

talkabout

Where we speak for ourselves



IN MY OWN WORDS

MEDICAL CANNABIS

PLEASE STAY ON THE LINE

PET POWER



TALKABOUT

WHERE WE SPEAK FOR OURSELVES

EDITION #208

CONTRIBUTORS

Alice, Frances Parker, Kim, Melissa Carolus,
Peter McGrath, Philippe Smets, Stephen Lunny,
Tim Alderman

EDITOR

Craig Andrews |
editor@positivelife.org.au

2024 TALKABOUT ADVISORY GROUP

Kim, Maria, Tim Alderman

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Administrative Support Catherine Beck
Positive Speakers Bureau Coordinator Peter Schlosser
Consultant Simon Wilson

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ADVERTISING

contact@positivelife.org.au

SUBSCRIPTIONS & FEEDBACK

editor@positivelife.org.au

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

Cover artwork: 2024 Sydney Mardi Gras Parade

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

In this edition, Alice shares her personal journey in her own words (page 8) as an “ordinary suburban mum” dealing with an unexpected diagnosis and a young family, towards a new future out of a profound sense of isolation.

Positive Life NSW Board Director, PSB speaker and GLTBI ally, Melissa Carolus shares her pride in being a black heterosexual woman living with HIV leading the Positive Life contingent in the 2024 Sydney Mardi Gras Parade (page 13). We offer a sampling of photographs from the 2024 Sydney Mardi Gras parade across a middle page spread (page 14-15).

Community member, Philippe Smets writes about a regular queer meditation group he chairs with an invitation to readers, regardless of gender or sexual orientation from the inner city suburbs to join in this meditation experience of connection, mindfulness, and support (page 17).

Long time writer and Talkabout Advisory Group member, Tim Alderman shares his frustration with the increasing trend accessing government services via online and the lengthy waiting times on hold (page 18). Kim, a woman living with HIV in a regional area, shares her delight with her new four legged companion, ‘Molly’ (page 21).

Positive Life NSW Board Director and PSB speaker Frances Parker shares her speech that she made at the recent 2024 National Day of Women Living with HIV (page 22), reminding all women of

the risk of HIV, while Kim reports on the 2024 National Day of Women Living with HIV event itself (page 25).

We wrap this edition up with community member, Peter McGrath who shares his experience with prescribed medical cannabis and the benefits he has experienced under medical supervision (page 26).

Earlier this year, the Talkabout Advisory Committee was refreshed with three Positive Life members from rural and regional areas, and I have appreciated the guidance and input from Tim Alderman, Maria and Kim for this edition.

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. I look forward to hearing from you in the near future.

CRAIG ANDREWS
EDITOR

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choice

IN THE LOOP



Firstly, I acknowledge the traditional owners of all the lands in NSW. We are truly fortunate to exist in a country with such a special culture, knowledge and heart that has stretched out before us for many, many, many generations.

As another Mardi Gras season draws to a close, Positive Life NSW is gearing up for another full year of activities. Once again, I was fortunate to march with my community as part of the Positive Life NSW Float this year, such a thrill and my favourite to date! Thank you to everyone who took part.

For me, Mardi Gras is both a time of celebration and of reflection. As I reflect on this history, I'm acutely aware of the impact that the HIV epidemic had in those early years.

The first Mardi Gras began in 1978, and 1981 saw the first known case of HIV. HIV created an urgency behind the push for homosexual law reform, which NSW achieved in 1984. As part of the HIV response, a strong network of community health organisations were formed and most are still operating today. Positive Life NSW was formed in 1988 (then called People Living With HIV/AIDS). The Kirby Institute for infection and immunity in society, formerly the National Centre for HIV Epidemiology and Clinical Research (NCHECR) was established in 1986, and the first Needle and Syringe Program in Sydney also opened in 1986. Some of these organisations have broadened their brief today to suit the changing climate.

As I reflect, I can't help but wonder what the community health landscape would look like today if the HIV epidemic never arrived at our door. Having said that, it would be remiss of me not to mention the huge loss that our communities have experienced as a result of the HIV epidemic and the impact this has had and continues to have on our communities today.

On Sunday 19 May, Positive Life NSW will host the Annual Sydney Candlelight Memorial (in partnership with ACON) at the Eternity Playhouse in Darlinghurst where we remember those we have lost and reflect on the journey our communities have taken. To attend this memorable occasion, reach out to the Positive Life team for more details.

I attended Positive Life NSW's National Day of Women living with HIV event on 9 March, and I was moved by the stories that women living with HIV in our community shared. They reminded me of both the similarities and the differences that all of us living with HIV experience. As I listened to the women speak, it became clear to me there is a disparity between the good work that's been carried out for men living with HIV and the need for more work to be undertaken for women living with HIV.

So let's not be complacent. Let's continue to support each other. HIV has not ended. It's vital we keep talking about HIV in the broader community – and the vital role that all people living with HIV play. By sharing our stories we keep the conversation alive and current.

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

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.

INAUGURAL ELDERS ADVISORY GROUP

On Monday 11 March, five people living long term with HIV met to form the inaugural Positive Life Elders Advisory Group. The Elders Advisory Group is convened by Positive Life NSW as the peak NSW peer-led and run advisory body on issues affecting the wellbeing of people living long term with HIV within the NSW HIV sector. The group provides advice, recommendations and feedback on current and emerging issues that affect the health and wellbeing of people living long term with HIV; improve health outcomes, health service access and navigation; and raise awareness of the needs of people living long term with HIV within NSW. Amongst other topics on the agenda, the group discussed the meaning of the term 'survivor', the importance of observing the Annual Long Term Survivors Awareness Day on 5 June, as well as different opportunities to acknowledge this day in 2024 and 2025.

