

talkabout

where we speak for ourselves

#200 | December 2021 | ISSN 1034 0866 | Positive Life NSW – the voice of all people living with HIV since 1988

INSIDE

When I contracted COVID-19

Part 2: Peers in conversation with GNP+

The right to die: a daughter's perspective

PHOTOGRAPHS: 2021 World AIDS Day

Positive  Life NSW

The voice of all people living with HIV

Letters to the Editor

Your messages, comments, thoughts and opinions are welcome here. Letters should short (be less than 200 words) and may be edited. All letters to be considered for publication must have a name, street address, and phone number for verification. Please specify if you want your details withheld from publication.

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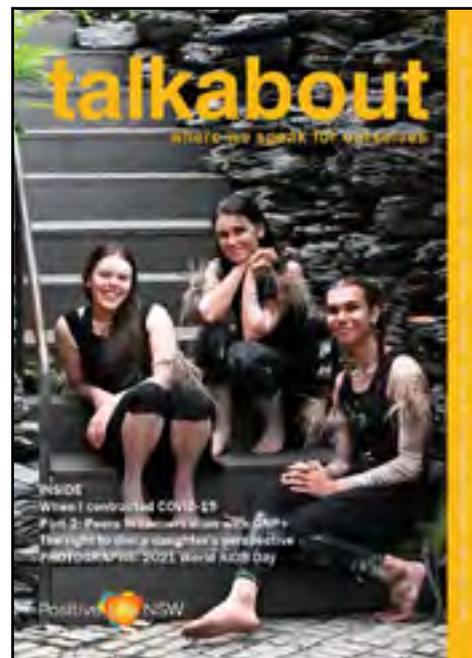
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Cover photo: Wagana Aboriginal Dancers at the World AIDS Day event co-hosted by Positive Life NSW and BGF.

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talkabout

Where we speak for ourselves

features

- 5** **When I contracted COVID-19**
Benny's experience with HIV and COVID-19
- 12** **Recipe**
Turkey & Tomato Toast with salsa verde
- 13** **Talkabout 2021 Evaluation Survey**
Summary report
- 16** **Michael and Phillis**
A love story (of sorts)
- 18** **Red Ribbons**
Some history of the red ribbon
- 20** **The Right to Die**
A daughter's perspective
- 22** **STI Data Report 2020**
Some early effects of the COVID-19 pandemic
- 23** **Peers in Conversation Part 2**
GNP+ talking with Positive Life NSW
- 26** **2021 World AIDS Day Event**
Community photographs
- 28** **In My Own Words**
Garry Wotherspoon

regulars

- 5** **In the Loop - President** Robert Agati
- CEO Jane Costello
- 10** **Talkshop**
- 11** **Nutrition Bites**
- 14** **Money Talks**
- 31** **Positive Life Membership/Subscription Form**

advertisers

- 4** Positive Life Ageing Support
- 4** Positive Life Aboriginal Health Program
- 9** HALC
- 9** Letters to the Editor
- 9** In My Own Words
- 14** Unusual Risks
- 15** Pozhet
- 19** HIV Futures 10
- 19** In My Own Words
- 19** Peers Connect Online!
- 19** The Women's Room
- 30** MHAHS



The voice of all people living with HIV



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

Contact Positive Life NSW on (02) 9206 2177 or 1800 245 677 (freecall)
www.positivelife.org.au peernav@positivelife.org.au



If you are an Aboriginal or Torres Strait Islander person and live with HIV, you're invited to have a yarn with Michelle Tobin, the Positive Life Aboriginal Health Program Officer about what makes a culturally-safe model to support Indigenous people across NSW on telephone (02) 9206 2177, 1800 245 677 (freecall) or email contact@positivelife.org.au



PRESIDENT

As 2021 draws to a close, I hope you've enjoyed reading this year's editions of Talkabout as much as I have. We've heard from a number of our members who are pleased to receive the magazine in print format once again, many of whom feel their connection with the wider body positive has been revived.

Unlike many of our members living in the inner city who are more closely supported by their like-minded allies, more than a quarter of our membership are not as online connected, especially in regional towns and across country NSW. The best news is that Positive Life has seen a jump in membership this year, many of whom are heterosexual people living with HIV. Welcome!

I believe we have a responsibility to continue targeted and nuanced efforts, operating from a position of equity as we reach out to people beyond our comfort zone. We must continue to ask 'Who are we leaving behind?' How do privilege and access play into this question, and more to the point what can Positive Life do to connect and engage with not only the broader HIV community but also with under-represented groups on the emerging needs of all people living with HIV across the state.

Happy holidays!!

ROBERT AGATI

CHIEF EXECUTIVE OFFICER

As this edition of Talkabout goes to press, we have just held a COVID-safe World AIDS Day event at the Chinese Gardens of Friendship. I am a great believer in the value of history in that by studying our past and telling those stories we contribute not only to our sense of belonging, but to our shared future. Our experiences have shaped our identities, engaged us as a community, inspired great leaders on whose shoulders we stand, and have taught us to think critically and creatively about what living with HIV means. We must ensure that for younger generations this history is not erased or forgotten as the lessons from it are just as pertinent today as they were then.

If we are to confront the challenges of stigma and discrimination we must as a community continue to build on our connections with others and our shared humanity. We must reject the divisive, toxic and polarising societal divisions that have been so at the fore and magnified by both the HIV and COVID viruses. The isolation of COVID lockdowns has contributed to an atmosphere of anger, pettiness and blame. We must urge people to practice compassion toward each other and embrace an ethos of kindness. To quote two renowned epidemiologists and global health leaders, Drs William Foege and Robert Kim-Farley, "public health might be the greatest measure of kindness – the greatest measure of how to treat each other. Public health is 'science with a moral compass.' Public health, as it seeks social justice and protects and serves the most vulnerable in our communities, is putting kindness into concrete societal action."

Wishing you a safe, kind and happy holiday season.

JANE COSTELLO



When I contracted COVID-19

Four years ago, at the age of 27, Benny was called to come back and chat with a social worker after having his usual routine testing for sexually transmitted infections (STIs). Finding out that he'd tested positive to HIV shook his world.

"At the time I thought it was a bit of a death sentence," remembers Benny. "I was very uneducated about it." He clearly remembers the news clouding his ability to absorb extra details.

"I could only take in about 60% of what they said, because it was a huge shock," he said. "It turned things upside down; I remember a couple of weeks before, I'd had this flu, where I lost heaps of weight, couldn't eat, couldn't operate. I thought it was a bit of depression as well."

Benny started HIV antiretrovirals shortly after. "When I first started taking it [HIV medication] I was able to sleep; I hadn't been able to sleep for twelve or fourteen hours in a very long time."

He recalls this time as a difficult time of adjustment. "I found it very hard to function because I had no self-esteem; I was just gutted. I had in my head that I couldn't do this, I couldn't do that. There's a huge stigma. That was one of the elements of me going into rehab."

After coming out of rehab, and some changes to his HIV medication, which took him around four to six weeks to get used to, he incorporated the regular medication into his routine, and life went on.

In August 2021, Benny was in COVID lockdown. Living in a Local Government Area of concern and not permitted

to work, he was eager to get back to his usual employment in construction. As soon as he heard the NSW Premier announce that workers who "get the jab" could return to work, Benny fronted up to his local pharmacy to get the first of two COVID-19 vaccines. "My work's policy was that you had to have the jab in order to go to work; I was like, okay sweet."

As part of his return to work, as he says, "I gotta get the jab, gotta get a test."

