



talkabout

where we speak for ourselves

INSIDE

Talkabout Evaluation Survey

Global peer conversation with GNP+

My journey through HAND

Creating change through art

SPOTLIGHT: Stanford House/ Tierney House

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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Women project participant

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talkabout

Where we speak for ourselves

features

- 14** **HAND Resources**
Two companion booklets
- 15** **Talkabout Evaluation Survey**
Postage paid self addressed pullout
- 19** **Peers in Conversation**
GNP+ talking with Positive Life NSW
- 22** **In My Own Words**
My journey through HAND
- 28** **Creating change through art**
Positively Women project

regulars

- 5** **In the Loop - President** Robert Agati
- **CEO** Jane Costello
- 6** **Treatments Briefs**
- 9** **Nutrition Bites**
- 10** **Money Talks**
- 12** **Talkshop**
- 21** **Calendar**
- 26** **Spotlight: Stanford House/ Tierney House**
- 31** **Positive Life Membership/Subscription Form**

advertisers

- 4** Positive Life Ageing Support
- 4** Positive Life Aboriginal Health Program
- 8** HIV Futures 10
- 11** Pozhet
- 12** Unusual Risks
- 13** In My Own Words
- 13** Peers Connect Online!
- 13** The Women's Room
- 25** HALC
- 25** Letters to the Editor
- 25** In My Own Words
- 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

By the time you read this, we'll be well and truly into the countdown towards Christmas. In November, the Positive Life Board will begin our annual Board nominations process. The Positive Life Board is unique in that it is made up entirely of people living with HIV, in the interests of ensuring the peer voice of people living with HIV remains undiluted and upholds the interests of all people living with HIV in NSW.

The Board's governance and strategic oversight ensures that our vision and mission of dismantling HIV stigma and discrimination is understood and resourced, so our staff can continue to advance this goal each day. All Full members of Positive Life NSW are eligible for nomination and if elected, can become a Director of Positive Life NSW.

We share the first of a two-part conversation between our CEO and Deputy CEO with the Co-Directors of GNP+, the Global Network of People living with HIV, over on page 19. I hope you find much food for thought on the role and responsibility of the peer voice at all levels of the HIV response. The HIV response is more than a biomedical or policy response. It must remain a very human response. It's only by maintaining a strong and effective peer voice that we can overcome complacency as one of the biggest impacts on an effective HIV response at all levels of society.

As the voice of all people living with HIV in NSW, I encourage you to let us know how you're getting on, or even to share your story in Talkabout. Let me know how we can better support you and the needs of the NSW body positive at president@positivelife.org.au

ROBERT AGATI

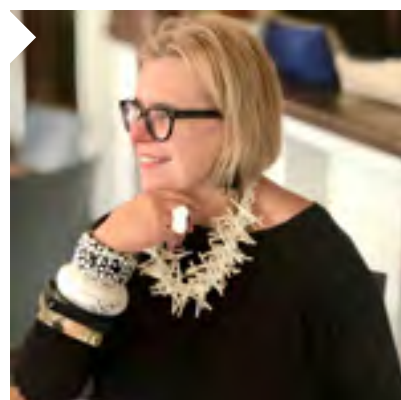
CHIEF EXECUTIVE OFFICER

As we approach the possible end of lockdown in NSW, our dedicated team of Peer Support Navigators continue to check in with community members on a daily basis. The Board and staff at Positive Life NSW continue to maintain a strong focus on our core business of advocating, supporting and representing the interests of all people living with HIV in NSW.

During September we participated in and presented on research that Positive Life NSW has been involved in, at the Joint Australasian HIV&AIDS and Sexual Health Conferences hosted by the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) in a virtual format. From the thoughtful reflection on 40 years of HIV/AIDS advocacy from Professor David Caron at the University of Michigan to the perennial questions of tackling HIV stigma within health systems, once again we were reminded of the diversity and breadth of our community of people living with HIV that we leave no one behind in our efforts.

Emerging from lockdown here in NSW will be both exciting and challenging for many of us and I encourage you to reach for support when you need it, either from your personal support network, your clinicians and allied health professionals, or from other people living with HIV at Positive Life NSW.

JANE COSTELLO



TREATMENTS BRIEFS

Treatments column offering health news in relation to living with HIV.

- Do you take more than five prescription medicines?
- Are you being treated for more than three medical conditions not including HIV?
- Do you take vitamin supplements or herbal remedies?
- Have you been on the same medicines for years? or
- Have there been a few changes recently?
- Are you just struggling with the sheer number of medicines you take each day?
- Has it been more than 12 months since your last medication review?

If you answered 'YES' to any of these questions it might be time for a medication review! Talk to your pharmacist or doctor about organising a medication review.

Medication reviews can take place in a variety of settings, and can vary in how long they take to conduct and how comprehensive they are.

Over the last decade or two, the quality of life of people living with HIV has vastly improved and this has been largely due to the advance and simplification of HIV treatment options.

However, the management of HIV can still be very complex, especially for people who were diagnosed before the advent of combination therapy (HAART - Highly Active Anti-Retroviral Treatment) in 1996.

As people living with HIV age, they are at increased risk of developing age-related co-morbidities (heart, kidney, liver and bone disease, and some cancers), with the subsequent increase in both the number of prescribed and over-the-counter medications. Studies show that people living with HIV aged 50 years or over, take more medications (in addition to their antiretroviral treatment) compared to those who are of the same age but who are HIV negative. (FYI - around 50% of people living with HIV in Australia are now over 50!)

For every additional medication that a person takes, there is an increased potential risk for medication-related problems to arise. This may involve drug interactions, adverse effects, inappropriate prescribing of medications, under-utilising beneficial therapy and importantly, the impact that multiple medications have on a person's ability to take all their medications as prescribed, or their adherence.

For these reasons, it is important to inform your GP, your General Practitioner (GP) and your pharmacist of all the medications you take or wish to commence taking (prescribed, over-the-counter, vitamins, supplements or herbal remedies).

I know people living with HIV may be hesitant to disclose their HIV status to all their health care providers, but it is important that at least one of your providers has full knowledge of all your health care concerns, and all the medications, vitamins, supplements or herbal remedies you take. This allows your health care professional to assess and review your medication, and to identify, resolve and ideally prevent any medication related problems occurring.

The simplest may be an informal discussion with your doctor when they are writing a prescription, or when you're having a chat with your pharmacist when they are dispensing your medication, all the way through to a comprehensive, structured and proactive review known as a Domiciliary Medication Management Review (DMMR), or Home Medication Review (HMR).

A medication review also may consist of supplying your pharmacist with a list of all the medications you take, and then a follow-up discussion on any problems they might find and how best to resolve them. It may simply be providing you with information on how best to take your medication, or it may require involvement of your doctor.

MedsCheck @ your local pharmacy

MedsCheck is a specific type of medication review which fits somewhere between the simplest and most comprehensive. MedsCheck involves a one-on-one discussion and medication review with your Pharmacist in your local community pharmacy.

MedsCheck focuses on improving your understanding of the medication you take and identifying problems you may be having with that medication. The aim is to assist you in taking your medication correctly, and identifying any medication related problems that are present.