2024 MARDI GRAS PARADE

On Saturday 2 March, Positive Life NSW represented all people living with HIV in the 46th Sydney Gay and Lesbian Mardi Gras. With 75 registrations, an excited and motivated group of community members, our friends, family and allies met at the Positive Life NSW office. The *Sydney Academy of Makeup* once again offered five students to do makeup, Stephanie Tuckwell of *The Catering Specialists* provided a delicious snack box for each participant, and Woody from *Promotional Logistics* printed up our bright eye-catching t-shirts in Positive Life colours. This year the intrepid Mardi Gras staff placed us at an early position of 54 which meant our group was able to move forward in the parade by 8.20pm. Positive Life Board Director, Melissa Carolus shares her reflection on being in the parade and leading the group as a GLTBI ally and woman of colour living with HIV ([page 12](#)).

POSITIVE LIFE NSW HIV COMPLEX CARE AND COORDINATION COMMITTEE

On Wednesday 6 March, Positive Life NSW convened the 2024 HIV Complex Care and Coordination Committee. Attended by representatives from NSW Ministry of Health along with HIV sector partners,

and services throughout NSW, this group comes together three times a year to coordinate and provide advice on improving health outcomes; health service access and navigation; and retention in care for people living with HIV with complex care needs.

The group discussed a number of emerging issues and concerns within the NSW HIV sector particularly the high turnover of GPs around NSW which poses challenges recruiting and sustaining the clinical workforce particularly in South Western Sydney, along with the interlinked impacts of ageing and retiring GPs and s100 prescribers across NSW, especially outside inner city and inner western Sydney. Further discussion focused on the emerging need to ensure health promotion messages are appropriate within a broad mainstream wellbeing and health context to reach a mainstream audience.

POSITIVE SPEAKERS BUREAU INDUCTION TRAINING

After a long hiatus impacted by the 2020 COVID-19 pandemic and resulting lockdowns, Positive Life NSW conducted a Positive Speakers Bureau (PSB) Induction workshop over the weekend 16-17 March 2024. This NSW PSB Induction Workshop included four female speakers along with two male speakers. This particular induction group sees a strong spread of representation not only across genders and sexualities, but time of diagnosis and range of life experiences. Long-term PSB speaker, Peter Schlosser is volunteering in the office to logistically expand the reach of the NSW PSB, especially with the preparations for the NSW PSB 30th celebration this year.

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

I was a very ordinary suburban mum, two kids, the station wagon, and a dog. My husband, Tony and I were diagnosed with HIV on the same day.

I'd been in hospital with an undiagnosed illness in the last trimester of my second pregnancy. Tony was admitted to hospital with pneumonia, around the same time I gave birth. After I gave birth and returned home, I would return to the hospital to visit my husband. His pneumonia wasn't responding to treatment.

His infectious diseases specialist had been consulting with the doctors on my treatment, so when he saw me in the corridor with our then three-week-old baby, he asked, "What are you doing here?" I said, "I'm here to see my husband."

The next day when I visited Tony, he said, "I've been tested for HIV, and they want to test you as well." My immediate response was to laugh because I thought we were so far outside any possibility of having HIV.

Two days later, they came to us with the news that we were both HIV positive. Tony was diagnosed with an AIDS defining illness. He was so very ill. We were told he had four T-cells left and we were warned he was about to die. My newborn son's first Christmas was expected to be his last. The following year he developed mycobacterium avium complex (MAC) and was very ill again.

Our diagnosis was a shock wave to me, it just cut our lives off. Our lives completely changed. We'd made plans for our ordinary life. We weren't planning grandiose things. At the time, Tony was an economist, working for Foreign Affairs. He wanted to be a diplomat. We had plans to go overseas. We were talking about our children being educated overseas to pick up a second language. All of that possibility just got chopped off in that instant of our diagnosis. We had to recreate our lives from that moment.

The first thing my husband and I said to each other when we were given the diagnosis was

*"We're not going to blame each other.
There's no point in trying to say 'this was you' or 'this was me'.*

We don't know. We don't know. We'll never know."

For the next 18 years, we stayed together. We never, ever pointed the finger at each other. Even though we're no longer together, we're still friendly.

My immediate focus at the time obviously, was our two small children. Thankfully, after testing they were negative. The baby got quite a few viral illnesses in his first year because I didn't have enough immunity to pass on to him. He developed viral croup, while Tony was still in hospital with pneumonia.

So I found myself at home alone with a two-and-a-half year old and a 4-week-old baby, sitting on the bathroom floor crying, with a hot shower running to help my baby breathe. That was the start of feeling like I was in an 'isolation cell'.

Tony was in his own isolation. Between the two of us, we didn't really talk about it other than just our immediate medical needs. Once we got the new treatments, our health did settle down a lot.

While Tony stopped working, on the surface nothing changed in our lives. Nobody in our lives knew about the HIV, other than immediate family members.

My mother-in-law was great. She was someone who I could openly talk to about anything, however my family were more alarmed. While they were very concerned and supportive, it caused them so much distress that I couldn't discuss it with them. I definitely got the sense from my three siblings that they did not want me to talk about it. We didn't tell any extended family, we didn't tell any friends. My parents were so





concerned about anybody in their small rural community finding out, that I had to be super, super careful about what I said.

I can't remember how we explained why Tony wasn't working. I can't even remember that. I can't remember the lies we told people. That's how I felt, that I was lying.

I felt I was lying by non-admission, so I deliberately didn't make new friends, or even close friends. I've subconsciously pushed most of my friends away, because I felt every time I saw them, and didn't tell them something, in a way I was telling a lie, right? I had lots and lots of acquaintances. There were two people during that period who stuck with me, and just went along at my pace. They're still with me today and I feel I'm very lucky to have them.

