talkabout

Where we speak for ourselves

#215 | March 2026 | ISSN 1034 0866 | Positive Life NSW – the voice of all people living with HIV since 1988

NATIONAL DAY OF WOMEN LIVING WITH HIV > **PAGE 14**

AGEING WITH HIV: FRAILTY, FEAR & THE QUEST FOR A GOOD LIFE > **16**

WHEN HER STORY IS HEARD CHANGE FOLLOWS > **18**

TALKABOUT

WHERE WE SPEAK FOR OURSELVES

EDITION #215

CONTRIBUTORS Tim Alderman, Stephen Lunny, Nathan Rogers

COVER NATHAN ROGERS

INSIDE PHOTOS National Day of Women Living with HIV, Fair Day, World AIDS Day, Mardi Gras

CENTERFOLD PHOTOS National Day of Women Living with HIV High Tea

2026 TALKABOUT ADVISORY GROUP Kim, Maria, Tim Alderman

EDITOR Positive Life NSW

FEEDBACK & SUBSCRIPTIONS editor@positivelife.org.au

CURRENT BOARD

President Stephen Lunny | **Vice President** Phillip Quirk
Treasurer New Chaimongkol | **Secretary** Greg Horn
Directors Melissa Carolus, Gareth Graham, Frances Parker,
Philippe Smets and Sebastian Zagarella
Ex Officio CEO Jane Costello

CURRENT STAFF & VOLUNTEERS

Chief Executive Officer Jane Costello
Administration Manager Kelly Micallef
Peer & Ageing Support Officer Priscilla Njeri
Peer & Vocational Support Officer Billy Suyapmo
Peer & Administration Officer Gladys Makoni
Communications & Peer Navigation Nathan Rogers
Positive Speakers Bureau Coordinator Peter Schlosser
Consultant Simon Wilson

Positive Life NSW acknoweldges the traditional custodians of the land on which we live, work and play. We pay our respects to Elders past and present. Always was, always will be, Aboriginal land.

Printed by Pegasus Media & Logistics


Positive Life NSW
The voice of all people living with HIV
Positive Speakers Bureau
HIV Health Promotion
CAUTION
YOUR STEP

CONTENTS

REGULAR

FEATURES

EDITION 2 JUNE 2026 – #216

SUBMISSIONS AND ARTWORK: **MONDAY 25 MAY 2026**
DISTRIBUTION: **MONDAY 29 JUNE 2026**

FROM THE EDITOR

Welcome to the latest issue of Talkabout! It certainly has been a busy time of year and since the last edition our community calendar has been full. From social inclusion gatherings to national and international days of recognition, annual events and local community activities, the past few months have been an immersive and meaningful period for many of us.

Traditionally, the March edition of Talkabout has focused on the Sydney Gay & Lesbian Mardi Gras Parade, highlighting the incredible visibility and pride our community brings to this iconic event. While Mardi Gras remains an important celebration of identity, solidarity and advocacy, in this edition of Talkabout we have chosen to take the opportunity to shine a brighter light on women living with HIV. With International Women's Day recently observed, it felt like the right moment to centre the voices, experiences and leadership of women in our community.

At Talkabout, we aim to share stories and information that are both relevant and empowering. In this edition we explore topics such as women, HIV and ageing — issues that resonate across our entire community. Ageing with HIV is becoming an increasingly important conversation, with more than half of people living with HIV now over the age of 50. It is a reality that touches many of us today and will impact all of us with time.

This year also marks the 11th anniversary of the National Day of Women Living with HIV — a significant milestone and an important reminder to recognise and celebrate our diverse community of women living with HIV. Historically, women living with HIV have not always received the same level of visibility and support as other groups. Days like this provide an opportunity to acknowledge their experiences, strengthen connections and advocate for greater inclusion.

In this issue, Priscilla shares a powerful message for women living with HIV. When women tell their stories, they create change. Their voices challenge stigma, raise awareness, influence policy and encourage others to step forward. Every story is unique, yet together they form a collective narrative of resilience, leadership and hope.

We also invite you to enjoy the images captured at World AIDS Day, Fair Day and Mardi Gras moments that remind us of the strength, pride and solidarity within our community.

As always, thank you for being part of the Talkabout community.

IN THE LOOP

STEPHEN LUNNY, POSITIVE LIFE NSW PRESIDENT

Walking in the Sydney Gay and Lesbian Mardi Gras Parade in 2026 as part of the Positive Life NSW float was one of those moments where celebration, remembrance, and community all blended into something powerful.

When we finally stepped onto Oxford Street, the atmosphere was electric. Crowds stretched as far as you could see, cheering, clapping, and waving as we marched by. Walking beside others who share similar experiences created an incredible sense of connection. Some of us danced and some waved signs about HIV awareness, celebrating community and 'Positive Vibes'.

What made it especially meaningful was the sense of history. Mardi Gras has long been a space where activism and celebration meet, and being part of the Positive Life NSW float felt like contributing to that legacy. It honoured the people who fought for HIV awareness, treatment access, and dignity during much harder times.

By the time we reached the end of the route, our feet were sore, but our spirits were high. The cheers from the crowd still echoed in our ears. Walking in the 2026 Mardi Gras Parade wasn't just a night of glitter and music—it was a reminder that community, visibility, and pride can still change lives.

A big thank you to all those who marched and to the Positive Life team who worked hard to make this happen for us.

On 09 March 2026, I attended the National Day of Women Living with HIV event hosted by Positive Life NSW. The gathering was a powerful space for connection, reflection, and solidarity.