For a pharmacist to offer this service, they must be an Approved MedsCheck Service Provider and ensure that they provide this service in accordance to strict guidelines. This includes that the consultation must occur in a private consulting area to maintain your privacy and the confidentiality of information shared.

To be eligible for this service, you must be a current Medicare or Department of Veteran's Affairs cardholder, who lives at home in a community setting and meets one of the following conditions:

- You take five or more prescription medications, OR
- You take a medication with a high risk of adverse effects, OR
- You have 'recently experienced a significant medical event' (an event which has the potential to affect medication adherence, understanding, and may include a new diagnosis, or changes in health status).

While this service does not cost you anything, the Pharmacist will receive payment from the Australian Government via the Pharmacy Programs Administrator. MedsCheck is also only available once every 12 months for each person.

If you would like to have a MedsCheck, talk to your local community pharmacist. They will check your eligibility, get your consent for the review, and then schedule an appointment at a time that is suitable for you. The pharmacist will ask you to bring in all your medications to that appointment, and that includes prescription medication, over the counter medication, and also any vitamins, supplements or herbal remedies you take. The pharmacist will check through all the medications, and check your understanding of what they are for, how you take them, how you store them, and provide advice accordingly. Don't forget to ask questions if you have them!

Any concerns the pharmacist has will be discussed with you, and they may also need to follow-up with your doctor/s. The pharmacist will provide you with an up-to-date medication list. This can be paper-based, or can be added to a secure smart phone app (such as NPS MedicineWise, Medadvisor, MyLife+, etc). If you wish, it can also be uploaded to your My Health Record if you have one.

DMMR/HMR @ your home

The most comprehensive review is the Domiciliary Medication Management Review (DMMR), more commonly known as the Home Medicines Review (HMR). These are usually requested by your GP and are conducted by an Accredited Pharmacist with you, at your home.

These comprehensive medication reviews are particularly useful for people who are taking more than five medications a day, those who have three or more medical conditions, those who have recently been discharged from hospital, and those who are concerned about their medication or just finding their medication regimen challenging.

The HMR is funded through Medicare (Medicare Benefits Schedule Item 900) and the GP requesting the review and the pharmacist receive payment from the Australian Government. There are eligibility requirements, but the majority of people living with HIV who are Medicare or Department of Veteran's Affairs cardholders should qualify



if their GP believes there is a clinical need for the service. These reviews can only be conducted every two years, with some exceptions, of course.

The HMR process consists of a pharmacist interview with you, usually in your own home. The pharmacist will comprehensively assess all of the medications you take to ensure they are the most effective, appropriate and the safest possible for the medical conditions that are being treated.

The aim is to identify, resolve and prevent actual or potential medication related problems. Among other things, the pharmacist will check for any drug interactions, adverse effects/allergies, and if any current therapy or medication is unwarranted, ineffective or duplicated, or where additional therapy or medication is required.

One of the main purposes of this comprehensive review is to determine whether or not changes to therapy or medication are needed. The pharmacist may ask you numerous questions as they need to gather lots of information before writing a report. Don't forget though, the pharmacist is also there to answer any questions you may have. Don't be afraid to ask!

The pharmacist will provide a detailed report to your GP outlining any issues identified, the potential or actual impact these have on you and provide suggested recommendations. The report can also include any concerns that you may have.

At your next appointment, you should have the opportunity to discuss this report with your doctor, and in conjunction with them, agree upon a new medication management plan. This may involve simplifying treatment and discontinuing medications which are no longer clinically needed, changing the dose of a current medication, switching your medication to one that might be more appropriate or more convenient/easier to take, or prescribing additional medication that may be required.

The goal of this whole process is optimising your health by assisting you to manage and understand the medications you are taking, and to ensure those medications are safe, effective and appropriate. Where possible, the objective is to simplify your regimen and ensure that you are only taking exactly what you need, when you need it.

Please don't be hesitant in speaking up about any concerns you may have about the medications you take, and if you would like a review of your medications, talk to your pharmacist, your GP, or your specialist.

Note: MedsCheck and HMR are usually conducted face-to-face, either in the pharmacy (MedsCheck) or in the home (HMR). Due to the COVID-19 pandemic, these services may be done by phone/telehealth, however there are additional eligibility criteria that need to be met.

For up-to-date information on this, please check with your pharmacist.

– Bruce Hamish Bowden
Clinical Pharmacist (HIV)



HIV Futures 10

**A national survey of
people living with HIV**

hivfutures.org.au

NUTRITION BITES

We have all been living with COVID-19 for a while. We know about hand hygiene, QR codes, social distancing, mask wearing, vaccinations, and most of us, if not personally affected, would know someone who has had to isolate, or who has experienced COVID-19 itself.

Our clients living with HIV tell us about the impact of COVID-19 on their health and the connection between exercise, nutrition, food and mood. The side-effects of COVID-19 and lockdown include gaining weight (from a few kilos up to 20kg or more) or losing weight and muscle and becoming frail. Some reasons for this include a lack of motivation to exercise, and spending more time sitting searching the internet or watching TV. Many have read or heard about nutrition from 'Dr Google', and then are unsure if the information is true or 'fake news'. Some describe not feeling like cooking. Many recognise comfort eating. It seems common to be relying on takeaway or home deliveries. Others are drinking more alcohol. For some, the struggle has been to find enough money for food.

Research tells us that when we are confined, we usually eat more snacks and processed foods. Less physical activity coupled with more snacks and processed foods is a sure way to gain weight. There is a link between poorer quality diets and mood, and exercise. Even a one hour walk a week has been proven to lift mood.

Does any of this strike a chord? If so, here's some tips which might be of help:

- Create a routine for yourself
- Get up and out of bed daily
- Eat some superfoods every day. These include berries (frozen or fresh), a handful of nuts, fatty fish (e.g. canned salmon, sardines), leafy greens and cruciferous vegetables (e.g. spinach, kale, broccoli, cabbage, cauliflower), wholegrains (e.g. wholegrain bread or crackers, rolled oats), yoghurts with 'live active cultures' added, and foods rich in vitamin C, for example citrus fruit, strawberries and tomatoes.
- If you notice you're comfort eating, one tip that works is to eat an apple. It works because it takes you time, you get to think and work out if you're really hungry or if you'd feel better doing something else. At the same time, you're eating a quality food. If you don't like apples, try an orange.
- Be active every day. Do it even if you don't feel like it. Team up with a friend to keep each other on track. If you're stuck at home, you can walk or 'slog' (slow jog) around inside for five mins every hour!
- If you can get outside, get your vitamin D from the sun – all you need is about 15 minutes each day.

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. Right now, we're offering telehealth (video and phone) appointments.

– The Albion Centre Nutrition Team



MONEY TALKS

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

Now that we're moving out of lockdown, we're also seeing more effects of debt and financial stress brought about by the COVID-19 pandemic.

People are questioning the way they live and work, with many choosing alternate options to make more positive change to their work/life balance. Massive financial support by our governments have resourced the COVID-19 response, with many in our community fast tracked for vaccination, access and treatment.

The lessons learned from HIV, test early, get immediate treatment and build a community of support have informed our COVID-19 response. While the lessons learnt from the early days of the HIV/AIDS epidemic have served NSW Health well, the conversations we are having now are not the same as those in the 80s and 90s.