He returned home after the COVID-19 test. It was then that the sweating started. "I remember saying, I've gotta go to bed. I thought I'd just grab a short nap. I slept for about sixteen hours."

He woke to a phone full of missed calls and messages. Still somewhat confused in a sleep-filled haze looking through these, the phone rang. "I answered," he said. "It was the contract tracers telling me I'd tested positive to COVID."

By this time, he hardly needed to be told something was very wrong. Benny felt terrible. "It wasn't just one symptom at a time," he says. "I had a high fever, and [I felt] like I was freezing. Then I'd be hot, and I'd be cold, and I had a cough." His symptoms worsened.

Four days later, Benny called the ambulance. He recalls "when the paramedics rocked up, I walked downstairs from my place out to the front of the ambulance, I had to sit down, and she [one of the paramedics] looks at me and I was like I just [got] out of the shower. I was that wet. She's like 'oh whoa!' The sweat just rolled off me."

He noticed another symptom had started. "I don't know if you had a skateboard or a BMX as a kid and you scraped your knees. That's what my lungs felt like. When I told the paramedics this, they said, you need to go to hospital."

Benny also started realising his memory seemed affected. "Another symptom of COVID is mental fog; you'll be going to pick up a book off the shelf but you forget what you're doing. That kept progressing."

After he was admitted to hospital, Benny was on a COVID ward for six days. It was here the gravity of his situation really started to sink in. "At this point, all your health care is taken out of your hands. All you can pretty much do is go to the bathroom."

After six days, Benny was transferred to Special Health Accommodation because he was unable to return home. His flatmate had contracted COVID as well. Now in isolation, Benny says, "I started to notice that the symptoms weren't in sequence [any more], I started getting really strong single symptoms."

By this time, he hardly needed to be told something was very wrong. Benny felt terrible.



In Special Accommodation, he noticed how much physical muscle loss he had. He recalled, “My calves were bigger than my quads!” Isolated from everything, he reflected “It’s not a great experience. Fatigue. You can’t engage, whether it’s muscular or mentally.”

“I also had trouble breathing. It’s like someone’s giving you a bear hug, kind of like being winded, but [the air’s] not getting in there. I knew it was serious. At the same

time, I’m trying to keep as positive as possible. It doesn’t really help when you go to the hospital. You find out how quickly other people deteriorate.”

While he’d started with medication and oxygen, Benny was fortunate enough not to need ventilation. His clinical team told him that COVID had affected his heart more than his lungs, “so they were putting me on heart medication [but] it was exacerbating the situation. One of the side effects of me having COVID is an

elevated heart rate. But that slowly [went away], so now it’s not as strong.”

Eventually after four and a half weeks in isolation, Benny was discharged home to slowly regain his health and strength.

“Once I got out [of hospital], I knew straight away I wasn’t able to work, purely because of the state of my body, and also mentally. When I got home, I took it really easy and I slowly started going for walks. I was [able to do] about fifteen percent of what I was doing before and I was cracking up a sweat.”

After about two and half weeks, he was cleared to return to work.

“I did a shift back at work. They started me off on the machine and then they slowly worked me into it. A lot of the sites in the city require a mandatory COVID test in order to gain entry to the site. I couldn’t provide that because if I get tested, I’ll come up positive. Now that I’ve actually been reinstated back into work as of today, I’m really happy about that.”

It was back in the workplace, that Benny started to become aware of a familiar challenge: stigma.

As a person living with HIV, Benny had felt his fair share of HIV stigma and discrimination. “Through going to work, I’ve noticed stigma, as in people don’t want you around,

people don’t want to talk to you. You get the stigma. And it’s really driving me up the wall. People will try and stand back when they talk to you.

“There’s people who are really open minded, they’re all right with it. Then there are individuals who are close minded. When people choose not to be educated on this topic, it’s like talking to a brick wall. And there’s so much misinformation about this stuff.”

“I’ve told close friends that I’ve had it. And they were cool about it, because they know me and I’ve noticed within my friendship circles, everyone’s open-minded but I’ve also seen the other side, a bit of an ugly side.”

Normally a straight shooter, when Benny started to suspect he might not be getting some of the work allocation because of his run in with COVID, he asked them straight out. To their credit, he got an equally direct answer. “Yes it is.”

Despite this, Benny says, “My work team and bosses are all cool. I reckon with the state of where COVID is now, everyone’s starting to realise that we’re at the point we have to live with it. I’m the first person from my employer who’s actually come back from having COVID and is working. I’m a bit of a guinea pig. The interesting thing is that [HIV] has more privacy rules around it than COVID.”

Benny says he only knows of four colleagues in his industry who’ve contracted COVID. He says one of his workmates “is really stressing out because his missus was eight months pregnant. So he’s pulling his hair out, which is understandable.”

He shared about another colleague who also had a similar experience. “He was quite fearful of leaving home. It was tough for him to get out of the house, because it can lead people down a bad path, mentally. Not connecting with people.”

Keen to get himself back into peak physical condition, Benny focused on getting himself back into the gym. “Construction is hands on,” he said. “The first day I went back to the gym was a real eye-opener. My physical wellbeing is pretty much having my goals sustained towards the gym side of things.

“Before I went back to exercising, I made sure with my doctor that it was okay, not only to engage in physical activity but the last thing you want to do is offload it onto someone else. Once you go through the phase of being contagious, you go through the phase of having the fragments but also shedding the virus, so you can cough up some nasty stuff.” [laughs]

While getting physically back to normal, Benny acknowledges, “I still have the brain fog. I also have a history with PTSD so I have a system in place of engaging with the trigger. I could imagine if an individual didn’t have that previously, that could be quite challenging because it

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can either take away self-esteem or it can make you second-guess yourself or be a trigger for something else. You go through the phase of being like you're not you, not really disabled, but you're not yourself."

Aware that the lessons learnt from the HIV epidemic have informed the NSW response to COVID, Benny philosophically looks at HIV as 'a bit of a front runner' to COVID.

Conscious of the impact that mental health and wellbeing can have on his life and especially employment, Benny says, "I've definitely noticed I have a different outlook on life in how I interact with my day-to-day life."

"My mental wellbeing, that's for me to keep in check. After all, my happiness is me, type of thing. That's up to me if I want to be happy. I've taken it on board, and I came to the conclusion that I have to implement positive structure around it in order to move forward."

– Benny

With the end of lockdown provisions, many of us may have thought that the risk of COVID is over, until the Omicron strain arrived. Don't overlook any coughs, sore throats or fevers, and get tested at the first sign of symptoms.

Visit <https://covid-vaccine.healthdirect.gov.au/booking/> for more information and bookings.

Letters to the Editor

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(less than 200 words)
and may be edited.

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editor@positivelife.org.au or

Write to Talkabout
PO Box 831,
Darlinghurst NSW 1300

halc

The HIV AIDS Legal Centre

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

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

For confidential legal assistance please contact us: Phone 02 9206 2060 or email halc@halc.org.au

In My Own Words

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

Phone Craig or Louisa
(02) 9206-2177 or 1800 245 677
Email contact@positivelife.org.au

TALK SHOP

The NSW Body Positive is represented across a range of NSW HIV/AIDS community partners. Below are brief details of advocacy issues impacting the interests of people living with HIV in NSW.

Positive Life NSW & BGF World AIDS Day

On Wednesday 1 December, Positive Life NSW in partnership with Bobby Goldsmith hosted a World AIDS Day commemoration at the Chinese Gardens of Friendship in Darling Harbour.

We were joined by approximately 70 guests at this COVID-safe event to reflect and publicly acknowledge our grief and the losses we've suffered as we remembered our loved ones lost to HIV/AIDS.

