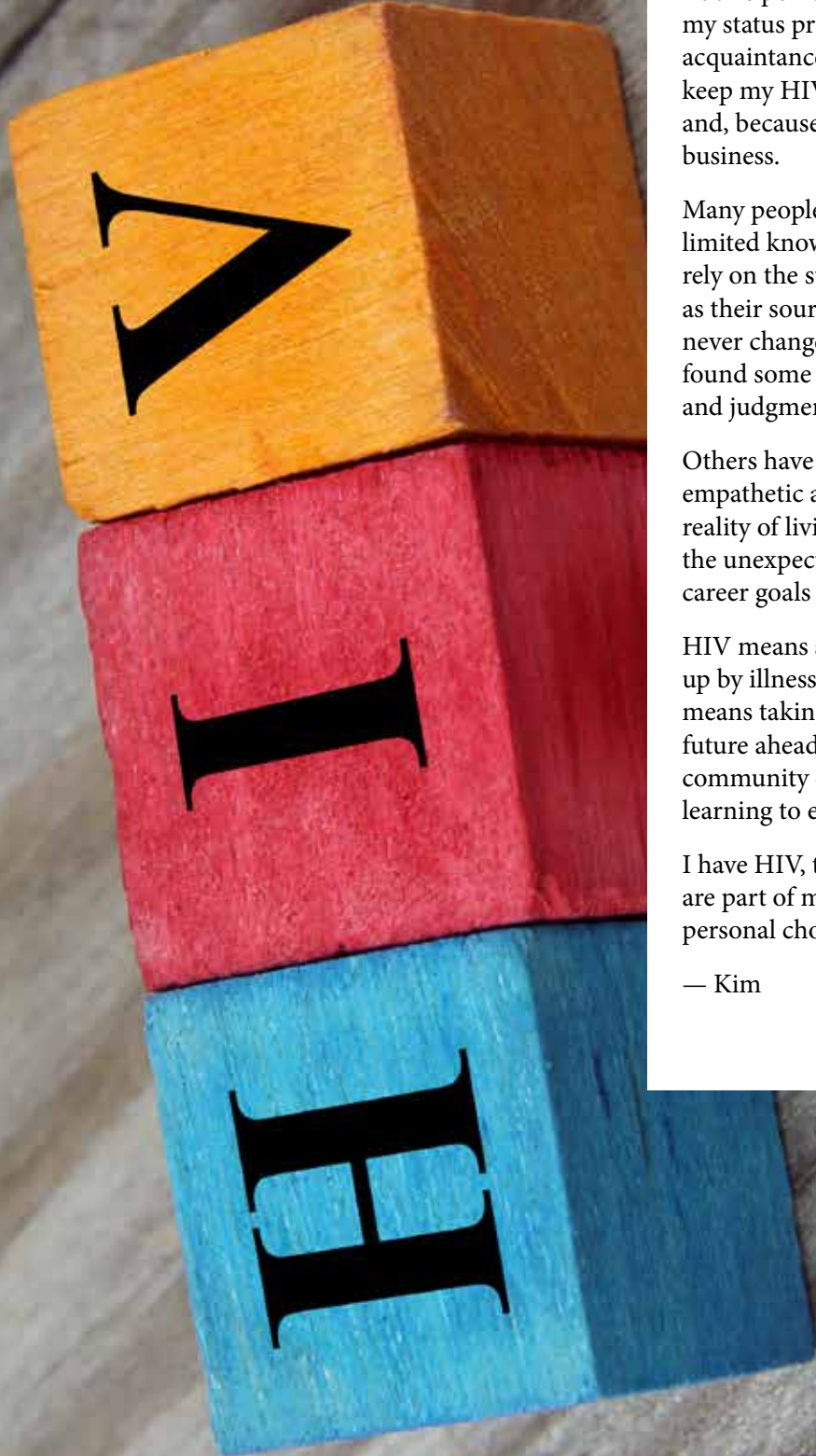
Many people are very uneducated and have limited knowledge of what HIV means today and rely on the stereotypes and myths from years ago as their source of information. Their beliefs have never changed and can be deeply ingrained. I've found some people's views about HIV to be cruel and judgmental.