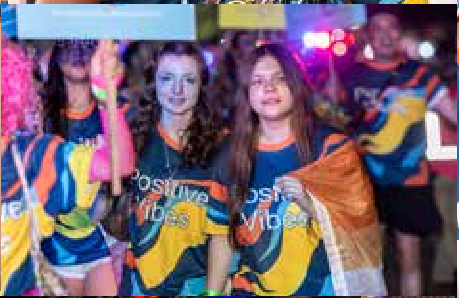
The event gave me a new perspective—it was a deeply meaningful and eye-opening experience. The stories shared reflected courage and optimism, revealing the powerful bonds within the community. At the same time, the event brought attention to the persistent barriers women living with HIV continue to navigate, including stigma, limited access to care, and lack of visibility. Throughout it all, there was a clear and inspiring sense of solidarity and empowerment in the space.

Being part of the day reinforced the importance of the work that Positive Life NSW does around community-led advocacy and our continued commitment to dignity, health, and equality for women living with HIV.

Go well and be kind to each other.


Positive Vibes
Positive Vibes


Positive


Positive Vibes
Positive Vibes


Positive


Positive Vibes
Positive Vibes


40
Knowledge is Power
Knowledge is Power
Positive Vibes
Positive Life NSW


HALC
HIV/AIDS legal centre
Positive Vibes
Positive Vibes


#99 D3 K12
Positive Life NSW


Positive Vibes
Positive Vibes
Positive Vibes

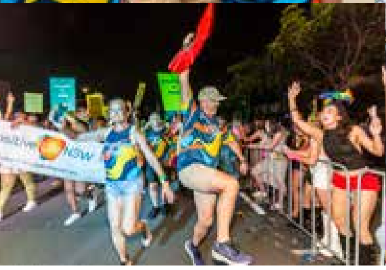

Positive


Positive Vibes
Positive Vibes
Positive Vibes


Positive Vibes


Positive Vibes


Positive Vibes
Positive Vibes


Positive Life NSW


Positive Life NSW
The voice of all people living with HIV
Positive Vibes
Positive Vibes


Positive Vibes

NSW MULTICULTURAL HIV & HEPATITIS SERVICE

About MHAHS

We support diverse communities across NSW to access HIV, hepatitis B, hepatitis C and STI care safely and confidently.

HIV Clinical Concierge Program

We offer free and confidential one-on-one support for people living with HIV. Our bilingual Cultural Support Workers provide help in your language and with cultural care. Get in touch to find out how we can support you.

Community Education Sessions

We deliver free multilingual community education sessions in 15+ languages on HIV, hepatitis B and C, liver health and sexual health, helping people feel confident to get tested, treated and access care.

✉ : info@mhahs.org.au   f : TheMHAHS   🌐 : www.mhahs.org.au

Otis

Hello, my name is Otis. I'm a 3.5 years-old Maltese Terrier who resides happily with my human parents, Paul and Paul (P1 and P2) on the NSW Central Coast since my adoption when I was three-months old. I am a very loyal little guy, I just loves human company and hate it when I am not allowed to go out with my parents but fondly greet them when they return. They have told me that they will never take me to Bunnings. That's fine by me because I don't think I'd like being put in a shopping trolley anyway.

I have loads of toys and ropes which I cherish and get upset when one of these goes missing. Despite this I am fond of cardboard (especially toilet roll and paper towel inserts) and empty 300ml PEP Coke bottles which I love tossing around and chasing them in the kitchen. As the only 'Fur Baby' I am spoilt and tend to sulk when I don't get my own way, but not for very long. Sometimes I can be better persuaded to move faster or doing something that I've been asked to do if a Schmackos is offered. I am very proud of myself for having mastered the requirements of outdoor toilet protocol. This is not to say that I am perfect because occasionally I forget that I am inside and it's too late. I hate Glen 20; it's a great deterrent.

I didn't get desexed until I was almost eighteen-months old when it became necessary because I unfortunately developed behavioural issues which really distressed my parents. I suddenly hated having a lead/harness put on me and wasn't interested anymore in daily walks. For some strange reason I hated being picked up for any reason, unless it was to put in the car to go somewhere important.

I was introduced to another Paul (Newcastle Mobile Vet) and his staff when I had a two-day stay when I got the chop and life for all of us improved dramatically. I tend to stamp my paws alternatively when things don't go right, but not too often. 'Walk-time' is now cherished once again, and I go running to the rear door of the garage to get my lead on.

I still don't like those horrible harnesses, so instead my parents use a choker lead, which is fine by me. I don't like some of the hoons and the loud traffic noises that are generated in my neighbourhood. These only seem to occur when I am taken out! However, I hate the lead being taken off after my walk. I just can't understand why its not left on me permanently. One day I'll have a 'light-bulb' moment and understand why.

My parents think I might be bored. I can assure you I am not because they keep me very busy, and I love to supervise all their home projects (it's exhausting). They are thinking of acquiring a male sibling to keep me company. It had better be another male and not older than me, as I want to remain the boss.

NUTRITION BITES

Healthy and Delicious Middle Eastern Shakshuka

Try this healthy shakshuka for a nourishing, quick, affordable and easy meal. Ready in 20 minutes, Serve it with a warm pita or toasted bread for an easy breakfast, brunch, or dinner!

Ingredients (Serves 3)

2 TABLESPOON EXTRA-VIRGIN OLIVE

1 MEDIUM YELLOW ONION, DICED

1 RED BELL PEPPER/CAPSICUM, SEEDED AND DICED INTO BITE-SIZED PIECES

1 SMALL ZUCCHINI, QUARTERED INTO SMALL PIECES

3 MEDIUM GARLIC CLOVES, THINLY SLICED OR CHOPPED

1 ½ TEASPOON GROUND CUMIN

1 TEASPOON PAPRIKA

¼ TEASPOON GROUND GINGER

2 ½ TEASPOON RED CHILI FLAKES (OPTIONAL)

2 CANS DICED TOMATOES

1 CUP FRESH OR FROZEN SPINACH, ROUGHLY CHOPPED

1 CUP FRESH CORIANDER, ROUGHLY CHOPPED

SALT AND PEPPER TO TASTE

6 LARGE EGGS

1 CUP CRUMBLED FETA CHEESE

1. In a deep non-stick saute pan, heat olive oil to medium heat. Add in the diced onion, bell pepper/capsicum, and zucchini. Cook for 5 minutes, until the onion is translucent.