Yvonne Weldon made a thoughtful and moving Acknowledgement of Country and CEOs, Jane Costello and Nick Lawson welcomed guests.

Our Positive Life CEO delivered a meaningful and poignant speech to community which is on our website titled '2021 World AIDS Day'. We enjoyed a performance from the Wagana Aboriginal Dancers, followed by David 'Polly' Polson who shared some reflections on his 37 years living with HIV as one of the first 400 men diagnosed with HIV/AIDS in Australia.

ELKI and her accompanist Paul bought the evening to a close as community members and guests socialised in a COVID-safe environment, many of whom welcomed one of the first face to face events after a long COVID-related lockdown period.

(See page 26 for photographs from our 2021 World AIDS Day.)

Voluntary Assisted Dying Bill 2021

In November, Positive Life made a submission in support of the NSW Inquiry into the provisions of the Voluntary Assisted Dying Bill 2021.

Voluntary assisted dying (VAD) allows for the end to long periods of pain especially in the case of an incurable and terminal illness. It is a rational decision-making process in which the individual makes the choice.

We advocate strongly for the right of all people living with HIV to die with dignity and with the same autonomy as in life. This right to die with dignity should not be removed by increasing incapacity to a point where the manner of death is decided by others.

VAD is a treatment option worthy of the same support as palliation. VAD makes the process of death less terrifying, degrading and painful. and allows us to make decisions about our own bodies and lives.

Positive Life NSW supports the right of all people living with HIV that when no other options are acceptable to a terminally ill person to relieve their pain, their rational request to a medical practitioner to assist in the ending of their pain should be respected and granted.

Positive Life believes the VAD legislation brings regulation and scrutiny to a space that is currently unregulated. It specifically insists that doctors examine questions of competency and coercion, and offers vulnerable people protections they currently do not have, with strict eligibility criteria and strong safeguards which apply only to those for whom the law is written.

(‘Right to Die: a daughter’s perspective’ on page 20 shares a personal reflection about the VAD Bill legislation.)

Our reports and submissions are published on our website at www.positivelife.org.au/publications/submissions/



NUTRITION BITES

Christmas and New Year Festive eating can make it easy to put on weight. On the back drop of our longest lockdown can this be the time to reverse the trend? Some suggestions to keep your weight stable over the festive period:

- Use a smaller dinner plate and keep the potato or other carbohydrates e.g. pasta/noodle/rice salads/bread to $\frac{1}{4}$ of the plate. Enjoy another $\frac{1}{4}$ of your plate as roast turkey, ham, beef or seafood. Pile up the remainder of your plate with lots of colour from salad vegetables.
- Choose a small dessert/pudding, and fresh fruit when available.
- STOP when you feel full.
- Try mindful eating; eat slowly and enjoy the tastes, textures, temperature and smell of food. Mindful eating can help reduce the amount of food you eat.
- Keep finger foods to a minimum. Choose your favourites instead of selecting everything. Go for fruit or vegetable sticks and grilled rather than fried food.
- Drink at least eight cups of water each day, and try having a glass before you eat.

What about alcohol?

Wine, beer and spirits contain lots of kilojoules that can stack up the weight. Drinking can also increase your appetite so that you eat more than usual. Some tips which can also help with any hangovers:

- Start with a glass of water to quench your thirst.
- Try to limit to two standard drinks (a standard drink is about 100mls of wine or a middy of beer or a nip of spirits).
- Alternate each alcoholic drink with a glass of still or sparkling water.
- Fresh mint, ice, lemon or lime with sparkling water can make a refreshing drink with or without a spirit mixed in.
- Avoid sweet pre-mixed drinks and soft drink mixers as they can add lots of sugar.

Had lots of late nights?

- Limit sugary energy drinks to stay awake. Opt for skinny coffees if having milk coffees.
- Try black teas and healthy snacks, e.g. fruit or a low fat fruit smoothie.

Lastly, keep moving...do those 10000 steps a day...check out the local Christmas lights after dinner or put on your favourite tunes and start dancing!!

If you have any questions or would like to chat to a dietitian, call reception at The Albion Centre on (02) 9332 9600 to make an appointment (both Telehealth and face to face are available).

- The Albion Centre Nutrition Team





Recipe

Turkey & Tomato Toast with salsa verde

10 minutes (preparation 15 minutes)

Serves 4

Ingredients

3 large tomatoes, cut into 1½ cm thick slices

4 x 50g slices mixed grain sourdough bread

1 large avocado, coarsely mashed

250g skinless roast turkey breast slices

60g baby rocket and spinach leaves, to serve

Salsa verde ingredients

1 cup firmly packed basil leaves

2 green shallots, thinly sliced

¼ cup olive oil

1½ tablespoons white wine vinegar

1 teaspoon Dijon mustard

¼ cup pepitas, lightly toasted

Method

To make salsa verde, process basil, shallots, oil, vinegar, mustard and 2 tablespoons pepitas in a food processor until finely chopped and well combined.

Transfer to a small bowl. Season with freshly ground pepper.

Heat a lightly oiled grill pan or barbecue plate over a high heat.

Add tomato slices and cook for 1-2 minutes on each side until lightly charred.

Meanwhile, lightly toast bread slices. Spread with avocado.

Top with turkey and tomato slices.

Spoon salsa verde on top. Sprinkle with remaining pepitas. Serve with rocket and spinach leaves.

Tips

Try this recipe as a tasty way to enjoy leftover Christmas turkey.

You can swap any lean roast meat for turkey eg. beef, pork, lamb or chicken.

From: <https://www.heartfoundation.org.au/Recipes/Turkey-and-tomato-toasts-with-salsa-verde>

TALKABOUT

2021 Evaluation Survey

We brought back Talkabout this year after we surveyed Positive Life Full members.

More than 90 percent of the 81 people who responded to that survey had seen Talkabout in the past, and also agreed or strongly agreed with the statement that Talkabout kept me aware of news, policies, events and HIV-related issues in NSW. So Talkabout is back in 2021, and to make sure we are giving members what they want, we asked you to respond to an evaluation survey in the October issue. Thanks to all our Talkabout readers who took the time to reply.

This survey has had responses from a wide range of ages, geographical locations, and views. A number of responses indicated that some readers aren't aware that Talkabout is online at www.positivelife.org.au/publications/talkabout-online/. This should help the Thai-born survey respondent who wanted a digital version so that they can use Google Translate to turn some articles into Thai. They also said that Talkabout "provides me and my partner resources that we didn't know were available."

Another respondent said that what they liked the most about Talkabout was the Treatment Briefs page, supported by another reader who said he liked getting medication advice from Hamish; another, succinctly, just said: "info". Other aspects of Talkabout that people mentioned liking were reading HIV stories, "finding out what's happening in our community."

On the question of having both a print and an online version of the magazine, which are published simultaneously, readers may not be aware that more than a quarter of our membership do not have access to the internet. We get consistently positive feedback from those members, including those in regional and rural areas with poor internet connection.



Feedback on our content has been thoughtful. One reader said that Talkabout "keeps me up to date with things, e.g. I had not heard of HAND before this issue."

Robert, whose story of living with HAND (HIV-Associated Neurocognitive Disorder) was in the October issue, was very pleased to hear this comment. (Robert's story is also a blog post on our website and can be found at www.positivelife.org.au/blog/my-journey-through-hand/) Another respondent reminded us to remain easy to read for people living with HAND.



Reader suggestions about future content of Talkabout included finances. "All the extra costs we have had over the years – vitamins, supplements, costs of trials etc. etc." said one respondent. We welcomed this suggestion and will continue to include articles on finances in 2022.