Others have been extremely supportive, empathetic and can see past the myths. The reality of living with HIV for me is coping with the unexpected, reevaluating my life's direction, career goals and family goals.

HIV means sacrifice; my time being swallowed up by illness, hospitals and recovering. HIV also means taking one tablet a day and having a great future ahead of me. HIV means being part of a community of diverse and amazing people and learning to enjoy life.

I have HIV, three little words; my words, that are part of my story, my identity and it is my personal choice if, how and, when I share them.

— Kim



# MY DECISIONS ABOUT DISCLOSURE

I have had nearly three decades to ponder and fret over the issue of disclosure.

It is mind bending to be aware that I work with clever young people whose whole lives span a shorter period than my life with HIV, and that I was older than many of them when I acquired the virus. Jeez.

Across the years my attitude towards many HIV related matters has shifted and transformed depending upon my circumstances and the changing fields and layers of context. Some things though, seem not to have changed for me at all.

Front and centre is 'disclosure', with its direct relationship to overt and the more insidious covert stigma. My disclosure decisions are predominantly clear-cut situations that present an obvious choice, and it is rare for me to disclose. However, right now I am reflecting upon the blurriness - those tricky bits around consideration of the big revelation that create a conundrum for me.

My sometimes immovable position of non-disclosure sits uneasily with the fact that I've also grown tired of the need for caution, and any HIV disclosure I enact these days is likely to be spontaneous rather than much thought through. Regardless of occasional clumsy disclosures, I do always give at least a moment's thought to a lesson I learnt early on. Mindful of having to live with myself after any disclosure, I firstly look to the motivation for **why** I am considering disclosure - here at least lies clarity! Then should follow a risk assessment, and after weighing risk against potential gain, landing cleanly on a decision. Voila! (Oh, ummm then...now where did I stash that damn crystal ball?)

Okay, more on motivation. Mine always seems to be about either, A) aiming to obtain **superior health care**, in both traditional and non-traditional fields, due to my holistic beliefs around wellbeing, or B) **seeking deeper connection** - and this is where my focus lies today and primarily where the conundrum pops up - more skin in the game.

The recent COVID-19 pandemic has starkly accentuated the impacts on wellbeing when people are separated. Listening to a podcast, I recently heard a psychologist say that humans are the "groupiest" species on earth. We need togetherness and various kinds of human connection to survive and thrive. I experience enjoyment through social and work activities, and I am often surprised by lovely, unexpected, shared moments with people who have no idea that I have HIV. But still, these

days there's that niggling...missing...feeling of belonging? Or is it missing being fully seen? I'm not sure. They are probably connected. I do know that both concepts require other people knowing me more than most do.

While HIV does not on its own define who I am, my HIV story is woven into the shaping of me over 29 years. Intertwined with all the other threads and bindings that make me, it is inextricably interwoven with how I am in the world - how I move through it, and face up to it. It is a colourful, tragic, magnificent and terrible part of my life. Can't ignore it. It changed the direction of my life, and it continues to figure in decisions, big and small. But most of the time it is hidden, ignored.

Here I hit the double-edged situation, that is, the conundrum. Of course having HIV is **private**. It's considered variously as an illness or a condition, and it sucks for sure. People can be weird about it, and judgey. They can hold themselves **separate** from you - GRRRR. You can be sick, or not, and basically no-one can get things right for you a lot of the time. And I'll freely admit to being hypersensitive to judgement, pity, aversion, rejection, or diminishment of any flavour, and maybe I have read things wrongly at times. I could go on...

and yet...