2. Add in the sliced garlic clove, cumin, paprika, ground ginger, and optional chili flakes. Cook for an additional minute.

3. Add in the crushed tomatoes, spinach, and coriander. Season with salt and pepper, stir and bring the sauce to a simmer. Taste and adjust seasonings to your liking.

4. Using a large spoon to make 6 small wells in the sauce and crack the eggs into each. Cover the pan and cook for 5 – 8 minutes, or until the eggs are done to your liking.

5. Garnish with crumbled feta, extra coriander, and serve with warm pita or toasted bread.

CALENDAR

For more info call Positive Life NSW
(02) 8357 8386 or 1800 245 677 or visit
www.positivelife.org.au/events-calendar/

March

24th For Women – Online discussion group for women over 45

31st Positive Conversations – Monthly online presentation for all people living with HIV

April

10th Kitchen Table Stories: African – Social inclusion event for people living with HIV from Africa

10th Kitchen Table Stories: Asian - Social inclusion event for people living with HIV from Asian backgrounds

15th Peer2Peer – Face to face social discussion event for men who identify as gay or bi-sexual

17th The Social Club – Face to face social event for people living with HIV who identify as heterosexual

19th [+Connect] Casula – Inclusive social event for all people living with HIV

21st The Woman's Room – Online discussion group for women living with HIV under 45

28th Positive Conversations – Monthly online presentation for all people living with HIV

May

1st The Social Club - Face to face social event for people living with HIV who identify as heterosexual

12th The Men's Room - Online discussion group for men living with HIV who identify as heterosexual

17th Candlelight Memorial - Memorial to reflect on and remember our loved ones, friends and family who have passed away from HIV/AIDS

19th For Women - Online discussion group for women over 45

26th Positive Conversations – Monthly online presentation for all people living with HIV

June

3rd [+Connect] Strathfield - Inclusive social event for all people living with HIV

5th Long-term Survivors Day - Day to honour long-term survivors of HIV and raise awareness

10th Peer2 Peer - Face to face social discussion event for men who identify as gay or bi-sexual

12th The Social Club - Face to face social event for people living with HIV who identify as heterosexual

16th The Women's Room – Online discussion group for women living with HIV under 45

Details correct at the time of printing.

World AIDS Day

No One Left Behind: a continued commitment to equity, empathy and community leadership

World AIDS Day 2025 was commemorated on 01 December at Customs House in Circular Quay, bringing together community members, advocates, and allies for an evening of commemoration, reflection, and renewed commitment. We thank everyone who attended and helped make the event so meaningful.

This year's theme, 'No One Left Behind,' reminds us that progress is not real unless it reaches everyone. It speaks clearly to our values and to our purpose. It calls us to look critically at where we are, how far we have come, and where we must go next. It underscored the importance of ensuring that progress is inclusive, equitable, and shared by all.

World AIDS Day is always a moment of reflection. It is an occasion to remember the people whom we have lost to HIV and AIDS — activists who shaped the HIV response, created the building blocks of the services we now have, challenged stigma, and long advocated for the rights that we cherish as a given today. Their courage is the foundation of our progress. We honour them not only with our words, but with our continued commitment to equity, empathy, and community leadership.

The evening opened with a powerful Welcome to Country by Yvonne Weldon representing the Metropolitan Local Aboriginal Land Council. Moving performances by the La Fiesta Dance Group and the Natalie Claire Entertainment Choir were accompanied by reflections from Jane Costello of Positive Life NSW, Michael Woodhouse of ACON, and Nick Lawson from the Bobby Goldsmith Foundation.

We also thank community members Dai, Gareth, and Priscilla for sharing their personal stories. Their honesty and courage reminded us why lived experience must remain central to the HIV response.

World AIDS Day 2025 was jointly hosted by Positive Life NSW, ACON, and the Bobby Goldsmith Foundation. We are grateful to ViiV Healthcare for their ongoing support, and to everyone working together to ensure that truly, no one is left behind.


NSW
World AIDS Day

National Day of Women Living with HIV

Celebrating Women Living with HIV: National Day, 9 March

On 9 March, communities across Australia marked the National Day of Women Living with HIV — a time to recognise, celebrate, and stand in solidarity with women living with HIV while amplifying their voices and experiences. The day recognised all women, including cisgender, transgender, and non-binary people who identify with womanhood, ensuring that diverse experiences are acknowledged and valued.

Globally, women account for more than half of all people living with HIV, while in Australia they represent an estimated 10% of the population living with HIV. While HIV awareness campaigns have historically focused on gay and bisexual men — who remain priority populations for testing and prevention — the day served as an important reminder that HIV does not discriminate. Women of all backgrounds and identities can and do acquire HIV.

For many women, a diagnosis brings layered and complex challenges. Stigma, gender inequality, cultural expectations, and barriers to accessing appropriate healthcare can shape their experiences. Women living with HIV are mums, sisters, daughters, aunts, grandmothers, partners, friends, and community leaders — roles that make support, understanding, and inclusive care essential. The National Day of Women Living with HIV provided an opportunity to challenge misconceptions, reduce stigma, and advocate for gender-responsive services that reflect the realities of women's lives.

Despite advances in treatment and long-term health outcomes, women in Australia are less likely to be offered routine HIV testing and may not perceive themselves to be at risk. This can contribute to delayed diagnosis, sometimes after significant immune system damage has occurred. These patterns highlight ongoing gaps in research, public health messaging, and clinical guidance tailored specifically to women, including trans women.

Positive Life NSW hosted its annual National Day of Women Living with HIV Afternoon Tea, bringing together women from diverse backgrounds — including cisgender and transgender women — alongside healthcare professionals, carers, and allies. The gathering fostered connection, shared understanding, and a sense of collective strength.