I went back into the workforce fairly quickly. I had an opportunity to work with my then step father-in-law in setting up an antiques business. So I took that and did that for the next 14 years, until Tony and I separated and ultimately divorced.

Now as a working sole parent, nothing really changed for me. I was still in my isolation cell, with nobody knowing anything. I felt separated from the world, as if I was no longer a part of the world. I wasn't part of the world I was in before the diagnosis. That suburban mom of two, with the dog, the station wagon, and the husband. I was no longer part of that life. Something had happened to me, that made my view of that life completely different.

I wasn't part of a positive community either. We lived in Canberra at the time, but there wasn't any kind of group for heterosexual people with HIV then. It was all gay men. I didn't have a role in that community. There was no conversation with me, about me being a part of that community. I felt very isolated from them all.

For the first two years after my diagnosis, I was involved with a small women's group of five women. They were great. I was meeting with them regularly and I was seeing a counselor. However, those women moved away, or got sick and passed away, until I didn't have any contacts like me in that positive community.

The change came about when we decided to tell our children. The youngest would have been 12 or 13 years old. We'd been waiting until he was ready to start high school. Our older son would have been closer to 15 years old. We decided to tell them because we didn't want one of us to get sick and go into hospital, and they find out that way from strangers. We wanted to tell them ourselves.

We felt they had a level of maturity that they would be able to understand. So we prepared. We both got advice from my counsellor, we had educational materials, we'd really thought it out.

We sat down with them and told them. My oldest son said, "*So are you going to die?*"

We said "*no, no, no, we're both really healthy.*" They said 'okay', and got up and went to their rooms. After a short time, I saw my oldest son come out of his room, knock on his brother's door, and go into his room. They shut the door and I guess they had a conversation then. We were left sitting outside. So much for all the worry and prep!

We obviously continued to give them information whenever we had an opportunity. We told them, "*it's up to you who you tell. You need to be aware that not everyone is going to take it well. So be careful. But it is entirely up to you who you tell.*"

We didn't want to say to them, '*you can't tell anybody*'. So from that moment on, it changed for me and I felt I had less need to keep it hidden now.

I still didn't discuss it with my family, and I would never have said anything that would have hurt my parents.

Around six months later, my oldest son came out to us as gay. When I told my parents, my mother could only say, "*how could you say that about your own son?*" So from then until her death, things between us were closed.

The real openness for me came once both of my parents had died. I finally decided that's it. I was done keeping this hidden. This was 2017. That's when I decided,

'I don't need to keep this a secret anymore.

I can't hurt my children, I can't hurt my parents anymore.

My siblings are living their own lives, it won't have an impact on them.'

So I started to tell people who I wanted to be friends with. I told my nieces and nephews. They are just so adorable, and loving and supportive.

My sons are proud of me. They're proud of me for being an advocate whenever I can be. I told the two women who had kept with me and one of them immediately said, '*Oh! your life is so much more interesting than mine!*' Which is so not true! Bless her! She's had some struggles of her own.

I started sharing more of my life with my siblings, including a video of me talking about the isolation I had felt. It brought my brother and I closer together - he was very emotional and said he was sorry he wasn't there for me at the time. I feel very loved by my family.

So from that moment on, it changed. The other thing that changed was that I, around that time, turned 50.

In the very early days, someone had said to me, *you'll be lucky if you see 50*. Even though intellectually I knew the medication was better, and I've had an undetectable viral load for years, part of my subconscious was obviously still hanging on to that.

I turned 50, and I had nothing, my life was blank again. I hadn't planned past that point.

So I worked on finding out who I was now. That opened up my life to a whole lot more things. I went through a process of finding my voice, which had been quiet and silent for so long.

The biggest change was in 2022 when I moved to Sydney. Around this time I found Positive Life NSW, and found a community for me where I belonged - my tribe. Since then I have developed more confidence about reaching out and being part of other communities as well.

I'm completely out of the isolation cell. It's a completely different experience. I found so much grief, that I was holding inside me for so long.

After I did the Body Mapping workshop with Positive Life NSW, I took that back to my psychologist, and it gave us more of a direction to work towards. I went and did a heterosexual retreat in June 2023 with Positive Life NSW where I was at just the right point to move forward. I experienced a real emotional release and I spewed my grief out into the garden. Since that moment, I've been free of that guilt and grief.

All these positive changes are a kind of journey I'm on. I was at the right point in my life to take on that change that came along, and I'm still there. Still doing little changes. I feel new things are coming along. Yeah, so it's been a hugely beneficial thing.

If there's anything I could say to other women who might be diagnosed with HIV, I'd say get in touch with an organisation, straight away. Straight away.

The internet has made things much easier to find things. There is a community out there that you can find. I feel it's very important to connect with peers living with HIV. Then it's a shared experience.

Even if you don't think that you need support. Even if you're only dipping in and out, or you just talk to someone on the phone occasionally, or attend a Zoom meeting, or just read something in a magazine or on the internet, keep in touch with a community. There'll be a point when you're ready to engage.

There's nothing like being with your own community of people.

I'd say that's for any circumstance. One of the biggest mistakes I made in my life was when I had a stillborn daughter between my two boys. I didn't go to support groups, I didn't look for support. I felt like I didn't want to sit in a room full of people talking about their grief. But that was the biggest mistake I made. It's contributed to me holding all this stuff in. I realise now what a benefit that could have been for me at the time.

It's important to find people who share your experiences, and who know they don't know everything, because we're all different.