...getting HIV is also an **occurrence** - and to ignore it wipes out one of the most profound influences in the trajectory of my life. HIV has forced me to stare down my greatest fears and shortcomings, to mine previously unexplored strengths, to learn how to live with vulnerability and constant ambiguity, and to hone, deepen, and clarify my values. Seen like this the experience is not unlike a crazy, life-changing, badly-prepared-for overseas backpacking trip into volatile countries, full of potential hazards, illnesses, unexpected disasters, thrills and wonders, and concluding with fabulous dinner party stories.

Sigh, I know that living with HIV is not a holiday. I also know that when I've risked sharing my HIV status in the right context and with the intention of enriching a friendship, it has usually been well worth it. Without weaving my HIV storyline through the complexity of my greater life story, many of the wonderful, meandering, intense conversations I share with close friends would not be possible.

Essentially, my decision about disclosure rests on whether to remain superficially engaged, which is sometimes the right choice, or to cross the gulf. Taking the awkward middle ground means I am



diluted, particular other events don't make sense, and I am always on watch remembering to be consistent with previous conversations. Although sometimes unavoidable, I find that road exhausting and unfulfilling.

The common adage that you are the sum total of your experiences seems a little relevant here. A viewpoint I prefer because it offers more choice, is this: *at the end, the sum total of all the things that you have paid attention to will have been your life.*

I take this to heart. I will muddle along with my conundrum, paying attention to the good things - all the moments of delight, tiny and grand, to be found in ordinary days. I will notice and offer kindnesses and generosity. I will listen and share. I will fail constantly at all of this and many other things, and that will make me cranky. I will expect a lot of myself and laugh at my ridiculousness. I'll pay attention to and show up for those people who do see me and love me regardless, and sometimes we'll get out of tune. I will take care of myself, keeping an eye on how resourced I am, from where I can draw strength and nourishment, and where I can offer it.

There will always be pros and cons to disclosure. Conundrum or not, I will continue to take risks when it feels right because inviting deep connection with others is something I will always prioritise. And if it all goes belly up, it turns out I do have people to call on. Glad I took the risk.

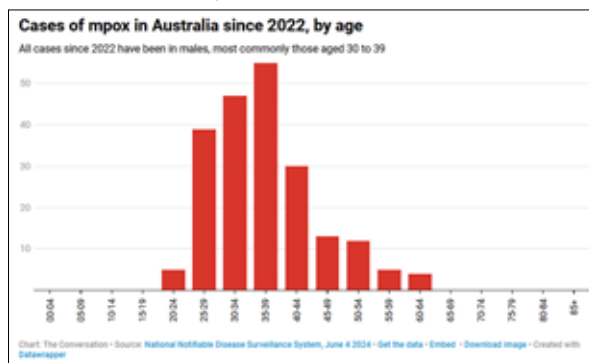
- Maria

**H**ere's what to know about the virus – and who should get vaccinated

Australia appears to be experiencing a re-emergence of the infectious disease mpox, formerly called monkeypox.

Some 40 cases have been recorded so far in 2024, already surpassing the total number recorded for 2023 (26). Victoria has reported 24 cases this year, while Queensland saw ten cases reported in May.

There was previously a significant mpox outbreak in 2022, with a total of 144 cases across Australia. All cases since 2022 have been in males, most commonly those aged 30 to 39. Mpox cases are on the rise elsewhere, too.



So what is mpox? And is there a vaccine available? Here's what to know about this virus.

**What is mpox?**

Mpox belongs to the orthopoxvirus family, which is also responsible for smallpox.

Symptoms include fever and rash, typically starting on the hands, feet and face. The genitals may also be affected. The rash is infectious until the lesions have scabbed over.

There are two clades, or varieties, of mpox: clade I and clade II. Up to 10% of people infected with clade I may die, compared to 1% or less of those infected with clade II.

Traditionally, both clades of mpox have been endemic in countries in central and western Africa, where it transmits from animals to humans, and has occasionally caused human outbreaks.

Mpox outbreaks began occurring outside Africa in 2018, with cases detected in the

United Kingdom, Israel and Singapore in people travelling from Nigeria, which began experiencing outbreaks in 2017.