The day was commemorated with a high tea and clothing exchange event. We thank Brendan Kerin from the Metropolitan Local Aboriginal Land Council for delivering a thoughtful Welcome to Country. We are especially grateful to the community members, Eva and S who shared their inspiring experiences of strength, hope, and resilience. We also thank Dr Rachael Thomas for sharing her perspective as an HIV clinician supporting women, and Anna Chinni for her passionate reflections on social work and advocacy spanning Kenya and Australia.

This year marked the 11th National Day of Women Living with HIV — a moment to celebrate resilience, highlight lived experience, and raise awareness of the unique challenges women face. Increasing awareness remains essential to challenging stigma and ensuring women have access to inclusive, woman-centred healthcare, peer support, and services that support sexual, reproductive, and overall health.

Positive Life NSW is deeply committed to supporting women living with HIV through dedicated programs, including The Women's Room for women aged 45 and under; For Women for those aged over 45, and social gatherings such as The Social Club, residential workshops and [+Connect]. This commitment is further strengthened by a team of supportive female staff who understand the importance of peer connection and gender-responsive care. In the coming months, the organisation will announce the regional locations it will be visiting as part of expanded outreach, ensuring that women outside metropolitan areas have greater access to information, support, and community connection.

Ageing with HIV: Frailty, Fear and the Quest for a Good Life

For many people diagnosed with HIV in the 1980s and 1990s, old age was never part of the plan and for some in fact is a bit of a surprise. Advances in antiretroviral therapy have transformed HIV into a chronic, manageable condition. Today, more than half of people living with HIV (PLWH) are over 50, and by 2030 nearly a quarter globally will be aged 65 or older. Survival is no longer the sole focus. The pressing question now is: what does it mean to age well with HIV?

A new qualitative study published in AIDS Care explores how older PLWH in Sydney perceive frailty, ageing and quality of life (QOL). Conducted by a community-based team within the Sydney Local Health District, the study involved 40 in-depth interviews with people aged 53 to 74. What emerged was a nuanced portrait of resilience, anxiety, gratitude and a fierce determination to retain control.

"I Never Thought I'd Get This Old"

Many participants described ageing as unexpected. Diagnosed at a time when life expectancy after HIV was measured in months, some had internalised the belief that they would die young. Growing older, for them, felt like a bonus — even a privilege — especially after losing friends during the early epidemic.

Yet longevity brings new challenges. PLWH experience higher rates of comorbidities such as cardiovascular disease, diabetes, bone disorders and cognitive changes. In the study, 91% of participants were considered vulnerable to or already experiencing some level of frailty, as measured by the Edmonton Frailty Scale. Nearly one-third reported low quality of life scores.

Frailty — defined as a decline in physiological systems leading to increased vulnerability — proved to be an emotionally loaded concept. Many participants felt they were "too young" to be described as frail. The very word carried stigma, conjuring images of dependency and decline. Still, most were open to assessment. Some found it confronting; others described it as empowering. Screening prompted reflection, increased awareness and, for some, a renewed commitment to self-management. A number expressed altruism — if being assessed could help others with HIV, it was worth the discomfort.

Control, Independence and the Fear of Aged Care

Four major themes surfaced: control, change, independence and the future.

Control was paramount. Participants feared losing autonomy — over their bodies, finances, housing and end-of-life decisions. Many lived on government benefits and worried they would have little choice about where or how they received care. Aged care facilities were a particular source of anxiety, often informed by negative experiences with parents or friends.

Some voiced stark contingency plans, including support for voluntary assisted dying, should their quality of life deteriorate beyond what they deemed acceptable. These views were less about despair and more about preserving dignity and agency.

Independence was closely tied to quality of life. Participants spoke of the importance of creative expression, social connection, sexuality, and feeling safe to disclose their HIV status. Financial strain, rising living costs and reliance on pensions threatened that independence. For many, quality of life meant more than viral suppression — it meant having enough to "live with dignity."

The Weight of Change — and the Power of Resilience
Ageing amplified existing concerns. More diagnoses, more medications, more appointments — the burden felt heavier for those already managing HIV. Some described feeling trapped by cascading health issues. Others worried about ageing alone, without children or partners to advocate for them.

And yet, the study also revealed striking heterogeneity. Not everyone feared the future. Some participants were optimistic, even joyful, about growing older. They saw each year as a gift. Decades of navigating stigma, discrimination and loss had forged resilience that now shaped how they approached ageing.

From Survival to Quality of Life
The findings align with the goals of the NSW Health HIV Strategy (2021–2025), which aims for at least 75% of PLWH to experience good quality of life. The study underscores that achieving this target requires more than clinical management. It demands holistic, person-centred care that addresses frailty, mental health, housing, finances and social inclusion.

Importantly, the research highlights the need to reframe frailty conversations. Rather than equating frailty with old age and decline, clinicians can focus on physical function, prevention and empowerment. Early, sensitive discussions may normalise screening and open pathways to interventions that maintain strength, mobility and independence.

As HIV care enters its fifth decade, the paradigm must shift from survival to flourishing. PLWH are not a monolith; they are diverse individuals with complex histories and aspirations. Listening to their voices — especially about control, dignity and what makes life worth living — is essential.

Ageing with HIV is no longer a rarity. It is a reality. The challenge now is to ensure those extra years are not only longer, but better.

This article is based on the work of Denise Cummins, Daniel O'Raw, Kurt Andersson and Samantha Bennett (03 February 2025), *"I'm too young to be frail!". HIV and attitudes on ageing, quality of life and being assessed for frailty, published in AIDS Care.*

WHEN HER STORY IS HEARD, CHANGE FOLLOWS

Women living with HIV are experts in our own lives. Our perspectives are not optional add-ons to policy or healthcare — they are vital contributions to the narrative of HIV in Australia. When women's voices are heard and valued, they lead to better health outcomes, stronger communities, and more inclusive services.