While these days, we have the science behind HIV treatment as prevention (TasP), also known as U=U, HIV stigma and the fear of HIV stigma still remains.

Another pervasive social stigma alive and well in our society is the stigma around personal finances. This 'financial stigma' around money, discussing finances, getting financial support or help is something we see every day: people get into financial hardship and they hide it from their friends and family. Losing control of their finances carries shame and stigma. They avoid opening bills. No one talks about it.

This I do know, ignoring it won't make it go away. Getting help early and finding out how to treat the problem, with the right support can change everything.

The holiday season will shortly be upon us with offers to *Buy Now Pay Later* with extravagant gifts, but isn't this an opportunity to say to our loved ones "let's do this differently"? Give memories, not stuff.

Let's start some positive money practices and head off crippling financial stigma. Some suggestions:

- A positive money practice is to set up a Billing account for regular expenses.
- Another positive money practice is to only use a credit card that you can pay in full every month.

- Using 'Buy Now Pay Later' to spread payments only works when you can afford the debt anyway and are just holding in a savings account to maximise interest.

- Building Super early to take full advantage of the available tax breaks will mean you could retire at 60 years and be comfortable.

- Consistently spending less than you earn will change your life.



In terms of housing, if you spend more than one-third of your income you are under stress. The solutions are beyond this article but, as COVID-19 has taught us, remote working has become more practicable. Sharing or moving has become possible solutions. A post-pandemic jobs boom is being promised. Time will tell if wages will follow. The roaring twenties?

There are ways to approach debt and ways to get it paid down or written off, but the most important factor is to act early and not let it get out of control. Would you do that with your health? If the pandemic has given us a chance to reset our lives, can we also use it to reset our approach to debt?

Get advice and talk with someone who is non-judgemental, confidential and independent; it can help you break the vicious cycle of financial stigma and fear.

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

BGF Financial Counsellor

T 02 9283 8666 E reception@bgf.org.au

Free, confidential, independent and non-judgemental



STRAIGHT AND HIV+?

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

WEBSITE

pozhet.org.au

EMAIL

pozhet@pozhet.org.au

FACEBOOK

[@pozhet](https://www.facebook.com/pozhet)

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

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.

New Women's Groups at Positive Life NSW

Since June 2021, Positive Life NSW offers two new social support groups for women living with HIV in NSW as monthly online discussion groups.

The objective of these two peer-based groups is to bring women living with HIV across NSW together to share and discuss their experiences and challenges they might be facing in a safe and friendly environment.

The Women's Room offers a safe online discussion forum for women living with HIV under 40 years who face specific experiences around their reproductive options, while the corresponding social support group, *For Women* focuses on the experiences of women living with HIV over 40 years of age who are facing separate experiences of living with HIV.

Both social support groups have proven immensely popular within these communities, proving the life-changing benefits of peer-based support. Responses include "I feel so alive and hopeful for the future" and "It was such a great feeling to see so many other women all from different walks of life, sharing our Positive status in common."

The Women's Room attracts on average between 17 and 20 active members while *For Women* reaches between 25 and 30 attendees.

Alongside the expertise of our HIV sector and allied health partners, Positive Life supports attendees to build their health literacy capacity, while addressing their unique social impacts and share strategies to respond to and mitigate the impact of gender-based stigma and discrimination on their lives as women living with HIV.

Pos Life NSW at ASHM 2021

At the 2021 Virtual Australasian HIV&AIDS Conference in September, alongside colleagues Allie Carter and Patricia Morgan from the Kirby Institute, Positive Life NSW CEO Jane Costello co-presented results from the *Positively Women* project. This research study used an innovative art meditative process to explore and understand the experiences of women living with HIV. The *Positively Women* project included moving quotes from study participants to help explain the process: "It was like my body was dancing through the pencils," said one woman.

The study was in two parts, the first taking ten women through a four-week workshop using drawing,

painting, meditation, movement, and storytelling, and the second was an online exhibition of their art.

The *Positively Women* project was one of several presentations in the session titled 'Rethinking women and HIV: new paradigms for prevention and care', which presented a range of work by women including Rita Broughton, with 'Perspectives from women living with HIV', Kirsty Machon of Positive Women Victoria with 'Women and PrEP'; and an abstract from Heather Mugwagwa from Positive Women Victoria, '#Missing Voices: Building HIV positive women's meaningful engagement with HIV clinical and cure research'.

More about the *Positively Women* project is on page 28.

HIV no barrier to COVID-19 vaccination

In September, Positive Life became aware there have been some misleading assumptions, particularly by the media but also by other sources, that all people living with HIV are immunocompromised (defined as CD4 count below 200 cells/mL) and therefore may be ineligible for the COVID-19 vaccine.



unusual risks

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unusualrisks.com.au

choice

Unless people living with HIV are taking immunosuppressive therapy (such as for kidney, lung or liver transplant) or other cancer treatments, or not taking HIV antiretroviral medication or have a CD4 count below 200 cells/mL, the majority of people living with HIV are **not** immunocompromised due to effective HIV antiretroviral treatment.


Like anyone else living in the community, people living with HIV face no barriers to getting a COVID-19 vaccination if we wish. We offer this information to our community and the media, to combat this misinformation, and also to allay the concerns of anyone living with HIV for whom this may cause some anxiety.

The Australian Government strongly recommends anyone who is immunocompromised receive the COVID-19 vaccination. People living with HIV with a low CD4 count (below 200 cells/mL) should seek medical advice about the priority of getting vaccinated. If you want to discuss your eligibility for a COVID-19 vaccine, or have any further questions about the COVID-19 vaccine itself, please speak with your GP or HIV specialist. If you are living with HIV in NSW, you can also call Positive Life NSW on (02) 9206 2177, 1800 245 677 (freecall outside metro) or email contact@positivelife.org.au

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

Peers Connect Online!

A safe, online meeting space for anyone living with HIV regardless of gender or sexuality. Contact Positive Life for more details (02) 9206-2177, 1800 245 677 or contact@positivelife.org.au



In My Own Words

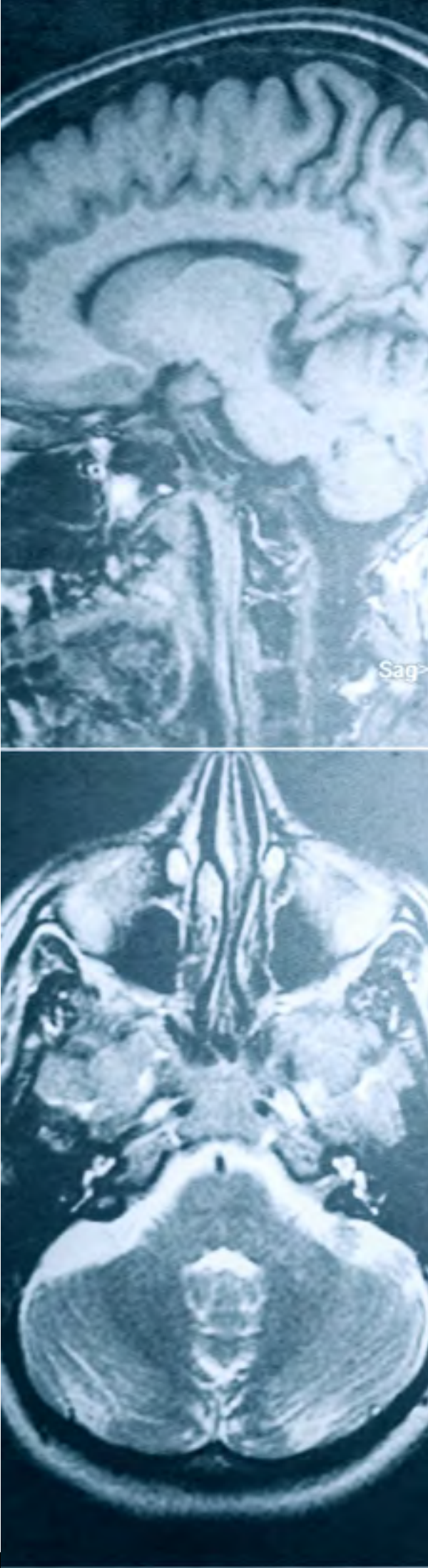
**Tell your story.
Share your experiences.
Call and have a chat.**