The 2022 epidemic spread to non-endemic regions such as Europe, the Americas, and Australia, with more than 97,000 cases confirmed globally to date.

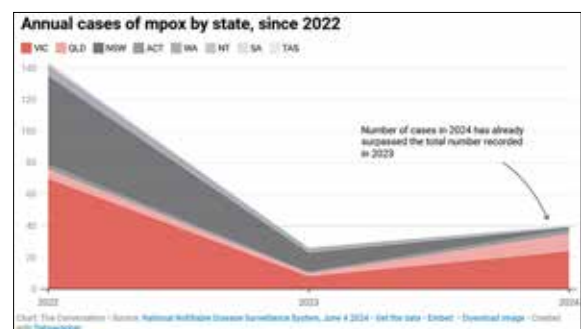
These outbreaks were caused by clade IIb, a variant of clade II, with case fatality below 1%. Clade IIb is also behind the current cases in Australia.

**How does mpox spread?**

Recent research indicates both clades of mpox are undergoing rapid mutations, with genetic changes in clade I that may enhance its transmissibility among humans.

These mutations suggest a shift from its historical zoonotic transmission patterns toward sustained human-to-human spread.

Mpox spreads between people primarily through close contact with infected lesions or bodily fluids. Sexual transmission accounts for most of clade IIb's spread, especially among high-risk groups like gay, bisexual, and other men who have sex with men.



The pattern of spread appears different for the two clades. Like smallpox, mpox is a respiratory virus and has been found in ambient air, so respiratory transmission is possible.

Clade I is causing large epidemics in the Democratic Republic of Congo (DRC), with more than 20,000 suspected cases since 2023.

The estimated fatality rate in DRC is 4.6%, with 70% of cases and close to 90% of deaths in children under 15.



This suggests respiratory and close-contact transmission are the primary modes of spread in DRC. However, sexual transmission of clade I has also been reported.

### **Vaccination is our best bet**

The primary strategy for preventing further outbreaks of mpox in Australia is vaccination. The recommended shot is the JYNNEOS vaccine, which was developed as a smallpox vaccine.

Older smallpox vaccines are made from a live virus called vaccinia, a related orthopoxvirus that protects against smallpox and mpox. The older vaccines have fully replicating vaccinia virus in them, which can be risky for people with weakened immune systems. The JYNNEOS vaccine is modified so the vaccinia virus doesn't replicate in the body and is safer for people with conditions such as HIV.

For full protection, two doses are required at least 28 days apart. Two doses given before exposure to the virus is 84% effective in preventing mpox and protection is believed to last for at least a couple of years.

Cases may still occur in people who are vaccinated, but these infections are typically milder. The vaccine is also effective after exposure to the virus, but less so than if it's given beforehand.

### **Who should get vaccinated?**

Australian guidelines recommend vaccination in gay, bisexual, and other men who have sex with men. They also recommend vaccination for sex workers, and people with HIV who may be at risk of exposure to mpox. Health-care workers who treat or are likely to treat patients with mpox are advised to consider having the vaccine.

Post-exposure vaccination is recommended for people who public health authorities classify as having had a high-risk mpox contact in the previous 14 days.

Australia's approach to the 2022 mpox outbreak involved ensuring early access to vaccination and working closely with LGBTQ+ community and health organisations. These organisations raised awareness of mpox symptoms, modes of transmission, and vaccination.

In 2023, 48% of gay and bisexual men in Sydney and Melbourne reported having received at least one dose of mpox vaccine. Rapid uptake of vaccines may have contributed to low rates of mpox in Australia.

### **Future focus**

It appears mpox has become established as a sexually transmitted infection in gay, bisexual, and other men who have sex with men. Achieving and maintaining high rates of vaccination in this group will be crucial in long-term prevention efforts.

Ongoing surveillance is also important, while contact tracing will help minimise the size of any clusters, facilitating post-exposure vaccination where warranted. In Australia, state and territory health departments have extensive experience in contact tracing and work with affected communities.