Yet many women still face barriers that silence their voices. For women from culturally and linguistically diverse backgrounds, particularly women of colour, these barriers are often layered — stigma, racism, gender inequality, and gaps in culturally appropriate care.

When these voices are excluded, entire experiences are left behind.

Despite advances in HIV treatment, women-specific research remains critically underdeveloped, particularly in areas such as menopause, reproductive health, and long-term wellbeing. Many women living with HIV begin menopause as early as 45 years of age, yet research, clinical guidance, and treatment pathways often fail to reflect this reality.

As a woman of colour living with HIV and navigating menopause, I have encountered numerous barriers within the healthcare system. While I can advocate for myself, I have experienced situations where specialists assume authority over my health decisions without consultation or collaboration with my GP — even when I insist on this approach. These moments can be exhausting, disempowering, and deeply frustrating.

What troubles me most is not only my own experience, but the question it raises: "What happens to women who are still finding their voice?" Women who are newly diagnosed, socially isolated, or navigating trauma may feel completely shut down in these spaces. Without advocacy, their needs risk being overlooked, misunderstood, or dismissed altogether.

The management of HIV in women — especially when it intersects with menopause, reproductive health, mental health, and ageing — must be led by professionals who have a genuine interest and expertise in supporting women living with HIV. This care must be collaborative, respectful, and grounded in consultation with the woman herself.

Women are not passive recipients of care. We are partners in decision-making.

Healthcare systems must move beyond one-size-fits-all models and invest in gender-responsive, culturally appropriate care that recognises the complexity of women's lives. This includes prioritising research on women living with HIV, funding women-led programs, and ensuring that healthcare providers are trained to listen — truly listen — to women's experiences.

When women living with HIV share their stories, they create change. These stories challenge stigma, educate communities, influence policy, and inspire others to step forward. They remind us that no two journeys are the same — yet together, they form a powerful movement rooted in resilience, leadership, and hope.

Her Story: Unique, United reminds us that every woman's voice matters. When these voices unite, they amplify women's leadership, strengthen advocacy, and ensure that no woman — regardless of background, age, or stage of life — is left behind.

Today, we honour the courage, wisdom, and diversity of women living with HIV. We stand together in solidarity, knowing that while each story is unique, our collective strength lies in unity.

Written by Priscilla Njeri

pozhet

HETEROSEXUAL HIV SERVICE

STRAIGHT AND HIV+?

- Get the latest information on topics such as pregnancy, treatment and living well
- Find out about other useful services
- Connect with other heterosexual people living with HIV

WEBSITE

pozhet.org.au

EMAIL

pozhet@pozhet.org.au

FACEBOOK

@pozhet

Pozhet is a government-funded NSW-wide service for heterosexual people at risk of or living with HIV, their partners and family.

THE NEW AGED CARE ACT: REFORM OR REGRESSION

In Talkabout issue #214, we introduced readers to the New Aged Care Act, rolled out nationally on 1 November 2025. From a policy standpoint, the reforms were intended to future-proof the aged care system against Australia's ageing population, while addressing long-standing challenges exposed by the 2021 royal commission. Central to the changes are a strengthened charter of rights for older Australians, a new code of conduct for providers, and updated quality standards aimed at improving safety and accountability.

Yet for many older Australians, the reality has been far from reassuring. Rather than improving access to care, the new system has triggered widespread confusion, delays and distress — affecting both those seeking support for the first time and those already reliant on home care services. To understand the depth of this upheaval, it's necessary to look beyond the policy intent and examine how the system now operates in practice.

The Assessment Backlog

One of the most consequential changes has been the partial privatisation of aged care assessments. Late last year, contracts worth around $1.2 billion were awarded to private providers, replacing the state and territory public health clinicians who had conducted assessments for decades.

The fallout has been severe. More than 116,000 people are currently waiting for a home care assessment. While the government maintains the median wait time is 23 days, families, carers and aged care workers describe a vastly different experience.

Following a recent 7.30 report, the ABC was inundated with emails. One couple in their 70s said they were told it would take "nine to 10 months" just to be assessed. Another woman described waiting eight months for her father's reassessment — only to be contacted two months after he had died. An elderly man said he had simply given up.

Even after approval, individuals are placed on a separate waiting list for a home care package — a list now exceeding 120,000 people. Complaints to My Aged Care often lead families back to the same assessment agencies, while the health and independence of those needing support continue to decline. According to families and industry insiders alike, the assessment system is in crisis.

Decisions by Algorithm

Compounding these delays is the introduction of the Integrated Assessment Tool — an algorithm that determines how much care an individual receives. While a clinician still conducts a home visit, assessors say they are unable to override the algorithm's outcome, even when it clearly fails to reflect a person's needs.

One assessor told the ABC the tool frequently assigns low levels of care to people with complex or high needs, leaving clinicians powerless.

When support proves inadequate, individuals must apply for reassessment, further clogging an already overwhelmed system.

Waiting for Care

Approval, however, does not mean help arrives. More than 107,000 people are currently waiting to receive a home care package, with standard wait times stretching to 10 or 11 months. Although the government has promised an additional 80,000 packages by the end of the financial year, this is unlikely to eliminate the backlog or ease mounting frustration.

One woman said her father was discharged from hospital while waiting for a package and was told the delay could be up to nine months. She resigned from her job to care for him full-time. Another wrote that her 92-year-old neighbour with Alzheimer's disease had been told she would wait at least a year.

Taken together — assessment delays and package shortages — it is estimated that around 200,000 people need home care and are not receiving it.

Commonwealth Home Support Co-Payments

Alongside access issues, the reforms have also reshaped how care is paid for. The introduction of Non-Clinical Care Contributions (NCCC) means many essential in-home services — including showering, dressing, cleaning and shopping — now attract co-payments. These are not discretionary extras, but fundamental supports that underpin health, dignity and quality of life.