Some respondents called for more content detailing the current state of HIV in Australia, current numbers on new infections by state, number of people living with HIV by age. There was also a request for information on new treatments under development or being considered for approval here in Australia. Respondents who requested these should look for Talkabout interviews in 2022 with the people at The Kirby Institute who produce the Annual HIV Surveillance Report and other clinicians.

Other ideas for future content included regional service groups; getting older with HIV and other co-morbidity issues; introducing doctor profiles; who's who in the zoo; and things that matter to people with HIV.

One thoughtful response, to the question about your expectation of a magazine for people living with HIV, was: "to reflect the HIV community of NSW and beyond, and to bring to light our stories, events, treatments and creativity." We trust we meet that brief!

– Positive Life NSW

MONEY TALKS

A column focused on money matters in relation to people living with HIV in NSW

Holiday season and a new year is upon us, allowing us some time for reflection.

It's a great time to put in place some of the 'Positive Money' practices we have talked about in Talkabout this year. When you look back over your life you will be amazed at the amount of money you squandered on pursuits and products that proved meaningless. Imagine if you had invested it instead.

START A FIRE

It's called the FIRE movement - *Financial Independence, Retire Early* (Google it). FIRE is different for everybody but it usually involves building enough passive investments to generate an income that buys you enough freedom not to have to work. That doesn't mean they don't work, most of us enjoy to be actively involved in a community, but they are free to say no to having a regular job.

There is a whole movement of people doing exactly that. They often start young and very determined. In many cases they are faced with limited prospects of buying a house so instead they focus on stripping back their expenditure to the minimum and save as much as they can.

And it doesn't have to be at age 35, it can work at any age. For me I hit that point at age 57 and what was interesting is how any depression and anxiety I may have previously experienced melted away. So maybe this holiday season you should start a FIRE!

POSITIVE FUTURES

For those of us who are a little older we sometimes look at our superannuation balance and panic. Funding a retirement of over 30 years is daunting. Those articles in the paper saying how you need at least \$1m to retire may dishearten us. Certainly for non-homeowners, and this will likely impact the younger generation more, you really do need to boost your Super or savings.

Yet the chances are that younger people will have had super their whole life and will by definition have higher balances.

Some people may choose to boost their super or investments early rather than paying a mortgage and then use that to buy a home later in life. And don't forget the huge transfer of assets that may come as an inheritance from the baby boomers.

The reality for home owners is somewhat less bleak. A couple reaching 67 years of age today with \$405,000 in their combined Super, their own home paid off and no other assets would qualify for the full aged pension of nearly \$38,000pa, and they could draw around \$20k to \$25k from their super per annum for life.

That's a combined income of nearly \$60k for life. Now if they need they can also use the Pension Loan Scheme to boost that by a further \$18,670pa to be paid back when the house is sold. Now we are up near \$80k pa tax free.

If they have the capacity to earn money from casual jobs, that can add another \$15k pa. That's a potential tax free income of \$95k pa with only a modest super and a house.

See an adviser to get personal financial advice as this will not apply to everyone's situation. What is true is that taking some time now to plan for the future will make sure that your future is positive.

Enjoy your break.

If you have questions, email us at fc@bgf.org.au. We will try to respond personally and if not, will include ideas in future newsletters.

– Barry French

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

Michael and Phillis

A LOVE STORY (of sorts)

A strong theme that runs through the rich narrative of Michael O’Keefe’s life is art.

His love affair with art started when he was a young man in Melbourne, after he suddenly became a parent, courtesy of his new partner’s children, and continued through a long period of “discovering sex, drugs and rock n’ roll” after visiting Sydney for the Sleaze Ball; he never returned south. More recently, art once again proved a loyal companion through depression, meditation, multiple hospitalisations and medical crises.

Michael’s art began conventionally with painting; a large glass jar with a collection of regularly used paintbrushes sits on his coffee table. At the same time as studying for and acquiring a range of academic qualifications, he pursued art classes, print making, photography, ceramics and more, at a number of venues from the Sydney Gallery School to the National Art School and the Bobby Goldsmith Foundation.

Just as the pandemic hit in 2020, he began classes with Aaron McGarry, a multidisciplinary visual artist who works in sculpture, performance and site-specific installations. Michael was making several collages a week at this time and then moved to assemblage, a form of three-dimensional collage, following Aaron’s encouragement to “just recycle something”. Enter Phillis!



Michael had large milk cartons and plastic drink bottles. By cutting off the top of the milk carton and turning the drink bottle upside down and fitting it into the milk carton, he eventually saw the shape of what would become Phillis’ head and torso.

Papier-mâché arms, bottle tops for eyes and the lids of his medication bottles for earlobes, were wonderfully topped with a feather hat, gold beads, curly hair and lipstick. Phillis was ready for the races, specifically the Melbourne Cup, where she once used to meet her friend Susan Renouf. She also attends the polo with her old friend Julie Bishop.

At this point, Phillis’ CV began to expand. The original Phillis was born into a wealthy landowning family, the Kidmans (no relation to Nicole). She went to school with Gina Rinehart and Jennifer Hewett, and later held a flame for Barnaby Joyce, but her parents said no. She’s great friends with the Grimaldis, and went to the weddings of all of Princess Grace’s children.

Phillis number 2, sexy in her “itty bitty, teeny weeny, polka dot bikini”, was ready for Copacabana, perhaps with the Perons (“music and passion was always the fashion”). Phillis number 3 is gloriously decked out in a sari and veil for her trip to the Taj Mahal with Princess Di; they had of course been besties for years.

Phillis number 4, who is waiting for her finishing touches and so declined to be photographed, is the result of an observation by Michael’s friends who said that the next Phillis needed legs. So Phillis number 4 is born of two milk cartons and the drink bottle, and is dressed in a chic black and white ski suit. She’s due in Saint Moritz this coming northern winter for the ski season.

The gently satirical back story for Phillis has political undertones. Michael was once asked what Phillis would wear to Mardi Gras; he was shocked. “As if Phillis would attend Mardi Gras!” he said.

A rusted-on coalition voter, Phillis has firm views on many topics. But there’s nothing misogynist about Michael’s creations; they are warm, happy people, who enjoy dressing up and having a good time with like-minded people.

Michael’s art, spanning twenty years, has been a central part of his life, with Phillis now keeping him company.

– Positive Life NSW





Feature

RED RIBBONS

Those of us in the HIV community, whether living with or affected by HIV, think of the red ribbon that we wear on World AIDS Day (1st December) as being the internationally recognised symbol for AIDS awareness, worn in support of people living with HIV and in remembrance of those who have died from an AIDS-defining illness.

This use of the red ribbon, which in fact does not belong uniquely to HIV and AIDS, began in 1991 with a group founded by arts professionals called *Visual AIDS*, as a response to the effects of AIDS on the arts community. They were inspired by the yellow ribbons honouring American soldiers serving in the Gulf war. The artists chose a red ribbon to symbolise solidarity with people living with HIV and to remember those who have died from AIDS-related illnesses.

The colour red was chosen for its “connection to blood and the idea of passion -- not only anger, but love, like a valentine,” the founders say of the idea that was to become known as the *Red Ribbon Project*.

Red Ribbon Project volunteers sent letters and red ribbons to all attendees at the 1991 Tony Awards in the United States where actor Jeremy Irons stepped out on national television with a red ribbon pinned prominently on his lapel.