Australia has so far been successful in avoiding a major epidemic, including in early 2023 when Sydney WorldPride brought thousands of gay men from around the world to Sydney.

In the next few years, unequal access to vaccination around the world will likely mean continued introductions of mpox from settings with lower vaccination rates. Ensuring equitable vaccine access is vital to global and local disease control.

A global approach to controlling mpox is essential, as infections in one country can spread rapidly internationally, as the 2022 epidemic showed.

- **C Raina MacIntyre**, Professor of Global Biosecurity, NHMRC L3 Research Fellow, Head, Biosecurity Program, Kirby Institute, UNSW Sydney;
- **Andrew Grulich**, Professor and Program Head, HIV Epidemiology and Prevention Program, Kirby Institute, UNSW Sydney, and
- **Mo Hammoud**, Group Leader, LGBTQ+ Population Health Research Group, and Research Fellow, HIV Epidemiology and Prevention Program, Kirby Institute, Faculty of Medicine and Health, UNSW Sydney

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I've had a very intense start to 2024 when everything that could go wrong has gone wrong in the past few months. It's made me think about how life throws a curveball.

My very small family, my relationships, and my home have all been up-ended. To put it in context, within less than three months I have faced:

- A destructive break-in and car stolen – subsequently written off.
- My aunt passed away in February after a very rapid decline that began on New Years' Eve, following her cancer diagnosis in June 2023.
- A plumbing disaster destroyed my apartment in Sydney.

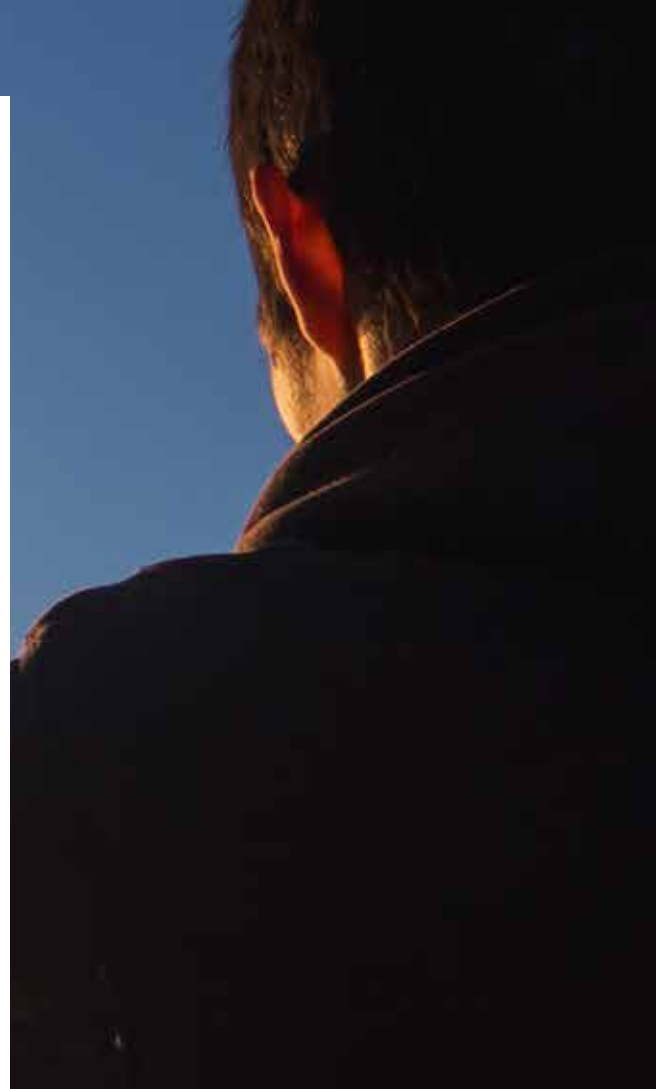
I also moved from Sydney to a regional town, which carries its own complications, stress, and time devoted to personal administration, packing and moving, not to mention a new life with upended and unfamiliar routines. The fact that we had decided to move with and for, my auntie has made settling into a new life poignant and painful with grief.