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



The Women's Room

A safe, online meeting space for young women living with HIV. Contact Priscilla or Jane for more details (02) 9206-2177, 1800 245 677 or contact@positivelife.org.au



Feature

RESOURCES

WHEN DIAGNOSED WITH HAND

When we first contract HIV, the virus immediately penetrates many different cells and organs throughout our body, including the brain and/or our central nervous system (CNS), possibly within the first eight days. Around 40% of people living with HIV can develop a condition called HAND, which stands for *HIV-Associated Neurocognitive Disorder*.

Most people living with HIV who are affected by HAND have mild signs or symptoms so it remains unnoticed. The impacts of HAND are related to thinking, memory or mood. With today's HIV anti-retroviral medications, the incidence of HAND has been dramatically reduced. However, it is estimated that around 30% of people living with HIV still experience some HAND symptoms.

For people living with HIV who notice memory, mood or cognitive changes, HAND can be diagnosed through a series of painless, non-invasive assessments. Diagnosis is a combination of excluding other causes and working out what needs more investigation. Assessment for HAND will most likely be a neurocognitive assessment which is a question and answer type screening test. This can indicate the need for further testing e.g., MRIs etc.

People living with HIV in Australia are fortunate to have one of the world's more experienced neurologists (Brain Specialist) with a particular interest in neurological complications of immune deficiencies, and infections of the nervous system including HAND. Professor Bruce Brew's clinical team based at St Vincent's Hospital in Darlinghurst offers world-class assessment and treatment for people living with HIV who experience the effects of HAND.

Early assessment and detection of HAND as well as a treatments review can reduce the impact of diagnosed HAND on people living with HIV, either by slowing or reversing the progression and providing support. Early treatment means that symptoms can improve or even reverse. Most people continue living productive and engaged lives with HAND.

In 2016 Positive Life published our community report on a 2015 community-based survey on '[Developing resources to assist people living with HIV associated neurocognitive disorder \(HAND\)](#)'. The results of this research identified five key areas for resource development and in response, Positive Life published two booklets: '[HIV Associated Neurocognitive Disorder Booklet](#)' and '[HIV Associated Neurocognitive Disorder \(HAND\) Booklet for partners, friends and family](#)'. You can download these booklets and report from our website or call the office to get these free copies posted to you.

If you have concerns about yourself or someone living with HIV, you can call Positive Life on (02) 9206-2177, 1800 245 677 (freecall) or email contact@positivelife.org.au

– Positive Life NSW

Read Robert's story on page 22 about his diagnosis and experience of HAND and return to work.

No stamp required
if posted in Australia



Positive Life NSW
Reply Paid 831
DARLINGHURST NSW 1300

Pull out middle sheet, complete survey and fold at dotted line, staple or sticky tape together before posting.

Talkabout Evaluation Survey

After Positive Life NSW ran an online consultation with Positive Life members and community in January 2021, we began to publish Talkabout again as a printed bi-monthly 28-page magazine.

To keep Talkabout relevant and growing as a community-driven magazine for and by people living with HIV, with a subhead: 'Where we speak for ourselves', your feedback is important. Please tell us what you think about your magazine.

Part 1: About You (please circle)

1. My age is:

- a** Under 20 years
- b** 20-29 years
- c** 30-39 years
- d** 40-49 years
- e** 50-59 years
- f** 60 years plus

2. I am:

- a** Female
- b** Male
- c** Transgender woman
- d** Transgender man
- e** _____

3. My sexual orientation is

- a** gay
- b** lesbian
- c** heterosexual
- d** bisexual
- e** labels don't apply
- f** _____

4. My postcode is:

5. The country I was born in is:

6. Language spoken at home:

7. I am: (please circle all that apply)

- a** a person living with HIV
- b** friend, partner, carer or relative of someone living with HIV
- c** social worker/ counsellor
- d** community volunteer
- e** employed in the NSW HIV sector
- f** other (please specify)

8. I know about Talkabout:

- a** through a friend
- b** through a health care worker
- c** picked it up at a service or clinic
- d** it's posted directly to me
- e** from a social media post
- f** from the Positive Life website
- g** other (please specify)

9. Number of people who read my copy:

- a** only myself
- b** two other people
- c** three other people
- d** more than three other people

Part 2: Your thoughts about Talkabout (please circle)

10. I find Talkabout easy to read and understand:

- a** Yes
- b** Most of the time
- c** Some of the time
- d** No

other comments: _____

Talkabout Evaluation Survey

11. What do you like **most** about Talkabout?

12. What do you like **least** about Talkabout?

13. What would you like to see **more** of in Talkabout?

14. Topics and issues suggestions that you would like Talkabout to cover?

15. What are your expectation of a magazine for people living with HIV?

16. What are your thoughts about the advertising that is in Talkabout? (please circle)

- a** There is the right amount
- b** There's too much advertising
- c** There's not enough advertising

What kind of advertising do you think is appropriate?

Talkabout Evaluation Survey

17. Please include any final comments, feedback or suggestions here:

Thank you for your thoughts and time in completing this survey.