The symbol came to Europe on a mass scale on Easter Monday in 1992, when more than 100,000 red ribbons were distributed during the Freddie Mercury AIDS Awareness Tribute Concert at Wembley Stadium. More than one billion people worldwide watched the show on television. Throughout the nineties many celebrities wore red ribbons, encouraged by Princess Diana’s support for AIDS.

Before the link with HIV/AIDS, red ribbons have been linked with a range of different associations. In 1985, it was used in the USA as a symbol of intolerance towards drug use, after a drug enforcement agent was murdered by drug traffickers in Mexico City.

The red ribbon is used for heart disease awareness, along with a red heart. A red ribbon plaited into a horse’s tail is a universal warning that the horse kicks, and you should stay away. In Canada, the red ribbon represents people with multiple sclerosis; and MADD (Mothers Against Drunk Driving) adopted a red ribbon in 2011 as part of their campaign. After the 2021 army coup in Myanmar, the red ribbon was adopted as a symbol of opposition to the military regime.

For those of us who mark World AIDS Day, the red ribbon will always be about HIV/AIDS awareness and commemoration.

Sources: www.unaids.org, www.visualaids.org, www.redribbon.org

– Positive Life NSW



HIV Futures 10
A national survey of
people living with HIV

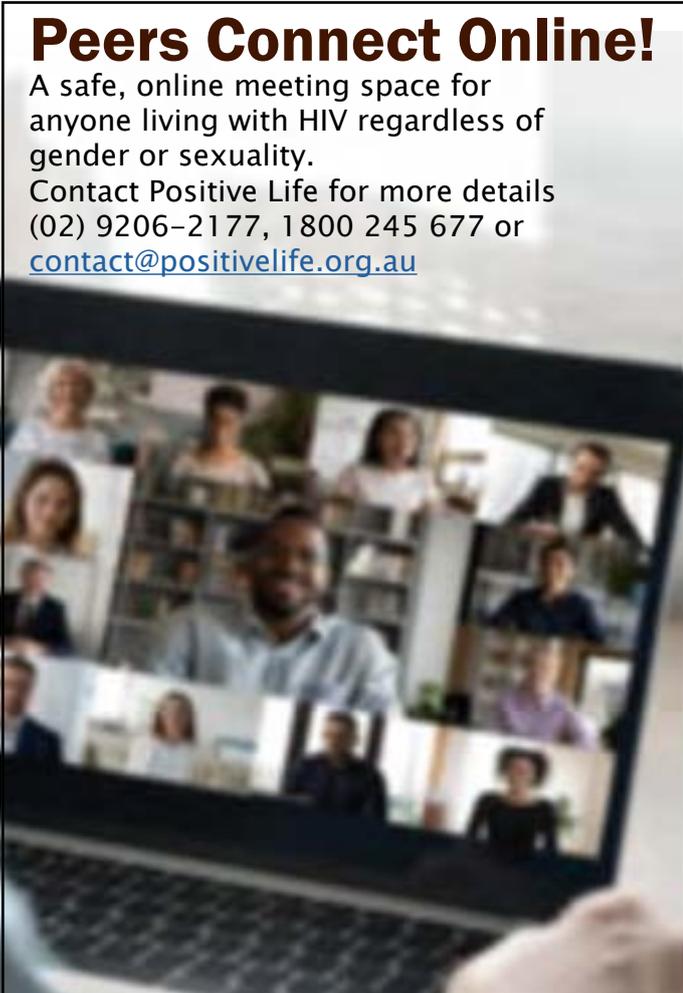
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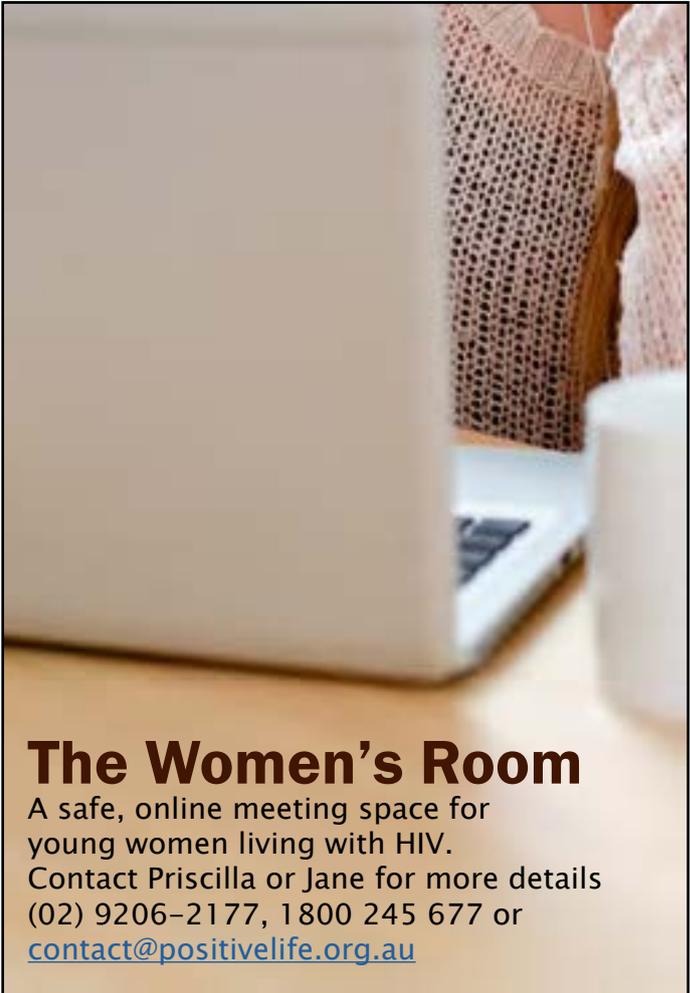
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The Right to Die

A daughter's perspective

Amy was just 19 when her vibrant, vivacious mother Tasha told her that she was living with HIV. “She had kept the diagnosis away from me,” Amy says, “so I don’t know how long before that she’d been diagnosed.”

Tasha died about a year later, in 1996, at home, cared for by her daughter, sister Jo and devoted partner Ed. “I took that last part of her journey with her,” Amy said.

“Before that, I kind of suspected she was sick and that she could have HIV. She was pretty awesome and had a very colourful lifestyle.”

In that last 12 months, Tasha talked openly to Amy.

“She talked to me a lot about how she was feeling. She kept nothing away from me, and she was not backward in letting me know things. I wasn’t shocked when she told me her diagnosis, so that helped her to be open with me.”

Tasha had been in hospice care but wanted to come home to die. “That last month or six weeks at home with her, even with the help of the awesome palliative care team from the hospice, and mum’s sister, and family coming in and out, and friends, and myself and her partner Ed, it was still tricky to navigate that end stage,” Amy said.

On her bad days, Tasha begged Amy to help her end her life. “She said, ‘I need you to help me die, I can’t do this anymore.’ To see somebody in that state... I said, I’ll go to jail, I can’t. It was so horrible.”

If Voluntary Assisted Dying (VAD) had been available, would Tasha have requested it?

“On that particular day, she would have,” Amy said. “Like anybody toward the end, there were a few good times and some deep-down, horrible times and she fluctuated between not wanting to live and wanting to be with the people she loved.”

With the passage of time since Tasha died, Amy feels strongly about the right to choose an assisted death.

“If someone in end stage and terminal decides it’s time, we need

to respect that. All these people saying no, well I say to them, that’s ok you don’t have to, but don’t deny it to the people who do want it.”