'No Worse Off' Promises

A core aim of Labor's reforms is to make aged care financially sustainable. From 01 November, all people receiving home or residential care are required to contribute to its cost. To quell concern, the government assured the 250,000 people already in the system that they were "grandfathered" and would be "no worse off".

While providers are now capped on management fees, some have responded by sharply increasing hourly service rates — in some cases by 30 to 40 per cent. The result is fewer hours of care each week, even though funding levels have not increased.

At Senate Estimates, Senator David Pocock questioned how an 84-year-old whose respite costs rose from $132 to $447 per hour could be considered "no worse off".

While the government argues that those who can afford to contribute should do so in order to protect fully funded clinical care, advocacy groups and providers warn the line between clinical and personal care is dangerously blurred. "We need to make sure that poor access to showering services doesn't actually create more hospital admissions," said National Seniors Australia's Ian Grice. Australian Unity's Rohan Mead Bowden echoed the concern, describing personal care as "deeply personal" and closer to clinical support — and warning against forcing older Australians to choose between essentials like heating, food and basic hygiene.

This original article published ABC News 13th December 2025. To read the full article: https://www.abc.net.au/news/2025-12-13/aged-care-package-reform-worse-off-confusion-despair-waitlist/106136364

FAIRDAY

Positive Life NSW Shines at Fair Day 2026

Positive Life NSW was proud to take part in the 2026 Fair Day, one of the headline community events of the iconic Sydney Gay and Lesbian Mardi Gras festival calendar. Despite an early downpour and grey skies, thousands of attendees streamed through the grounds, and the day remained a vibrant celebration of pride, connection, and community — with Positive Life NSW right at the heart of it.

Powered by Community

Our presence at Fair Day was made possible by an incredible team effort. Six dedicated staff members were joined by four members from across NSW and 16 passionate volunteers, and Miss Rainbow, all working together to ensure our stall was welcoming, informative and engaging.

From early morning setup to the final conversations of the afternoon, the team brought warmth, expertise and boundless energy. Events like Fair Day are a true reflection of community spirit, and this year was no exception.

800 Showbags and Countless Conversations

One of the highlights of the day was the enthusiastic response to our showbags — with 800 distributed to festival goers. Packed with resources, information and practical tools, the bags were more than giveaways; they were conversation starters and gateways to support.

Our stall saw a constant stream of visitors throughout the day. People stopped by to ask questions, share stories and learn more about the services and advocacy work of Positive Life NSW. The atmosphere was open and affirming, creating space for meaningful exchanges that extended well beyond a quick hello.

Raising Awareness, Saving Lives

A standout feature of the day was our prosthetic (affectionately named George) and his tireless health promotion work, engaging the public in conversations about anal cancer awareness. George helped provide clear, accessible education on risk factors, screening, and the importance of regular health checks — topics that are often overlooked but critically important within our communities.

These discussions weren't just informative; they were empowering. By breaking down stigma and encouraging proactive health choices, the team helped turn awareness into action.

Outreach That Matters

Fair Day is more than a celebration — it is a vital platform for outreach and connection. For many attendees, stopping by the Positive Life NSW stall meant accessing trusted information, discovering support networks or simply feeling seen and heard.

The success of the day cannot be measured by numbers alone — Its true impact lies in the significant interactions, the strengthened relationships and the reminder that community-led organisations remain at the core of health promotion and advocacy in NSW.

As the sun set on another unforgettable Fair Day, one thing was clear: Positive Life NSW's commitment to education, support and connection continues to make a tangible difference — and we're already looking forward to doing it all again next year.