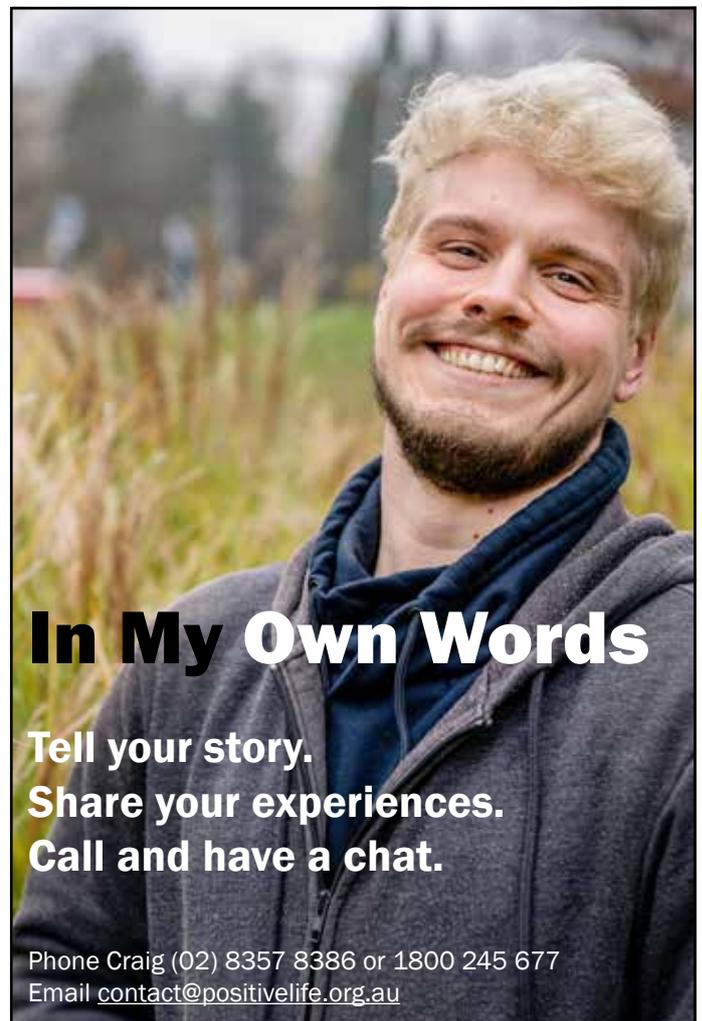
Even though their journey is different, you can sit down and understand each other in a way that people who haven't got your experience will never be able to understand, no matter how many people they've talked to, or how much they've read or studied, it will never be the same.

That's what makes Positive Life NSW so effective and relevant. Knowing that everyone involved is living the same life as you.

There's a freedom in that.

- Alice

Editor's Note: Today Alice is a speaker with the Positive Life NSW, Positive Speakers Bureau (PSB) and sharing her story of missed HIV diagnosis, coming to terms with living with HIV, resilience and strength with audiences throughout NSW.



In My Own Words

**Tell your story.
Share your experiences.
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Phone Craig (02) 8357 8386 or 1800 245 677
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#54



Positive Life
NSW



IT
STARTS
WITH
NSW
M

This year when I saw the email about the Mardi Gras Parade, I didn't hesitate to sign up. This would be my second time walking in the Parade. The thought of walking with Positive Life NSW again, made me happy and being that the previous year I had an awesome time, meeting new people and feeling so much joy and pride. I wanted that feeling again.

My family were going to walk with me but they had to pull out at the last minute, so I felt like I may be alone. Walking into the office where we all met, took away the feeling, as I saw many people who walked last year and we got to chat.

After getting my make up done, we all lined up to start walking to Hyde Park. The walk was short and fun. By fun, I mean the cars passing by were waving at us, we heard chants of happiness and I saw beautiful costumes on other people coming to the parade.

Once we were at our starting spot on Liverpool street, I saw our beautiful float with the flags, lights and music. We had a short wait before walking, and in that time I spoke to many other people who were walking in the parade. I heard their stories and shared an immense amount of excitement regarding the march we were about to do.

When the time came to start getting ready to walk, I was preparing to hold one of the signs we have or simply just march with the rest of the participants behind the truck.

I was approached by our Board President at Positive Life NSW, telling me I have been chosen to hold the banner that introduced our float. Naturally I freaked out and got nervous, as it meant I would be at the front of the float. I accepted the challenge, and for a moment I had all these emotions and thoughts running through my head, as well as thoughts of all the hats I wear at Positive Life NSW and how to represent each hat with pride.

The first hat was as a member walking in the parade. I thought about how wonderful it is to walk with these lovely people who gain a great deal of support from Pos Life, and showing the world so very publicly how proud I am to be apart of this organisation.

The other hat I thought of was my Board Director's hat and what that means to me marching in the parade, where people are watching me to see my reactions, and my emotions. I thought about my reasons for being on the Positive Life NSW Board. What an opportunity it is going to be marching at the front of our float, and putting into practice my goal of connecting with women, black women, women of all races, women no matter what their pronoun preferences are, people of colour, and those from culturally and linguistically diverse

communities. Then I thought about my other hat, as a Positive Speakers Bureau speaker and that meant I'm actually walking the talk, as many times I talk about my pride in Positive Life NSW, my pride in my community and my personal pride.

Having the moment to stop and think about all these hats and emotions, I felt so much joy. My nervous feeling of walking out front went away. I grabbed the banner which had our name on it and number, and walked to the front of the float. I saw Jane and Andy sitting in the truck and their smiles of support and pride gave me so much confidence. I had a pep talk with the Board President again. He also encouraged me and guided me through what I would need to do.

When the time came to walk, I felt the most overwhelming feeling of happiness. It was a beautiful feeling. As we walked, I held our banner high and waved to the crowd, many times connecting with women and people of colour. I heard them yelling out to me things like "go sister", "we see you", "beautiful". The most touching comments were "thank you". I remember making eye contact with what I thought was a group of ladies of colour, and they yelled out "thank you sister, we love you"! I yelled those same words back and waved and also teared up, as I felt like I was representing them!