### **What did I do to manage myself?**

Firstly, I think it's important to recognise that I felt tremendously overwhelmed most of the time.

As each new calamity took place, I felt hopeless in that moment. It felt unfair and I was demoralised. I know that these feelings are natural, and leaning into them is better than trying to ignore them. Recognising our negative thoughts is an important first step in reframing how we think and feel.

1. I celebrated the things I had achieved in my life and put other calamitous periods of my life in perspective – Like all of us, my life has been punctured by tumultuous periods. I drew strength in remembering I faced each of these times and adapted.
2. During each crisis I sat down and mapped out how I was feeling, including jotting down positive ways of framing what happened.
3. I kept the big picture firmly in mind by focusing on my personal goals and plans.
4. I made sure I kept in control of the things I could control, and relinquished worrying about the things that I can't control. I made small, measurable improvements each day by keeping a list and actioning it.
5. Most importantly, I sought help when I needed to and gave myself permission to be vulnerable.



Taking care of myself has also been a big part of the process, so I restarted my mindfulness and meditation journeys, using apps on my phone that provide guided meditation (you can also use YouTube) as well as eating healthy, and cutting down on booze. I've gotten back into walking and hiking. I've also started doing the daily crosswords and puzzles to keep my mind active.

I've noticed that I have a far greater capacity to work through change than I give myself credit for. Even when change is unforeseen or devastating.

It's not been easy, and these steps I've outlined above require conscious thought and effort to achieve. I can confidently say that a few months into being more intentional about how I feel and taking better care of my holistic health, I feel much better. I'm doing alright.

If you'd like to discuss strategies like these and more, we can help you make sense of a crazy world, listen, and share our strategies as peers (someone else also living with HIV). Get in touch with a Peer Navigator at Positive Life NSW on (02) 8357 8386, 1800 245 677 (freecall) or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au).

– Andrew Heslop



**C**ardiovascular disease, or heart disease, is the leading cause of death globally, including for all people living with HIV.

Now that we're living longer due to effective antiretroviral medication, the persistent inflammation that we live with and impact of HIV means we have up to two times the risk for cardiovascular disease compared to people without HIV. We also know those of us living with HIV experience an increased risk of build up of plaques in our arteries sooner compared to people who don't have HIV.

**The outcomes of the REPRIEVE study offers a critical step to address the issue of heart disease for people living with HIV and may be one of the most significant research outcomes in 2023.**

REPRIEVE was a large global randomised trial which investigated the use of statin therapy to prevent major adverse cardiovascular events (heart attack or stroke) in people living with HIV. Statins are a class of medication that are prescribed to help lower total cholesterol and reduce the risk of a heart attack or stroke.

The REPRIEVE results showed the simple use of a daily statin, substantially reduces the incidence of a major adverse cardiovascular event for people living with HIV. As reported in the New England Journal of Medicine in August 2023, the trial was stopped after early analysis showed a **35% lower incidence of heart attack or stroke** among participants who received the statin compared to participants who only received a placebo. The benefit of a daily statin was clear in almost all participant subgroups across gender, race, ethnicity, CD4 count and geographical area.

The study was conducted using 4mg of Pitavastatin (Livalo, Zypitamag), which is currently unavailable in Australia. This availability may change as it goes off patent sometime in 2024. Pitavastatin was chosen for the study because it tends to be well tolerated and doesn't interact with HIV antiretrovirals. However, there are a variety of similar statins available on prescription in Australia for people living with HIV.

In the light of this research, having a discussion with your HIV specialist about the REPRIEVE study is an important conversation for all people living with HIV to have as soon as possible. It's a good idea to explore the benefits of a statin with your doctor, as well as any potential side effects, along with your diet and lifestyle options to reduce your risk of heart attack or stroke.