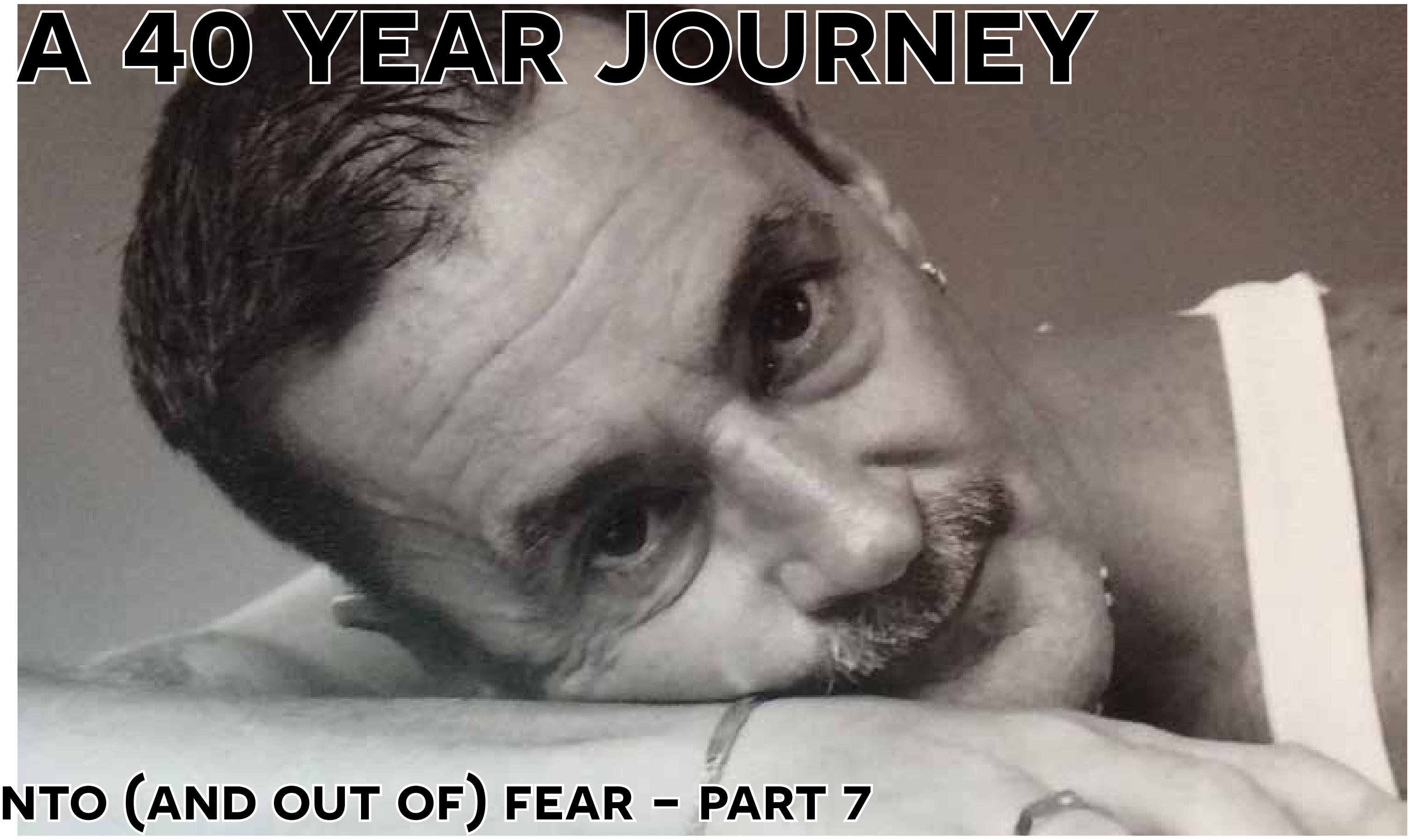

Positive Life NSW


POZ LOUNGE


ve Life NSW
of all people living with HIV
ive Speakers Bureau
V Health Promotion
eatments Information
Navigation & Support
l & Peer Support Events
atory Community Research
Advocacy & Policy
MARDI GRAS
Positive


Positive Life NSW

A 40 YEAR JOURNEY



INTO (AND OUT OF) FEAR – PART 7

TIM ALDERMAN

One of the major problems that concerned both my doctor and myself was my weight. Having dropped to 48kg when admitted to Marks Pavilion, and being of slight build, I was having trouble putting it back on. Fortunately for me, the Albion Street Clinic started running a Deca-Durabolin (an injectable anabolic steroid) trial at this time to attempt to counter the effects of Wasting Syndrome, a common problem within the AIDS demographic. I'm not sure this far down the line of it's duration, but I think it was 6-8 weeks, with a weekly injection, and weigh-in. What I do remember about it was the drastic change to my eating habits. For the period of the trial, I was obsessed with eating! From the moment I woke up, to the time I went to bed…all I thought about was food! I was continually planning my next meal, my next snacks! The (successful) end to this was a meteoric weight gain in a very short period of time. My usual weight was around 64kg…by the time the trial ended I was at 84kg. On going out for dinner with friends I hadn't seen for a while, one guy exclaimed "What have you done…you look like a teddy bear!". To be honest, I was thrilled to have put so much on, especially seeing how I had seen myself in the low, and scary, weight range. I'm thankful to say that after the trial ended, my weight dropped back to my usual range.

There is a big problem with surviving AIDS and spending 18 months recovering and keeping busy with doctors, clinics, hospitals, peer groups, and treatment compliance sessions…and having a lot of same either end, or become more spread out… BOREDOM! Sitting at home watching "Days of Our Lives" and "The Bold and the Beautiful" daily is not a fulfilling experience! But what to do was the big question. Not fit enough to return to full-time work, and not wanting to return to my old profession in retail. As frightening as the whole AIDS experience had been, its lasting legacy was the overwhelming desire to change my life direction. It made me realise how much of my life I'd wasted doing work I hated, and never being brave enough to take the leap to follow my dreams, to step into the unknown with confidence! This was the point where everything changed, where I finally found enjoyment and fulfilment in my life's choices.

But the question still remained…how to take the first step? I had been receiving "Talkabout" for some time, and recollected that I had seen an ad for volunteering at the…then…PLWHA office in Darlinghurst. A phone call, and a meeting with another volunteer in the Oxford Street offices…and I found myself on the reception desk, initially one day a week, but it was a fun office to be in, so I started turning up daily. This was also my first encounter with computers (other than my experiences in the 80s with owning a Commodore 64). This pushed me to do courses in basic computing, and the Microsoft Office Suite. Around the same time I did a Peer

Group Facilitator course with ACON, brought about by me having done a HIV/AIDS survivor group with them. I went on to facilitate some groups.

After around 6 months on reception, Jo Watson…the then Research Officer…asked me if I'd like to work with her as an assistant research officer. The office manager (Ryan McGlaughlin) interviewed me and I got the job. It was here that I wrote my first article for "Talkabout", a quite humorous piece on my doctor, Cassy Workman. Though not named, it was obvious (by those who knew her, or were patients) who it was about. From this point I became a regular contributor to Talkabout, and 28 years later, I'm still writing for the magazine…with occasional breaks! I also became a member of the Talkabout Working Group. Like many occasions in community groups, funding dried up, and I had to move on.

It was just after this that I was informed that a research position was opening up with another community-funded project called Positively Working. Having survived AIDS, and now being in a position to orientate myself to new work experiences…outside what I had been doing post AIDS… it was a position I slotted into quite neatly. At Positively Working, we were compiling a report (I was working with Sonia Lawless) on the return-to-work needs of guys like me who had survived AIDS, and we're now faced with the very real situation of… what do I do now; and where the hell do I go now! I personally interviewed a number of the guys, and it was quite eye opening! Once again, after six months the funding dried up. We got the report out, and once again I was faced with what to do!