They are me. I am them. I am a black heterosexual woman walking in a parade that some may think my culturally and linguistically diverse community don't always agree with. With me walking would hopefully make a difference to others watching. My feeling of connection with my community was amazing, and I got to do it that night. What a powerful statement I was making, holding our banner with so much pride and dignity.

The Parade was filled with colour, love, lights, joy, pride, people from all walks of life. I firmly believe there were people who needed to see a black woman introducing a float, and not just any float, a float representing an organisation that supports all people living with HIV.

I felt very honoured to be in my position, and I am very grateful to be walking alongside heterosexual women, heterosexual men, lesbian women, gay men, transgender women and men, and at the end of the day were all just people who gathered to march at this amazing event. We all had a fab time connecting with others in what ever that meant to us individually.

Thank you Positive Life for choosing me, a mum, a sister, a daughter, a friend, a co-worker, a director, a speaker to introduce our float to Australia and the world.

- Melissa Carolus





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.

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02 8357 8386 or 1800 245 677 (freecall)

Positive Life NSW



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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

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www.positivelife.org.au

Queer Meditation & Social

Greetings Talkabout readers,
I am Philippe, an active member of Positive Life NSW, and also the Chair of Queer Meditation & Social; Sydney's only (or at least I think we are) inclusive meditation group that's been creating community and mindfulness non-stop for 17 years and counting.

Like many others living with HIV, I've faced my fair share of anxieties and stress. Life's challenges can often feel overwhelming, and the weight of stigma can be particularly burdensome. However, the discovery of Queer Meditation & Social four years ago became a turning point for me, opening doors to new friendships and connections that have become invaluable sources of support.

Meditation, with its regular practice, has been a beacon of tranquillity in my life. The group doesn't adhere to a specific method; rather, it's a diverse journey where each week brings a fresh perspective with someone else guiding us through the meditation. We gather in person **every Monday evening at 6.30pm at the Darlinghurst Community Space** and welcome everyone, regardless of gender or sexual orientation.

Our group is a testament to inclusivity; we embrace all, recognising that each person's journey is unique. Whether you're an absolute beginner or an experienced meditator, Queer Meditation & Social opens its arms wide to create a safe and nurturing space for all.

We're not just about meditation, but also actively strive to create an environment where you can create connections. That's why, after our weekly meditation sessions, we gather at the **Lord Roberts Hotel, 64 Stanley Street, Darlinghurst**, for a drink and/or meal. It's a time to share stories, laughter, and build bonds that extend beyond the meditation cushion.

Queer Meditation & Social operates as a non-funded charity, relying on the generosity of our participants. We kindly ask for a small donation to support our mission of creating a space that fosters well-being and community.

In the lead up to the annual Sydney Candlelight Memorial, which will be held on **the third Sunday in May at The Eternity Playhouse, 39 Burton Street, Darlinghurst**, we will have a very special session on **Monday 13th of May**. We will be honoured to have The Sisters of Perpetual Indulgence - Sydney House lead us in a moment of mindfulness and remembrance for those in our community who have passed away from HIV/AIDS. All donations from this evening will directly contribute to Positive Life NSW, dedicated to supporting those living with HIV.

Join us on this incredible journey of connection, mindfulness, and support. Queer Meditation & Social is more than a meditation group; it's a community that supports the power of unity and shared experiences.

Wishing you peace, connection, and love,

— Philippe Smets

When: Monday 13 May at 6.30pm
(we start at 6.45pm sharp)

Where: Darlinghurst Community Space,
277 Bourke Street (entrance on the
side in Liverpool Lane), Darlinghurst

Donations: cash, PayPal or card payments on
the night

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KARUMAH

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

Mention a government service to me, and I start whimpering...tears are close to flowing... followed by a string of expletives.

To say I have developed a phobia about government services is an understatement. I would rather have my nails pulled out...less pain would be involved!

It's not as if this is a recent frustration...it's been ongoing over the decades. Now that I've arrived at my three score and ten years, my tolerance for this bureaucratic nightmare is at an all time low.

Who remembers the old Centrelink of the 80s and 90s, tied into the CES (Commonwealth Employment Service) with their job boards!

Every week (or fortnight...I can't remember) we had to trot into a Centrelink office to hand in our forms to say we'd been searching for work. Of course, we crossed our fingers that they wouldn't choose our form to check up on the submitted details. I was thankful for a mate I had who worked in our local office. Yes, he did oil the wheels.

When I finally had to leave the workforce in 1993, ACON had an advocate ...Fred Oberg...who did all the dirty work for us, both getting onto the disability pension, and applying for the housing subsidy for those of us in private rental.

All the same, we still had to have occasional interactions with the relevant government departments, and for some unknown reason it was inevitable that SOMETHING wouldn't have been done by the book, and your single visit turned into three, with you trailing sheafs of paperwork that must have kept somebody in the job.

Then there was the Dental Hospital...when they finally realised many of us were losing our teeth, thanks to candida. Back in the day, the receptionists had to be the crankiest people I have ever encountered! Once you got in...no easy feat...they yanked all your teeth out.

Then they made you dentures. My first set...I'd love to know what photo they used ...had teeth so big I looked like Bugs Bunny. I thanked them profusely... and used a BGF subsidy to get a set from a private dental clinic.

Now that I've survived AIDS...I thought naïvely that my battles were over!

Then I encountered the new, cleverly disguised, Housing Bureaucracy. Having tried ringing Centrelink, Housing, and My Aged Care, to hear:

"Your call is important to us. Your place in line is...257...please don't hang up.

We are experiencing a higher than usual number of calls...a consultant will be with you shortly Here is some music while you wait",

so I decided to apply online.

Wrong choice!

Not only is it extremely time-consuming, and frustrating including time outs...it enjoys...(I'm pretty sure of that terminology)...taking you in circles.