Along with starting a statin, it's recommended that you include some or all of the following diet and lifestyle changes to support your heart health. Lifestyle changes include stopping or reducing smoking; aiming to be physically active for at least 30 minutes most days; and losing weight if you need to or maintaining a healthy weight. Diet options include reducing or limiting the saturated and trans fats that are mostly found in processed meats, butter, full-fat dairy products and deep fried foods; reducing or limiting salt and alcohol; as well as ensuring you eat a healthy balanced diet that includes plenty of fruits, vegetables, wholegrain cereals, lean meat, fish, eggs, nuts and seeds, legumes and beans, and low-fat dairy products.

If you need support to start this conversation with your doctor, you can call Positive Life on (02) 8357 8386, 1800 245 677 (freecall in NSW) or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

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**KARUMAH**

Enriching the lives of People Living with  
HIV in the Hunter-New England region

**T**he HIV long-term survival journey is one where it is easy to get lost along the way. Low motivation, low self-esteem, social isolation, lethargy, and a victim mentality can lead to feelings of worthlessness, seeing no value in your own existence, and survivor guilt...all my friends have died so why am I still here! It can be overwhelming.

We have already spent 30+ years of our lives popping lifesaving pills, thousands of pills... and still with no end in sight. Pretty well every organ in our bodies has been subjected to incredible stress. Our minds have been tested beyond belief. We have been so low that we thought there was no coming back. Lipodystrophy and lipoatrophy have ravaged and aged us early, made us unrecognisable, made us feel ashamed of our own bodies, reticent to strip in front of strangers, in front of even lovers.

We have lived without immune systems, a state of inherent danger, not knowing what was going to attack you next, a world where even a cold or the flu could be deadly. We have been eroded by strange diseases, live right now with their devastating consequences. Now we live in a world where younger generations don't understand us, don't understand why we carry rage, why we roll our eyes at recent seroconversions, who carry on as though death was lurking around the corner. We have met death, witnessed its cruelty. You have nothing to fear!

Yet...we are here! Present! Sentient! We carry a world of knowledge that no one seems to want to know about.

So what do we do, wandering in this alien landscape? Do we bend, fold and cower...or do we BLOOM! This world is trying to put us down, humble us when we have already been humbled. But there is one thing this world doesn't know...we are, and always have been, fighters.

We stand tall, collect our strength and take the next step! Then we stand back and roar at it "You are not going to win!"

Our world is not what it was! Having already been deconstructed, the only choice left is... reconstruction. So we stop! Re-evaluate! Pry around our fragile edges, gouge out the positives! Rip our lives to pieces, then sew it back together again into a fabric of renewal. We re-educate, for our past is not our present!

We reconnect, seek out those from our past who valued us for who we are...and take steps to make new acquaintances, find those who bring joy, laughter and value into our lives. We feed our bodies, this indestructible machine, with goodness, purity, health. We strip ourselves naked, stand proudly in the light, and rebuild our broken frames.

We glare at those who put us down, and yell "Listen here!...if you want to learn, come to me...otherwise, good luck with your ignorance!"

We reconnect with life! Everything is right there in front of us...you just need the hunger to demand loudly from life, and bellow "make me whole again!" Don't give it choices!

Never accept no as the answer! Take it...mould it...your new, renewed life waits!

Don't waste the opportunity! Long term survivor is not three dirty words! It is empowerment!

Having survived, you rise up...proud... enduring...and step confidently into the new.

The survivor's mantra: I am here! I'm not going away!

— Tim Alderman

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Positive Life NSW works to promote a positive image of people living with and affected by HIV with the aim of eliminating prejudice, isolation, stigma and discrimination. We provide information, targeted referrals and advocate to change systems and practices that discriminate against all people living with HIV, our partners, friends, family and carers in NSW.

**Phone** 02 8357 8386 **Freecall** 1800 245 677

[www.positivelife.org.au](http://www.positivelife.org.au) **contact@positivelife.org.au**

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