There was one very interesting…and disturbing… occurrence that resulted from my time there. Several of the guys I interviewed mentioned that they had used the "services" of a supposed HIV/AIDS employment service on Oxford Street called "Options". Evidently Options had been using guys attending there as a free workforce in the office under the guise of "work experience". I was very angry to hear this, and decided, as a writer for Talkabout, to investigate and expose this issue. I approached the office as a return-to-work client. Not only were they using their clients as an unpaid workforce, but they were also not providing the services they were touting, to help guys break back into the workforce. Clients were being placed in front of computer screens with the usual run-of-the-mill employment services and told to find a job. Contrary to their name, Options provided no options.

I wrote a scathing article on them for Talkabout. The editor forwarded the draft onto them, basically saying this is about to come out! Well, didn't the shit hit the fan! The Manager, Peter somebody, demanded to see me. I turned up at his office, and he tried the good old sweet talk! Naw, didn't sway me. The threats came next, to sue Talkabout, the editor, and me! I was amused! Anyway, to calm the waters, and ensure no action was taken, the editor did a rewrite. I wasn't happy about it, but at least wanted Options thrown into the spotlight, so allowed a very, very watered-down piece to be published. Several months later, Options closed. I just smiled!

I undertook Positive Speaker Bureau training in 1998. My first gig was to a group of nurses at the Albion Street Centre. At the end of the talk, I opened the floor to questions. The final question floored me …did I have survivor guilt? I did…after a long pause…give an answer. Yes, I did! I spent 12 years as a PSB speaker, being quite in demand with community groups, universities, and nurse training talks. I had no problems filling an hour. I was also on the PSB working group.

Two of our major community groups instigated return-to-work groups, but in many respects, they missed the mark. The Positively Working report pointed out that one of the major requirements of AIDS survivors contemplating how to move on, or approach a return to the workforce, was choices, be it returning to their previous profession, or taking up education or training, or a myriad of other options such as opening a business, or moving a hobby to a business. What they were finding in the groups that were set up was a repeat of information that wasn't new to them, or of no use at all. There needed to be more options than resume writing, or interview techniques. One project that did have a different approach was "Reconstruction", a group facilitated by Pene Manolas. In my own time, I did a few talks at these group meetings, encouraging guys to follow dreams and desires to find more fulfilment in lives now "reset to zero" and going off in new directions.

In 1999, I was on a very unpleasant… understatement…liquid protease inhibitor called Ritonavir. It was very effective but disgusting to take. Cassy Workman supplied her patients on it with gel capsules and a dropper. Putting it into the capsules made it a lot easier to take. I made an appearance on a popular television series at the time called "Healthy, Wealthy & Wise", who were doing a segment on HIV and its impacts. I can be seen sitting in a park in The Rocks, and filling gel capsules with Retonavir. I guess that was my 15 minutes of fame!

Also in 1999, following my stint with the Positively Working project, I briefly returned to my old retail career…but as a cash office supervisor this time, with Angus & Robertson booksellers in the city. The manager there had a large group of gay friends, so when, during my interview, I explained a long absence from employment on AIDS and recovery, she understood exactly what was going on. It wasn't why I got the job, but my long retail background on cash handling.

1999 was another busy, and scary, year. I noticed I was having problems walking a straight line up the footpath. It wasn't neuropathy, as at that stage it wasn't as bad as now. As I walked, I drifted to the left of the path and had difficulty getting myself back to the centre. Over a few weeks, it got progressively worse. At one stage I was using a walking stick to maintain balance. Cassy sent me to see Bruce Brew, a well-known neurologist at St. Vincents. He was baffled, as was Cassy. At one stage he sent a letter to Cassy saying he suspected it may be PML (Progressive multifocal leukoencephalopathy is a rare, severe, and often fatal viral brain infection characterised by progressive white matter damage. It is caused by the JC virus (JCV), which lies dormant in most adults but activates in individuals with severely compromised immunity. Common in HIV/AIDS, cancer, or patients on specific immunosuppressants, it causes rapid neurological decline). A very scary prospect! AIDS dementia was another possibility. For her part, Cassy ordered up a raft of tests…iron, folate, B12, cortisol, thyroid, CT scan, gallium scan, Addison's disease. The last resort was an MRI! And there it was! THE VIRUS…on my brain! It could frightened be seen in the scans! During a drug combination change, it had picked a small opportunity when the new combination was starting to kick in to cross the blood/brain barrier, and up into my head. The solution was actually very simple…when the new combination kicked in, it kicked the virus out.

I was at A & R's for about 4 months…and encountered the difficulties other guys had of obtaining meds from hospital pharmacies during lunch breaks, and fitting in doctors appointments… when I got a phone call from Bill Whittaker (now deceased) to help out doing data entry for the AIDS Research Initiative, which was run out of Cassy's medical practice in Little Oxford Street (called Ground Zero Medical, as it was on the site of the original Club 80). So, I returned to Darlinghurst!

It turned out to be a double job. On days I wasn't working for AR, I was doing reception work in the medical practice. It was here on a working day in the practice that I developed excruciating pain in my back, in the kidney area. Cassy diagnosed Indinavir sludge, a build up of Indinavir in the kidneys. I was told to drink a lot of water…it didn't help! I spent a good part of the day in the nurses station with Janice (the practices nurse) unable to keep still because of the pain, which just wouldn't let up! By mid afternoon, Janice took it upon herself to call a taxi to take me to St. Vincent's. I needed to have a stent inserted in my kidneys to drain the sludge.

A new relationship started with Dr David Austin, at Holdsworth House Medical Centre.

Positive Minds

Free one-to-one counselling support for all people living with HIV in NSW

Confidential, supportive and safe

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

Email contact@positivelife.org.au | www.positivelife.org.au

The voice of all people living with HIV

Positive Life NSW

Images are stock photos posed by models

Positive Life NSW

The voice of all people living with HIV

Positive Speakers Bureau	Employment + Vocational Support
HIV Health Promotion	Advocacy + Policy
Peer Navigation + Support	Talkabout Magazine
Counselling	a[STARTx]
Ageing Support	Treatments Information + Support
Social Support	Aboriginal Health Program

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 **contact@positivelife.org.au**