Amy’s career goal is to work in palliative care. Currently, she’s an assistant in nursing (AIN), is completing a certificate in mental health and is now working in aged care. “Even in this setting I hear the same thing all the time: ‘I don’t want to do it any more.’ I can’t tell you how many times I’ve heard it. People should be able to navigate their end of life and it’s bewildering that people don’t talk about it.”

Tasha is described by Amy as “a tiny pocket rocket, loved by so many people.” She was very clear about her choice of music at her funeral: Cyndi Lauper’s *Girls Just Want to Have Fun*. A special guest at her funeral was her beloved dog Mac, rescued as a small puppy and who remained her constant companion until the end.

At the suggestion that her mother was very fortunate to have such great support around her before her death, Amy said: “I think I was the lucky one.”

– Positive Life NSW

Progress of the NSW VAD Bill 2021

In October 2021 the Voluntary Assisted Dying Bill 2021 was introduced into the lower house of the Parliament. The Bill was passed in the Legislative Assembly on 26 November 2021 by 52 votes to 32. At the time of printing, it will proceed to the Legislative Council where the bill is expected to be voted on by the Council in the first quarter of 2022.

The current provisions of the bill states a person may make a request for a voluntary assisted death to a specialist doctor, which is lodged with the Voluntary Assisted Dying Board (VADB).

If the doctor is satisfied that the person has the capacity to make the decision and is doing so voluntarily and determines that the person meets the criteria (i.e: they have a terminal illness that will result in death within six months, or a neurodegenerative condition that will result in death within 12 months, and whose suffering is such that it creates a painful condition that cannot be tolerably relieved), they can approve the request.

The same process must then be followed by a second

“If someone in end stage and terminal decides it’s time, we need to respect that...don’t deny it to the people who do want it.”



independent doctor, whereupon the person may then make a written request declaring their intention to end their life, which must be witnessed by two people and then be submitted to the Board.

A final request must be made five days later and a review done by the first doctor, who can then apply to the VADB to allow access to a substance to end their patient's life. The person can choose to administer the relevant substance themselves or have a health practitioner do it.

At the time of publication, advance care planning is available throughout Australia and a patient can elect to not receive any treatment for a terminal illness and can also elect to have their life support turned off.

Victoria has an assisted suicide scheme which has been in place since June 2019. Western Australia adopted a similar scheme in July 2021. Tasmania passed VAD legislation in March 2021 to come into effect in October 2022. South Australia passed similar legislation in June 2021, while Queensland passed legislation in September 2021 that comes into effect in January 2023.

STI DATA REPORT

NSW HEALTH

The release of the NSW STI Data Report 2020 was delayed because of staff being redeployed to the COVID-19 response, but is now live on the [NSW Health website](#). The authors caution that while notification rates have reduced, the trends should be interpreted with caution as the effects of the COVID-19 pandemic are not yet fully known.

- **The Gonorrhoea notification rate** in 2020 was the lowest it has been since 2017, but highest among people aged 25 to 29 years and males. Testing for gonorrhoea dropped significantly in 2020. The highest gonorrhoea notification rates continue to be observed in the Sydney and South Eastern Sydney Local Health Districts for both males and females.
- **The Infectious Syphilis notification rate** in 2020 was 12% lower than the rate in 2019, yet 43% higher than the rate in 2016. Males continue to have a substantially higher rate than females. However, since 2016 there has been a four-fold increase in the female rate. The infectious syphilis rate among Aboriginal and/or Torres Strait Islander people was the highest it has ever been.
- There were four cases reported of **Congenital Syphilis** in 2020, significantly higher than any year in the previous five years. A Syphilis Taskforce has been established to investigate and develop strategies to eliminate congenital syphilis.
- **The Chlamydia notification rate** dropped to the lowest it has been since before 2016, 17% lower than in 2019. Rates continue to be highest in people aged 20 to 29 years. Testing for chlamydia in 2020 dropped to the lowest levels since 2016. Chlamydia notification rates among males and females in regional and remote areas and females in major cities have declined, while notification rates among males in major cities have increased.
- Vaccination against **Human Papillomavirus (HPV)** was significantly impacted by COVID-19. The data indicate that 81% of females and 79% of males in Year 7 in 2019 completed the two-dose course of HPV vaccine, including a catch-up vaccination in Year 8 in 2020.
- **Self-reported STI diagnoses** among gay and bisexual men increased in 2020 to one in four men reporting any STI diagnosis in the previous 12 months. The trend was consistent for chlamydia, gonorrhoea, and syphilis.
- **Condom use** among gay and bisexual men was at its lowest levels since 2011. Condoms and other HIV risk reduction strategies used by gay and bisexual men are measured through the annual Sydney Gay Community Periodic Survey (SGCPS), conducted each year during February/March. There has been a steady reduction in the proportion of gay and bisexual men with casual partners reporting consistent condom, particularly since 2016 with the introduction of HIV Pre-Exposure Prophylaxis (PrEP).



PEERS IN CONVERSATION

In the first of a two-part series, Positive Life NSW and GNP+, the Global Network for and by People living with

HIV, got together over zoom to discuss a range of topics related to people living with HIV.



In this second of a two-part series, the co-directors of GNP+, Sbongile Nkosi and Gerard van Mourik and Positive Life NSW's CEO, Jane Costello and Deputy CEO, Neil Fraser discussed our shared experiences of HIV as a rights-based movement, and reflection on World AIDS Day as a global event, and how we can continue maintaining the relevance of World AIDS Day to today's community.

GNP+ is a global network of interconnected individuals and organisations. Under the leadership of co-directors Sbongile Nkosi, based in Cape Town, and Gerard van Mourik, based in Amsterdam, GNP+ supports national and regional networks of people living with HIV to improve access to quality HIV prevention, treatment, care and support services.

Positive Life NSW's CEO, Jane Costello and Deputy CEO, Neil Fraser, based in Sydney lead the largest peer-led and peer-run representative organisation of the body of people living with HIV in Australia, to eliminate prejudice, isolation, stigma and discrimination and to advocate for the optimum well-being, care and support for people living with HIV/AIDS, our partners, family members and significant others.

A HIV diagnosis is one where we quickly discover we are affected by a range of assumptions, judgement and for some of us, even legislative control. Unlike other manageable, chronic health conditions such as diabetes, asthma or arthritis, a diagnosis of HIV comes uniquely coloured with stigma and discrimination. In the face of this new reality, many of us living with HIV quickly find ourselves with a new identity which knits us into a rights-based movement.

Co-director of GNP+, Sbongile Nkosi, shared her personal experience to describe this intersection of health and stigma: "I'm going to give a South African perspective. When I was a young girl in the 80s and 90s, I saw so many of my family members and neighbours, dying of this disease. Everybody was scared in the community, it affected all parts of society. That's how you're born into the movement. I grew up in the movement because of my parents."

"I leave and I try to work in health journalism. Then I get HIV and somehow I know where home is. HIV displaces you in the world and therefore you have to find people like you that can give you a community. To find home and to find refuge, you have to join a movement, because that's what everybody has had to do, because of this displacement in so many ways."

Positive Life's Neil Fraser responded, "Yes, and I think that experience is a global one. Wherever you are in the world, a diagnosis is still a lot to process, and that commitment to community crosses nations and boundaries and languages and cultures. That sense of community is there and available to everyone, but stigma still plays a big role in preventing people from being able to engage with that community. We're not a homogenous group; just having HIV doesn't make us all friends. But there is something special there."

"I put myself in that second generation of people living with HIV. I had an uncle who passed away from AIDS, and it was just something that wasn't spoken about in the family.

"Today living with HIV, I see people who have that generation of elders, with that lived experience and unconditionally provide that sense of community and support, particularly early on."