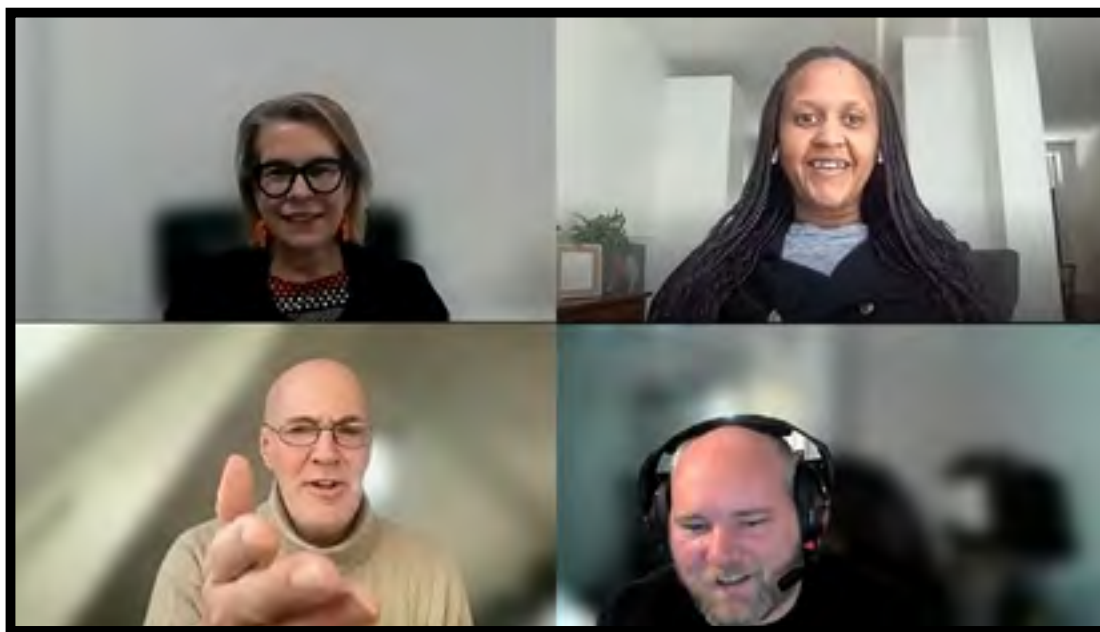
Responses received by Monday 15 November 2021, will be included in the write-up for Edition #200, December 2021.
Responses received after this date will be used to inform ongoing editions of Talkabout.

– Positive Life NSW

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.



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 the role and value of the peer voice, and the challenges of the current competing agendas of HIV and COVID-19. In December's edition, we talk about our shared experiences of HIV as a rights-based movement, and reflect on World AIDS Day as a global occasion, and how we can continue maintaining the relevance today.

GNP+ is a network of interconnected individuals and organisations working to support national and regional networks of people living with HIV to improve access to quality HIV prevention, treatment, care and support services. Sbongile is based in Cape Town and Gerard in Amsterdam.

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

With the 1994 signing of *The Greater Involvement of People Living with HIV/ AIDS* (GIPA) Declaration, based

on *The Denver Principles*, it quickly became apparent that this involvement must also be meaningful (MIPA), so the voice of people living with HIV would be and remain central across all domains of HIV policy, funding, services, advocacy and research.

As we reflected on the role of peer-led agencies in today's world along with the value of the peer voice together, Sbongile highlighted the continuing global conversations around the GIPA principle, "specifically in countries around sub-Saharan Africa. When you look at the history of HIV, it was the people living with HIV that fought governments, that pushed governments to make sure it becomes a health priority. What you start seeing is the networks saying, we know the solutions, we know what the issues are, we are doing the work on the ground. If you look at it from a global perspective, we and other global networks have been pushing for greater involvement in those processes. We're seeing a lot of networks saying we want the GIPA principles to apply in every aspect of the strategies."

Gerard said: "The first time I came across GNP+ was in 2000 when I was Portfolio Manager with the Global Fund. From the very start of the Global Fund, activists demanded a seat at the table, to design the fund not only for policies and strategies, but also to create the financial mechanism

that it should be. That was in 2001, and I remember that gradually, GNP+ was able to claim a seat at the table. In our office in Amsterdam there's a long corridor with photographs that illustrate the developments of GNP+ and these are photos that I always look at with great respect. I realised that despite the geographical distances and the absence of social media at that time, we were faxing and phoning and sending letters with stamps, activists were speaking out and insisting that for example, antiretroviral drugs would become available and affordable in an equal manner. So these are some thoughts I have about what is GNP+; we are a global network of country networks and regional networks in all continents, including yours."

Neil reflected on his early realisation of the interconnectedness of the HIV community, "that blew my mind thinking about the way global networks mobilised, and it reminded me of a photo that we have with a bunch of people manning the phones, in our old office, probably late 80s, early 90s. The concept of creating this global movement, using letters and faxes, and the power that community responses had, and how effective it has been."

Gerard highlighted particular strengths of the peer voice across two vital domains, HIV awareness and HIV stigma. "When it comes to HIV awareness, this is where you see the impact of peer-led organisations, because in communities on the ground, the people that they listen to are their peers, it's not anyone else. There's still so much stigma and the only way to stop stigma is using peer-led mechanisms and frameworks of educating people on the ground. This is how from a GNP+ perspective we've seen it play out. We trained the network and gave them capacity on how to engage within these big structures when it comes to decision-making accountability issues. What we want to see is building solidarity within countries, because different countries have different mechanisms of peer-led organisations."

"Sbongile touched on some of the different structures of peer-based organisations," said Neil. "We are part of a federated structure; Positive Life NSW is the jurisdictional organisation of people living with HIV for our state, with other organisations for other states, but even in our response, we are all very different organisations. Positive Life NSW plays a big role in holding our public health officials and our researchers accountable for the work that they're doing."

He shared an example meeting with epidemiologists and policymakers discussing what was a preventable HIV transmission. "When they're talking about *preventable*, they're talking in the context of Australian-born or people living in Australia and thinking about how HIV is acquired overseas and brought back into Australia. A large part of our role is making sure that we're not pathologised by public health officials. Hey, we're people, not just statistics, we are more than just a dot on a graph. A big part of our

role is making sure that the HIV response continues to have that humanist approach."

Gerard replied, "I find it extremely interesting to hear from you how you do advocacy and influence your government. I wonder how you influence your government to make sure that funding is not diverted? The biggest challenge facing current people living with HIV movements is not only COVID-19, it's also complacency with global health. The idea that the battle against HIV has been mostly won with better antiretroviral drugs, including PrEP, and the new status being undetectable and untransmissible. Yet communities continue to struggle with funding and capacity and resources. There are many parts of the HIV community, in parts of Africa and Asia, also among poorer, isolated communities within Europe and the US and your part of the world I believe, such as refugees and immigrants and homeless people, where these global goals have not yet been met."

"In Australia, a lot of money and whole sections of health departments have been redeployed to work on COVID," said Jane. "And we're not entirely sure what is going to happen in terms of HIV funding in the future, because so much money has been diverted to the COVID response. As Sbongile was saying, COVID has exposed those inequities that existed in HIV all the time."

"When COVID hit, there wasn't a global perspective," said Sbongile. "Yes, we knew that it would have an impact on HIV, but I don't think we understood the impact it would have, particularly on those who live in marginalised communities. COVID is a big mirror on the inequalities in the world."

"When COVID came, we thought, actually, HIV is fine, we have a handle on it," said Sbongile. "If you look at it from a global health perspective, there's a narrative that we must sort out COVID so that we can get back to HIV. But we're saying, you can't do that. The Global Fund released a report that showed that HIV interventions have slowed down, it became harder to access health care. There were huge treatment interruptions."

"Another thing we need to talk about is around what COVID did in terms of being locked down," said Sbongile, "and this big reliance on digital platforms. If the epidemic continues, certain people will be left behind because the world is moving into a digitised world. Currently that's the biggest question: how do we make sure that in 2026, we've made progress? We've set new targets: 95-95-95 and certain countries have not even reached 90-90-90."

Neil shared an example of how COVID-19 impacted people living with HIV at a local service delivery level. "Right now we're fighting a battle to keep a service that provides crisis accommodation for people living with HIV open. Once COVID hit, and we started to plan for emergency departments to overflow, that was one of the

first services to go. They cleared out the residents in that service to create an overflow service for patients from the Intensive Care Unit. So even as blessed as we are with our HIV response here, we are definitely seeing HIV being sidelined for COVID.”