You've gone to the trouble to have a medical assessment form filled out by your GP. You upload all the documentation they request. You submit it!

Within minutes, you get an email saying they need more documents for, say, your medical evidence. You think...I've already submitted this...so you resubmit the documents you have already submitted. Then another email saying they require more documents than you have submitted.

I got so frustrated by this stage that I contacted the then Housing Officer at Positive Life NSW, and begged for help before I had a total meltdown. They got me through the process.

Now...My Aged Care! The web site finally tipped me over the edge. There's page after page of information...each page with a dozen links...you click on a link and instead of just being given the information you need you get...another dozen links...which leads to...yet another dozen links.

The lists of providers for those lucky enough to get the highly prized client number, is staggering, and you are left on your own to sort the good from the bad, knowing that...at the end of the day...they are all really after the government subsidy cash.

How much subsidy you get depends on which of four categories you end up in when assessed. It seems that no single provider will deliver all the services you need, so you could end up having two or three providers to have all your requirements covered.

I just went through and picked four who didn't appear to be attached to a religious body. When my sanity finally returns, I'll check them out more thoroughly.

It's time the government learnt that at seventy...I'm old!...I'm cranky!...I'm impatient!...and I just want information in a form I can digest easily...and *please* don't keep me waiting on phones!

- Tim Alderman

All people living with HIV across NSW are invited to get in touch for support from someone else living with HIV (peer navigator). Call us (02) 8357 8386, 1800 245 677 (freecall in NSW) or email on contact@positivelife.org.au





Having a pet can enrich our lives, uplift our spirits and improve our emotional well-being. It has been said pets can also reduce feelings of loneliness and alleviate stress, anxiety and depression.

Having a pet can also be a big commitment, so when I started thinking about getting a pet, it was a big decision for me to think what kind of pet I would get?

After much deliberation I decided to get a dog. There were so many aspects to consider.

Would I be moving in the near future? – It may mean less options for accommodation.

Could I afford it? – some dogs can eat a lot and then there would be vet bills.

Would it restrict going out or going away? - dogs cannot stay for excessive amounts of time on their own.

Did I really want to walk a dog every day for the rest of its life? - That's a really long time.

After carefully weighing up my options I made the decision to get a Maltese Shih-tzu cross, who I named Molly. She has changed my life.

Molly wakes up happy every single morning, filled with excitement and she lives in the present moment. It has encouraged me to live my own life more in the present rather than regretting the past or worrying about the future. Molly also never wants for much, just the necessities.

Molly gives me a sense of purpose by caring for her and in return she offers loyalty, companionship, and dependability. She is always by my side and I take her wherever I can.

I'm surprised actually by the number of establishments that welcome dogs from cafés to motels. Living near the sea also means there are many beaches and walkways where I can walk Molly.

We have had our challenges though. Mainly, I think, because not having owned a puppy before my expectations were quite different to reality.

I thought I could take Molly along to a dog training group and I would have the most perfect, obedient dog! Instead, Molly was a very mischievous and curious puppy, who loved to get into everything; stealing my socks and chewing anything plastic were her favourite things to do!

Now that Molly is two years old and we have had training, and kept some objects out of temptation, she is a more relaxed dog.

Molly is a very sociable dog, Taking Molly for walks means I get out in the fresh air, rather than just relying on my car to get places and increases my physical activity. It really is so much more fun.

The neighbours stop and chat with me, which they had never done before and I tend to see the same dog parents walking their dogs at about the same time as myself, so we also have a chat.

Other people who are out and about also love to say hello and give Molly a pat. Our walks are never rushed and it feels good to have friendly interactions with other people and other dogs along the way.

Molly is a great companion; I would even say my best friend. She really has changed my life.

– Kim

PAWS AND RECOVER

Paws and Recover is a registered Not For Profit Organisation that is an infrastructure of volunteers who support people by sharing the care of their pets during a health crisis and difficult times. Paws and Recover offers volunteer respite pet care through fostering in a home environment, transporting pets to the vet and support in assisting people care for their pets in times of crisis.

The service is available to those who are unable to care for their pet. Situations may include people who have been hospitalised, escaping domestic violence, have a disability, aged or frail. Services offered are dependent on availability of volunteers and the ability for Paws and Recover to intake the animal.

MORE INFORMATION: www.pawsandrecover.com

HIV IN MY BACKYARD? OR BEDROOM?

Today we celebrate and honor the lives of all women living with HIV with our friends and supporters at this annual National Day of Women living with HIV! with our theme today - Yes Women get HIV TOO!

For those of you who don't know me. I'm Frances, I'm a 65 year-old heterosexual woman and I've been living with HIV for 20 years. And I'm embracing my positive life.

As a single mum I raised three daughters, now 45, 44 and 30 and I have seven grandchildren. I'm on the Board of Positive Life NSW. I'm a peer support for women living with HIV in the Hunter-New England region based in Newcastle, NSW. I'm a beauty therapist of 25 years, a nurse before children, a business owner, and operator of a home beauty salon in Cooks Hill, Newcastle. My number one theme song of all time is Helen Reddys'...*I am Women. I am strong, I am invincible!*

In 2004 at 45 years of age, I was diagnosed with HIV...

My world as I knew it stopped as I heard the words, you have tested positive for HIV...You know, I NEVER expected a HIV diagnosis.

- 1 it could never happen to me
- 2 how could I be at risk for HIV?
- 3 and certainly not in my backyard!

Yes, today, I'm here to tell you - all of you wonderful women that women get HIV too. This my story.

At 45 I was living my absolute best life. A single mum, out on the town with my girlfriends, partying, dancing, drinking and having great sex! What's not to love about your naughty 40s!