"In regard to the comparison with diabetes or any other disease," GNP+ codirector Gerard van Mourik said, "HIV comes with the stigma and discrimination and shame, and HIV is also about sex and sexuality and identity.

"My husband is Nigerian, and we have daily conversations about evolving MSM and trans communities in Lagos and in Abuja, and even in the north where the Boko Haram is fighting. The inability to speak about your identity and who you are makes HIV distinctively different from diabetes. I find it an emotional thing to talk about, it's so different from diabetes, and even cancer, sorry to say."

Positive Life's Jane Costello agreed. "If somebody told you that they had cancer, they would invariably hug you. If somebody says, I've acquired HIV, it doesn't evoke the same response. HIV is completely different. It's not like cancer, it's not like diabetes.

"I think we've been forced to come together as a movement, because that's what we have. It's a movement that finds us because of the stigma, and to a degree, the shame. As Gerard said, it's about sex.

"It's about all of the social mores that we don't like to talk about in society and the conversations that we don't

like to have. You can call it a movement, you can call it whatever it is, but we come together, it is a moment of solidarity because as peers, we can have those conversations because you are walking a journey in somebody else's shoes."

Neil responded with an analogy: "When the Titanic is going down, and

two people survive, they have the shared experience of something that was life-changing. When they get back to land, they separate, and probably never see each other again. Whereas with HIV, because of that experience of stigma, we do collectively continue to come back together from time to time. There is something there. The stigma draws us back together in that communal movement."

Conversation turned to World AIDS Day as an annual global day of recognition of the shared experience for all people living with and affected by HIV. Reflections turned to the value and relevance of World AIDS Day for today's communities.

"I remember the 80s and the 90s and what we went through," said Jane, "Today I look at young people now who've got no reference point for this time of recent history. World AIDS Day is an abstract for so many people.

"There seems to be a genuine lack of understanding about what it was like and why we became activists, why this was something that we absolutely had to do, and what people went through."

"Yes, for me, this is a critical internal dialogue," Sbongile said. "How do we make sure that this day commemorates what we see on the ground? I don't see celebration!

"Let's look at someone living with HIV in India, who lives in the slums and wakes up on World AIDS Day and has to think about their livelihood, about eating and fetching treatment which probably does not exist, and probably has not had a viral load test.

"Or if you're a young sex worker in South Africa, you wake up on World AIDS Day or every day, to stand on the street corner to do your work, but also to run away from the police and to deal with the stigma every day. There's a context to it and I don't think we have these conversations when we talk about World AIDS Day. I don't think any of us think about people living with HIV, and the daily struggles, even on that day. There's a disjoint that we are seeing within our response.

"How are we having critical and open conversations around inequality?" she said. "How do we put inequality in the HIV response? We need to ask these questions around World AIDS Day about who is it important to, and why is it important?"

"I work for the GNP+ and I'm HIV positive, but I've now moved into a more privileged position in society. Therefore World AIDS Day means so much more to me. If we're talking about inequality, how do we allow World AIDS Day to no longer be led by the global north* institutions?"

"I think we could elaborate more about the global north," Gerard said. "It dictates the debate around HIV and notably on World AIDS Day, intentionally or not, but it still happens."

"HIV is a movement that finds us because of the stigma, and to a degree, the shame. HIV is completely different. It's not like cancer, it's not like diabetes."

Neil responded: “I take your point, Sbongile, about the global north setting the agenda, even with last year’s global theme around ‘global solidarity, shared responsibility’ as set by UNAIDS. Australia doesn’t even participate in that. We continue to have a very isolated engagement, and I think that’s something where we could work with GNP+ to learn from those experiences.

“In Australia, by and large what happens on World AIDS Day is that policymakers launch new HIV strategies, pharmaceutical companies publish research around the latest and greatest drugs to try and get subsidised in Australia; here it’s about building political capital.

“I think Australia could be more reflective on the global experiences. It is not a day for self-promotion, it is a day to remember.”

“Yes, World AIDS Day was designed to be around international solidarity,” said Gerard. “Regardless of what they figure out in Geneva, international solidarity might be a very interesting theme for you and with all the technology that you have and the connectivity.”

“Even the theme ‘global solidarity, shared responsibility’, I still questioned the global solidarity and I keep questioning the shared responsibility,” Jane said. “Are we really seeing that shared responsibility?”

“The global north, and ourselves in Australia, are in a very privileged position, where we have access to medication, where we have good health care systems. It’s how do we ensure that everybody’s experience of HIV is enhanced in some way and that we’re not leaving people behind?”

“We’ve ignored populations or they’re labelled too difficult to deal with or we really don’t know what to do with them, or we haven’t got an answer for it. I think we need to do better in terms of finding those answers and creating those solutions and acknowledging that our own privilege does not absolve us from that.”

Sbongile agreed: “It speaks to seeing HIV-positive people as human beings. There’s been such a biomedical approach to our lives but even with the inequalities, it’s showing that there’s more to us than HIV. Yes, HIV is a big part. And there are other parts that are key to ensuring that I stay on treatment, and I stay healthy, and we haven’t had those conversations.”

“We don’t have a ‘one size fits all’ philosophy when it comes to HIV, we’ve got very different experiences from very different populations,” Jane said. “We need to celebrate that diversity, but we also need to call that diversity out, particularly where there is inequality caused through that diversity, where people have quite different health outcomes.”

“Globally, in the past thirty to forty years, we’ve had roughly 43 million lives lost to AIDS,” said Neil, “With 4.5 million

lives lost to COVID-19, our health ministers proclaim this as a once in 100 years event. We have a very short memory of what has happened, and what is continuing to happen. We really haven’t learned well from the past.”

Jane agreed, “There needs to be a recognition around World AIDS Day of what has gone in the past, so that we can use that to inform our future,” Jane said. “How do we move forward and change people’s lives, not just the privileged few?”

“For me, it’s ending HIV transmission. We’ve still got people living with HIV who have very poor outcomes. What are we then doing about the populations of people living with HIV, and the extreme ends of the spectrum that we live on within that continuum, and that, for me, is really critical to our conversations around World AIDS Day.

“It’s been an absolute pleasure, an honour and a privilege to speak with you both, and for sharing so much of your valuable time. Thank you very much. It’s been really affirming. I think the opportunities for collaboration would be wonderful to explore.”

**The Global North refers to those countries which are technically and socially well-developed. These are normally located in North America and Europe.*

– Positive Life NSW



In My Own Words

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Garry WOTHERSPOON

Garry Wotherspoon has been an academic, a political speechwriter, an historian, an author, and a close observer of gay life in Sydney. He is both elder and activist, and a chronicler of the gay community's lives, with half a dozen books published. This is his story, in his own words.

Growing up in Sydney, I was lucky enough to be exposed to the city's counterculture in the 1960s. As a generation then, we had good jobs, with good income and opportunities, so we could afford to move out of home, and experience freedoms early.

This was not long after the Police Commissioner had announced that the two greatest threats to Australia were Communism and homosexuality, so we learned to live a discreet, secret life. I worked in a bank and then did postgraduate studies, which led to me being offered a job at the University of Sydney. The old Merewether Building there was 'Gay Central' in the 1970s. It was a wonderful time, with people like Dennis Altman, Lex Watson and Sue Wills nearby. We could pursue gay studies, but it was the gay political activism that mostly involved us, initially on law reform. And then, in the early 1980s, with the advent of AIDS, we switched our focus to deal with it and its repercussions.