Gerard asked how COVID-19 might have impacted attitudes and efforts to focus internationally. “I think Australia has been really short-sighted in our global responsibility,” said Neil. “We have become so inward looking. I think Australia’s international response is really disappointing. In Papua New Guinea, as an example, I think there are only 60 or 65% of people having access to antiretroviral treatment. We are sitting here at 98% in New South Wales.”

“We’re not only talking about Asia-Pacific countries, and Australia’s responsibility to those countries, but we’re also talking about our Aboriginal and Torres Strait Islander populations here in Australia who are 1.6 times more likely to be diagnosed with HIV than a non-indigenous person,” said Jane. “And the same can be said for COVID-19. So we are seeing that similarity in terms of highlighting and exacerbating those inequalities.”

“There is an island mentality, fearful around opening borders. Fear tends to mitigate compassion. We need to really hold our institutions accountable for that ongoing impact. S bongile raised a point of what’s happening in the Asia-Pacific. Very quickly we’re going to find ourselves left behind, unless our government starts to take a more human rights-based approach than what they are doing today. It’s also not being a good global citizen to our Pacific Island and Asian neighbours.”

S bongile echoed these sentiments, “One of the things we are just so tired of at GNP+, of sitting down in these meetings where the political declarations don’t translate, and talking about targets, coming up with strategies, but if they don’t translate to people living with HIV accessing quality care, then we’ll still find ourselves here five years later and the inequalities are still there, right? I mean, why are we sitting in 2021, with over 57 countries still criminalising HIV? Why are we in 2021, still with Venezuela getting treatment from Haiti, and activists having to stretch themselves to actually get treatment? Our biggest fear currently is that the Global Fund might focus on COVID-19, and we say we can’t do that, we have to keep our eyes on the poor because we’re no nearer to achieving ending AIDS.”

“I think our experience in the HIV response has a valuable role to play in the ongoing global COVID response as well,” said Neil. “I see it as an opportunity for the people living with HIV to go out there and challenge our global leaders and funders to make sure that the HIV response isn’t overlooked in the COVID response and that the ongoing commitment remains to respond effectively to HIV.”

– Positive Life NSW

Calendar

COMMUNITY

The Social Club

A monthly get together for heterosexual people living with HIV in a safe, friendly and accepting social environment over a meal and discussion.

FRIDAYS

November and December 2021
6pm to 9pm

Peers Connect Online!

A safe, online meeting space for all people living with HIV in NSW, regardless of identity or sexuality. All welcome, especially people from rural and regional settings. Discussion facilitated by a person living with HIV from Positive Life. RSVPs are essential for these online sessions.

THURSDAYS

11 November 2021
6pm to 7.30pm

[+Connect] and [+Connect]OutWest

An inclusive social event for all people living with HIV, our partners, family and friends.

THURSDAYS

Resuming in 2022
7pm to 9pm

The Women’s Room

A safe, online meeting space for young women living with HIV. RSVPs are essential for these online sessions.

TUESDAYS

November and December 2021
6.30pm to 8pm

For Women

A safe, online meeting space for women living with HIV aged over 40 years. RSVPs are essential for these online sessions.

THURSDAYS

November and December 2021
6.30pm to 8pm

World AIDS Day

Celebrate the 2021 World AIDS Day with us. Venue arrangements are yet to be finalised. This event will be under strict COVID-19 restrictions and require COVID-QR code sign-in procedures.

WEDNESDAY

1 December 2021

For more information about any of these events or to RSVP call Positive Life on (02) 9206-2177, 1800 245 677 (freecall) or contact@positivelife.org.au

My journey through HAND

I'm 67 years old and HIV positive since 2003. At that time I was living in London and had started to have very bad psoriasis. As a gay man, I had friends who had died from HIV/AIDS in the 1980s prior to any medications, so I didn't want to think about anything like this until I had to. It just seemed too grim.

Eventually, after I was diagnosed with psoriatic arthritis, the specialist asked me, 'Have you had a HIV test?' I said no, and he said, 'Well, you know, high viral loads can cause a psoriatic reaction.'

When I got the result, it didn't surprise me. I mean, it wasn't a devastating diagnosis. It was just, you know, 'Oh shit, here we go'. I've got to adapt to these new circumstances and medication and so on.

At that time, I had a CD4 count of four, and a viral load of 144,000. My doctor was surprised. For the immune system to be so degraded and with such a high volume of the virus, that should have basically been AIDS.

So I went on meds, the whole HIV meds trip. I've had all the ups and downs and the different medications. Going on the initial combination, working for a bit and then not working. Anyway, over the years I've been quite stable. The meds were working fine, my viral load was undetectable. My CD4 count improved.

In 2017 I noticed that I was starting to tremble slightly. I just thought I must be getting old. But over the next few months it got worse and worse, to a stage where I couldn't actually eat with a knife and fork.

I was so trembly and jerky. It was difficult on one occasion when I joined my work crew for lunch. I had to be very careful, because I might unintentionally fling a piece of food across the room, this is now a source of grim humour

with one of my friends, so I knew something wasn't quite right.

I was attending the Western Sydney Sexual Health Clinic at the time, and my s100 specialist GP who I've been with the whole time was a rock. She referred me to get a brain scan. Just after it was

done, I moved house. So my results were sent to my old address and I never got them. I was getting worse and worse and eventually my GP said 'We've got to do the brain scan again', so I did.

By now, the trembling and unsteadiness was on an accelerating downward curve. By the time the scans came back, I was having real trouble walking which had turned into a slow shuffle.

There was a long delay until I could get onto Professor Brew's schedule and I was getting really very bad. By then I was moving with great difficulty, and couldn't walk down stairs without hanging on to the handrail taking each step really carefully. At the time, I was living about half a mile from the health clinic, and I'd have to get a taxi there. It was impossible to walk to the clinic as I had done before.

I got to the point where I needed to get everything delivered to the door. Shopping was something that I did try to push through, probably not a good idea. At one time, I was in a supermarket at North Parramatta. I was carrying my shopping bags and fell over on the stairs, flat on my face.

A couple of concerned guys came over and helped me up. They asked, 'Shall we call you an ambulance?' And I was thinking, 'I know what this is about,' and said, 'No, no ambulance, can you call me a taxi?' They said, 'No, no, no, we'll take you home.' They drove me home and carried my groceries to my apartment door. The memory of their kindness and care still overwhelms me, even today.

My balance was badly affected. I was at the stage where I couldn't stand up in the shower. I would have to kneel. And then I wouldn't shower every day because it was dangerous to do even that. One morning I was making the bed, a simple job, but fell flat on my back. I was in pain for about a week.

In terms of my mental state, I just felt utterly weary. Physically I was completely lethargic and turned myself right down in terms of things I would be doing mentally, but still conscious of wanting to maintain my mental life.

I spent a lot of time reading and watching TV, doing Sudoku. Things like cooking, the washing, showering or bathing, or even opening a can of food was impossible. I basically lived on sandwiches.

"Things like cooking, the washing, showering or bathing, or even opening a can was impossible. I basically lived on sandwiches."