I was in my prime. Yes and looking back grinning, I was always going to be that girl dancing on the bar at The Star hotel in my late teens (if my knees hold out!) that is. My girlfriends always laughing, called me the condom queen, always handing condoms out at the end of night as they exited with a potential.

So, how did this happen to me? Well..! I met this exotic looking guy on the dance floor at The Exchange, the local 'it' Hotel in Newcastle. End of night, back to my place.

I had the responsible sex and condom conversation before sex. Raising three daughters, it was always an open discussion! We all practiced safe sex with regular testing.

I told him I'd had my STI testing recently. Including an HIV test. ALL NEGATIVE! He assured me he

had too, so all good to go. Then a month later he rang to tell me I needed to get tested for HIV.

I was stunned and speechless.

WHAT!! WHAT THE...

WHAT do you mean?

We had had the conversation...

We'd even mentioned HIV. WHAT?

He told me he had tested positive for HIV and admitted to being notified several times earlier that he was a contact of someone diagnosed with HIV. Again WHAT THE??

It wasn't the only lie he told me. I thought I was in a monogamous relationship. I found out he was much more sexually active. There were other women and men. Needless to say that was the end of our short six month relationship!

I felt sick, numb, shocked and scared, filled with disbelief, fearful and apprehensive. How could this happen to me? HIV...isn't that a gay man thing? or men who have sex with men?

I'd never heard of, or knew of another woman with HIV or any men, for that matter, where I lived.

I felt scared and apprehensive about my future. I worked in a skin penetration area of beauty, and I remember thinking thank God I had had my children! I thought I'd never be able to have a sexual relationship with a man again. I felt my freedom of choice had just been taken away from me.

The three people I confided in at the time then betrayed my confidence, outed me, shattering my employment, family and social worlds. I was yet to know my rights.

I was so alone in the HIV world...Scared, I hid in isolation, me and HIV. The threats, stigma, discrimination and rejection all hidden away. Small country towns can be brutal.

I was fortunate to be diagnosed early in 2004 and I started treatment in 2008. Sure, the medications were a little rough back then. They're amazing now. Sticking to my medication, and taking it as prescribed has been my key to living a healthy, positive life with HIV.

Today, I **CAN'T** transmit HIV to a sexual partner.

In case, I need to say it again.

Thanks to medication, I **CANNOT** give HIV to anyone else, no matter how much sex I have.

For 10 years I lived hidden in fear, till I couldn't any longer. I had the classic teary meltdown, probably more like a volcanic eruption! stirred with a dash of perimenopause, with my Immunologist and it ALL came crashing down. He directed me straight to the Social Worker, thank you, which coincided with a Positive Heterosexual Retreat. It was the first time I had met or knew of another woman that was HIV positive!

I thought I was alone. I cried the entire weekend. A release and relief.....And then came the realisation - I was not alone! This was life changing for me.

Then I met Jane Costello, the now CEO of Positive Life NSW, who gave a talk to a small group of regional positive women and the rest is me standing here today.

You Jane, and Positive Life opened my life to the endless possibilities of living positive, while being positive. The friendships I've made are fulfilling, rewarding and life lasting. The knowledge I've gained is powerful. The encouragement, significant and meaningful. The encouragement to come out of hiding to be a strong advocate for women living with HIV to be acknowledged, seen and heard. Thank you! I'd like to acknowledge the tireless work of Positive Life NSW. From the CEO Jane Costello, to my colleagues and friends on the Board, the staff and volunteers, you significantly enrich my life.

It was exciting to hear our messaging of inclusion for all on national television the other night where we featured prominently in the Sydney Mardi Gras Parade with commentary by Courtney Act. As a positive woman I felt valued, significant and heard.

HIV awareness is extremely low among women in Australia. Women have a false sense of security about HIV. Today, sadly we have a slowly rising number of women diagnosed late with HIV. Women who have lived with HIV for many years without knowing it. Being told by health professionals we don't fit the demographic

Positive people come in all different shapes and colours, AND we are united

by our shared experience of living with HIV. While our stories differ, we share common themes of diagnosis, trauma, rejection, and stigma.

On this National Day of Women Living with HIV, I want to acknowledge our unique challenges as women living with HIV. I want my friends, supporters and allies to know about the stigma and barriers we women living with HIV face in Australia.

On this day, I want to call for more equality in healthcare. We MUST reduce the barriers to appropriate testing and treatment for women. Together, we MUST make HIV-related stigma in our communities a thing of the past.

Most importantly, today, together let's celebrate our courage, our resilience, and our achievements as women, whether we live with HIV or not.

Let today be the day, that together we highlight the need for all women, especially those of us who are sexually active, to include an HIV test in your regular health check-ups!

If the test turns out negative - that's fabulous.. Keep testing. If the test turns out positive - start medication as soon as possible and yes - life will go on!

It's time all of us knew our HIV status. Not a guess Not a hope Not a probably.

HIV did happen to me. And to many of us in this room today. I never thought HIV could happen to me. I never thought I was at risk of HIV and I certainly never thought HIV was in my backyard!.... And certainly not in my bedroom!

I'm Frances, I'm a Mum, a Sister, I'm a Granny, a beauty therapist and business owner. I'm a Board Director...and a healthy happy woman living with HIV. I'm living my best life.

Thankyou

Delivered as a speech by Frances Parker on 9 March 2024, at the 2024 National Day of Women living with HIV in Sydney, NSW.