I had been in a long-term relationship from 1980, an open relationship, and we'd negotiate safe sex with outsiders. My partner had been born in South Africa, and in 2002 we went to live there, initially for a year, but we quickly realised it wasn't going to work for us. We broke up soon after we came back to Australia, and some time after that, I went to a sex-on-premises venue, smoked some marijuana, and was having a good time. In those days we all had a vial on a leather thong around our necks for our amyl –

easy access. By the end of the evening, I was having a very good time, but wasn't really paying much attention to the safe-sex necessities any more.

It was some weeks later that I started to feel ill. I went to my GP at Taylor Square for blood tests. It was early 2004 and the results came back; I had joined the HIV tribe.

The doctors there, Ross Price and Robert Finlayson, put me

in touch with Positive Life, where I did the Genesis program with other people who had recently seroconverted. They were of a diverse collection of backgrounds and ages: I was in my sixties, and there were others in their twenties. Genesis was designed to acclimatise you to the fact that you had seroconverted. After that, I did the After Hours program, run by Glenn Flanagan at Positive Life, one evening a month, where we swapped stories about how to live with HIV and create a worthwhile life. They were also a quite diverse group, and I have friends from that program who I still see.

People adapt differently to the diagnosis. I was lucky, I always had other interests that kept me busy, and an extensive network of friends, so HIV didn't come to dominate my life as it did for some people... there was one person at After Hours who kept referring to the 'Immaculate infection', and it had become the obsession of his life.

I take my pill every morning; it's just modern life, although in the early days I was taking four or five tablets a day. We're very lucky to have the advantages of modern medicine and its technology. My Taylor Square GPs give a lot of support with my pills.

I bought an apartment in Oxford Street in 2007, and I used to buy a newspaper downstairs every morning. I noticed a hunky man from the building next door, who I saw most mornings in a suit, off to work in the city. Eye contact was made! One day he was in a t-shirt and shorts, and I asked him why the change; he said his contract was finished. I asked if he would like a coffee; no, he didn't drink coffee. So then I offered him herbal tea - and me. I was open about my sero-status, and he said it didn't matter to him, and serendipity, we've been together ever since.

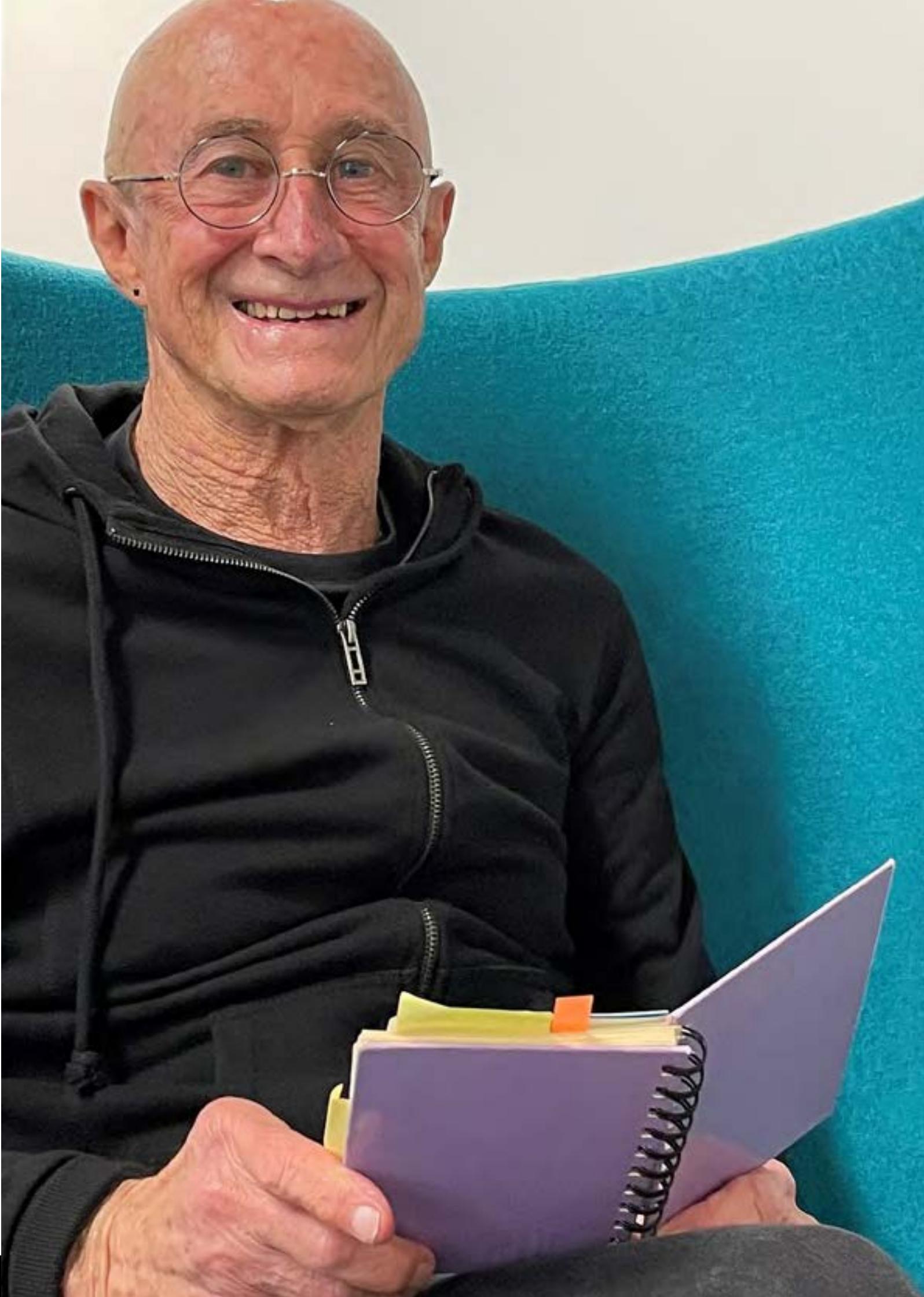
Of course, there is still stigma attached to HIV, and you have to be cautious about who you come out to, because it can impact your life. Be honest among your friends, because if they reject you, they aren't really your friends.

Looking back, it wasn't exactly a relief when I was diagnosed; it was more of a sense of an arrival; I could stop worrying about whether I'd get HIV - I was there now. But I also knew I wasn't going to die from it.

After a diagnosis of HIV, you still have a path in life, and it need be no different to what you envisaged it might be. These days you're more likely to have trouble with high blood pressure or diabetes.

– Positive Life NSW

“Looking back, it wasn't exactly a relief when I was diagnosed; it was more of a sense of an arrival.”



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AGREEMENT

- I have read the privacy statement below and consent to my details being collected and stored by Positive Life NSW

Signature _____ **Date** ____/____/____

PRIVACY STATEMENT

Positive Life NSW collects your personal information in accordance with our Privacy Policy. Your details are strictly confidential and only used to add you to our membership and subscription database. If you provide your email address we will send you information about Talkabout by email. You can unsubscribe from email updates following the instructions in the email. We store your personal information in hardcopy or electronically or both. Access to your information is strictly limited to Positive Life NSW staff and will not be passed on to any other organisation or individual. You can access and correct your information by contacting us on (02) 9206 2177 or freecall 1800 245 677 or email contact@positivelife.org.au



The voice of all people living with HIV

Positive Speakers Bureau

Employment + Vocational Support

HIV Health Promotion

Advocacy + Policy

Peer Navigation + Support

Talkabout Magazine

Housing Support

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 9206 2177 **Freecall** 1800 245 677
www.positivelife.org.au **contact@positivelife.org.au**