At the bottom of that descent, I felt hermetically sealed in on my own; I did it alone. I'd lost 13kg.

In hindsight, this was something I didn't need to do. There's a sort of stoicism about our family. My father was born in the late 19th century and actually fought on Gallipoli. He had Scottish Presbyterian roots and a stern sort of stoicism that our family has inherited. My parents married in late middle age and my mother tended to hold herself in. So you know, that's just how I did things, kind of the way I am. My GP offered things like home help, but I just didn't want anybody in the house in the condition I was in. So that's where I got to. That was the real rock bottom.

I finally got to meet with Professor Brew. He arranged for me to have a lumbar tap. The result identified a strain of HIV in my spinal column and the medications I was on at the time weren't effective against it. He put me on a new

medication, and said, 'It'll probably take six months to a year to notice any changes.' It took me about three months before I regained my mobility.

I think I'm lucky, in so far as I don't think my mental acuity was damaged. I improved very quickly over three months to where I am now physically and mentally. It was only just a change of meds; that was it really.

The whole experience made a very deep-rooted and fundamental change of orientation in my life. It's like when you have an angle that starts off very small and moves further and further apart.

As time went on, I got further and further away from the person that I used to be. It's brought a kind of emotional openness that I didn't have before. To be ground down like that and coming out the other side.

When I say 'down', I don't mean feeling depressed, I wasn't depressed about it. I mean, I was a bit worried at times about what kind of a life I would lead if this was going to be the way I was going to live. I wondered if I might have something terminal. Being ground down was my metaphor, grinding and grinding, Down, Down, Down.

When members of my family, like my nephew and his partner, found out, they said 'Why the hell didn't you tell us? We'd come and do things for you!' That was one of the things that I look back on and wish I'd done. This experience has deepened my relationship with them. Since then I have become very, very close to them as well their two kids, so it changed me emotionally.

Prior to all this, I would normally go for a walk in Parramatta Park early in the morning, and I mean very early, like 4am. After maybe a couple of months, I went out for my first walk, not the whole distance, but I did it. There was a feeling of, you can do this now.

This sounds corny, but it was like the air had a kind of magic about it. I became far more conscious of being alive, of living in this world. I used to be more of a worrier. Worry, worry, worry, and go to sleep at night worrying.

Looking back, the experience brought about a very fundamental change within me, and this might be something that others with HAND would want to hear. I found a new me. I've found that I really like what it's done to me. It's been quite powerful and, paradoxically, has had a very positive impact on my life. I'm fortunate, I'm not sure that everybody would be able to say that.

During the worst of it, I felt so helpless. I was living a day-to-day existence, moment by moment, because that's how I had to do it. Life felt so constraining. So physically limiting and pressing and hard. Whether it's physical or mental or memory, the effects can be devastating.

But my experience of HAND has helped me transition into a new way of thinking about myself, and a new way of living. I think the thing for me is, if I lived through that, I can get through anything. I think that's one of the lessons I would take away from it.

Yeah, even going through the darkness, which I probably wouldn't have had to if my diagnosis had been sooner, or if that first scan hadn't gone astray, and I might have gotten there sooner, I think there's a lesson in that about early treatment.

And also, to have loved ones with you on that journey. I didn't do that, and I could have. With hindsight, I recognise now how much those loved ones actually would have wanted to be involved. It's not necessary to go it alone.

If I were talking to another person with HAND, I'd probably be asking what treatment are you getting? How are you coping with that? Are you talking to your physician about what's happening? Have you got a loving circle around you? If not, how could we build something like that? I think it's important to have people around you who can keep you afloat, help keep your head above water. I think I went underwater for a period there, and if I'd brought my family close to me, I probably wouldn't have gone that deep. If I'd had a holding circle who knew what's going on for me, that would have been very empowering and supportive.

I think there's enough residual shame around living with HIV, particularly for people in my age group. For people who are dealing with HAND, I think it's important that they're not alone. And they should know, not to be alone. I think there's a temptation to kind of do that, because it's embarrassing

"I become far more conscious of being alive, of living in this world... looking back, the experience brought about a very fundamental change within me..."

if you can't hold a cup of coffee. It's embarrassing if you lose track of where you are in a conversation, and you don't want to be embarrassed.

I'd probably say, look, I went through this, and got it bad, but I came out the other side. It was a life-changing experience. I wouldn't say that's going to happen to you. But I'm saying, you can come out of it.

It's taken me to a frame of mind that's more settled, more peaceful, more loving, more forgiving. Just prior to this experience with HAND, my partner and I split up very acrimoniously. I really resented him and when I'd get email from him, I'd just go delete, delete, delete. And bless him, he kept reaching out. After recovering I responded, and he was surprised. But that was just part of that change, you know. What's the point carrying all that crap around?

After about six months, I started work again. I'm a project manager working in social services, like housing and for local government. I got a contract with an intra-state organisation, and that three-month contract turned into a year because they were happy with the way I worked. So I'm saying, it's not the end of you. It's not the end of your life.

– Robert

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

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Your messages, comments, thoughts and opinions are welcome here.

Letters should be short
(less than 200 words)
and may be edited.

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Please specify if you want your details withheld from publication.

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A place to showcase
our sector partners
who benefit the lives of

WORKING FOR ME

all people living with HIV

A self-described child of the 70s, Health Services Manager Cameron French witnessed the early days of the HIV epidemic in Sydney during the 80s and early 90s. Those devastating days crystalised his passion for the care and support of people living with HIV, especially those who experience, or are at risk of, homelessness.

These days, Cameron manages two significant accommodation services for experiencing or at risk of homelessness and/or who are living with HIV: *Stanford House* and *Tierney House*, both of which function under the stewardship and oversight of St Vincent's Hospital since 2016 and 2012 respectively.

"Stanford House opened in 1991 as an NGO for people living with HIV who were experiencing homelessness or at risk of homelessness," says Cameron. Originally owned by the Daughters of Charity of St Vincent de Paul in Stanmore, alternate arrangements were required by 2014 to safeguard the long-term survival of the service.

"One of the planning and project team here at the hospital saw an opportunity to bring Stanford House over to St Vincent's and place it under the umbrella of the homeless health service here at St Vincent's Hospital where the period of time that residents can stay is three months," said Cameron. "The unit falls under a greater umbrella, called the Integrated Care Team, consisting of the drug and alcohol service, the mental health service, the community health service, and the homeless health service."

Tierney House was established in 2012 by St Vincent's Hospital, in partnership with the NSW Ministry of Health and philanthropic input, as a response to people experiencing homelessness, who are presenting with a primary sub-acute physical health complaint, more often than not to the St Vincent's emergency department (A&E). "Unlike others in the community who have an ongoing relationship with a GP, those experiencing homelessness tend to see the A&E as a kind of a GP service," said Cameron. When people

experiencing homelessness and/or are living with HIV from this itinerant population are admitted to hospital for care, the discharge process becomes more complicated without established housing.

"Where patients are normally sent home with a discharge summary and a bit of a plan, people who don't have established housing find it more difficult to follow up appointments, medication, access home nursing or home help and these kinds of things," explains Cameron. "With the availability of Tierney House, they can stay for a period of two weeks, where they can rest and recuperate in safety, finish off their health care plan, get back to those appointments, and we can ask them about the many and varied secondary physical health issues that they may have.