APRIL

- 16 **The Men's Room Online 6.30pm**
For all heterosexual men living with HIV
- 16 **The Women's Room Online 6.30pm**
For all women living with HIV under 45 years of age
- 23 **Digital Mentors Sydney 12pm**
For all people living with HIV
- 30 **Positive Conversations Online 6pm**
For all people living with HIV
- 2 **Tai Chi Sydney 8am**
For all people living with HIV



MAY

- 3 **Social Club Sydney 6pm**
For all heterosexual people living with HIV
- 5 **[+Connect] Parramatta**
For all people living with HIV, our partners, friends and family
- 16 **Tai Chi Sydney 8am**
For all people living with HIV
- 19 **Sydney Candlelight Memorial Sydney**
- 21 **Digital Mentors Sydney 12pm**
For all people living with HIV
- 21 **For Women Online 6.30pm**
For all women living with HIV over 45 years of age
- 23 **In The Know Parramatta 6pm**
For all people living with HIV
- 28 **Positive Conversations Online 6pm**
For all people living with HIV
- 30 **Tai Chi Sydney 8am**
For all people living with HIV



JUNE

- 1 **More than a patient Sydney 10am**
For all people living with HIV
- 7 **Social Club Sydney 6pm**
For all heterosexual people living with HIV
- 12 **Peer2Peer Sydney 6pm**
For all gay and bisexual men living with HIV
- 13 **Tai Chi Sydney 8am**
For all people living with HIV
- 16 **[+Connect] Liverpool**
For all people living with HIV, our partners, friends and family
- 18 **The Women's Room Online 6.30pm**
For all women living with HIV under 45 years of age
- 18 **The Men's Room Online 6.30pm**
For all heterosexual men living with HIV
- 23 **TORQUE Sydney**
For all heterosexual and bisexual people living with HIV
- 25 **Positive Conversations Online 6pm**
For all people living with HIV



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



The National Day of Women Living with HIV is held on 9 March each year to celebrate all women including cis women and transgendered women.

It also recognises the courage, resilience and strength all women living with HIV have. Everybody is encouraged to host or take part in a morning or afternoon tea to further raise awareness of women living with HIV.

The theme this year ‘Yes, women get HIV too.’ is timely and relevant as it highlights the manner in which many women living with HIV can feel invisible and ‘hidden in plain sight’. Promoting the message ‘Yes, women get HIV too.’ can help lay to rest the misconception from many in the general community and still even some health care providers, consider on only certain groups of society are at risk of HIV, such as gay men. This in turn may encourage women to seek out testing, treatment and support. Knowing our own HIV status can reduce the impact and improve the health of women all around the world.

Positive Life NSW hosted a high tea in the afternoon at PHIVE, a new event centre in Parramatta, which had such a welcoming vibe. Jane Costello CEO introduced Bruce Gale, a local Dharug Elder who began proceedings with an Acknowledgement of Country.

Several speakers followed, each touching on the theme of the day; ‘Yes, women get HIV too’. Frances Parker shared her inspiring personal story of how she never thought she would get HIV because she’d done all the right things. Nicole Oliviera spoke out about her personal story also, and the challenges she faced when she came to Australia. Both Frances’ and Nicole’s lives changed so dramatically after being diagnosed with HIV, but this also gave them strength and the determination to become the empowered women they are today.

The next speaker was Jade, a social worker from South West Sydney Local Health District. She spoke about the unique challenges faced by women living with HIV. And Dr Melissa Kelly, an HIV clinician from the Albion Centre, spoke about some of the specific needs that some women living with HIV have, including pregnancy, menopause and aging.

At the end of the afternoon tea, there was the successful ‘bring and swap’ clothing exchange. Those who wished to participate had brought along three items and received tokens which could then be used to select three items to take away with them.

Celebrating the National Day of Women living with HIV with a morning or afternoon tea is quite special. It brings together women living with HIV and their allies and it raises awareness that women get HIV too. It also demonstrates that through their strength and resilience, women living with HIV inspire and empower others to live their best lives, regardless of their HIV status.

– Kim

If you’re a woman living with HIV, talking with another woman living with HIV in similar shoes offers one of the fastest ways to feel better and find solutions to live well with HIV. Get in touch with Positive Life NSW on (02) 8357 8386 or 1800 245 677 or email contact@positivelife.org.au

YES, WOMEN GET HIV TOO!

MEDICAL CANNABIS

Originally, to manage my pain, my doctor suggested consuming cannabis through baked goods to avoid the potential downsides of smoking and the fact that cooking destroys the moulds and fungi in the raw product. I tried eating cookies baked with green butter. While they did offer me some pain relief, I found them overwhelming at times and they gave me the munchies.

About two years ago, I had to change to a new doctor for various reasons. After a friend told me about medical marijuana and the benefits he got from it, I decided to talk to my doctor about it. He was very supportive and informed on the beneficial effects of medical marijuana on the treatment of chronic pain. He had no problem prescribing it for me for my pain management.

He handled all the necessary paperwork, and within a week, I obtained a prescription. Following his recommendation, I visited a local pharmacy, where the staff treated me with professionalism and no judgement.

The pharmacy staff provided excellent guidance, and I followed a routine of spraying the inside of my mouth twice a day. Although the taste was somewhat earthy, I didn't experience any intoxicating effects.

Instead, I felt more comfortable and relaxed, with no noticeable side effects or cravings for food. After a few months of consistent use, I observed a significant reduction in my pain levels, which greatly pleased me despite the substantial cost exceeding \$100.

I'm now on a new oil formulation, which is administered through drops under the tongue. It retains the familiar grassy taste and is much simpler to use compared to the spray version. With the oil I don't get stoned, and I am able to go to work and concentrate fully with no bad side effects, like paranoia or feeling tired or hungry.

I've also noticed a big reduction in my depression and anxiety since using the liquid. I still get depressive episodes, but they are fewer and less intense in nature, and are a lot easier to control. This may be the placebo effect, or of just feeling a bit more relaxed from the oil, but I know I am more outgoing and at ease in social situations now.

— Peter McGrath



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The voice of all people living with HIV

Positive Life NSW



The voice of all people living with HIV

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Advocacy + Policy

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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**