"Given they're with us for two weeks, we can formulate a care plan around things like housing, Centrelink, legal, financial, and all the psychosocial stuff that goes along with their physical health issues."

Tierney House offers a step-down discharge model from an acute bed on a ward to a non-acute bed, supported by non-clinical residential support workers. Referrals to Tierney House come directly to Cameron as Manager and to a registered nurse who is also a member of the homeless health service. "Tierney House offers nine beds for men and three beds for women, and there are five beds at Stanford," he said.

The referrals and acceptance of residents to both units remain steady. "It's a bit tricky trying to find out who's most at need or risk," Cameron explains.

"For example, if we had two referrals, where one person's tenancy was at risk, while the other person was rough sleeping, we'd obviously be inclined to go with the person who's rough sleeping so long as their health need is also appropriate for care within a unit that does not have clinical cover.

"Wading through some of that material to determine who's most at need at that time is probably one of the most crucial elements of the work. We're usually able to accommodate most of the referrals that come into Stanford, whereas at Tierney House we're declining twice as many referrals as we're accepting. That's tricky."

The demand on both Stanford House and Tierney House remains high. "You wish you could support everybody

"They're here among staff who care, they're getting good sleep, good nutrition, their needs are getting met...It's a bit of an epiphany for them."

who was referred to you,” says Cameron. “The fact that we’re taking over 200 a year into Tierney House, knocking back more than 400, tells you about the demand. I’d like to be able to have more beds at Stanford too, because I see the demand there as well.”

As residents move on from both supported accommodation units, their trajectories are quite different. As Cameron explains: “People from Stanford generally discharge to much more favourable outcomes. That’s probably to do with the fact that a) they’re case managed and b) they have a housing application active upon entry.” People move on from Stanford after three months with the support of a case manager and an application with either community housing or public housing, which means there’s more likelihood the individual will experience stability sooner.

“Whereas people who come through Tierney House, discharged from a ward after some health issues, normally don’t have the support of a case manager, and often they have no housing application or it’s deemed inactive because nobody’s looked at it,” he says.

“The transfer of care out of Tierney House is somewhat trickier. We do see some people go straight into NSW housing properties. But we also see people go to drug and alcohol rehab, family and friends, crisis accommodation, short term accommodation like caravan parks, boarding houses, rooms above pubs and so on. Sometimes people go into custody or back into hospital, there’s many, many different outcomes.”

Cameron says they have seen some absolutely heart-warming outcomes at both Stanford and Tierney Houses. “Sometimes people see their stay here at Tierney House as a real turning point. They’re here among staff who care, they’re getting good sleep, good nutrition, their needs are getting met,” he says. “They’re accomplishing so many things in two weeks. It’s a bit of an epiphany for them. Some of the outcomes are just fantastic.”

He describes a recent example of a man who had come to Tierney House and then moved onto Stanford House. “He was struggling with HAND-related dementia, due to not taking his HIV medication regularly. He was really isolated in the world, given that Sydney is not his home city. After this experience through Tierney and Stanford, I saw fabulous outcomes for this gentleman, now that he’s been able to secure safe, sustainable accommodation. He has a good collection of professional supports, and some good social support. I think you really need a nice balance of both. Being able to provide some sort of connection to community, or to mob, is fantastic.”

Referrals to Stanford House are through the NSW HIV Supported Accommodation Program, phone (02) 9382 8602. Referrals to Tierney House are available directly through the St Vincent’s Homeless Health Service, phone (02) 8382 1512 or 1800 602 417.

– Positive Life NSW



Creating change through art

An estimated 3,370 women are living with HIV in Australia. This invisible 10% of the country's HIV population face HIV stigma and isolation as well as barriers to appropriate health and social care.

Since March 2020, the Kirby Institute, in close partnership with Positive Life NSW and HIV community organisations across Australia, have been developing a qualitative arts-based research study called the *Positively Women* project, using art and meditation to express what it means to be a woman living with HIV in Australia.

In September 2021, the *Positively Women* online exhibition was launched through an online exhibition space which shares the results of this national collaboration of women living with HIV, researchers, clinicians, artists, and members of community organisations.

"The Positively Women research project was developed to make women's lived experiences of HIV more visible," said Jane Costello, CEO of Positive Life NSW and investigator on the research team. "It was critically important that this project was co-designed and co-produced by women for women to document the impacts of creative methods in changing stigmatising and discriminatory attitudes in the general public."

Chief Investigator and senior research fellow at the Kirby Institute at UNSW, Dr Allison Carter says, "The team is exploring the impact of viewing the women's art and stories on people's knowledge and attitudes to HIV, and examining

how art can influence health and bring about change, both for women and for those who view their artwork."

"I am more than a walking virus; I am a daughter, a mother, and a nanny; I am me...and I am grateful for HIV treatments and still being here in 2020."

The project manager Dr Patricia Morgan described benefits of the Meditative Process Art (MPA) method created for and used in the workshop, "We found that this application of the MPA method led to increased peer support,

enhanced agency and provided a means to release suppressed negative emotion and trauma." The connection between art, healing, and public health has a strong body of evidence.¹ Two decades of the effectiveness of art-based and art therapy, demonstrates the research field has extended its scope and is growing.²

The art in the *Positively Women* study was created by ten Australian women living with HIV, through a four-week virtual workshop in late 2020. This involved a range of activities such as drawing, painting, meditation, gentle movement, and storytelling. The workshop became a safe space for the participants to share their stories of life with HIV, engage in discussion and art making. Many women spoke of late diagnosis, the trauma of diagnosis, and the impacts this had on their parenting style. Some spoke of feeling the need to live a double life, of loneliness, problems with medication, reproductive coercion and agency, realisation of being more than HIV, and everyone, from women diagnosed in the 1980s to a woman diagnosed in 2016, spoke of their experiences of HIV stigma and marginalisation.

Some examples of the realisations and changes the participants experienced include Diane who said "...I am stronger than I think...I am going to have a voice." An older woman living with HIV, Ange wrote: "...Wise I Am; Awesome I Am; I Am Grandmother, Human, Whole." Katherine share her insight: "...I am more than a walking virus; I am a daughter, a mother, and a nanny; I am me... and I am grateful for HIV treatments and still being here in 2020."

These stories about the women's empowering and transformative journey have informed the project's second stage which includes a tour of the online exhibition and group discussions with a range of audiences, including with women living with HIV, healthcare providers, policy makers and the general public.

To view the online exhibition website visit www.positivelywomenproject.com.au

– Positive Life NSW

1. The Connection Between Art, Healing, and Public Health: A Review of Current Literature. [Am J Public Health](https://doi.org/10.2105/AJPH.2008.156497). 2010 February; 100(2): 254–263. doi: [10.2105/AJPH.2008.156497](https://doi.org/10.2105/AJPH.2008.156497)

2. Effectiveness of Art Therapy With Adult Clients in 2018—What Progress Has Been Made? [Front Psychol](https://doi.org/10.3389/fpsyg.2018.01531). 2018; 9: 1531. doi: [10.3389/fpsyg.2018.01531](https://doi.org/10.3389/fpsyg.2018.01531)

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